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Effective Advocacy On Behalf of the Nursing Home Resident Client

"The price of [good nursing home care] is eternal vigilance."

1. Introduction

It is a sad fact that substandard care in America's nursing homes is common. As recently as February of 2014 the United States Office of Inspector General reported as follows:

> An estimated **22 percent** of Medicare beneficiaries experienced adverse events during their SNF stays. An additional **11 percent** of Medicare beneficiaries experienced temporary harm events during their SNF stays. Physician reviewers determined that **59 percent** of these adverse events and temporary harm events were clearly or likely preventable. They attributed much of the preventable harm to substandard treatment, inadequate resident monitoring, and failure or delay of necessary care. Over half of the residents who experienced harm returned to a hospital for treatment, with an estimated cost to Medicare of $208 million in August 2011. This equates to $2.8 billion spent on hospital treatment for harm caused in SNFs in FY 2011. [**Emphasis added.**][1]

[1] U.S. Department of Health & Human Services, Office of Inspector General. (2014). *Adverse Events in Skilled Nursing Facilities: National Incidence Among Medicare Beneficiaries.* Pg. ii. (OIG Publication No. OEI-06-11-00370).Washington, DC: Author. Retrieved from http://oig.hhs.gov/oei/reports/oei-06-11-00370.pdf.

Other studies have similarly found care in our nation's nursing homes to be below par. One from 2008, also from the Office of Inspector General, found that for the period of 2005 through 2007 more than 91 percent of nursing homes surveyed were cited for deficiencies.[2] A similar report from 2003 found that,

> [t]he proportion of nursing homes that received a deficiency in any of the three categories related to "substandard quality of care" increased by 8 percentage points from 70 percent in 1998 to 78 percent in 2001. The proportion of nursing homes that received an immediate jeopardy deficiency (2.3 percent) has increased slightly from 1998 to 2001.[3]

As alarming as these government statistics are, the problems are likely much worse than reported. The data analyzed largely comes from state surveys conducted in nursing homes. Previously, the United States General Accounting Office studied the rate of missed findings by state surveyors in conducting the survey process. That study found that from 2002 to 2007 state surveyors failed to cite at least one deficiency at the most serious levels of noncompliance--actual harm and immediate jeopardy -- based upon the study's "comparative surveys" (where federal surveyors conducted their own surveys and then compared those findings with the state surveyors). The failure to cite lower level deficiencies was found to be much higher.[4]

This is not to say that all nursing homes are bad, or even that the people operating bad nursing homes are bad people. There are a number of factors affecting the quality of care in the nursing home settings, not the least of which is the level of Medicare and Medicaid reimbursement rates (although before going too far down the road of this defense, it would be wise to check out the annual profit reports of some of the larger, publicly traded nursing home chains). Moreover, the same nursing home that is deemed substandard today may very well be above standard next month, meaning that over time the quality of care in any given nursing home will fluctuate because of any number of factors – the acuity level of the residents, changes

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[2] U.S. Department of Health & Human Services, Office of Inspector General. (2008). *Trends in Nursing Home Deficiencies and Complaints.* (OIG Publication No. OEI02-08-00140). Washington, DC: Author. Retrieved from https://oig.hhs.gov/oei/reports/oei-02-08-00140.pdf.

[3] U.S. Department of Health & Human Services, Office of Inspector General. (2003). *Nursing Home Deficiency Trends and Survey and Certification Process Consistency.* (OIG Publication No. OEI02-01-00600). Washington, DC: Author. Retrieved from https://oig.hhs.gov/oei/reports/oei-02-01-00600.pdf.

[4] U.S. Government Accountability Office. (2008). *Federal Monitoring Surveys Demonstrate Continued Understatement of Serious Care Problems and CMS Oversight Weaknesses.* (GAO Publication No. GAO-08-517). Washington, DC: Author. Retrieved from http://www.gao.gov/products/GAO-08-517

in staff make-up and ratios, changes in facility corporate leadership and management, etc.

Unfortunately, many if not most of the tools available to guardians to respond to quality care issues in the nursing home focus on how to *choose* a nursing home in the first place. Nursing Home Compare[5], for instance, is a wonderful resource to see just how a particular nursing home rates in quality care indicators, but its main value comes in deciding on which nursing home to choose in the first place.

But what do you do to promote quality care for the person under guardianship for whom you are responsible as guardian, once that person is in the facility? We often hear that, in dealing with a demented patient, you shouldn't try to bring them to your reality because that's a losing battle. Instead, we're told, be with them in their reality. To some degree the same can be said for dealing with a nursing home; knowing that the reality is that there will be care problems in a nursing home, some avoidable and some not, how do we act as guardians within that reality?

That shall be the main focus of this paper.

2. The PCOPA Model

When approaching the advocacy needs of a nursing home resident client, one can draw from a number of frameworks within which to address issues. Much can be learned from the art of advocacy in the public sphere as explained for instance in The Community Toolbox[6] or the art of advocacy in the courtroom as explained by noted attorney Gerry Spence[7], or the art of self-advocacy as promoted by groups like the National Multiple Sclerosis Society[8].

One effective approach to advocacy on behalf of the nursing home resident can be referred to as PCOPA, an acronym for the following:

- **P**ersuasiveness

[5] *See* http://www.medicare.gov/nursinghomecompare/search.html.

