### Cognitive Impairment Intervention Protocol (CIIP) for a Person with Cognitive Impairment

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### CAREGIVER INTERACTIONS

### INTRODUCTION AND INSTRUCTIONS

### INTRODUCTION

This Cognitive Impairment Intervention Protocol (CIIP) is designed to be used with the Cognitive Impairment Assessment Protocol (CIAP). The CIIP gives a list of possible interventions for each response on the CIAP that suggests the caregiver interactions with the person with cognitive impairment need to be more supportive for the person with cognitive impairment.

The four parts of the CIIP and CIAP, and the factors they address are: Cognition of the Person, Environment, Caregiver Interactions, and Task. Each part of the CIIP has its own introduction and instructions.

This part of the CIIP relates to caregiver interactions. Use the Caregiver Interactions CIIP and the Caregiver Interactions CIAP together.

The Caregiver Interactions CIAP is composed of two documents with the same questions in each document:

- 1. Yes/No Response Sheet
- 2. Four Point Scale Response Sheet

There is information in each of the CIAP Caregiver Interactions documents that will help you understand and use the Caregiver Interactions CIIP. All of the questions in the CIAP are included verbatim in the CIIP.

An important asset of both the CIAP and the CIIP is their ability to individualize assessment and intervention to a particular person with cognitive impairment at a particular time. Because the abilities and desires of a person with cognitive impairment will be different from every other person with cognitive impairment, and might fluctuate and change over time, it is important to assess frequently and to frequently modify interventions to adapt to the changes. As a person changes, interactions with this person must change. The brain has more difficulty figuring out what to do in the absence of enough or the right kind of information and support from the caregiver, or when the caregiver is unfamiliar. A person with severe cognitive impairment will likely depend heavily on the caregiver to suggest what to do, where to go, and sometimes even how to feel. Often the cognitive impairment of a person becomes increasingly severe over time due to changes in the brain, and this dependency on the caregiver increases even more.

The goal of this Caregiver Interactions CIIP is to create interactions between the caregiver and a person with cognitive impairment that support this particular person with cognitive impairment by: drawing on the strengths and abilities of this person, making tasks and interactions easier for this person, compensating for her/his specific impairments, stimulating this person to grow beyond her/his abilities, and most of all, helping this person feel pleasure and contentment.

In general, caregiver interactions that are supportive:

- 1. Help a person with cognitive impairment to feel comfortable and be safe.
- 2. Stimulate a person to have energy and a desire to do something.
- 3. Tell this person what is happening and will happen, and provide options of what to do and how to participate.
- 4. Help this person save energy for other pleasurable or difficult tasks by making this task as easy and relaxing as possible.
- 5. Help this person feel competent, independent, respected, and engaged.
- 6. Support only as much as this person needs or wants; not too much or too little.

At all times your interactions with this person should reflect respect, warmth, and calm support in a way that helps this person relax and feel comfortable and competent. It is important to be predictable to this person, even as you change your actions and communication strategies to accommodate changes in this person's needs and desires.

The CIAP questions are designed to be asked by yourself to and about yourself. They are not intended to be used as a means of criticism. They are intended to support you as a caregiver by giving you ideas of how to continue improving your relationship with and your support for this person.

The CIAP questions will help you assess your caregiver interactions to see if they are supportive for a particular person at a specific time. Your responses to the questions provide a profile of strengths and weaknesses about the effectiveness of your caregiver interactions with this person at this time.

The list of CIIP intervention ideas that accompany each CIAP question offers you possible strategies to improve the effectiveness of your interactions with this person.

