

chapter 8

HOW TO GET THE BEST POSSIBLE CARE

Once you find a nursing home placement for your loved one, you can begin the process of easing the transition from one level of care to another. If you have been providing some or all of your loved one's care, you will notice a change in your role. Rather than functioning as a caregiver, you will become a care advocate. You will still be caring for your loved one, but in a new way.

Your key roles will be to participate in planning your loved one's care, communicating frequently with the facility staff, and ensuring that your loved one gets the best possible care in the new environment. If your loved one has assets set aside that have been properly protected using some of the techniques discussed in the previous chapter, these assets can now be used to enhance the level and quality of care that will be provided to your loved one. You can use these protected assets to hire a private caregiver or a Geriatric Care Manager, to purchase the best medical equipment, and to hire the best doctors for your loved one.

CARE PLANNING

Federal law requires every long-term care facility to create a care plan. The care plan begins with a baseline assessment, which should occur within two weeks after a resident moves into the new facility, by a team from the nursing home (which may include a doctor, nurse, social worker, dietician, and physical, occupational, or recreational therapist). This team will use information provided by the resident and the family about the resident's medical and emotional needs to generate this baseline assessment, which then

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becomes the yardstick against which the caregivers can measure the resident's progress.

You can help by making a list of your loved one's medical, psychological, spiritual, and social needs, as well as his or her preferences and usual routine. For example, you might give the staff the following type of information: "Dad likes to listen to classical music on the radio as he falls asleep" or "Mom's always been a night-owl; she goes to sleep at around 1 a.m. and wakes up at 10am." You should also note signs of depression, or symptoms of dementia. Since the assessment team does not know your loved one as well as you do, your input may be invaluable, especially if the resident is not able to provide meaningful input. Although development of a care plan is something required to be done by a nursing home, a care plan can, and ideally should, be created in advance, well before the need for nursing home care. By planning in advance, when you have a clear mind and the ability to communicate effectively, you can much better guarantee that your wishes, lifestyles and desires are documented and will be communicated to your future caregivers, whether these be family members, private nurses, home health aides, or staff in a nursing home.

The easiest way to develop your own care plan is to use a tool such as the Advance Care Plan, created by Advance Care Planning, Inc. The Advance Care Plan is a proprietary document that is created by special software that gathers, organizes, stores and disseminates information provided by you in an interview, in order to better serve your future healthcare needs and to guide those who you will depend on for future care. The Advance Care Plan identifies your specific needs, desires, habits and preferences and guides your caregiver in a unique manner. An Advance Care Plan should be created as part of your basic Estate Plan or as part of your Long-Term Care Plan, because the best person to create a care plan for

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you is you. The following example is provided by Advance Care Planning, Inc. of how an Advance Care Plan can help improve a day in the life of Lynn, a typical nursing home resident:

Lynn, at the age of 85, has been placed in the nursing home due to a stroke. She is incontinent, but if taken to the restroom at appropriate times she will be continent most of the time. She is alert, but somewhat confused at times. She very much knows what she wants but cannot always verbalize it. She is able to feed herself finger foods.

Without an Advance Care Plan	With an Advance Care Plan
5:30 AM: Awakened. Hospital gown taken off, given some quick care, dressed for the day in someone else's house dress. It is a pretty house dress, but she does not like house dresses.	7:00 AM: Awakened. Taken to the bathroom for quick morning care, then placed in a comfortable chair in her room in front of the TV with a requested show on to await breakfast. Stays in her short PJ's and a robe since it is a shower day.
7:30AM: Taken to the dining room for breakfast. Given one cup of coffee, not offered more coffee. Not served bacon due to her high cholesterol.	7:30AM: Served bacon and eggs for breakfast. Her cholesterol is high, but she stated her wishes to eat a regular diet, including bacon and eggs for breakfast, in her Advance Care Plan. She has two cups of coffee, as she has done for the last 65 years.

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<p>After Breakfast: Taken to sit in the hallway outside of her room.</p>	<p>After Breakfast: Taken to the bathroom and then to shower room. Her hair is washed, as it is with every shower per her Advance Care Plan. She prefers to shower in the morning. After shower, dressed in her navy blue jogging suit with her red tee shirt, per her Advance Care Plan.</p>
<p>1-2 hours Later: Taken to her room, has her brief changed and then is set in the hallway by the nurse's station. Her lips were not moistened, nor does she have access to chapstick.</p>	<p>1-2 Hours Later: Has her chapstick around her neck and is able to put it on herself frequently. Though her lips do not look dry, they feel dry to her. Her Advance Care Plan notes that the staff should help her moisten her lips frequently.</p>
<p>10:00 AM: Given six pills – two for high cholesterol, one for irregular heartbeat, one for hiatal hernia to prevent heart burn, one for hypertension and one for arthritis.</p>	<p>10:00 AM: Given three pills – one for hiatal hernia to prevent heartburn, one for hypertension and one for arthritis. Decided in her Advance Care Plan that if she ever entered a nursing home she would prefer not to take the other medications.</p>

