SHARING WITH OTHERS

Suggestions for
Sharing Information, Support, & Intervention Ideas with Caregivers about a Person with Cognitive Impairment

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TO KEEP IN MIND

1. All of us who are **caregivers are also educators and supporters**. We are obligated to share information and interventions ideas with each other (and with a person with cognitive impairment) in an effort to improve our ability to help someone with cognitive impairment. This handout is about sharing with caregivers.
2. Sharing could include simply **informing** another caregiver about what has happened that day, observations we've made about what a person needs or what makes them feel more comfortable or happy, or new information about a disorder, **explaining** how to do something or why something is important, **giving ideas** for interventions or modifications of interventions they have been trying, **problem solving** with them, **teaching** them a skill or a new level of understanding, **advising** them to try interventions, to have more empathy for a person they are helping, or to get more rest, **delivering** things they need to improve their caregiving such as a book, handouts, equipment (such an assistive device or new technology), **listening** to them as they share emotionally and intellectually , or **encouraging** them in a way that boosts their self confidence and pleasure in their caregiving.
3. We may be sharing as a peer or colleague, a supervisor, advisor, consultant, health care professional, family member, friend, community service provider, support group member, religious counselor or mentor, teacher/trainer/professor, or in some other capacity.
4. Sometimes a person with mild cognitive impairment is caring for themselves and we may be sharing information and ideas with them that is similar to the information we might share with caregivers.
5. In general, when we share with a caregiver we need to consider using the same strategies and caution that we use with persons with cognitive impairment. We need to try to **read the person** we are sharing with and to "sit in their skin" or **see** things **from their perspective**. We need to be sensitive to their **emotional status** and their sense of **timing**. We need to share when they are **most receptive**, that is, most ready to receive and understand what we are sharing. We need to **tailor** what we share and how we share it to the individual caregiver and the situation.
6. Most interventions that work best with a person with cognitive impairment are quite **simple**. But to work, they need to be used consistently and with compassion and understanding.
7. Sometimes we are frustrated with a caregiver's style and apparent ineffectiveness. We wonder why they don't use the advice we give them. We need to keep in mind that **caregivers may not do simple interventions because** they:
    a. **Think they are** doing the intervention. They may not see themselves or the situation objectively.
    b. Are **exhausted** emotionally & physically so they simply don't and sometimes can't.
    c. Are **too occupied** or busy. There is too much to keep track of, so they miss opportunities or evidence that the person they are caring about and for needs or wants something.
    d. Think the intervention is so small or minor they **don't need to** do it, for example establishing eye contact or getting a person's attention before speaking.

   e. Don’t think of the intervention; it just **doesn’t occur to them** at the time.
   f. **Don’t understand the disorder** and the brain functioning underlying it.
   g. **Don’t know or understand the person** they are caring for.
   h. Are **emotionally distressed** or stressed at the moment. They may be angry or anxious.
   i. Are **cognitively impaired themselves**, with a brain disorder or for some other reason.
   j. Assume the problem or cause is the brain disorder, so **believe the intervention is useless**.
   k. Aren’t used to analyzing people, interactions, needs, or situations, and problem solving, so they **don’t know** to do it or **how** to do it.
   l. Have always been dependent on the person with the cognitive impairment (or on people similar to that person), so they have **difficulty seeing that person as needing help**.
   m. **Afraid** of the person with the cognitive impairment so they don’t feel they have the power or permission to meet that person’s needs or desires, especially if that requires preventing that person from doing something. This might occur especially when the caregiver has been abused.

8. We need to think carefully about how we interact with a caregiver. Here are some suggestions. As you can see, they are very similar to strategies we might use when interacting with someone with cognitive impairment.

SUGGESTIONS FOR SHARING

THE CAREGIVER

9. See the caregiver first, as a **person**. Try to understand their goals and dreams. Consider their cultural and ethnic background, age, their first language, what they were like before they were a caregiver, and their current health, physically, emotionally, and cognitively. What tasks and **challenges** are they now facing? Note the level of functioning or severity of cognitive impairment and other challenges the person they are caring about and for are facing.
10. Consider and address all aspects of the caregiver (that is, the **whole person**), the emotional, physical, cognitive, and spiritual as you interact with them.
11. Try to **see from the individual caregiver’s perspective**. Avoid assuming they will react or think like you do, or that they have the same assumptions and beliefs about ethics or health that you do.
12. Consider the caregiver’s **needs at this moment** in time, especially during times of transition or difficulty, such as when the person with cognitive impairment needs to move to another residence, has to stop performing a task like driving, no longer recognizes the caregiver, or is hurting the caregiver.
13. Note the **changes and fluctuations** in circumstances and the caregiver’s needs and emotions as the disorder either improves or becomes more severe.
14. Every time you are with the caregiver **assess** the caregiver again in your own mind. They will change over the course of your relationship and fluctuate from time to time. Watch their body language and their words. Don’t assume they can tell you how they are.
15. Note if there are **other demands** on this caregiver that might be unrelated to the person with cognitive impairment.
16. Note the **resources** this caregiver has available, including social and financial sources of support.
17. Caregiving may be new to this caregiver, so **don’t assume they know the basics**. We might forget that when we have been caregivers for so long.