[6] The Community Tool Box is a service of the Work Group for Community Health and Development at the University of Kansas. *See* http://ctb.ku.edu/en/table-of-contents/advocacy/advocacy-principles/understand-the-issue/main.

[7] Spence, G. (1996). *How to Argue and Win Every Time.* St. Martin's Griffin; Reprint edition.

[8] *See* http://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Brochures /Paper-Self-Advocacy-Overview.pdf.

- **C**uriosity
- **O**bjectives
- **P**ersistence
- **A**llies

Each element is important in achieving the overall goal of the guardian: to ensure that the person under guardianship receives quality care and an optimal quality of life.

2.1 Persuasiveness

As guardian, you are looking to have a nursing home do what should be done for the person under guardianship. There are two aspects to "what should be done". First, there are the things that should done according to best practices in nursing homes – things that the nursing home should know what to do and how to do it because they are in the business. Second, though, there are the things that should be done for your particular client or family member under guardianship because of their unique needs or characteristics.[9] In order to achieve "what should be done" it will be necessary to advocate for the nursing home resident. Such advocacy is at the heart of guardianship practice.

But advocacy can take many forms. One can stand on a soapbox on the corner and advocate for your point of view on a subject matter, but isn't that advocacy empty if it's not *persuasive* to the listener? One can shout all day and still not be heard. Are they an effective advocate? They may feel better about themselves, and clothe themselves with the warm, comforting embrace of self-righteousness, but at the end of the day have they achieved what they want to achieve?

In the nursing home setting, the power to persuade requires getting off on the right foot with the nursing home staff and leadership. And this is unlikely to be a one-time thing you do; staff turnover rates are significant enough that your client/family resident is very likely to be present longer than most of the staff you encounter.[10] So, from time to time, laying the groundwork for your persuasiveness may need repeating.

2.1.1. Defining Roles and Responsibilities – The Team Approach

[9] Careful observers will rightly point out that the standards of practice in nursing homes include individualized plans of care, so in reality the two aspects are really one. But for the moment, bear with me.
[10] According to one nationwide study of nursing home staffing levels, "[t]he annualized turnover rate is found to be the highest among certified nursing assistants at 74.5%, followed by registered nurses at 56.1%, and licensed practical nurses at 51.0%." *See* Donoghue, C. (2010). *Nursing Home Staff Turnover and Retention, An Analysis of National Level Data.* Journal of Applied Gerontology. Vol. 29 No. 1. Abstract.

As obvious as it may be to those of us serving in the guardianship role, the role of a guardian is not always understood by others, including nursing home staff. A guardian is *not* a health care provider. A guardian is *not* a discharge planner. A guardian is *not* just a "yes man" or someone who just signs consent forms, etc. A guardian is defined by the National Guardianship Association's Standards of Practice as "A person or entity appointed by a court with the authority to make some or all personal decisions on behalf of an individual the court determines lacks capacity to make such decisions."

A common way of thinking of guardians is as the "surrogate decision-maker" responsible for exercising "informed consent" on behalf of someone who has been deemed incapable of exercising such consent themselves. This model, however, is an insufficient one when it comes to guardians of a nursing home resident.

We say "informed consent" meaning that the experts – the doctors or nurse – are providing us with information upon which we are asked to say "yes" or "no" – yes to that procedure, no to that drug, etc. But in the nursing home setting, where the person under guardianship shall be *living,* not just convalescing, the decisions to be made are not only with regard to medical or nursing procedures. They also involve the resident's quality of life. What foods and activities do they enjoy? What were their living habits before moving to the nursing home? Were they "night owls"? Was lunch or dinner their biggest meal of the day? Briefs or boxers?

Many of these questions are incapable of being answered by the nursing home itself. They are questions the social worker in the nursing home will want answers to, perhaps, but the social worker may not know the questions to ask.

All of which is to say that the guardian and the nursing home staff need to be a team to meet the needs of the resident. The guardian relies upon the nursing home employees to provide the care and services required, but the nursing home relies upon the guardian to provide not only consent, but is many ways resident history, guidance, and direction.

As between the nursing home staff and the guardian, which team analogy makes the most sense? Is the guardian the coach? I would argue not – a coach tells the players how to do their job, how to improve their skills, etc. That's not the role a guardian must play; a guardian cannot be expected to have the expertise to tell nursing homes how to do their job. Is the guardian the CEO? This is perhaps a better analogy in that the CEO defines the outcomes she wants from the employee team, although this analogy comes across as too top-down and too egotistical.

Maybe the best analogy (and not just because I'm a lawyer) is that of "Managing Partner," in that the guardian is keeping a "team of equals" on track in meeting the needs of the nursing home resident. The guardian still holds the team accountable to the team goals (see discussion on Outcomes below), but recognizes and respects the individual expertise of each of the team members. As with a Managing Partner so it is with guardians: the power of persuasion trumps the power of commandment when it comes to achieving the team's mutual goals.

2.1.2 Being A Persuasive Managing Partner

In large part, the art of being persuasive as a guardian of a nursing home resident lies in following the other parts of this PCOPA framework. You will want to learn to be curious – dispelling the fear of not knowing something you think you should already know and thereby genuinely building your knowledge base. You will want outcomes clearly defined and measures of success towards the outcomes clearly set forth. You will need to be persistent. And you will need to build allies to your cause.

