



Talking To Professionals *An Insider's Guide*

You're going through a stressful time, and talking to professionals shouldn't add more stress to your life. Here are a few tips for having successful interactions.

1. **Most professionals don't realize they've slipped into "geek-speak,"** so feel free to remind them to speak in terms you understand. Please don't terminate (or agree to terminate) the interaction until you understand.
2. **Have your agenda prepared ahead of time.** Make a list of what you want to discuss, and go into the appointment ready. Use the attached template to help you plan this out.
3. **Do not leave the appointment/meeting until you've had your questions answered and you understand the plan for going forward.** Although questions do occur to all of us after the fact, ideally, you should leave the visit feeling confident you can recount the visit to a family member and answer any questions.
4. **"Good luck" is NOT professional advice!** My sincere belief is that professionals have an obligation to either help you or, if they are not able to provide the help you need, to point you in the right direction. This is one of my pet peeves, as I get lots of calls from people whose heads are spinning--they've essentially been told 'Good-bye and good luck.'
5. **Call out professionals who aren't nice to you.** You are paying for a professional service, which means the service provider works for you. There's never a reason for a professional to be a jerk to you! On the flip side of that, it's okay for you to be nice, too :) We know we aren't meeting you on the best day of your life, but we really want to help you and that's easier to do when we can all be pleasant.



Hugs & Endless Buckets of Patience!

Christy



Insider Lingo (AKA Geek-Speak)

Understanding the alphabet soup of long-term care services can often feel like learning a whole new language. This list, though not comprehensive, covers the terms you're most likely to encounter. Some terminology you may see only in chart notes.

AAA	Area Agency on Aging; also called by other names depending on location
AD	Alzheimer's Disease; most common cause of dementia
ADL	Activity of Daily Living, eg, brushing teeth, bathing
ALF	Assisted Living Facility (also, "AL")
APS	Adult Protective Services
Bedlock	Usually in a SNF, when desirable beds aren't available; can cause families to be pressured to agree to a room change
CCRC	Continuing Care Retirement Community; offers multiple levels of care on same campus and usually requires a buy-in fee
CHF	Congestive Heart Failure
COC	Change of Condition
COPD	Chronic Obstructive Pulmonary Disease
Cornell	Cornell Scale for Depression in Dementia; observational scale to assess for depression
CPR	Cardiopulmonary Resuscitation
DHS	Department of Human Services
DNR	Do Not Resuscitate; in the absence of this written order, all persons are considered "full code," ie, use every intervention necessary to resuscitate
DSS	Department of Social Services
ED	Emergency Department or Executive Director
EMS	Emergency Medical Services
ER	Emergency Room

FAST	Functional Assessment Staging Scale; used to assess for hospice appropriateness, correlates with GDS. For dementia, two or more must be true in level 7
FTD	Frontotemporal Dementia
GDS	Global Deterioration Scale for Assessment of Primary Degenerative Dementia; used to determine stage of disease process; correlates with FAST
H & P	History & Physical; report of visit with PCP
HIPAA	Health Information Portability and Accountability Act; used to ensure privacy
IADL	Instrumental Activities of Daily Living; eg, placing a phone call, balancing a checkbook
ICF	Intermediate Care Facility; commonly called a “nursing home;” for people who do not meet criteria for AL and require more supportive care 24/7
ICU	Intensive Care Unit
IHSS	In-Home Supportive Services
IL	Independent Living
LBD	Lewy Body Dementia
LOC	Level of Care
LTC	Long Term Care
LTCI	Long Term Care Insurance
MAR	Medication Administration Record
MMSE	Mini-Mental State Exam; commonly used in PCP offices and no longer preferred test
OT	Occupational Therapy
PAINAD	Pain Scale for Advanced Dementia; observational scale to determine pain; more accurate than asking a person living with dementia
PCP	Primary Care Provider
PD	Parkinson’s Disease
POA	Power of Attorney
POLST	Physician Order for Life Sustaining Treatment; the hot pink document
PRN	As needed; direction often used for pain medication that is very ineffective for people living with dementia
PT	Physical Therapy
RCF	Residential Care Facility
SLUMS	St Louis University Mental Status; preferred test
Sig Change	Significant Change in Condition
SNF	Skilled Nursing Facility

SPD	Seniors & People with Disabilities
TAR	Treatment Administration Record
TCU	Transitional Care Unit
UR	Utilization Review
URI	Upper Respiratory Infection
UTI	Urinary Tract Infection



Scripts for Effective Advocacy

I've often said my first word was "why?" and it's one of the huge keys to my success in the work I do. Make "Why?" and other questions an integral part of your repertoire, too.

Remember that YOU are always the expert on your loved one! For example, I've worked with over 1,110 people living with dementia, so I likely have way more experience with dementia than you, but I surely don't have the same knowledge you do about what your loved one likes, or hates, etc.

