

SHARING IDEAS WITH OTHERS

Suggestions for Sharing Information, Support, and Intervention Ideas

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TO KEEP IN MIND

1. All of us who regularly relate to, support, and assist a person with cognitive changes (and changes or differences in the brain), as well as those within this person's support network, are **partners**. We may be health professionals, family members, friends, paid staff, employees, direct care partners or caregivers, or have some other relationship with this person and their support network. We will have a variety of duties and tasks in a variety of settings ranging from a person's private home to an office, day program, assisted living, group home, nursing home, or hospital. But we share a **goal** of helping this person as best as we can, live the life they would choose to live no matter how many challenges and cognitive needs they may have. We also formally or informally fill the role of **educators** and **supporters**. We often share information and interventions ideas (support strategies) with this person and with someone (each other) in the support network to improve our ability to help this person.
2. This handout is about **sharing** information, support, and ideas **with someone** (each other) **in this person's support network** as health professionals, family members, care partners or caregivers, or in some other role.
3. Sharing with someone might include:
 - a. Giving **information** about what has happened that day, our observations about what this person needs or what might make them feel more comfortable or happy, or new information about a disorder.
 - b. **Explaining** how to do something or why something is important.
 - c. **Problem solving** with them.
 - d. Giving **ideas** for **interventions** or modifications of interventions they have been trying.
 - e. **Teaching** them a skill or a new level of understanding.
 - f. **Advising** them to try interventions, to have more empathy for a person they are helping, or to get more rest.
 - g. **Providing** or suggesting **resources** they may need to improve their relationship and support with this person, such as a book, handouts, equipment (for example, an assistive device or new technology).
 - h. **Listening** to them as they share emotionally and intellectually.
 - i. **Encouraging** them in a way that boosts their self-confidence and pleasure in their relationship and time with this person.
4. We may be sharing as a peer or colleague, a supervisor, advisor, consultant, health professional, family member, friend, community service provider, support group member, religious counselor or mentor, teacher/trainer/professor, or in some other capacity.
5. Sometimes a person with mild cognitive changes is caring for themselves and we may be sharing information and ideas with them that is similar to the information we share with others.
6. In general, when we share with someone, we need to consider using some of the same strategies and caution we use when sharing with a person with cognitive changes. 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 **timing**. We need to choose a time to share when they are **most receptive**, that is, most ready to receive and understand what we are sharing. We need to **tailor** to the individual and the situation, what we share and how we share it.

7. Many interventions or support strategies that work best with a person with cognitive changes are quite **simple** (for example, identifying for this person the food on their plate, explaining to this person what the next step of a task is). But to be successful, they need to be used consistently and with compassion and understanding by those in the support network.
8. Sometimes we are frustrated with someone's style and apparent ineffectiveness when helping or relating to this person. We wonder why they don't use the advice we give them. We need to keep in mind that they **may not do simple interventions because** they:
 - a. **Think they are** doing the intervention. They may not see themselves or the situation objectively or as we do.
 - b. Are confused about the intervention and **don't understand** what it is
 - c. Are sleep deprived, stressed, and **exhausted** emotionally & physically so they simply don't and sometimes can't.
 - d. Are **too occupied** or busy. There is too much to keep track of, so they miss opportunities or evidence that this person needs or wants something.
 - e. 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).
 - f. Don't think of the intervention; it just **doesn't occur to them** at the time.
 - g. **Don't understand** the **disorder** or the cognitive abilities and brain functioning underlying it.
 - h. **Don't know** or **understand** the **person** they are relating to.
 - i. Are **emotionally distressed** or stressed at the moment. They may be impatient, angry, or anxious.
 - j. Have **cognitive changes themselves**, from a brain disorder or for some other reason.
 - k. Assume the problem or cause is the brain disorder, so **believe** the **intervention** is **useless**.
 - l. Aren't used to problem solving or analyzing people, interactions, needs, or situations, so they **don't know** to do it or **how** to do it.
 - m. Have always been dependent on this person with the cognitive changes (or on people similar to that person), so they have **difficulty seeing this person as needing help**.
 - n. **Afraid** of this person with the cognitive changes so they don't feel they have the power or permission to meet this person's needs or desires, especially if that requires preventing this person from doing something. This might occur especially when they have been under this person's control or have a history of physical, emotional, or sexual discomfort, pain, or trauma with them.
9. We need to think carefully about how we interact with someone. Some suggestions are below. As you can see, some of them are similar to strategies we might use when interacting with a person with cognitive changes, since in fact, these interventions can apply to all of us.