But being persuasive starts with the introduction. First impressions are important.

- Introduce yourself to both floor staff and management.

Introducing yourself to the certified nursing assistants and nurses should occur soon after admission and regularly thereafter. Obviously, you will not meet all staff tending to the needs of your nursing home resident all at once. This will be an ongoing process. If you encounter a staff person who you haven't met before, introduce yourself!

- Double-check to make sure that your Letters of Guardianship and contact information are in the nursing home resident's chart.

Asking the charge nurse to check and make sure your contact information is accessible serves as both a reminder that you expect to be contacted with regard to concerns or issues involving your client or family member, and as a means of expressing your desire to be seen as a member of the team.

- Wear a name badge or label.

Isn't it nice to be able to see a staff person's name badge as a reminder of who they are? What's good for the goose… You should have your own

name badge so staff can refer to you by name. Don't only include your name, but also your title: "Guardian" or "Guardian for John Doe". This reminds staff that you are in fact playing an important, defined role; that you are a member of the team.

- Have business cards made with your contact information.

Business cards don't cost much. Being able to hand then out freely to staff and to include in the chart will ensure that everyone knows how to get ahold of you. Handing out such cards may require navigating the intra-staff waters at a nursing facility. Some nurses or administrators will be uncomfortable with the idea that one of their Certified Nursing Assistants (CNAs) is carrying your business card around in their pocket. Some nursing facilities will feel that your giving a CNA a business card is an invitation for them to call you directly, whereas management would strongly prefer that such contact be made by one of the nurses, or the social worker, etc.

- Explain your role as guardian.

When first meeting a staff person at the nursing facility, let them know not only your name, but the role you are playing. This can be a short sentence or two. Even if you are a family member, it is still important to establish your credentials as the guardian. "Hi, my name is Mary Smith. I'm Jane Doe's daughter, but I am also the court-appointed guardian for Jane Doe. I am responsible for making sure her needs are met and making any important decisions regarding her care." (Using the term "court-appointed" is always a helpful reminder to others that as you are overseeing the work they do for your client or family member, you too are subject to oversight from a court.)

- Offer to help.

When first introducing yourself to a staff person, it is helpful to ask them to let you know how you can help. Obviously, this does not necessarily mean help them with the hands-on care of the resident, but rather to help in other ways – providing information about the resident, obtaining items for the resident such as clothing, items for the room, etc. The point to this offer is again to demonstrate your desire to be part of a team with common goals as it relates to the nursing home resident. If a request for help is in fact made (and is appropriate for a guardian to fulfill), then be sure to follow through on the request.

- Find out when care plan conferences are scheduled and attend.

More will be said about care plan conferences a bit later, but early on in a nursing home placement you will want to be sure to know when the first care plan conference is scheduled and plan on attending. Specifically asking staff to tell you when the first care plan meeting will be held is a signal to them that (1) you are aware that a care plan conference is required, and (2) that you intend to fully participate in the meeting as a team member. Moreover, this query may help demonstrate your willingness to work "within the system." While you will still need to address immediate care issues and needs before a care plan conference can be held, there will likely be longer term goals for the nursing home resident that you can tell staff "we can wait to address that at the care plan conference."

- Golden Rule.

One of the most obvious, and often-ignored rules of behavior in society: If you want respect, show respect. If you want to be heard, then listen yourself. If you want people to be responsible for their actions, take responsibility for your own. Embracing this Golden Rule as a pattern for your own behavior will strengthen your hand when you have to exert your authority as guardian, which you will no doubt be required to do from time to time. You are more likely to be seen as persuasive in situations where a care issue is unacceptable to you if your efforts at holding staff accountable are preceded by an atmosphere of mutual respect you helped foster in the first place.

In many ways, developing your powers of persuasion starts with building a reserve of good will with the staff of the nursing home. This is done by establishing your credentials with staff as the guardian, expressions of timely, sincere praise when due, and demonstrations of your "team spirit."

2.2 Curiosity

A guardian needs to be curious. Curiosity is defined as "the desire to learn or know more about something or someone."[11] The great management consultant Peter Drucker once said, "My greatest strength as a consultant is to be ignorant and ask a few questions."

Too many people bestowed with certain leadership positions (such as "guardian") believe that they need to demonstrate an "I know best" or "I knew

[11] http://www.merriam-webster.com/dictionary/curiosity

that" attitude. They fear being seen as not knowing something more than they fear not actually knowing something in the first place.

But the fact of the matter is that when you are seen as intellectually curious, you become seen as knowledgeable. In turn, being seen as knowledgeable increases your chances of being persuasive, and being persuasive increases your chances of achieving the outcomes you want for your client or family member in the nursing home.

So what do guardians of nursing home residents need to be curious about?

Well, of course, you want to be curious about the nature of the issues presented by your particular client or family member in the nursing home. They suffer from Huntington's disease? Then learn all you can about how the symptoms of that disease, the medications commonly prescribed for it and why, the side-effects of those medications, what the likely trajectory of the disease will be, etc.

You will also want to know the basics about how nursing homes are structured, who the players are, and what defines the standards of good practice in the nursing home setting. In very large part, such knowledge comes from the federal nursing home regulations applicable to any nursing facilities accepting Medicare and/or Medicaid (i.e., virtually all nursing homes).

