



Seven Suggestions

for Communicating with Someone with Brain Change

<u>Common Tactics</u>	<u>Skillful Adjustments</u>
<i>Arguing</i>	<i>Empathizing</i>
<i>Reasoning</i>	<i>Reframing</i>
<i>Shaming</i>	<i>Validating</i>
<i>Lecturing</i>	<i>Reassuring</i>
<i>Quizzing</i>	<i>Engaging</i>
<i>Restricting</i>	<i>Facilitating</i>
<i>Insisting & Imposing</i>	<i>Encouraging & Guiding</i>

<u>Common Tactic</u>	<u>Example</u>	<u>Skillful Adjustment</u>	<u>Example</u>
Arguing	"I already told you"	Empathizing	"I'm sorry, I thought I told you"
Reasoning	"That won't work <i>because...</i> "	Reframing	"I'm wondering, what if we..."
Shaming	"Look at what you did!"	Validating	"I have trouble with that too"
Lecturing	"How many times..."	Reassuring	"We can figure this out together"
Quizzing	"Do you remember..."	Engaging	"I remember when..."
Restricting	"You can't..."	Facilitating	"What if we tried this..."
Insisting	"You have to..."	Encouraging	"We can do it together"

Arguing vs Empathizing

Many people find that arguing with someone with brain change is not a successful way to change that person's beliefs or actions. There are many reasons for this. For arguing to be successful in modifying what a person with brain change thinks and does, many cognitive processes are required.

Arguing requires the person with Brain Change to:

- (a) have self-awareness of their position,
- (b) be able to conceptualize your point of view,
- (c) use logic and reason to evaluate the comparative value of your claims versus their own,
- (d) make adjustments based on conceptual frameworks,
- (e) retain and maintain the adjustments made.

Empathizing, by contrast, requires the person with brain change to do none of the above. Despite this, arguing may provide benefits to the care partner that are hard to give up.

The value of arguing for care partners may include:

- (a) providing a sense of comfort (we have always argued),
- (b) satisfying a need to be right,
- (c) helping care partners maintain their own sense of order and how things should be,
- (d) mitigating a sense of loss and grief (wanting the person with brain change to interact as they have in the past).

One way to start moving from arguing to empathizing is to understand the added benefit of this new approach.

The value of empathizing for care partners may include the following:

- o Empathizing may provide a pathway to end the disagreement. Since empathizing often helps the person with brain change to feel heard and understood, often what is being argued about becomes much less of an issue.
- o Empathizing often avoids escalation. Arguing is frequently the reason why a small disagreement leads to profound irritation or worse, aggression.
- o Empathizing helps build stronger bonds based on understanding the desires and viewpoints of the person living with brain change. This will help not only the current situation but lays the foundation to help avoid similar disagreements in the future.

To further explore this, let's look at an example. Al has Alzheimer's disease. Carin is his care partner. Al wants to drive, even though he lost his license due to his condition.

Arguing Approach: Carin might say: "You can't drive. Your doctor told you that you were no longer a safe driver."

Al might say: "I am a safe driver! That doctor is a quack."

Carin's approach will be successful if (a) she is able to have Al correctly assess his own level of ability and lack of ability, (b) understand and accept the new information being provided by his physician, (c) retain this new information, (d) have the capacity to make the needed adjustment in the moment.

The arguing approach requires a lot of Al's brain: to have self-awareness, to remember, to conceptualize, to analyze, and adjust.

Empathetic Approach: Instead of trying to convince Al that he is an unsafe driver, using empathy, Carin attempts to see how (a) Al is processing this information in the moment, (b) determine what is sparking his desire to drive at this particular time, (c) evaluate a range of responses, and (d) select a response that best fits not only what Al is thinking but also how he is feeling.

The empathetic approach requires a lot of Carin's brain: to be able to pause in the moment, to be willing to attempt to see things as Al does, to be able to accurately assess Al's mental and emotional state, and to make in-the-moment adjustments to reframe what she could say to better fit what Al is able to hear, understand, and accept.