SUGGESTIONS FOR SHARING

The Care Partner (or Caregiver)

10. These suggestions can apply to anyone, but in this handout we will refer to someone we are sharing with as the "**care partner**" (that is, the "**caregiver**"). The two terms will be interchangeable here.
11. See the care partner 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 care partner, and their current health, physically, emotionally, and cognitively. What tasks and **challenges** are they now facing? Consider the person the care partner is supporting and note this person's ability to perform tasks and communicate and their emotional and physical status.
12. Consider and address all aspects of the care partner (that is, the **whole person**), the emotional, physical, cognitive, and spiritual as you interact with them, including any history of trauma or pain.
13. Try to **see from the individual care partner'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.
14. Consider the care partner's **needs at this moment**, especially during times of transition or difficulty, such as when the person with cognitive changes needs to: move to another residence, has to stop performing a task like driving, no longer recognizes the care partner, or is hurting the care partner or

someone else.

15. Note the **changes** and **fluctuations** in circumstances and the care partner's needs and emotions as the disorder either improves or becomes more severe.
16. Each time you are with the care partner **assess** the care partner 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.
17. Note if there are **other demands** on this care partner that might be unrelated to the person with cognitive changes.
18. Note the **resources** this care partner has available, including social and financial sources of support.
19. The tasks and role of a care partner may be new to this care partner, so **don't assume** they **know** the **basics**. We might forget that when we have been care partners or health professionals for so long.
20. Ensure the **care partner is safe** and knows how to **access help** and services, particularly in an emergency or crisis.
21. Ensure the **person** this care partner is supporting is **safe** and the care partner knows how to help and protect them.

Your Perspective

22. See the care partner and the person they support **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 in a variety of interactions with each other. Avoid assuming you are there primarily for the person with cognitive changes. For you to be effective, you must consider the person with cognitive changes and the care partner within this person's support network. Get to know others in this person's support network as well.
23. Clarify your own feelings and views about the care partner. Make sure you **respect** this care partner, and assume they have potential and the ability to grow and learn.
24. Clarify the **goal** of your time with this care partner. 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 this care partner (particularly if they are rather isolated), or help them emotionally through a hard decision?
25. Consider your **relationship** with this care partner. What will you call them? What might they expect from you? Clarify that early in your time with them.
26. **Model** in your relationship with the care partner how this care partner might best interact with the person with cognitive changes.
27. **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 behavior represents an unmet need or desire on their part, even as you act and work to **protect the person** from the care partner's anger and frustration.
28. If you intend to communicate with health professionals about health issues or services for any reason, or to report abuse or neglect, **inform** the **care partner** first if that is appropriate.
29. Talk to other care partners or authorities if you need help figuring out how to relate to this care partner, what services might be available, how to protect the care partner and the person they are supporting, or how to report abuse.
30. **Record your notes** and observations regarding the care partner and the person with cognitive changes, 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 professionals in times of crisis or transition.
31. Most importantly, keep in mind what you find in this care partner to **admire and appreciate**.

Nurture your own supportive emotions for this care partner. Seek advice and help if you need to examine or alter your own emotions, such as impatience, irritation, disgust, anger, or fear.