This is really "background knowledge," worth having mainly so you are conversant in, and have context within which to engage in, the specific discussions you *will* be having with the doctors and nursing home staff about your particular resident.

What you must be particularly curious about, in your role as guardian, is how your client's or family member's *particular* disease process manifests itself in their day-to-day lives, and how their *particular* nursing home is organized, and the particular players you will be working with at the nursing home with respect to their care needs.

This is more "foreground knowledge." You can prepare yourselves in advance with certain "background knowledge" (which we will begin to do here shortly), but you can only gain the necessary foreground knowledge by being curious.

2.3 Outcomes

In the nursing home setting, the care plan is the primary tool to measure the success of the care for the nursing home resident. This tried and true process by which nursing homes will map out the plan of care for a resident is, in many ways, similar to the a standard model of strategic planning.

> "Successful RBA *[results-based accountability]* efforts involve strategic planning, implementation, monitoring, and evaluation (which will ultimately provide data that will be used in future planning and implementation efforts). Strategic planning, an essential first step in the development of a results-based accountability system, is defined as the process of addressing the following questions:
>
> - Where are we?
> - What do we have to work with?
> - Where do we want to be?
> - How do we get there?"[12]

In the context of nursing home care for our client or family member in the nursing home, what do we mean by "Where do we want to be?" The guardian's goal for their nursing home client is (or should be) shared by the nursing home itself: ensuring quality care, and achieving an optimal quality of life.

But we also learn from strategic planning processes that to achieve goals, you need to define outcomes (or objectives) along the way towards achieving those goals. Such outcomes are steps towards achieving the "goal" for the nursing home resident. They are more capable of measurement. Establishing clear outcomes allows you as the team leader to be able to measure success.

The methodology of defining clear outcomes and clear measures of success applies both when you and the nursing home staff are defining a general plan of care, and when you are addressing particular care issues and concerns as they come up. For example, if because your client or family member has a condition that makes them prone to falls with injury, then their care plan should have in place from the beginning a care plan to minimize the risk of falls and/or the risk of injuries from falls. This is a plan that will be ongoing, but there should be a clear outcome (e.g., no falls with injury) and clear measures of success, namely that all defined interventions are put into place. On the other hand, let's say that a new problem crops up – Mrs. Jones starts becoming agitated and combative with her evening hygiene care. The same problem-solving approach used in the general care plan process can and should be used to address this particular issue, too. A clear goal or outcome

[12] Shilder, D. Harvard Graduate School of Education, Harvard Family Research Project. (1997). *Strategic Planning Process: Steps in Developing Strategic Plans*. Retrieved from: http://www.hfrp.org/publications-resources/browse-our-publications/strategic-planning-process-steps-in-developing-strategic-plans

is defined – e.g., a full week of evening hygiene care without instances of agitation or combativeness – and interventions are defined to achieve that outcome.

2.4 Persistence

Thomas Jefferson is famously quoted as having said, "The price of liberty is eternal vigilance." The same price applies to good nursing home care. It is undeniable, and unavoidable, that there will be problems with the care in virtually any nursing home.

2.4.1 Choosing Your Battles

Being persistent requires energy, and it is best to understand early on that to be an effective advocate for your client or family member in the nursing home, you will need to conserve your own energy as much as possible. More than anything else, this means picking your battles wisely. This is not to say that you should "let things slide." Rather, it means to assume the best of the caregivers providing the care, politely point out the problems as you encounter them, and give them the benefit of the doubt the first time (on more significant lapses), or the first few times (on the more minor things.)

For example, if you encounter soiled linens, you need to bring it to the attention of the floor staff on the assumption that it was just missed this time. Maybe you follow this same approach even the second time. But if the problem becomes a pattern, it's time for you to take further steps to hold the facility accountable for the lapses.

On the other hand, if you observe only one staff person attempting to transfer your client or family member from the bed to the wheelchair, and you know that according to the care plan two people should always be involved in such a procedure, you need to immediately bring this error to the attention of the nursing staff.

Persistence is a quality that by definition has no conclusion. It's not as though being persistent will result in something concrete – such as never ever finding your client or family member soiled again. Forget that, because you will. The sooner this is understood, the better. Ninety percent of the time a plane is off-course, but through constant course corrections, and persistence in the navigation effort, it arrives at its destination.

2.4.2 Arming Yourself for Battle

When you do choose a battle, persistence means staying focused on the problem you are trying to address and pursuing the best routes towards a resolution of those problems. Staying focused on the issue, in a clinical way, is much harder than it sounds.

Remember that as a guardian, your role is to manage the team towards the mutual goal of good care. Do not presume that you know, or should know, the job of the nurse, or the administrator, or the activities director, etc. You don't. Those professionals will hopefully know their job well enough. But unlike them, your focus is on a particular nursing home resident among the many they will be responsible for. Therefore, your role is to identify for the staff what your client or family member needs, and to keep bringing them back to those needs until they are addressed.

You are likely to get into "arguments" or "heated discussions" with staff at the nursing home. While it is a good rule of thumb to always keep your cool, sometimes a little righteous anger is not only understandable but also effective. As a tactic, though, such anger is most effective when it is used sparingly. Let's face it: if you are one to be shouting all the time, about everything, those shouts will soon be ignored.