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11:00 AM: Still sitting in the hall by the nurse's station.	11:00 AM: Taken outside to sit in the shade. She does not like crafts, but prefers to be outside in the shade, weather permitting.
12:00 Noon: Taken to the dining room for lunch. Given a lean hamburger, no salt allowed, a salad with lowfat dressing and applesauce. Needs assistance with the applesauce.	12:00 Noon: Taken back to her room for lunch; placed in her chair in front of the TV with her program of choice. Given a cheeseburger, packets of salt, french fries and apple slices. Her Advance Care Plan states that she does not want to be spoon-fed and would prefer finger foods.
After Lunch: Taken to the nurse's station to sit in the hallway.	After Lunch: Taken to the restroom and then placed in her recliner to rest and watch her favorite movie on her DVD player.
2:00 PM: Placed in bed to have brief changed, and rest.	2:00 PM: Still watching her movie.
3:30 PM: Placed in wheelchair and taken to ceramics class.	3:30 PM: Gets her weekly manicure instead of going to ceramics class. She does not like crafts.
5:00 PM: Taken to room to have brief changed.	5:00 PM: Taken to the restroom. Prepared for dinner.

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<p>5:30 PM: Taken to dining room for dinner. Served chicken. Lynn loves hot dogs but they are not served to her due to her high cholesterol.</p>	<p>5:30 PM: Placed in her chair in her room for dinner. Served hot dogs with green pepper slices, cherry tomatoes and veggie dip. Enjoyed a brownie for dessert.</p>
<p>After Dinner: Taken to the nurse's station to sit in the hall. There is a TV with DVD at the nurse's station; staff puts a movie on for those sitting in the hall to watch. The movie is one which Lynn has seen several times and does not like.</p>	<p>After Dinner: She continues to watch TV until 7:30 PM.</p>
<p>8:30 PM: Taken to the shower. She prefers to bathe in the morning.</p>	<p>7:30 PM: Taken to the bathroom and helped to prepare for bed. She wears her short pajamas per her Advance Care Plan.</p>
<p>After Shower: Dressed in a hospital gown and put to bed with one pillow at her head.</p>	<p>8:00 PM: Placed in bed with a talking book. It is a legal mystery, the type of book she likes. She has stated in her Advance Care Plan that she likes to go to bed by 8:00 PM to read. She is only able to make use of talking books at this time.</p>

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<p>The room is 75 degrees and she is very warm. She throws her covers off since she is too warm to sleep. The staff does come in and turn her several times. They place her on her back (she has never been able to sleep on her back) and they always cover her back up. Her brief is changed once during the night.</p>	<p>In bed, she has down pillows (5 ft.) on either side of her, between her legs, and 3 at her head, as she has slept for 40 years. The room temperature is 70 degrees, which is slightly warm for her. The temperature cannot be adjusted due to her roommate, so her personal fan is turned on to keep her cooler. She sleeps well but is awakened by the staff twice to take her to the toilet, per her Advance Care Plan. She remains continent at night.</p>
<p>The following day, she falls asleep in her chair by the nurse's station since she did not sleep well the night before. Her children come to take her out to lunch but she appears too sleepy so she does not go.</p>	<p>The following day she is rested and has a strong sense of well-being. Her children come and take her to lunch. She is gone several hours, and rests in her chair for two hours upon her return.</p>

If you have not created an Advance Care Plan prior to entering a nursing home, the assessment team at the nursing home will gather information from your friends and family members to develop a care plan. The formal care plan defines specific care the resident needs and outlines strategies the staff will use to meet them. The assessment team meets during the first month of a new resident's placement at a care planning meeting. Family members, as well as the resident, may attend. When you go to the care plan meeting,

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bring along a copy of the list of needs you gave the assessment team earlier. Together, you can discuss your loved one's needs and the care plan the team has developed. If some need has been overlooked, you can ensure that the assessment team addresses it during this meeting.

The formal care plan becomes part of the nursing home contract. It should detail the resident's medical, emotional and social needs and spell out what will be done to improve (when possible) or maintain the resident's health.

Federal law requires that nursing home care result in improvement if improvement is possible. In cases where improvement is not possible, the care must maintain abilities or slow the loss of function. For example, if your mother has a slight problem with language when she moves into the nursing home, the care plan should include activities that encourage her use of language unless or until the disease's progression changes this ability.

Federal law also requires that nursing homes review the resident's care plan every three months and whenever the resident's condition changes. It must also reassess the resident annually. For example, if your father had bladder control when he entered the nursing home, but has since become incontinent, this significant change in his status means the nursing home staff must develop a new care plan that addresses his new need.

As a care advocate, you'll want to monitor your loved one's care to be sure the nursing home is providing the care outlined in the care plan. You should also attend all care planning meetings, whether regularly scheduled or when held because of a change in your loved one's health. By being as involved as possible with the care planning process, you will help to ensure that your loved one gets the best possible care while in the nursing home.