What To Share with Them

32. Help them better **understand the person** they are supporting and relating to. This may help them feel more compassion and to problem solve on their own more easily.
33. Comment frequently on what is **admirable** and **likeable** about the person with cognitive changes they are supporting. Nurture their relationship with this person.
34. Give them **information** about assisting, cognitive changes, and the disorder this person is living with.
35. Acknowledge that relating to and supporting this person can be extremely **exhausting** physically, emotionally, and mentally.
36. **Compliment** them whenever possible. Tell them what you admire about them and their efforts.
37. **Build their confidence** in their abilities and their level of insight. Tell them to trust their instincts about this person and situation, whenever appropriate.
38. Help them recognize and understand the **cognitive abilities** underlying this person's behavior, emotions, and ability to communicate or perform tasks.
39. Give them **resources** and **information** about services they can make use of. Make the contacts yourself if they are too overwhelmed.
40. Help them ask themselves "**Why?**". Help them find the trigger, cause, or reason for this person's **behavior** or **difficulty in performing a task**, and how their own behavior (that is, the care partner's behavior) or the environment might be playing a role by overestimating or underestimating this person's cognitive abilities, or by not meeting this person's needs. Behavior is often a coping strategy
41. Avoid giving them intervention suggestions without first coming up with ideas **jointly**.
42. Help them **analyze** and understand a situation, and to be **creative** in problem solving.
43. Help them develop a **repertoire of interventions** to accommodate varied situations and fluctuations in this person's abilities, emotions, and behavior.
44. Help them be **flexible** with their interventions so they can adapt to each situation as necessary.
45. Help them know **how to do** the interventions.
46. Help them be **systematic** (to avoid using the trial and error method) in their generation and implementation of interventions, so the interventions are done consistently over time and across this person's support network.
47. Help them analyze or consider carefully their **own interactions** with this person, come up with ideas of how their interactions might contribute to the situation, and how to change their own behavior or communication strategies. Help them understand that this person with cognitive changes might sometimes see someone else's (including the care partner's) behavior as difficult or distressing.
48. Help them examine and consider ways to **modify the environment**, the structure and timing of each **task**, and their own **interactions** with this person to see how they can:
 - a. Make **communication** and **tasks easier** for this person
 - b. Help this person feel more comfortable and competent
 - c. Improve this person's quality of life
 - d. Prevent or respond to distress and behavior that might cause distress
49. Teach them basic **simple interventions** (for example, to verbally and nonverbally reassure this person). Sometimes we are so used to doing them we forget to emphasize their importance.
50. Help them know **when to act** and when to take **risks** on this person's behalf. Become familiar with their wishes and comfort level and those of the person with cognitive changes. For example, help them know what to do when this person: puts them or other people in danger; puts their or other

people's property in danger; puts this person themselves in danger; puts this person's own property in danger; is distressed; or has experienced physical, emotional, or sexual trauma, pain, or discomfort.

51. Help them know how to recognize when they as the care partner, **need help** and where to get it.
52. Avoid challenging or contradicting information from other professionals (e.g. the physician or social worker). Either say nothing or present various alternatives.
53. Share any of the resources below that might be helpful to them
54. See the Cognitive Abilities and Intervention Strategies (**CAIS**) **Handouts**, the **CAIS Educational Series**, and the *CAIS Questions to Ask* and *CAIS Intervention Strategies* by S Weaverdyck for more information and details about cognitive abilities, options of specific intervention and support strategies, and other topics. These provide **detailed intervention** strategies that address specific cognitive abilities, the environment, tasks and daily routines, and your communication with this person. These interventions can be **individualized** to a particular person and situation. All of these and other resources are available at <https://www.improvingmipractices.org>