2.4.3 Recognizing in Advance What Victory Looks Like

When presenting problems to staff in nursing homes remember that your role is not necessarily to present solutions to those problems. It's fair to say that, because of your closer observation of the situation, possible greater life experience generally, or your own skills at creative solutions, you will sometimes have ideas to address the problems. *(E.g., "I've discovered that because Mrs. Jones' eyesight is poor in her right eye, she will become less startled and less combative if you gently approach her on her left side.")* You define the outcome you want to see, engage in the discussion with staff to find a way to that outcome, but let the staff define the plan towards achieving the outcome.

There is an added advantage to keeping these roles clear. When staff come up with the approach to solve the problem or address the issue, they own it. You now have a tool to hold them accountable.

Victory does not always mean success in solving the problem. Proposed solutions to some problems are nothing more than educated guesses as to what will work. Indeed, experimentation is sometimes necessary to determine what interventions work. The team is succeeding even when the problem is not solved right away, so long as the team defines an approach,

implements that approach, and then readjusts or rethinks a new approach until the objective is reached.

2.4.4 Celebrating Success

Celebrate with the team when a problem is solved or an issue is addressed. Recognizing success is important with every team, in every sport and in every endeavor. It reinforces the value of "team" in demonstrating that together it can accomplish worthwhile things. It also reinforces the value of each team member if the celebration includes recognition of the part played by each.

Celebrating success doesn't always require a cake or fllowers. Sometimes the best form of celebration is targeted praise – a verbal expression of thanks in the hallway, a thank-you card to the administrator (suitable for posting on the break room bulletin board) identifying by name the team members that led to success. When possible, identifying what created the success helps the team understand what worked so that next time that success can be replicated.

2.5 Allies

In the nursing home setting, there are internal allies and external allies to which you can turn in times of need. They are not always self-evident, however.

2.5.1 External Allies

The first external ally that comes to mind, of course, is your local ombudsman.

> "Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities and similar adult care facilities. They work to resolve problems of individual residents and to bring about changes at the local, state and national levels that will improve residents' care and quality of life.
>
> "Begun in 1972 as a demonstration program, the Ombudsman Program today exists in all states, the District of Columbia, Puerto Rico and Guam, under the authorization of the Older Americans Act. Each state has an Office of the State Long-Term Care Ombudsman, headed by a full-time state ombudsman. Thousands of local ombudsman staff and volunteers work in hundreds of communities throughout the country as part of the statewide ombudsman programs,

assisting residents and their families and providing a voice for those unable to speak for themselves.

"The statewide programs are federally funded under Titles III and VII of the Act and other federal, state and local sources. The AoA-funded National Long-Term Care Ombudsman Resource Center External Web Site Policy, operated by the National Consumers' Voice for Quality Long-Term Care (or, Consumer Voice), in conjunction with the National Association of States Agencies on Aging United for Aging and Disabilities (NASUAD), provides training and technical assistance to state and local ombudsmen."[13]

Your local ombudsman will likely have some experience with the particular nursing home your client or family member is in. That experience can be useful in private consultation with you in your efforts to solve particular issues. They may have seen a pattern of similar problems with other residents at that facility and offer suggestions for how to find a fix. With knowledge of any such pattern, they could also initiate their own contact with facility leadership to orchestrate a systemic approach.

The ombudsman is also empowered to be a direct ally for you in resolving care issues. As with any such resource, it should be employed sparingly in order to maximize its usefulness. Calling upon the ombudsman every time a problem arises without first attempting a resolution on your own will fatigue both the ombudsman and the facility leadership in such a way that you lose your persuasiveness as an advocate.

Your local ombudsman can be found through The Consumer Voice website: http://theconsumervoice.org/get_help

Beyond the help of an ombudsman, and with sufficient financial resources, a guardian could employ the services of a private geriatric care manager to help problem-solve in the nursing home setting.

You can locate a geriatric care manager through The National Association of Geriatric Care Managers website: http://memberfinder.caremanager.org.

2.5.2 Internal Allies

[13] U.S. Department of Health & Human Services, Administration on Aging. *Long Term care Ombudsman Program, The Purpose of the program and How It Works.* Washington, DC: Author. Retrieved from http://www.aoa.gov/aoa_programs/elder_rights/Ombudsman/index.aspx

Within most nursing homes, there are those staff members that seem to get things done. Maybe it's someone in leadership, such as the Director of Nursing, but it could also be a particular nurse working a particular shift, or it could also be a top-notch social worker, or a long-time serving (i.e. highly experienced) certified nursing assistant. Finding them requires careful observation and usually comes from regular engagement with staff members on all shifts. The point is these are people who seem to acknowledge problems in care and seem to have found ways within the facility to get them solved.

These are natural, internal allies for you as guardian. Building a relationship with them – one that acknowledges and appreciates their skills – can be useful along the way. Like any resource they should be used judiciously, but don't ignore them.

Federal regulations require that nursing facilities must allow and facilitate family councils.[14] This regulation not allows residents and/or families to form groups or councils, but to provide space for the meetings of such groups, and designate a staff person to help facilitate the work of the group.

A family council must be listened to by the nursing facility, and their complaints and concerns acted upon.