YOUR PERSPECTIVE

18. See the caregiver and the person they care about and for individually and as a **unit.** Consider each and both of them in your thinking and your recommendations. Consider how they interact and what their relationship with each other is. Watch them interact with each other. Avoid assuming you are there primarily for the person with cognitive impairment. For you to be effective, you must consider the person with cognitive impairment and the caregiver within the caregiving network. Get to know the other caregivers as well.
19. Clarify your own feelings and views about the caregiver. Make sure you **respect** this caregiver and assume they have potential and the ability to grow and learn.
20. Clarify the **goal** of your time with the caregiver. What is the order of priorities: for example, to build their confidence, give them information, help them problem solve and think of ideas, foster the independence of the caregiver (particularly if they are rather isolated), or help them emotionally through a hard decision?
21. Consider your **relationship** with this caregiver. What will you call them? What might they expect from you? Clarify that early in your time with them.
22. **Model** in your relationship with the caregiver how the caregiver might best interact with the person with cognitive impairment.
23. **Show empathy** and compassion. Acknowledge their feelings, before trying to discuss issues or interventions. They may be feeling guilt or anger. When their behavior reflects their anger, assume their behaviors represent an unmet need or desire on their part, even as you work to **protect the person** from the caregiver's anger and frustration.
24. If you intend to communicate with health care professionals about health issues or services, or to report abuse or neglect, **inform the caregiver** first if that is appropriate.
25. Talk to other caregivers or authorities if you need help figuring out how to relate to this caregiver, what services might be available, or how to report abuse.
26. **Record your notes** and observations regarding the caregiver and the person with cognitive impairment, so you can review them periodically to gain a sense of perspective of the changes over time, and also to have a more objective view that you can share with health care professionals in times of crisis or transition.
27. Most important, keep in mind what you find in this caregiver to **admire and appreciate**. Nurture your own warm feelings for this caregiver.

WHAT TO SHARE WITH THE CAREGIVER

28. Help the caregiver better **understand the person** they care about and for. This may help them feel more compassion and to problem solve on their own more easily.
29. Comment frequently on what is **admirable and loveable** about the person they are caring about and for. Nurture their relationship with the person with cognitive impairment.
30. Give them **information** about caregiving, cognitive impairment, and the disorder the person they care for has.
31. Acknowledge that caregiving can be extremely **exhausting** physically, emotionally, and mentally.
32. **Compliment** the caregiver whenever possible. Tell them what you admire about them.
33. **Build their confidence** in their abilities and their level of insight. Tell them to trust their instincts whenever appropriate.
34. Help the caregiver recognize and understand the **cognitive functioning** underlying a person's behavior and ability to function.

35. Give them **resources and information** about services they can make use of. Make the contacts yourself if they are too overwhelmed.
36. Help the caregiver ask themselves "**Why?**". Help them find the trigger, cause, or reason for a behavior or difficulty in performing a task.
37. Avoid giving them intervention suggestions without first coming up with ideas **jointly**.
38. Help the caregiver **assess** and understand a situation, and to be **creative** in problem solving.
39. Help them develop a **repertoire of interventions** to accommodate varied situations and fluctuations in a person's abilities.
40. Help them be **flexible** with their interventions so they can adapt to each situation as necessary.
41. Help the caregiver know **how to do** the interventions.
42. Help them be **systematic** (to avoid using the trial and error method) in their assessment and implementation of the interventions so the interventions are done consistently over time and across caregivers.
43. Help the caregiver see their **own interactions** with the person, come up with ideas of how their interactions might contribute to the problem, and how to change their own behavior or communication strategies. Help them understand that a person with cognitive impairment might sometimes see the caregiver's behavior as difficult or distressing.
44. Help the caregiver examine the environment, each task, and their own interactions with the person to see how they can modify them to make **tasks easier** for the person and to help the person feel more comfortable and competent.
45. Help them consider ways to **modify** the **environment,** the **task** structure and timing, and their own **interactions** to improve a person's quality of life, and to prevent or respond to distress and behaviors that might cause distress.
46. Teach the caregiver basic **simple interventions**. Sometimes we are so used to doing them, we forget to emphasize the importance of doing them.
47. **Repeat** yourself as often as necessary. Caregivers can forget easily, especially when they are busy and stressed.
48. Help the caregiver know **when to act** and when to take **risks** on the person's behalf. Become familiar with the wishes and comfort level of the caregiver and of the person with cognitive impairment. For example, help the caregiver know what to do when the person puts other people (including the caregiver) in danger, puts other people's (including the caregiver's) property in danger, puts themselves in danger, or puts their own property in danger.
49. Help the caregiver know how to recognize when they, as caregiver, **need help** and where to get it.
50. Avoid challenging or contradicting information from other professionals (e.g. the physician or social worker). Either say nothing or present various alternatives.