### INSTRUCTIONS

- 1. Complete the Caregiver Interactions CIAP Yes/No Response Sheet or the Four Point Scale Response Sheet by following the CIAP instructions.
- For each of your responses to the questions in the CIAP that is a "No" or a "1" or "2" find the corresponding question in the CIIP. All of the questions in the CIAP are included verbatim in the CIIP.
- 3. Study the intervention ideas listed in the CIIP for each of the questions identified in step #2 above. Choose interventions to try that are appropriate for this person and her/his circumstances.
- 4. Evaluate the effectiveness of the implementation of the interventions you've chosen by completing the Caregiver Interactions CIAP again.
- 5. Do steps #1-4 periodically or whenever you recognize a change needs to be made. It is often helpful to go through these steps with other people, sometimes including the person with the cognitive impairment.

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: I. RESPECT

#### Look for ways to:

- Show respect for this person, both verbally and nonverbally
- Treat this person as an adult, both verbally and nonverbally
- Express love and affection for this person, both verbally and nonverbally

### A. Do I respect this person?

- 1. Think of this person as an adult worthy of your respect.
- 2. Remember, you are with this person to meet her/his needs. She/he has a right to make as many decisions/choices as possible.
- 3. Imagine this person as your parent or grandparent or someone else you love, admire, and respect.
- 4. Get to know her/his culture, preferences, habits, history, and accomplishments.
- 5. Recognize her/his current physical and medical status and possible pain concerns.
- 6. Don't take her/his comments or actions personally.
- 7. Forgive this person.
- 8. Imagine this person with dignity, regardless of how she/he looks or acts.
- 9. Address her/his feelings with respect and kindness even when acting to stop a behavior.
- 10. Arrange for someone else to assist this person until you do respect her/him.

# B. Do I treat this person as an adult in my words and facial expressions (for example do I avoid calling this person "dear" when I don't really know her/him)?

- 1. Avoid thinking of "dependency" as "childlike". Understand that brain changes do not make this person childlike but simply present very specific cognitive challenges. She/he still retains much of the information and skills acquired over a lifetime.
- 2. Use this person's name frequently, and use the name she/he prefers (e.g., first name and/or Mr./Mrs./Ms.).
- 3. Express affection in adult terms appropriate for her/his culture and preference (e.g., sir/ma'am).
- 4. Use eye contact as appropriate for her/his culture and preference.
- 5. Keep a pleasant, reassuring and kind facial expression. Avoid frowns, tightened lips, clenched teeth, and facial expressions of irritation, disgust, or scolding.

## C. Do I offer normal adult objects and activities and avoid children's toys or games?

- 1. Avoid thinking of "simplifying" as "making childlike".
- 2. Try to make an adult activity simpler rather than offering children's activities.
- 3. Play simplified versions of adult games (e.g., bridge) rather than children's games (e.g., "go fish").
- 4. Encourage adult activities (e.g., using colored pencils or markers to color adult drawings, rather than crayolas to color in children's coloring books).
- 5. Use actual objects rather than toy facsimiles (e.g., a real screw driver or a normal deck of playing cards).

## D. Do I avoid talking about this person in a condescending way, such as "they are so cute together," or "she's the little lady over there"?

- 1. Imagine this person with dignity, regardless of how she/he looks or acts.
- 2. Remember this person has adult feelings and thoughts.
- 3. Speak about this person as you would want people to speak about you or about someone you admire, love and respect.
- 4. Remember this person's dependency does not give you permission to feel superior.

### E. Do I avoid talking about this person in front of her/him?

- 1. Use private spaces to discuss this person with others.
- 2. Assume this person hears and understands everything you are saying to others. Even with severe brain impairment, people can sometimes understand what is being said.
- 3. Include this person in conversations about her/him as much as possible.
- 4. Avoid embarrassing this person when talking about her/his condition, behaviors, or bodily functions, etc.

## F. Are my voice, gestures, and movements gentle and kind, even when clear and firm?

- 1. Listen to yourself talk. Imagine how you sound to this person. Concentrate on keeping your voice calm, smooth, and gentle, even when joking or being silly.
- 2. Avoid moving quickly. When rapid movement is necessary, concentrate on keeping the movement gentle.
- All touch conveys feelings. Keep touch kind and reassuring, even when the situation is
  extreme and requires physically putting yourself between this person and another person or
  object to prevent someone from getting hurt.