> "When a resident or family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility."[15]

The care problems your client or family member is experiencing is very likely a problem experienced by others as well. Patterns of problems suggest the need for systemic changes in the way the nursing home is operated or managed. Forming and participating in a family council is a way to build an internal alliance that is more likely to get the attention of the nursing home administration. Family councils are welcomed by the better facilities because it offers a means by which generalized concerns in care common to more than one resident can be addressed in an organized fashion. Indeed, family councils can be part of a good "quality assurance" program in that it provides good customer feedback.

3.0 Background Knowledge Basics

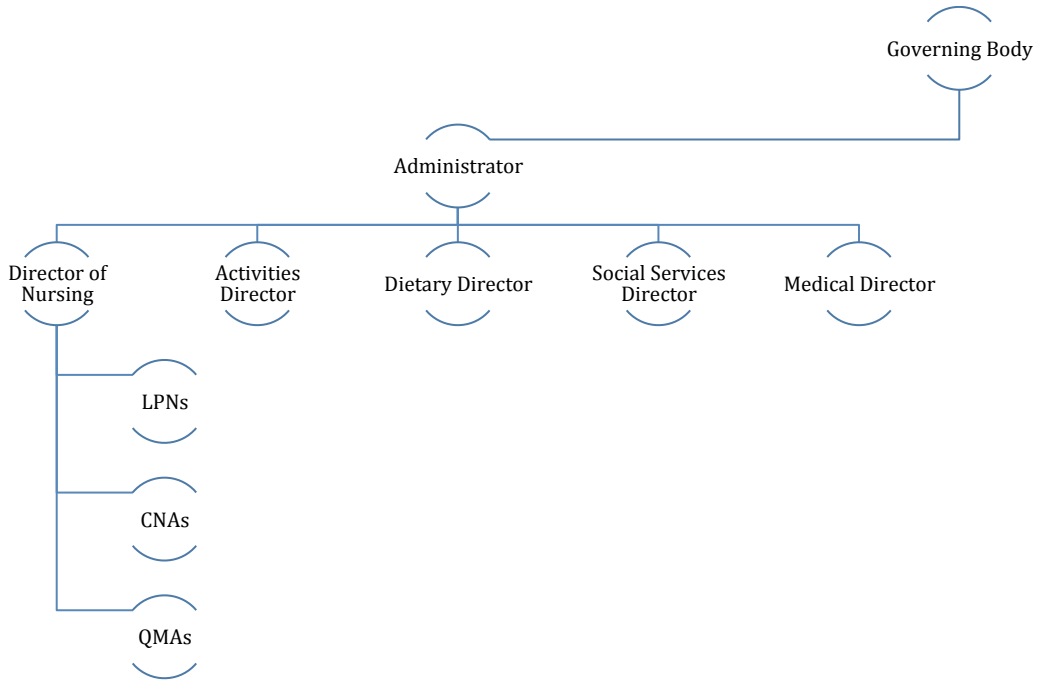
[14] 42 CFR §483.15(c)

[15] 42 CFR §483.15(c)(6)

It is beyond the scope of this paper to discuss the particulars of the diseases, disorders, and conditions that nursing home residents may experience. Thank goodness for the internet. Nowadays, if I want to get a basic understanding of Korsakoff's syndrome or Parkinson's disease versus essential tremor, or vascular dementia versus encephalopathy, then a half-hour in front of my computer will give me a good start.

But how nursing home care is structured, knowing what the common care concerns are, and what the standards of care look like, are something we can discuss here, at least in basic terms.

3.1 Nursing Home Organizational Structure



The particulars will differ slightly from nursing home to nursing home, but each nursing home has an administrator (sometimes referred to as Executive Director[16]), and Director Nursing. Because a nursing home is a multi-disciplinary setting for care, there tend to be basic departments that each have staff, and each of which is led by a director or "coordinator." By far, the largest department is the nursing department, which will employ Registered Nurses (RNs), Licensed Practical Nurses (LPNs), and Certified Nursing Assistants (CNAs) and Qualified Medicaid Aids (QMAs), and which will provide the majority of the hands on care of the residents.

[16] The term Executive Director is often used in multi-level care facilities, where there might be a nursing facility, an assisted living facility and even senior independent housing under the same roof or part of the

Some of the services provided within the nursing home may be provided by outside services with which the facility contracts – such as pharmacies, therapists, lab services, etc. Also, while the Medical Director is mandated by federal regulations to oversee the quality of medical services in a nursing home, they are almost never actual employees of the nursing home. Rather, medical directors tend to be outside physicians that contract to serve in the role as Medical Director.[17]

3.2 Nursing Home Standards of Practice and Regulations

Passed in 1987, the Nursing Home Reform Act was part of the Omnibus Budget and Reconciliation Act (OBRA) of that year.[18] This was a major change in the way nursing homes were regulated in that it established a framework for individualized care of nursing home residents, based upon their unique needs and circumstances. These regulations have changed slightly since then, but the basic framework has remained unchanged for the past 25 years.

You can find the OBRA Regulations at 42 Code of Federal Regulations, Part 483. The citation is usually 42 CFR §483. You can find these regulations online in several places. I like the Cornell University Law School web service: http://www.law.cornell.edu/cfr/text/42/part-483/subpart-B.

