



Penn

UNIVERSITY *of* PENNSYLVANIA

Penn Memory Center welcomes you to

Caring for the Caregiver:

people caring for som

Questions? Contact:

Felicia Greenfield, LCSW

Executive Director, Penn Memory Center

felicia.greenfield@pennmedicine.upenn.edu

Caring for the Caregiver: Week 6

- **Communicating with your Support Team**
 - **Planning for the Future**

Effective Communication

- Assertive communication can be difficult when we are experiencing stress.
- Being Assertive requires straightforward skills that not all people possess or know about.

Continuation of communication styles:

Passive

Assertive

Aggressive



Passive Communication

- Failing to express our feelings honestly.
- Thoughts and feelings are expressed indirectly and apologetically.
- Allows others to violate our rights and shows a lack of respect for our own needs.
- Seeks to please others and to avoid conflict at any cost.
- Sends the following message: “I don’t count. You can take advantage of me. My feelings don’t matter; only yours.”

Passive Communication: An Example

Sylvia takes care of her husband, who has memory problems. Sylvia has arranged for her brother, Daniel, to stay with her husband while she attends a weekly one-hour exercise class. An hour before she's scheduled to attend her class, Daniel calls to say he has changed his mind and he won't be coming after all. Sylvia responds by saying, "that's ok, I didn't really need to go after all, I guess." She begins to think that perhaps she is being selfish for asking to take some time away from the house at all. After all, she's sure Daniel has his own problems.

Aggressive Communication

- Involves standing up for your personal rights and expressing your thoughts in an inappropriate way (ie: attacking, yelling).
- Violates the boundaries of the other person.
- Seeks to force the other person to lose.
- Sends the following message: “this is what I think, and you’re stupid for disagreeing. Your feelings and wants don’t count.”

Back to our example:

Sylvia responds to Daniel's decision not to come by saying, "I'm sick and tired of you always giving me a hard time. You're so unreliable. You've always been this way! How could you be so thoughtless? Don't bother to come for Thanksgiving."

THIS
ISN'T
WHAT I
WANTED.



I
KNOW.



YOUR COMMUNICATION
SKILLS ARE SO POOR
THAT I GAVE UP TRYING
TO UNDERSTAND WHAT
YOU WANTED AND
INSTEAD PUT SOME
RANDOM NUMBERS ON
A SPREADSHEET.



Dilbert.com DilbertCartoonist@gmail.com

4-2-11 © 2011 Scott Adams, Inc./Dist. by UFS, Inc.

WHY
DIDN'T
YOU JUST
ASK ME TO
CLARIFY?!



APPAREN-
TLY YOUR
LISTENING
SKILLS
NEED WORK
TOO.



Assertive Communication

- Involves standing up for your own personal rights without violating another person's rights.
- Involves expressing your thoughts directly and honestly.
- Involves two types of respect: that for your own needs and feelings, and that of the other person's needs and feelings.
- Increases the chance your requests are heard correctly, which will lead to a better result.
- Engages you in a process of problem solving and negotiation.



Back to our example:

Sylvia takes a second to take a deep breath and says, “it’s very important to my health that I get a break from caregiving. I’d like to talk to you about this and try to work something out.”

What do you think *your* communication style is?

Tips for Assertive Communication and Getting the Help you Need

- Make a specific ask
- Explain specifically why this would be helpful to you and your loved one. Take opportunities to provide education, which builds empathy.
- Avoid thinking of requests as ‘either/or.’ Stay open to negotiation and compromise.
- Stick to the present issue. Do not raise issues from the past (ie: “you NEVER show up for me.”)
- Prepare them for what they may encounter in terms of language, behaviors, etc. and tell them how you handle these situations

Tips for Assertive Communication and Getting the Help you Need, Con't.

- Explain how you'd like for them to bow out if they need to (ie: "I understand that this may become unmanageable – if you're not able to come, please try to let me know a few days in advance so I can arrange for an alternate)
- If you are still learning to ask for help verbally, consider using a tool like Lotsa Helping Hands (<https://lotsahelpinghands.com/>), or Caring Bridge (<https://www.caringbridge.org/>)
- Express gratitude often

Another Example:

Sam says, “I don’t understand why my daughter won’t come around more than once a month or so. I mean, she lives in the same neighborhood as us – how hard could it be to stop by and see her mother? These are the last years of her life. Doesn’t she want to spend time with her? I know she’s busy with work, but this is only an hour out of her day. The other day she texted me, “let me know if you need anything. I can swing by the grocery store and pick up some food for you.” But that’s not the kind of help I need – my wife loves to go to the grocery store as an outing. Then I saw on Facebook that she had posted how hard it is to watch her mom decline. Hard for her??? She never sees her! I’m the one that lives here!”

Journal Entries

Take a minute to reflect in your journal:

- What would you suggest to Sam to help him communicate more effectively with his daughter?
- What are some areas in your own communication style that you would like to modify or enhance?
- What are some barriers?

Tips to help you Communicate with your Doctor:

1. Bring a list of questions;
2. Be clear and concise when reporting change in PWD status;
3. Ask doctor how they prefer to communicate between appointments;
4. Sign up for health system's EMR portal (My Penn Medicine)
5. Get to know support staff (nurse/PA, social work, receptionist)
6. Recognize that not all questions have answers; not all problems have solutions;
7. Educate yourself about the illness;
8. Have realistic expectations about what your doctor can do.

Future Care Planning

- Progression of Neurodegenerative disease is different for each person.
- Advance planning allows you make decisions before possible crisis happens.
- Ideal care plans will have multiple options. For example:
 - Plan A: Keep person home with me and care for them for the duration.
 - Plan B: Keep person home with me and bring in professional help when needed;
 - Plan C: Eventually move person to memory care/skilled nursing

How to pay for care

- Medicare covers doctor's visits, hospitalization, medications, and skilled nursing for a short-term, rehabilitated need.
- Medicare does NOT cover:
 - In-home dementia care
 - Assisted living facilities
 - Memory care facilities
 - Skilled nursing facilities

These are out of pocket expenses unless your person is Medicaid eligible. If so, PCA will cover some in-home care and skilled nursing can be covered by Medicaid.

General Tips for Care Planning

- Who needs to be involved?
- What are the specific care goals?
- Acknowledge reality of strengths AND limitations (time, energy, finances, etc.)
- Have a family meeting – invite mediator if needed.
- Document the plan and share with individuals involved.
- Create a Power of Attorney (POA).
- Consult with an Elder Law Attorney.

Power of Attorney

- Durable Power of Attorney (DPOA) – designated agent to act on behalf of individual once they can no longer act themselves (as designated by at least 1 doctor and an attorney). POAs can gain access to the following if the person is unable to manage:
 - Banking
 - SS or other retirement benefits
 - Medicare
 - Online patient portals/medical records

Living Will

- A living will documents the person's wishes for medical care when they are not able to communicate them. Decisions discussed may include:
 - Use of artificial nutrition
 - Ventilator use
 - CPR
 - Pain management methods

Consider visiting Penn's My Care Wishes (<https://www.ourcarewishes.org/>) for more information about living wills.

Thank you!

- We hope you found this class helpful.
- If you have specific questions upon completion, please email them to felicia.greenfield@pennmedicine.upenn.edu.
- If you are interested in joining an ongoing monthly caregiver support group, please email felicia.greenfield@pennmedicine.upenn.edu.
- I will respond to all email inquiries within a week and may ask a colleague to reply on my behalf.

- Visit the Alzheimer's Association website: Alz.org
- 24/7 Hotline: 800-272-3900