As with any other area of life, including "please," "thank you," and a smile will take you a long way toward getting the result you want ;)



On proposed treatments, medications, behavioral interventions:

- Why are you recommending this?
- What's the advantage of this treatment/recommendation/method over 'x' other option?
- What are the drawbacks to this treatment/recommendation/method?
- What are the alternatives?
- How will we know if it's working?
- When should we expect to see results?

***Pro Tip:** Restraints are not acceptable, either physical or chemical. Isolation is not acceptable.



On behaviors, falls, infections:

- Why did this happen in the first place?
- What can be done to make sure it doesn't happen again?
- Who will be responsible for implementing the changes we just discussed?

***Pro Tip:** People do have the right to fall, but that doesn't mean every effort shouldn't be made to prevent falls.



On proposed/recommended/"standard" tests:

- Why are you recommending this?
- What are the AMA guidelines on testing for this for people in my parent's overall condition/age?
- Assuming a bad result, what is the recommended treatment or medication?
- What are the possible adverse side effects of the recommended treatment or medication?
- How do other people in my parent's current condition typically come out on the other side of the recommended treatment/medication?
- What is the typical duration of the recommended treatment/medication?

***Pro Tip:** Carefully weigh quality of life vs quantity of life, prognosis with and without test (& follow-up treatment if a bad result), and any information in your parent's advance directive for health care or POLST before making a decision.



On poor communication from staff in assisted living or memory care:

- I need to be contacted when 'x' happens. Please pull the medical record now so I can ensure you have my up-to-date contact information. [Insist this happen right now, while you're standing there]

After contact information is verified:

- What prevented me from being contacted this time?
- What can be done to make sure it doesn't happen again?
- Who will be responsible for implementing the changes we just discussed?

***Pro Tip:** Be very explicit in when you want to be called (circumstances, times of day), which number should be used and when, and who should be called next if you aren't available.



On pressure to agree to a room change:

- How will this benefit my loved one?
- What is the downside to this room change?
- Why am I being asked to do agree to this?

Perfectly acceptable answers:

- No.

- I'll think about it and get back to you by 'x'.

***Pro Tip:** Room change recommendations are sometimes made because a person is experiencing a significant change and staff feels it would be safer if the person was closer to the nurses' station, or had a private room to accommodate increased family visitors at end of life. However, room change requests can also be made because it would help the building break a bedlock and increase their census. Make sure you know the 'why' behind the request.



On pressure to discharge from hospital before you believe it's safe/you're not able to provide necessary care:

- What is your rationale for discharge at this time?
- Walk me through what this looks like so I understand completely.
- This doesn't sound like a safe discharge plan to me. How will you make it safe?
- I am not able to provide for his/her needs at this time. How are you going to help me?
- What resources are available to me?
- What are you going to do to help me?
- Who is responsible for [name each component of discharge plan], and when?

***Pro Tip:** You must receive a written intent to discharge/termination of services or benefits at least 72 hours prior to discharge. This will also give you instructions on how to appeal. It is not uncommon for families to be pressured to make quick decisions with very little information. Rather than capitulate, please use the above questions AND call a family member, friend, or professional you trust to run the information by--you will almost certainly be asked questions/get input that hadn't occurred to you and can save you grief down the line.



On lack of providing pain management:

- Why are you certain my parent isn't in pain?
- Are you using the PAINAD Scale to make this determination?
- What leads you to believe my parent can accurately report pain despite having a dementia diagnosis?

***Pro Tip:** Ask for a 72-hour trial of medication if there's doubt about pain, then document changes in mood and behavior during the trial. Ask for a routine order if positive changes occur in the trial period. Avoid narcotics if at all possible, as they will significantly increase risk of falls and may also cause hallucinations. Always avoid Ultram (although not considered a narcotic) as it can cause hallucinations.



On refusal to refer to hospice:

- On what basis are you refusing my request for a referral?
- What evidence is available to help me understand your refusal?

Pro Tip:** Although rare, some PCPs take issue with the "6 months or less" criterium for hospice, stating they "don't have a crystal ball." While this is technically true, the determination for service is actually up to the hospice team and will, at the very least, give you a better idea of when your parent will be eligible for service. If you believe hospice could be appropriate and your parent's PCP refuses to cooperate, contact hospice directly; their team will help you make it happen. ***The truth is, the vast majority of people are only on hospice service for an average of 18 days before death; they are entitled to at least 6 months.



Service Date:
Provider:
Specialty:
Reason:



Chief concerns:

- 1.
- 2.
- 3.



Why I have these concerns:



Changes in condition/abilities since last visit:



Changes in medications since last visit:



Changes in living environment since last visit (include any hospitalizations):



Other providers seen since last appointment (include when, and any trips to ED or Urgent Care):



Provider's input on my concerns:



Our plan moving forward:



Action items/notes:



Per provider, follow up in ____ months OR if _____ happens.



Pro Tip: Do not leave until you can answer YES to the following questions!

Y/N I understand everything covered in this visit today.

Y/N I understand WHY the provider is making the recommendations/changes outlined today.

Y/N I can easily explain this later today to a family member who has questions.