

California Advocates for Nursing Home Reform

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A Guide for Preventing Abuse in Long Term Care Facilities

This Guide is inspired by a family member who wished that she had this information when her mother was in a skilled nursing home. It is her hope that some of the ideas shared in this Guide will assist you in improving the quality of care and life for your loved one.

More detailed information on all of these topics is available from California Advocates for Nursing Home Reform (CANHR) in Fact Sheets, resource materials and on the website at www.canhr.org.

Support Loved One's Transition to the Care Facility

The decision to consider placement in a long-term care facility like a residential care facility for the elderly (sometimes called assisted living) or a nursing home is a complex and emotionally demanding process. Pre-planning and the involvement of the person entering a care facility will help ease the transition. Unfortunately, there is limited or no planning for many placement decisions. A decision for out-of-home placement is often in response to a crisis such as a broken hip, heart attack or stroke.

Even in the best of circumstances there will be strong feelings of loss and abandonment by the person being placed and guilt by the person assuming responsibility for the placement. Acknowledging these feelings is one way to cope with the transition.

Visiting frequently can also be helpful. During some of these visits, if possible, try to meet other residents, talk to staff and explore other parts of the facility in an effort to familiarize yourself and your loved one to his/her new environment.

There are some other very practical things that can be done during the transition:

- Make sure that he/she is given a comprehensive assessment. If he/she is being discharged from the hospital, make sure they are checked for skin breakdown and possible over-medication.
- Become involved in the care planning process right away. You know your loved one the best. Assist the facility in getting to know them and work with the staff in developing a transitional care plan and then a more comprehensive one.
- Monitor their needs, changes and care during the transition. They might experience depression that will affect their appetite, sleeping patterns, motivation, and ability to socialize and to participate in therapy or activities. A new environment, a roommate, or different medications can also affect a person. Be attentive to changes and communicate them to the appropriate staff.

Make Your Visits Count

There is more to making your visits count than visiting frequently. Visit at different times and shifts and on different days of the week. It is also important to visit at meal times, when activities are planned and definitely at night and on the weekends. These strategies are important in order to get a full picture of the patterns of care in the facility and the performance and attitude of care staff at different shifts. The unpredictability of your visits can also keep the facility on its toes.

Visits can easily become routine or something that is done out of duty or even dreaded. In addition to the tips above, make a plan for weekly visits. This can bring new purpose, freshness and sometimes adventure to the visits. In making a plan, here are some considerations:

- What days and times will I visit this week? What do I want to discover this week?
- Who are the residents or staff to meet during this week?
- What section(s) of facility are we going to visit?
- What can I plan to talk about or do? Is there something that I can bring to talk about or do together? Is there someone that I can bring along for a visit?
- Anticipate special occasions and plan something special, e.g., birthdays, anniversaries, etc.
- Plan occasional outings, if possible.
- Coordinate visits and contacts from family, friends and volunteers. **Don't try to do it all yourself!**

Get to Know the Staff and Build Relationships

As part of your plan for visiting, you want to get to know all key staff on a first name basis on all shifts that care for your loved one. One of the hardest things can be turning over the direct, care-giving responsibilities to someone else, especially if you have been doing it at home for a number of years. Your new role is to provide emotional support to your loved one, to help the staff know your loved one on a personal basis and to be an advocate.

Generally, staff resent being told how to do their job but appreciate knowing more about what your loved one's likes and dislikes are and what might have worked for you. Genuine praise can go a long way in building good relationships. When you observe a staff providing good care or handling a difficult situation well, tell them that you appreciate their quality service. And let the supervisors know about good staff performance.

Develop good working relationships with key administrative and supervisory staff. The Director of Nursing and Charge Nurses for the wing will be particularly valuable resources in understanding, questioning and promoting quality care in skilled nursing homes. The administrator or supervisors in residential care facilities or assisted living facilities are also key persons.

Know the facility's policy and procedures on who you should go to with concerns or problems. Bring your concerns forward as matters come up that need to be resolved. Don't wait until you have a lot of problems or major issues. Communicate frequently and openly. Again offer positive feedback when concerns have been addressed or positive things are happening in the facility.

Be an Active Participant in All Care Plan Meetings

The plan of care describes the strategies that the facility and staff will use to enhance, restore or maintain a person's optimal physical, mental and psychosocial well-being. Care plans are based on assessments and need to be completed before or shortly after a person is admitted as a resident in a long-term care facility. Care plans are reviewed and updated whenever there are significant changes in a resident's physical, medical, mental, behavioral and/or social conditions. Skilled nursing homes have a quarterly review cycle while residential care facilities for the elderly only are required to review and update the care plan annually or when there is a significant change in the resident's care needs.

The care plan meeting provides an opportunity to evaluate whether the plan is working and to make necessary changes to better meet the individualized needs of the resident. Some tips to make the care plan work for your loved one are:

- Personalize the needs and interests of your loved one.
- Make sure that all key players will attend the care planning meeting including direct care staff.