Within these regulations there are those that address resident rights, discharge rights, quality care requirements, etc. Here is the Table of Contents to help you navigate them:

§ 483.1 — Basis and scope.
§ 483.5 — Definitions.
§ 483.10 — Resident rights.
§ 483.12 — Admission, transfer and discharge rights.
§ 483.13 — Resident behavior and facility practices.
§ 483.15 — Quality of life.
§ 483.20 — Resident assessment.

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same campus. In such set-ups there may be individual "administrators" of each level of care reporting to the Executive Director.

[17] Interestingly, the Medical Director is usually also known as the "nursing home doctor" in that they are the doctor that serves as the primary care physician for the nursing home residents. "(1) The facility must designate a physician to serve as medical director. (2) The medical director is responsible for— (i) Implementation of resident care policies; and (ii) The coordination of medical care in the facility." 42 CFR §483.75(i). To the extent that the "Medical Director" is policing the quality of medical care in a nursing facility, she is policing herself.

[18] You will frequently hear these regulations referred to as "OBRA Regs".

§ 483.25 — Quality of care.
§ 483.30 — Nursing services.
§ 483.35 — Dietary services.
§ 483.40 — Physician services.
§ 483.45 — Specialized rehabilitative services.
§ 483.55 — Dental services.
§ 483.60 — Pharmacy services.
§ 483.65 — Infection control.
§ 483.70 — Physical environment.
§ 483.75 — Administration.

These regulations apply to all nursing facilities licensed to receive Medicare or Medicaid payments. This is the large majority of nursing homes in the country.

Here's an important point to consider: While there will be complaints about "too much regulation," most of these regulations do nothing more than codify what has long been recognized as standards of good nursing practice.

Each state will have their own sets of regulations pertaining to the care in nursing homes. State regulations apply to nursing homes licensed within the state. These state regulations often look very familiar to the OBRA regulations. So, even if a nursing home doesn't accept Medicare or Medicaid regulations, they may likely be subject to regulations on a state level (for purposes of their licensing requirements) that in many ways mirror the OBRA Regulations.

3.3 Care Planning

The care planning process is elemental to good nursing practice. OBRA Regulations specifically require individualized care plans for nursing home residents:

> "(k) Comprehensive care plans.
>
> (1) The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident's medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment. The care plan must describe the following—
>
> (i) The services that are to be furnished to attain or maintain the resident's highest practicable physical, mental, and psychosocial well-being as required under § 483.25; and

(ii) Any services that would otherwise be required under § 483.25 but are not provided due to the resident's exercise of rights under § 483.10, including the right to refuse treatment under § 483.10(b)(4).

(2) A comprehensive care plan must be—

(i) Developed within 7 days after completion of the comprehensive assessment;

(ii) Prepared by an interdisciplinary team, that includes the attending physician, a registered nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs, and, to the extent practicable, the participation of the resident, the resident's family or the resident's legal representative; and

(iii) Periodically reviewed and revised by a team of qualified persons after each assessment."[19]

Care plans start with assessments. The assessment process is a formalized process reviewing various aspects of the resident's needs and abilities. It assesses their ability to participate in specific activities of daily living ("ADLs"), such as feeding, dressing or grooming themselves. It assesses their diagnoses and the medication regime prescribed. It assesses their nutritional status, their psychosocial well being, etc. The first assessment must be completed within 14 days of admission.[20] These assessments are reviewed periodically.

The assessments can trigger certain standardized protocols of nursing care. In the OBRA Regulations scheme, these protocols are referred to as Resident Assessment Protocols ("RAPs"). From these RAPs and from other information developed through the assessment process, the care plan is developed for the resident. Bear in mind that these care plans are developed as part of an interdisciplinary team process. You, as guardian, are part of this team. The care plan must be developed within seven days of the assessment.[21]

4.0 Acquiring Foreground Knowledge

Armed with the background knowledge about how the nursing home care is organized and what the basic requirements are for nursing homes, you will want to acquire knowledge specific to your client or family member and the

[19] 42 CFR §483.20(k)
[20] 42 CFR §483.20(b)(2)(i)
[21] 42 CFR §483.20(k)(2)(i)

particular nursing home they are in. There are any number of ways of acquiring this foreground knowledge.

In general terms, if your client or family member has been diagnosed with particular diseases, then you need to become generally familiar with the disease process – its symptoms, its course trajectory, the common medications used to treat it and how and when they are to be administered, the common side effects associated with those medications, and the overall impact such diseases have on your client or family member's quality of life. You are not the doctor nor the nurse and are not expected to be the expert on the medical conditions your client or family member faces.

Remember, though, that the reason for your having an understanding of your resident's disease process is to enable you to better serve in the Managing Partner and help guide the care team towards the overall goal of quality care and an optimal quality of life.

4.1 Care Plan Conferences

In the section on background knowledge above you learned the basics of the care planning process. The care plan becomes the organizing tool for your particular client's care needs. Therefore, a guardian must fully engage in the care planning process in order to fulfill their responsibilities.

There is a customary format for care plans, which will tend to look like the following:

Date	Planning Problem/Issue	Goal/Outcome	Interventions	Responsible Discipline
2/1/14	Resident is at risk for falls because of gait disturbance and generalized weakness	Resident will not experience a fall with injury over the next three months.	Ambulate resident with assistance every shift to build strength. Use bed alarm to respond when resident attempts to get out of	Nursing

			bed on her own.	