### G. Do I help this person save face and avoid embarrassment? For example, do I avoid calling attention to her/his mistakes and discreetly correct mistakes without her/him noticing?

- 1. Imagine yourself or someone you admire, love and respect in this situation.
- 2. Think of ways you can help this person feel good about her/himself and this situation.
- 3. Try to prevent this person from noticing her/his mistakes, so her/his energy is preserved for conducting the task or interaction.
- 4. Avoid requiring her/his brain to do unnecessary work (such as correcting mistakes and addressing feelings at the same time).
- 5. Note this person's mistakes in behavior and words, and correct them without this person or others noticing the corrections.

### H. Do I avoid scolding, shaming, or bossing this person?

- 1. Especially in challenging situations, avoid the temptation to "make this person behave", which may make the situation more difficult to resolve.
- 2. Understand her/his reduced ability to control her/his behaviors and words. Understand her/his feelings of anxiety, confusion, and anger.
- 3. Keep your voice, facial expressions, and body movements calm, gentle, kind, and reassuring.
- 4. Address the feelings of distress, not the behaviors or words. You are there to help this person feel better, not simply to protect her/him and other people in the situation.
- 5. Avoid taking this person's behaviors and words personally. Seek appropriate ways to express your own frustration, hurt, and anger.

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment II. EXPLANATION AND REASSURANCE

#### Look for ways to:

- Show reassurance to this person
- Clearly explain events, requests, and the environment to this person

### A. Do I give verbal reassurance as often as necessary?

- 1. Listen to what you say.
- 2. Use words as often as this person needs them, even if it means repeating yourself.
- 3. Use words and phrases like "It's OK." or "We'll do it together." or "That's good." or "You're doing that very well." or "She/he knows you're here."

### B. Do I give nonverbal reassurance as often as necessary?

- 1. Monitor your body movements and position.
- 2. Listen to how you sound (whether you are saying words or simply making sounds).
- 3. Remind yourself that this person may respond more to how you appear than to how you sound, and more to how you sound than to the words you say.
- 4. Use your face, gestures and body stance to communicate reassurance and calm.
- 5. Let your body say that everything is okay or that you will take care of a problem, whether or not this person can understand words.
- 6. Speak slowly and lower the pitch of your voice to keep the sound of your voice calm and reassuring.
- 7. Use touch and stroking to reassure.
- 8. Before touching, remind yourself that this person may be particularly sensitive to touch. Your touch might send sensations such as "pins and needles", "bugs crawling", or "tickling" up and down her/his skin, or be extraordinarily painful or uncomfortable. A soft touch might feel like a hit, or like intense heat or cold. Watch constantly this person's face and body and listen to what she/he says to recognize evidence of her/his level of sensitivity or discomfort with touch at this time.
- 9. When touching, minimize the number of times your hand leaves and returns to her/his body, since her/his body may have difficulty adjusting to the initiation of touch.
- 10. Use the palm of your hand rather than individual fingers when touching to minimize the number of contact points between your hand and her/his body.
- 11. Use a gentle but firm pressure when touching, when light touch seems to be particularly uncomfortable. Avoid applying so much pressure that your touch hurts this person.

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# C. Do I avoid giving this person information that would be distressing or embarrassing?

- 1. Remind yourself that your goal at all times is to help this person feel good.
- 2. Avoid situations or comments that might embarrass or distress her/him. For example, avoid discussing this person's incontinence when other people are nearby.
- 3. When this person must be told upsetting news, tell her/him only as much information as she/he needs.
- 4. Deliver any upsetting information compassionately, beginning with positive statements and reassurance of your love and support.
- 5. Avoid pointing out this person's mistakes. Instead, discreetly adjust a situation to "fix" the mistake without her/him knowing the mistake was made.
- 6. Avoid shaming this person into proper behavior (e.g., avoid saying "What would your mother say if she heard you talk that way?").
- 7. Focus on this person's feelings rather than her/his behavior. Avoid bringing the behavior to this person's attention. Reassure her/him with "It's OK." rather than "Stop doing that."
- 8. Give this person only truthful information.
- 9. Give her/him only as much information as she/he needs to feel comfortable and satisfied. Often with cognitive impairment, excess information is confusing and distressing.
- 10. Adapt the amount and nature of information you give to this person's needs and desires, level of functioning, and the circumstances. (For example, when she/he asks, "Where is my husband?" avoid saying her deceased husband is dead unless you are sure she won't be surprised and grieve. You might say "He knows you are here." or "He's not here right now.")

