

Patient Care From A Family Perspective

10/16/00

given at in-service program

Thank you for giving up your time today to come so we could talk. I appreciate the fact that you are concerned, not only with the care of our loved ones, but with how we, the family members, perceive that care.

First of all, I want to acknowledge the hard job that everyone in a "care facility" faces every single day. Most of us know that you are not paid commensurate with the work you do, that you risk injury from lifting/moving residents, and on and on. Normally, most of the family members understand that and most of the time remember it. When we do forget the complexities of your job it is usually because we perceive, whether it is true or not, that our parent, husband, wife, etc., is not being given the care they are paying for and deserve!

One of the biggest problems I have is emotional. I see that my strong, independent Mother has lost control of her life. My entire family has lost control in that we do not have the woman that we have leaned on and taken advice from our whole life. Our family has changed forever and the loss after a year is still almost impossible to comprehend. Though we try to spend as much time as possible with my mother, because of distance, age, and the requirements to work to earn a living, my mother is totally alone in your care for a great portion of each day. In essence, my mother is either taken care of or not taken care of while you are on duty.

One Sunday morning, after spending the night with my mother, I woke to find Mother's breakfast tray placed on a table where, even if she was able to feed herself she could not have reached it. No one came to feed Mother even after being asked. If someone had come in and said "We are short staffed; could you feed your mother for us?" I would have said yes. However, it seems that if anyone is "visiting" it is automatically assumed that the "visitor" will take care of the needs of my mother. This attitude concerns and angers me. If staff become dependent on our family, what happens when we cannot be there and staff "assume" my mother is being taken care of? This attitude has caused great concern to my father and me when we have been sick and unable to be with my mother and even worse, had us coming in sick when we might have exposed my mother to germs she couldn't fight just to reassure ourselves she was okay.

One day while at the nurses station, a call for a resident was turned off and in a couple of minutes I asked if they were going to respond, I was told, "No, it's just their normal call at this time." I was astounded! If a resident calls every day at the same time, what if one day it is a true emergency??? Even if a call is for "just reassurance," shouldn't the resident be reassured that someone is watching over them?

When ringing for assistance, a response time of 60 seconds can seem like an hour and five minutes like a day. When the call is responded to and you are told "that's not my job," the blood begins to boil. This is my mother we are talking about! A simple change in response - - "I can't handle this, but I will get someone to assist you as soon as possible" along with

a smile can make all the difference.

Talking to me, instead of my mother, belittles my mother. She has had a stroke, has difficulty making herself understood, but she is not senile - - quite the contrary. She is very much with it. My mother is ill - - SHE IS NOT DEAD!! Please do not be rude in your responses when being asked to assist. Please do not treat my mother like a stick of furniture when you come into the room; please do not talk to her as if she is a child or talk as if she couldn't possibly hear or understand what you are saying. Please do make eye contact with her. Please do smile at her. Please do let her know that she is cared for and that you personally know that whatever shape her body is in that her mind and intellect shine out from her eyes.

I could go on about every little thing that occasionally irritates, but that is not what I want to accentuate. Family members are grieving for the lost of our loved one; we are angry at the loss of their former being," we are angry at our loss of our "old" family life; and we are angry at ourselves for not being able to take care of them in their own home. This grief and anger frequently overflows onto you.

Logically, even though we are told that each resident is given two hours of care a day, we know that most days that is impossible. Someone calls in sick; there is an emergency with one or more patients, and that eats up a great deal of time. And, if our parent is having an emergency, they would be eating into another resident's allotted two hours. Emotionally, we do not care about these problems, we want our loved one taken care of and allotted the whole two hours promised. Logically, we know that the workers on duty, with paperwork, breaks and lunch, would find it almost impossible to spend two hours a day with any one resident due to the number of residents versus the number of nurses, CNAs, etc.

What I do want for my mother:

Don't avoid making a show when family is "visiting," explaining that you are saving care-time for when our loved one will need it most. Please continue normal routine care even when we are visiting.

All staff should remember that every resident is someone's mother, daughter, father, son, husband, wife, etc. Treat each individual as you would want to be treated if you were confined to a bed or chair.

All staff should keep reminding themselves that no two residents are the same and each has individual personalities and needs.

All staff should remember that family members are not a threat. We do want the best possible care for our loved one and sometimes can come on too heavy. Try to put yourselves in our place, and we will try to put ourselves in your place.

All staff should realize that we are not mind readers and that we know that we can irritate you as much as you do us. Tell us when we are getting in your hair and in your way. Take the time to educate us a bit, and it will make it easier for all of us. Communicate with us.

All staff should take the time to really listen to us and to what we are saying. When an explanation is required, give it to us, don't just "blow us off."

All staff should acknowledge that trust is a two way street and it has to be earned

by both parties. When things aren't going well and you need help, explain the situation to us and ask for our help - - don't assume. Family members will soon learn that they can be "up-front" with you as you are "up-front" with us.

REMEMBER that none of us is trying to take over your job because we know we couldn't. We will also try to say "thank you" more often.

We know that everybody's needs are special, no two people are the same; and trust goes both ways. Remember, the resident's room is "their home away from home," and we just want what is best for them.

Thank you for the opportunity to speak to you. But most importantly, thank you for taking care of my mother and working with me to make our stay a better experience for all concerned.