Arguing is easy for Carin but hard for Al. While empathizing is hard for Carin, it requires much less of Al. This leads to the questions: Who has the healthy brain? Who is more able to make adjustments?

Arguing can feel comfortable and maybe appear as the only way to approach the situation. Arguing can also satisfy many needs care partners have, including: upholding a sense of what is right and wrong, maintaining order, and even a need to win. However, arguing seldom enhances the sense of safety and well-being of the person living with brain change and often makes the person feel disrespected or devalued.

Empathizing is a skill. It can be learned. It can be developed. It has been shown to have a range of positive benefits for both parties. When arguing stops working for you, perhaps give empathizing a try.

Reasoning vs Reframing

Reasoning requires the same things of the brain that arguing does.

Reasoning requires the person with Brain Change: (a) has self-awareness of their position, (b) can keep track of the elements of an argument, (c) can evaluate the logical outcomes of their course of action versus the proposed reasonable course of action, (d) make adjustments based on logical conclusions and (e) retain and maintain the adjustments made.

Reframing, by contrast, is the act of attempting to meet the person with brain change where they are and craft the discussion to feel comfortable and acceptable.

For Example: Al wants to drive. Carin is concerned because she knows he is an unsafe driver.

Reasoning Approach: Carin might say, "Honey, you can't drive because you no longer have a license. Remember, you had those three accidents. We were so lucky no one was seriously hurt. But you wouldn't want someone to be injured, right?"

To which Al might respond: "I didn't have any accidents."

Just like arguing, reasoning requires a lot of Al's brain. He has to: have self-awareness, remember, conceptualize, analyze, and adjust.

And just like arguing, Carin's use of reasoning will be successful if (a) she is able to have Al correctly assess his own level of ability and lack of ability, (b) understand and accept the new information being provided, (c) retain this new information, and (d) have the capacity to make the needed adjustments in the moment.

Reframing, like empathizing, is based on being able to understand how (a) Al is processing this information in the moment, (b) determine what is sparking his desire to drive at this particular time, (c) evaluate a range of responses, and (d) select a response that might best fit with what Al is thinking and feeling.

In this way, reframing can be seen as implementation of empathic understanding. It requires that Carin not only have this level of understanding but also be able to adjust what she says and how she says it to fit Al's perception of his abilities and of the particular facts of the situation.

One example of reframing would be for Carin to make the deficit hers not his. Such as: "Honey, you have been driving for so long. And with all of your experience, I really need your help."

Where the conversation goes from here would depend on what Al is thinking and feeling in the moment and no one example would possibly be able to convey what would work for everyone or even for the same couple on different days. The principle here is to reframe the issue of driving from Al's inability to respecting his experience and finding a way to honor that.

The reframing approach includes the skills of empathy and understanding and requires a lot of Carin's brain, including being able and willing to attempt to see things as Al does, being able to accurately assess Al's mental and emotional state, and creatively adjust her logical/rational arguments away from pointing out his deficiencies to finding ways to recruit his sense of self-worth to be part of the solution.

Shaming vs Validating

We might think we would never shame a person living with brain change. And shaming is a harsh word. This is more about how the person living with brain change feels than the intent of the care partner. In some sense, it doesn't matter if you intended to cause shame. This principle is addressing the concept that the person with brain change feels shame, intended or not.

Example: Carin comes home from the store and goes to put the groceries away. She sees that Al has left the freezer door open and there is a puddle of water on the floor. When she walks into the kitchen she screams out: "Oh no! Al, look at what you did!" In that moment, was Carin trying to shame Al? Maybe not. But the result is the same.

Here, Carin's words were just an instant expression of her distress. But this same situation might also lead to her becoming frustrated and angry as she wants to make sure this doesn't happen again. When Al comes into the kitchen, she might say: "Al! You left the freezer door open and now I have to throw away all that food. You keep doing this!"

Al might respond: "It wasn't me."