### D. Do I give information or make a request only when this person is emotionally calm and ready to hear me, so she/he does not need to feel emotion and think about my words at the same time?

- 1. Wait until this person is calm and focused on you and your words, before giving her/him information or asking her/him to say or do something.
- 2. Avoid requiring this person to think about your words at the same time she/he is feeling emotion.
- 3. Before you speak, watch this person's eyes to know she/he sees and recognizes you and is paying attention to you.
- 4. Use calming, reassuring words rather than a request to stop, even when this person is doing something that needs to be stopped immediately.

### E. Do I give as much explanation as this person needs?

- 1. Give as much explanation as is necessary for this person to feel comfortable.
- 2. Clarify frequently to avoid confusion.
- 3. Explain to this person what is happening in the surrounding environment, in your interactions with her/him, and during the task she/he is performing.
- 4. Remind yourself that her/his ability to figure out why something is happening, why someone is saying something, or what she/he needs to do next may be impaired.

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### F. Do I repeat requests or explanations as often as necessary?

- 1. Repeat requests or explanations as often as necessary, since this person may easily and frequently forget what you say.
- 2. If this person understood you the first time but forgot what you said, then repeat the request or explanation in exactly the same words used the first time, since changing them might be confusing or tiring.
- 3. Watch and listen carefully to this person to see if another repetition would be helpful.
- 4. If this person doesn't understand you the first time, then give the same request or explanation using different words that may be more meaningful to her/him, or by speaking more slowly and clearly.
- 5. Watch and listen carefully to this person to see if she/he understood what you said.
- 6. Watch and listen carefully to this person to see if she/he realizes your comments apply to her/him.

### G. Are explanations short, simple and clear?

- 1. Use short and simple sentences (e.g., "It's ok. They are testing the alarms.") Avoid elaborate, multi-phrase explanations.
- 2. Watch this person to see if your explanation is clear and satisfying. If the person is relaxed and not distressed, then slowly give more explanation until she/he has heard enough.

### H. Do I use few words and short phrases and words?

- 1. Use as few words as possible to get the point across. Try to talk less and smile more.
- 2. Watch this person to see if it would help to use more or fewer words.
- 3. Listen to your own words.
- 4. Choose your words carefully.
- 5. Use only adult words.

### I. Do I use concrete and familiar words?

- 1. Use words that are meaningful to this person.
- 2. Use words that this person uses now or used in the past (e.g., "couch" versus "sofa"; "urinate" versus "pee").
- 3. Use words that are not too abstract (e.g., "the red dress" rather than "the fancy dress" or "go to the toilet" rather than "use the restroom").

### J. Do I wait to talk until there is no other noise?

- 1. Wait to speak until the background noises or voices are gone. Background noises make hearing more difficult with normal age-related hearing changes and attention more difficult with cognitive impairment.
- 2. Preserve this person's energy, even when she/he can hear and attend, by reducing the background or competing noise.
- 3. Turn off fans, TVs, etc.

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- 4. Close the door.
- 5. Move to a quiet place for conversations.
- 6. Have only one conversation occur at a time.

### K. Do I speak clearly and in a low pitch?

- 1. Enunciate clearly but normally (i.e., with a normal rhythm, pitch, and emphasis on syllables) to accommodate hearing loss and cognitive impairment.
- 2. Lower the pitch of your voice, since normal age related hearing changes make it more difficult to hear high pitched sounds (including consonants such as "f" and "s" and words such as "food" and "bath"). A low pitched voice may be more effective than talking louder, and may also sound calmer and more reassuring.
- 3. Listen to yourself talk, and watch this person to see if you are being heard and understood.