HOW TO SHARE WITH THE CAREGIVER

51. Be **flexible** with when you meet with a caregiver, what you say, and how you say it. Often a caregiver's life is unpredictable and their level of fatigue and responsiveness may vary.
52. **Individualize** your interactions and information to this particular caregiver at this particular time. Assume every situation is unique.
53. Choose an appropriate **location** to meet. Think about the potential distractions, the opportunity to see the caregiver interact with the person with cognitive impairment, the opportunity to see the environment in which the caregiver and the person interact, how well the location accommodates any sensory or physical needs of the caregiver. Consider what and how you want to communicate and

what setting would be most helpful.

54. Consider the **timing**. How long will you meet with them? How long in advance should you set up the meeting time? Do you or the caregiver need to prepare for the meeting? When you are talking, consider **when to say** or give certain pieces of information and **how long** it takes (for example, how many words you use) to say it. When during a conversation do you say it? Even within a sentence when do you say the most important piece of information? Consider the fatigue and distractibility of the caregiver, especially when they are under stress.
55. Consider **who is present**. Is the person with cognitive impairment there and how will that affect how easily you or the caregiver can share concerns? Are other caregivers present? Is there a group of people? Each situation allows for different opportunities and limitations.
56. Give notes, comments, information, and recommendations in **writing** whenever it is appropriate or possible, such as literature or reminders. The caregiver can then read them in parts or at odd times, such as at night when they can't sleep. They can also remind themselves of what you and they said or decided. Make sure the caregiver can read and can read the language in which it is written.
57. Consider the **layout** of the information on the page. How large is the print, how much white space is there, how much information is on one page, how dense is the writing, and is all the information in words or are there graphics, pictures, or photographs?
58. Give information or your comments in **pieces** the caregiver can absorb. Avoid assuming you have to give them everything at once. Think about what parts they are ready for or interested in receiving now.
59. Accommodate **sensory changes** and other **needs** of the caregiver, particularly if they are middle aged or older. Keep in mind all five senses and choose the various aspects of your interaction, such as location, the pitch and tone of your voice, and your body position accordingly.
60. **Conserve their energy**. Interact with them in a way that saves them time, focus, and mental agility. For example, make tasks as easy as possible for them, just as they should for the person with cognitive impairment. Help them think of ways they can save energy over the course of a day or week as well.
61. **Save face** for the caregiver. Avoid embarrassing them or putting them on the spot. Ascertain subtly if they are able to read or to read English, if they understand what you are saying, or if they realize they are doing something inappropriate.
62. **Avoid contradicting** or correcting the caregiver. Simply say what you see and how you interpret a situation, or suggest alternative ways it could be interpreted.
63. Choose **words** to use that are **simple and clear**, yet not condescending. Use few words. Put your most important words or ideas early in your time with the caregiver. This may not be as necessary if the caregiver is well rested and able to focus easily.
64. Consider how you **sound**. Keep your voice calm, friendly, and cheerful as appropriate for the situation. Convey warmth and reassurance in your tone.
65. Consider how you **look**. Note your stance, your pacing, your facial expression, and your gestures. Avoid appearing impatient, rigid, disapproving, rushed, or anxious.
66. Use **touch** as appropriate to communicate comfort and reassurance and to help the caregiver feel calm and relaxed. They will be able to think more clearly, absorb what you are saying, and contribute to the problem solving or interaction more easily when they are calm and relaxed.
67. When a caregiver needs or asks for help (for example with helping the person they care for bathe), **watch the caregiver in action**. That is, watch them perform the task or interact with the person. Avoid coming in immediately to interact with the person or to do the task in order to understand what the problems are. The problems likely involve both the caregiver and the person. So, for example, if the caregiver says they can't get the person into the shower, discreetly watch the caregiver try instead

of trying it yourself. That way, you might see the challenges the person is encountering, as well as the way the caregiver is setting up the task and interacting with the person.

68. When you do help a person perform a task, such as bathing, have the **caregiver watch** or participate so you can use the opportunity to model interventions, understand better what the caregiver is referring to so you can talk about it afterwards, show the caregiver you are truly trying to understand their situation better and that you do know what you're talking about, and finally to simply help out the caregiver and give them a break.
69. Be sure to **communicate** through your words, your body language, and the tone of your voice that you want to be **supportive** to the caregiver, and that you **have confidence** in their ability to do well with the person they care about and for.