From the guardian's perspective, the care plan is an important tool to ensure that all the needs of the client or family member are being addressed – that there is a plan in place. The "interventions" portion of the plan is the meat of the plan – the means by which you can help monitor that the goals identified are being met.

Care plans are established and reviewed within the context of a care plan conference that occur on a periodic basis. You will want to make sure that you know when these conferences are to take place and to be present. As your participation is important to the process, reasonable accommodations such as schedule changes should be made to allow you to participate.

You can request a care plan conference be convened, even if a regularly scheduled one is not due, if you identify a particular problem that requires team attention and/or if there is some significant change in your client's or family member's circumstances.

The guardian needs to be prepared for the care plan conference. This starts with getting a copy of the existing care plan so that you can review its contents, identify care issues missing from the plan, and assess for yourself whether the goals are being met with respect to those care issues that are identified in the plan.

Come to the care plan with your own agenda of questions you would like to have answered and issues that you would like to have addressed. At the meeting, ask as many questions as you need to ensure that you understand what you are hearing, take notes, and request a copy of the care plan resulting from the meeting.

4.2 Surveys

The Social Security Act requires the establishment of minimum standards of care that must be met by nursing homes participating in the Medicare and Medicaid programs. Generally, these surveys are conducted by state regulators following processes set forth by federal regulations. The surveys are conducted periodically and (supposedly) on an unannounced basis. There may also be surveys conducted in response to complaints registered with the state over a particular nursing home's care of a resident.

Following a survey, the state surveyors will complete a survey form that includes citations for any deficiencies found. These deficiencies carry "scope and severity" ratings, with the following matrix:

	SCOPE OF THE DEFICIENCY		
	ISOLATED (One or a very limited number of residents affected and/or one or a very limited number of staff involved, and/or the situation occurred only occasionally or in a very limited number of locations.)	**PATTERN** (More than a limited number of residents affected, and/or more than a limited number of staff involved, and/or the situation occurred in several locations and/or the same resident(s) have been affected by repeated occurrences of the same practice.)	**WIDESPREAD** (Situation was pervasive throughout the facility or represented a systemic failure that affected or had the potential to affect a large portion or all the facility's residents.)
(Immediate jeopardy to resident health or safety)	**J**	**K**	**L**
(Actual harm that is not immediate jeopardy)	**G**	**H**	**I**
(No actual harm with potential for more than minimal harm that is not immediate jeopardy)	**D**	**E**	**F**
(No actual harm with potential for no more than	**A**	**B**	**C**

minimal harm)			

The survey itself contains a "tag" number citing the regulation violated, a statement of the problem identified by the surveyor, and how that problem was in violation of the standards set forth by the regulations. To the right of each citation is a column where the facility must provide a "plan of correction" to demonstrate to the state surveyors how the facility intends to correct the problems identified.

The surveys for your client or family member's nursing home is required to be available to the residents (and you as guardian) and easily accessible.[22] Examining these surveys will give the guardian some idea of past citations applied against the nursing home and (perhaps more importantly) what the facility has promised to do to correct the problem. You may see problems identified in surveys that are familiar to your own experience with respect to your client or family member. If so, then your efforts to address the problem can include bringing the administration and staff back to the solutions they themselves proposed in their plan of correction.

4.3 The Nursing Home Record

Each nursing home resident will have their own clinical "chart" or "record". Within this record there will be the assessments previously discussed, the care plans, physician orders, medication administration records, "flow sheets" that document the resident's input and output, food consumption, and other measures, vital signs, lab reports, and progress notes for each of the disciplines – medical, nursing, nutrition, activities, social services, therapy, etc.

These various notes and flow sheets provide the reader with valuable information concerning the resident's experience of care in the nursing home. The chart is kept not merely because it's required under the law, but because it forms the basis for continuity of care of the resident from month-to-month, day-to-day, and shift-to-shift. Each entry in the chart informs the next person providing care what came before.

You, as guardian, are entitled to inspect the nursing home record. Here's what the law provides:

> "(2) The resident or his or her legal representative has the right—

[22] 42 CFR §483.10(g).

> (i) Upon an oral or written request, to access all records pertaining to himself or herself including current clinical records within 24 hours (excluding weekends and holidays); and
> (ii) After receipt of his or her records for inspection, to purchase at a cost not to exceed the community standard photocopies of the records or any portions of them upon request and 2 working days advance notice to the facility."[23]

Even though there are plenty of abbreviations, technical terms, and sheer bad hand-writing to muscle through, the exercise of periodically examining your client or family member's chart is valuable on several levels. First, you *will* be able to understand much of what's in the chart. Second, the mere act of asking the nursing staff a question about what a certain entry means will form the basis for a dialogue about issues that are important from your perspective as guardian. Third, developing a pattern of inquiry into the record will let staff know that you take your responsibilities as guardian seriously, and that you intend to be informed.

Now, having said all that, it is a fact that when a guardian or family member asks to look at the record, the nursing home can become defensive. Why do you want to see it? What are you looking for? What parts do you want to see?

The best way of defusing the defensiveness is to make looking at the record a regular habit, starting early on in your role as guardian. Doing so, you can explain in words and by action, "It's how I keep informed and do my job as guardian." Once the facility becomes used to your habit of examining the record, that natural defensiveness should be dispelled.

[23] 42 CFR §483.10(b)(2).