## L. Do I talk slowly when necessary and use pauses, to allow time for processing?

- 1. Preserve this person's energy by making it easy for her/him to understand you.
- 2. Slow the pace of your sentences to allow her/him time to understand what you are saying.
- 3. Pause between sentences or phrases to allow her/him time to process what you are saying.
- 4. Give this person any additional time she/he needs to produce speech.
- 5. Continue to sound natural and normal while talking more slowly. Avoid changing the normal rhythm and pitch of the sounds and words you use.
- 6. Watch this person to help you know how slowly to talk. She/he should not have to work hard to follow your words. Watch to see if the slow pace of your words feels calm and reassuring to her/him, particularly if she/he is anxious, confused, or uncertain.

### M. Do I give clear and honest answers to each question this person asks?

- 1. When this person asks a question or seems to want to know something, give an honest answer as clearly and as compassionately as possible.
- 2. Give only the information that was requested. Giving too much information can create anxiety and confusion.
- 3. Adapt the amount and nature of information you give to this person's needs and desires, level of functioning, and the circumstances. (For example, when she asks, "Where is my husband?" avoid saying her deceased husband is dead unless you are sure she won't be surprised and grieve. You might say, "He knows you are here," or "He's not here right now.")
- 4. Respond to each question as it is asked, rather than avoiding it or changing the subject. After a brief response, you can redirect her/his attention to something appealing, such as food or a favorite activity.
- 5. When a question reflects a feeling, responding to the feeling may be more important than answering the question with facts only. (For example, if she/he asks "Will you take me home?" when she/he feels confused or lonely, avoid saying "This is your home now." You might hug her/him and say "I can see why you'd want to go home. Let's have some ice cream now, and we'll talk more about that later."

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6. Avoid saying "no" as much as possible. Respond positively and with alternative suggestions. (For example, if she/he asks "When is the bus coming?" you might say "Let's look up that information in a little bit; right now I need your advice about supper."

### N. Do I answer questions as though this is the first time they were asked?

- When repeated questioning is due to memory loss, use the same response (words, facial expressions, and gestures) every time she/he asks the same question, if the first response seemed to satisfy or comfort her/him. Do this even if the question is repeated frequently over a very short period of time, since a repeated successful response will likely continue to be successful.
- 2. A question may be repeated because this person thinks more time has passed, since the last time she/he asked the question, than has actually passed. In this case, change your response to the repeated question.
- 3. Avoid embarrassing or confusing this person by reminding her/him that she/he has already asked that question or that you're tired of answering it. Calmly reassure her/him.

### O. Do I avoid saying "no" and suggest alternatives instead?

- Avoid saying "no" when this person makes a request verbally or nonverbally, since she/he
  may have difficulty processing both a "no" response and her/his own emotional reactions to
  the response at the same time. It may also be hard for her/him to consider how to act in
  response to the "no".
- Suggest another time or an alternative action. For example, instead of saying "No, it's too cold to go outside", try saying "Maybe we can later. Right now, could you please help me with supper?"

# P. Do my questions invite opinions or "yes" and "no" responses, rather than facts or information?

- Avoid asking this person directly for information. She/he may not be able to answer and might get nervous, embarrassed or flustered. She/he may have the information, but may have difficulty accessing it or telling it to you. Frequently, a "memory problem" is actually an access or communication problem.
- 2. Ask questions that only require a "yes" or "no" response (e.g., "Would you like eggs for breakfast?" rather than "What would you like for breakfast?")
- 3. Ask for opinions. Sometimes the information might be included in the response. For example, ask "They say parents should never give candy to a child now. What do you think about that?" rather than "How many children do you have?" This person might respond with "Honey, I gave my children candy after supper every day, and they are just fine now." She might continue to name all of her children, their professions, and their current cities of residence to demonstrate how successful they are!