In order for Carin's "shaming" approach to achieve her goal of preventing this from happening again, Al would need to (a) realize he did this, (b) realize what he did caused damage, and (c) remember not to do that again.

Validating might be the most important skill care partners can learn to create and maintain an atmosphere that upholds a sense of mutual dignity and respect. It also demands a lot. Validating requires Carin to: (a) pause, (b) assess her own emotions, (c) perceive Al's current emotional state, (d) perceive Al's thought process at the time of leaving the freezer door open, (e) understand how Al's cognitive difficulties could allow this to happen, (f) be able to reset herself from a place of frustration and anger to a place of calmness and compassion, and (g) communicate to Al with in a way that reflects compassion, dignity, and respect.

After cleaning up the kitchen and taking time to process her own emotions, Carin walks into the living room where Al is watching the game. This causes her to feel like she is going to lose her cool again, as he seems unaware of all the trouble he caused. It is easy for Carin to think: he just doesn't care.

Determined to build the skill of validation, Carin goes back into the kitchen and takes some deep breaths. She tries to imagine Al home alone and hungry. She tries to imagine what it would be like to have a brain disease which causes you to want to follow your impulses while at the same time making it common for steps in any given process to be missed. He was able to go to the kitchen and find the ice cream. Why he didn't think to close the freezer door might always be a mystery.

But Carin says to herself:

Missing steps is part of this disease. He missed the step of closing the door. And he looks like he missed the connection that he did something wrong. He's telling me he didn't do it. This is so hard. If I try to prove to him that he did it (he was the only one here) he'll probably just "fight that." Missing steps and lack of awareness are symptoms of the disease. I love Al. I could be angry at what he did. I could be angry that he is not accepting responsibility. And I am angry. But I also realize he has a very serious disease which is affecting the way his brain works. Yelling at him about what he did likely will not fix things. I want the old Al who would apologize for doing something so stupid and promise never to do it again. I know I will not get that, but that doesn't make me want it any less.

Carin says to herself:

I have a choice. I can choose to stay angry and act on that or I can choose to do something different. I can still be angry, but yelling at him, telling him how upset and disappointed I am, that will not help him to not do it again. Maybe we are at the point that he can no longer be left alone. I was hoping this wouldn't come for years. This is just breaking my heart.

In this situation, Carin was using the skill of validation not to communicate with Al but to communicate with herself. She was able to validate her emotions of anger and grief. She has every right to be angry and to be filled with sorrow. By validating her own emotions, she could then go sit on the couch next to Al and take his hand. As they sat and watch the game, she put her head on his shoulder. Secretly she was wishing for him to whisper, "I'm sorry." That never came, but they had a pleasant afternoon together watching a game that he couldn't keep track of and which she couldn't care less about.

Lecturing vs Reassuring

Just as arguing and reasoning go together, so too shaming and lecturing are often a package deal. Carin could have marched into the living room and said: "Al, listen up. You just spoiled \$50 worth of food by leaving the freezer door open. You cannot do that again. When I go out of the house, I don't want you opening the dang freezer door. Got it?"

Al might say: "I didn't."

Lecturing tends to not be productive for exactly the same reasons why shaming, arguing, and reasoning don't normally work as planned.

In the last example, we saw how Carin validated her own emotions to change her mindset and find a more productive way to respond to the situation. But what if they were sitting on the couch and Carin was starting to feel content and just then Al says, "I need to go home."

Carin doesn't want to argue and say: "We are home." She doesn't want to shame and say: "Why do you say crazy things?" She doesn't want to lecture: "how many times to I have to tell you..."

Using the skill of empathy, she tries to imagine what Al is feeling that makes him want to go home and what is not feeling like home to him in this moment. Using validation, she gives herself a moment to feel how awful that statement was to hear: "*Oh no, he doesn't even know we are at home? What do I do now?*"

Learning the skills of validation and reassuring along with empathizing, Carin takes a deep breath and says: "tell me about home." Learning about validation, Carin knows that if she just said: "It's OK," Al might not have felt heard. For him, in this moment, it's not OK. Carin is not telling him to feel something that he is not. Instead by saying "tell me about home" she is acknowledging she heard what he said and is willing to go where he is.

