

## EMPOWERED ADVOCACY for INDIVIDUAL SITUATIONS

BY Kathy Bradley

Long-term care is a partnership between consumer, provider, and advocate. Advocates often struggle to address the inevitable issues that arise in the care of a loved one. These steps offer effective strategies.

- 1. Stay involved.** Whether care occurs in a facility or in your loved one's home, visit often. Learn the plan of care, and make sure it meets your loved one's needs. Provide information to staff that will help the plan of care to be complete and meaningful. Communicate regularly with your loved one's social worker/care team leader.
- 2. Observe your surroundings in the care setting:** your loved one, the home/building, the staff, and if in a facility, other residents. Note anything good; let the staff know. Note anything that seems "off". Look for "trends" – more than one occurrence of something. **Write everything down in detail.**
- 3. Ask staff questions.** Work with them if you see anything that needs attention, even if it is not a trend. If not addressed, it could become one.
- 4. Become familiar with the provider's policies and applicable federal/state regulations** so that you know what should be happening. Identify specific problems or violations and talk with management staff.
- 5. Approach the provider's administration, and then the corporate leadership** if violations or problems persist. Cite the policies and regulations that are in violation; give examples of your observations and efforts to work with staff to correct them. Refer to your notes so you will be thorough and accurate when you approach these officials.
- 6. If these efforts fail, the state regulatory agency has a complaint reporting process.** They will need the information you have in writing and will refer you to the agency staff who takes reports of complaints or violations.
- 7. The regulatory agency will determine whether investigation is warranted.** Follow up with that agency after they have completed an investigation, to learn what they found and what to expect the provider to do in response.

Additional or alternative actions:

- 8. Many providers have Family Councils, organized to provide families with a voice and a venue** to discuss, learn, and interact with the administration on behalf of all consumers and their families. Often these Councils also occasionally conduct special activities for consumers. You may want to become involved with the Family Council if your loved one's provider has such a group. If not, you may want to advocate for the establishment of a Family Council.

**9.** Each state has a Long-Term Care Ombudsman program to assist consumers in advocating to resolve individual quality of care issues. You can find your state's Ombudsman [HERE](#). These programs vary in structure and scope, so ask: "Are you independent, or are you a part of a governmental agency?" and "Do you take cases in (assisted living/in-home care/day services, etc.)?" Some states serve only nursing facilities, while others serve any setting. If the program falls under a governmental agency, and the facility in question is government-affiliated in any way (funding, ownership, etc.), you will need to be alert for any potential conflict of interest.

Advocacy is hard work, requiring persistence and determination. But the rewards of success are immeasurable.