How To Share

55. Be **flexible** with when you meet with someone, what you say, and how you say it. Their life may be unpredictable, and their level of fatigue and responsiveness may vary.
56. **Individualize** your interactions and information to this particular care partner at this particular time. Assume every situation is unique.
57. Choose an appropriate **location** to meet. Think about the potential distractions, the opportunity to see them interact with the person with cognitive changes, the opportunity to see the environment in which they and this person interact, how well the location accommodates their own sensory or physical needs. Consider what and how you want to communicate and what setting would be most helpful.
58. Consider the **timing**. How long will you meet with them? How long in advance should you set up the meeting time? Do you or they 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 should you say it? Even within a sentence when do you say the most important pieces of information? Consider fatigue and distractibility, especially when they are under stress.
59. Consider **who is present**. Is the person with cognitive changes there and how will that affect how easily each of you share concerns? Are other individuals present? Is there a group of people? Each situation allows for different opportunities and limitations.
60. Give notes, comments, information, literature, reminders, and recommendations in **writing** whenever it is appropriate or possible. They 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 they can see and read, and can read the language in which it is written.
61. Consider the **layout** of the information on the page. How large the print is, how much white space there is, how much information is on one page, how dense the writing is, and if all the information is in words or presented with graphics, pictures, or photographs.
62. Give information or your comments in **pieces** they can absorb. Avoid assuming you have to give them everything at once. Think about what parts they are ready for or interested in now.
63. **Repeat** yourself as often as necessary. They can easily forget what you say, especially when they are busy, sleep deprived, fatigued, or stressed.
64. Accommodate **sensory changes** and other **needs**, 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. Consider alternatives to reading.
65. **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 changes. Help them think of ways they can save energy over the day or week as well.

66. **Save face** for them. Avoid embarrassing them or putting them on the spot. Ascertain subtly if they are able to read or to read English or see written materials, if they understand what you are saying, or if they realize they are doing something inappropriate.
67. **Avoid contradicting** or correcting them. Simply say what you see and how you interpret a situation, or suggest alternative ways it could be interpreted.
68. 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 them. This may not be as necessary if they are well rested and able to focus easily.
69. Consider how you **sound**. Keep your voice calm, friendly, and cheerful as appropriate for the situation. Convey warmth and reassurance in your tone.
70. Consider how you **look**. Note your stance, your pacing, your facial expression, and your gestures. Avoid appearing impatient, rigid, disapproving, rushed, or anxious.
71. Use **touch** as appropriate (and if they are comfortable with touch) to communicate comfort and reassurance and to help them 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 (especially when there is a history of emotional, physical, or sexual trauma or pain).
72. When they need or ask for help (for example with helping the person they care for eat), **watch them in action**. That is, watch them perform the task or interact with this person. To better understand what the problems are, avoid the temptation to jump in and interact with this person or to do the task yourself with this person. The problems likely involve both the care partner and this person. That is, keep the focus on both them and this person, rather than primarily on this person. So, for example, if they say they can't "get the person to eat", discreetly watch them try instead of trying it yourself. That way, you might see the challenges both the care partner and the person are encountering, as well as the way the care partner is setting up the task and interacting with this person.
73. When you do help a person perform a task, such as eating, have the **care partner watch** or participate so you can use the opportunity to:
 - a. Model interventions.
 - b. Understand better what they are referring to so you can talk about it afterwards.
 - c. Show them you are truly trying to understand their situation better and that you are capable of offering useful suggestions.
 - d. Assist the care partner.
 - e. Give the care partner a break.
74. Structure your problem-solving session so that you and they together review observations and conclusions. Avoid simply providing recommendations. When you produce suggestions together, they will more likely understand and use the suggestions. Analyze together the situation, this person's strengths and needs and those of the care partner, and the effectiveness of their interactions, the environment, and the task structure and timing. Then together generate ideas of interventions.
75. Convey verbally and nonverbally that you respect and admire them.
76. Be sure to **communicate** through your words, your body language, and the tone of your voice that you want to be **supportive** of this individual, and that you **have confidence** in their ability to do well with the person they are supporting and relating to.

FOR MORE INFORMATION

More details and specifics are available in **other CAIS Handouts** (43 total) and in the *CAIS Questions to Ask* and *CAIS Intervention Strategies* by S Weaverdyck. These provide **detailed intervention** strategies that address specific cognitive abilities, the environment, tasks and daily routines, and your communication with this person. These interventions can be **individualized** to a particular person and situation. All of these and other resources are on the Michigan website called Improving MI Practices at <https://www.improvingmipractices.org>