Al doesn't answer and just says: "I need to get out of here."

Carin fights wanting to use logic and reason and explain to him: "You are home. See, here is your favorite chair, and here is Buddy our dog."

Carin pauses and knows that repeating back his words can convey a sense that he was heard.

She says: "You need to get out of here."

Al response: "Yeah, I need to go."

Wanting to validate and reassure, Carin says: "I love going places. How about in the morning, we take a trip down to the park and feed the birds? You always get more coming up to you. Those birds love you."

Al response: "No, I need to go now."

Carin: "Great! Let's go." In this moment, Carin thought the best way to reassure him was not to try to convince him that he was home and safe, but to respond with action.

Al gets up and puts on his shoes. Carin cringes as she was hoping he might not find his shoes.

Carin: "Hey Al. Can Buddy come along?"

Al: "Yeah." Carin thinks, great! Now maybe we can just take the dog for a walk. Get out of the house. And once he is outside, coming back into the house might feel like "coming home."

Carin didn't argue with him. And she validated him by using his words when responding. Her form of reassurance was to be willing to go for a walk with him. And to try to make him feel comfortable and secure, she asked if Buddy their dog could come along. This was something they would do together.

After a 5-minute walk down the street, Al wanted to go back the other way. As they walked, Carin talked about the time Buddy got into the ice cream truck and ate about 30 popsicles. Al smiled. When they got back to the house, Carin tossed up her arms in excitement and said: "Here we are!" Then gave him a big hug and said: "Thanks so much for going on a walk with me! I think we both have earned some ice cream. What do you say?" Al said yes, and they went inside, had a small dish of ice cream and went to bed.

Notice that when Al said he needed to go, Carin didn't just say: "How about some ice cream?" First, she needed to validate his need to go. And her means of reassuring him was to actually leave the house so that they could come back to "find home." Along the way she set the tone that everything was alright by bringing Buddy the dog and reminiscing about one of his adventures.

Quizzing vs Engaging

The next day, Carin and Al's daughter Felisha comes over for a visit. She hasn't seen her dad for almost 6 months. As soon as she walks in the door she says: "Hi Dad, do you remember me?" Al smiles but doesn't say anything. Felisha continues: "Who am I?"

Later at lunch, Felisha shows her dad a photo, saying: "Hey dad, here we are in Seattle. Who is this right here?"

Al says: "I'm not sure."

Felisha exclaims: "Dad! You don't remember my husband Luke!"

Al gets up from the table and goes to lie down in the bedroom.

Felisha breaks down telling her mom how she can't believe how much dad has declined. Carin shares with her daughter some skills she learned at support group.

"Instead of asking: Do you remember? They suggest giving small pieces of information and then giving him time to respond. Often he can't remember and we don't want our conversations to feel like a quiz show."

Felisha is upset. "What am I supposed to do?"

"Well sweetheart," Carin sees her daughter really does want to learn how to interact with her dad as he is now, "you could show him the photo and tell him Luke's name. You could help him try to remember when we were at the Space Needle. We had so much fun that day."

"I thought so too," Felisha was crying. "But he didn't remember it at all. He didn't remember Luke. He didn't even remember my name!"

Carin encouraged her daughter to try again.

Knocking on the bedroom door, Felisha waited a moment before entering to find her dad lying in bed, awake and looking like he was just staring at the ceiling. Without saying anything, she climbed into bed and lay next to him.

"Hey dad, I was looking through some old photos and I found this one when you and mom came out to visit Luke and me in Seattle." Al weakly agreed: "yep."

"Here, look at this" she raised the photo up so he could see. "Here I am. Here's mom. There is you and there is my husband Luke." She paused. "We took this right after we came down from the top of the Space Needle." She paused. "I remember you saying, you had enough and wanted to get to the ground floor." She paused.