- Bring concerns and suggestions.
- Insist on concrete, measurable plans and timetable.
- Follow up the meeting with a written understanding of what is going to be done, by whom and when.

- Make a physical inspection of your loved one. A non-intrusive way to do this is to give a back rub to your family member. It is nice for the family member and a good opportunity to inspect for signs of redness or sores. If necessary, take pictures and make complaints to the Ombudsman Program and to the appropriate licensing agency.

Monitor Care

Use the care plan to monitor the overall care of your loved one. Hold the facility accountable for carrying out the plan in good faith. As indicated above, an effective care plan will be concrete, with many areas to observe and monitor. It will give you many practical things to look for in the overall care and in specific care approaches for your loved one.

In monitoring care, consider using the following approaches depending on the circumstances:

- Keep notes. Write down important facts by answering who, what, when, where, and how questions. Describe what happened. Be as specific as possible. Use quotes if a person made an important statement.
- Check records. With the resident's permission or if you are the legal representative or health care agent, you have the right to access and to obtain copies of the medical records, care plan, nursing and certified nurses aides progress notes and resident's file. Records can be important sources to see if the care that is planned for is actually being provided. Make sure that the records are an accurate reflection of what is actually happening and that the records are not being obviously changed or falsified.
- Obtain copies of relevant files whenever there is poor, neglectful or abusive care.
- Maintain close contact with the doctor. Get a second opinion or obtain assistance to interpret medical or resident records. Check on the medications that have been prescribed and monitor your loved one's reactions.

Act as an Advocate for Loved Ones

At the heart of effective advocacy is knowledge of the rights of residents and your rights as the representative of the resident. These basic rights should be explained at the time of admission and should be posted in the facility. One of the most important rights is the right to express concerns, suggestions or to make complaints and to do so without fear of retaliation.

In exercising these rights, strive to maintain a calm manner. Act with assertiveness. Be persistent. Ask for honest communication. And insist on accountability.

Listed below are some additional tips to make your advocacy more effective:

- Follow up on all concerns identified in monitoring care.
- Ask for meetings with key people to resolve problems. Plan carefully for the meeting by clearly identifying the results that you want. It is important to summarize your understanding of the agreed outcomes, persons responsible and timetables before the meeting ends. Whenever possible, put this summary in writing and ask that it become part of the resident's file.
- Contact the Ombudsman Program to assist you in exercising your rights. The Ombudsman is the resident's advocate. A poster with the telephone number for the local Ombudsman Program must be prominently displayed in Residential Care Facilities for the Elderly and in Skilled Nursing Facilities.

- File complaints with the appropriate licensing agency. You have the right to confidentiality in making complaints to both the Ombudsman Program and to licensing agencies.

- If you suspect abuse, don't wait and try to resolve this alone. Seek help. Contact the Ombudsman Program, make a complaint to licensing, refer any physical or sexual abuse to local law enforcement and seek the advice of an attorney through CANHR's Lawyer Referral Service.

Prevent Abuse

In July 2001, the Congressional Special Investigations Division found that 35% of nursing homes in the U.S. were cited for more than 10,000 instances of abuse over a two-year period. The truth is that the percentage is probably higher because abuse often goes unreported.

In order to prevent abuse, remain active in the care of your loved one by following the tips already presented for visiting, building relationships with staff, actively participating in the care planning process, monitoring care and acting as an effective advocate. It is also critical to learn signs of elder or dependent adult abuse and know how to report suspected abuse promptly.

- Some of the signs of physical abuse in care facilities are unexplained bruises, scratches or marks on face, on inner arm or thigh or on breast or genital areas. Check for marks caused by use of restraints, e.g., belts. Look for signs of over-medication like drowsiness, dry and cracked lips, drooling and vacant stares.
- Indicators of neglectful behavior are poor personal hygiene, urine smell, residents being left unattended for long periods in bed or on the toilet, unexplained weight loss, malnutrition or dehydration, frequent falling and signs of skin breakdown and bedsores.
- Financial abuse can occur with lost or stolen personal belongings. There can also be fraudulent billing practices.

Become Active in Quality of Care Issues

You are not alone. There are hundreds of thousands of people in nursing homes and residential care facilities in California and throughout the U.S. They share many of your concerns. Do not act alone. There can be support and power by acting collectively. Group action can offer protection from the fears of retaliation and produce change that can positively affect the quality of care and life for all residents.

- Encourage your loved one to become an active member of Resident Council. A nursing home is required to have a resident council and residential care facilities must support the development of a resident council if initiated by residents.
- Family members and concerned friends can either join or form Family Council. You can obtain helpful organizing materials, including a video, from CANHR.
- Contact your state and federal elected officials about your concerns of poor care and the need for increased funding for community-based alternatives.
- Join CANHR and support legislation that will enhance resident rights and improve quality of care.

For more information, contact **California Advocates for Nursing Home Reform** or visit our web site.

This Guide is provided by a donation from Roberta Dangcil in honor and memory of her mother, Melba L. McCord.