Al quietly said: "I don't like heights."

Alzheimer's disease progressively destroys the hippocampus, an area of the brain involved with transitioning information from short term to long term memory. In sum, forgetting is part of the disease. Long term memories are often preserved but usually become harder to recall on command. Asking someone with Alzheimer's if they remember a specific name, place, or event can feel like they are being quizzed. Instead of quizzing, we can shift our goal from having the person remember a specific piece of information to the goal of having a quality engagement. We can ask ourselves: is there a right answer to this question? And if so, how can we rephrase it so that no matter what the person says, it will be the right answer, because our goal is engagement not a specific piece of information.

Restricting vs Facilitating

Felisha was so glad to have this moment with her father. She felt she was getting the hang of how to build a new relationship with her dad. Just then he got up and made a bee line to the front door.

Felisha shouted out after him: "Dad, where are you going?"

Al said he needed to go to the store.

Her mom had stepped out for a little while, and Felisha panicked.

"You can't go" she shouted as she pushed herself in front of him, blocking the door.

He tried to push her out of the way, until Felisha screamed: "Dad, you're hurting me!"

Al went back into the bedroom and slammed the door.

When Carin came home, Felisha rushed up to her and told her what happened. Carin shared with her what happened the night before when Al insisted on "going home" and so they walked down the street together and came back to find home.

When Felisha was blocking the door, she was restricting him. When Carin was walking with him, she was helping to facilitate his desire "to go." Restricting is preventing. Facilitating is finding a way to address the person's needs and desires in a safe and manageable way.

Insisting & Imposing vs Encouraging & Guiding

On the third day of Felisha's visit, Al had an appointment with the neurologist. This is one of the reasons Felisha flew down. She was struggling to understand her dad's disease and Carin thought it would be helpful if she came to the appointment. That morning, Al didn't want to go. He refused to get dressed. Despite knowing better, Carin tried arguing, reasoning, and lecturing. That did not work.

Finally, Felisha said: "Dad I came all the way from Seattle for this. You have to go!"

Al sat on the couch and refused to budge.

Encouraging is the art of understanding what motivation matches the preferences, desires, and needs of the person with brain change.

For example, Al doesn't like taking his pills. A motivation for him to go to the doctor would be if, by going, the doctor could reduce the number of pills he has to take. By addressing his concerns, and providing motivation that matches those concerns, Felisha and Carin can set up the conditions where Al can make the decision to go to the doctor rather than feeling like he was forced to do so.

Imposing (or forcing) can take subtle forms such as taking over tasks. For example, Al and Carin are running late for the doctor's appointment and Al is struggling to put on his shirt. Carin steps in and says, "here, let me do it." Al pulls away, but Carin insists, shoving his arm into one of the sleeves.

Guiding is the art of setting the person up for success by providing the support needed while not taking away the person's autonomy. In this example, Carin might realize that she is getting frustrated because she is concerned that they will be late, so she steps away. She asks Felisha to help out. Felisha comes in and says: "Hey dad, this shirt would look great on you! What do you say, let's give it a try?"

Al says OK.

"Great!" Felisha has learned to use lots of positive reinforcement. "Help me out with this arm here" she gently coaxes him to raise his right arm. He puts his right arm into the sleeve. "Oh, that looks good. Let's get that other sleeve." Felisha breaks down the task into little parts and offers lots of praise and encouragement. She has learned to try to maximize his sense of autonomy by encouraging rather than insisting, by guiding rather than imposing.

Conclusion

Being a care partner can be difficult and demanding. It can also be one of the most rewarding experiences in life. These seven suggestions are intended to help you be the best care partner you wish to be. At the Alzheimer's Support Network, we believe that everyone with Alzheimer's and other forms of brain change deserve to be treated with dignity and respect. We believe the autonomy of a person with brain change should be maximized as much as possible. We hope these seven suggestions will be of value to all care partners looking to uphold these principles.