# Q. Do I let this person know how much time has passed and what time of day it is, whenever necessary?

- 1. Tell this person how much time has passed when she/he seems to need to know, since she/he may have difficulty accurately recognizing time and its passing. For example, when this person is sitting at the table eating a meal, she/he may not know whether she/he has been sitting there for 2 minutes or 2 hours. If she/he isn't feeling hungry, or if her/his attention has shifted from the food, she/he may leave the table after only a few minutes of eating. In this situation, you might casually say "These beans are delicious. Since we only just began eating them, they are still warm. I'll cool them a little."
- 2. Tell this person what time of day it is. For example, say that it is morning when you wake her/him up.
- 3. Keep daily activities, events, and task steps of daily routines in a consistent order, so this person begins to know what comes next. This provides a basic structure to time, even when she/he doesn't know what time it is or how much time has passed.

### R. Do I tell this person when a task is done?

 Gently tell this person when a task is done, since this person may be unable to stop doing the task, or to recognize when the task is completed. For example, she/he may wash the same placemat over and over. If it is time to stop, say "Oh, what a nice job you've done." as you gently remove the placemat from her/his hand.

## S. Do I prepare this person before touching any part of her/his body, for example by asking permission or by informing her/him verbally?

- Alert this person that you are going to touch her/him before doing so, since she/he may be
  particularly sensitive to touch. Your touch might send sensations such as "pins and needles",
  "bugs crawling", or "tickling" up and down her/his skin, or be extraordinarily painful or
  uncomfortable. A soft touch might feel like a hit, or like intense heat or cold. Anticipation
  can help her/him prepare emotionally and help her/his body to reduce the undesired
  sensation.
- 2. Ask permission to touch. Acknowledge this person's autonomy and right to choose or say "no".
- 3. Watch this person carefully and constantly for evidence of resistance to or discomfort with touch.

### T. Do I prepare this person before she/he moves, nonverbally by touching and stroking a body part before moving it and verbally by asking her/him to move it?

1. Prepare this person both physically and emotionally, since moving a body part can be difficult, painful or uncomfortable due to age, brain impairment, weakness, or rigidity (particularly in the joints).

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- 2. Remind yourself that discomfort with touch and movement may be unpredictable. Each part of this person's body may have a different level of sensitivity and discomfort. The presence and degree of sensitivity or discomfort may also change from one moment to the next, or may fluctuate rapidly (for example she/he may feel the water temperature is too cold then too warm then too cold again within just a few minutes).
- 3. Watch this person's face and body constantly and listen to what she/he says to recognize evidence of the level of sensitivity or discomfort with touch and movement at this time.
- 4. Go slowly enough to allow this person time to prepare for your touch, to move, and to respond to your questions and comments.
- 5. Encourage this person to move the body part her/himself, rather than your moving it for her/him. This will likely be less uncomfortable.
- 6. Ask this person verbally to move the body part (e.g., "Please lift your arm.") before touching her/him.
- Ask this person verbally for permission to move the body part (e.g., "May I lift your arm? or "May I help you?") if this person cannot move it.
- 8. Add a nonverbal gesture with your verbal request (e.g., point to the body part or to your own body). Whether or not this person easily understands and/or produces words, a nonverbal gesture can make it easier for her/him to do focus on the body part.
- 9. With the palm of your hand, gently but firmly touch or stroke the body part to be moved, to draw this person's attention to that body part when necessary.
- 10. Stroke, with the palm of your hand, the body part and joint to be moved, firmly but gently, before it is moved by either you or her/him, since the body part might be stiff or uncomfortable. Begin away from the joint or painful area, and stroke toward the joint and painful area.
- 11. Use warm water or warm, damp washcloths draped on the body part and joint, to reduce discomfort.
- 12. Remind yourself that this person may be particularly sensitive to touch. Your touch might send sensations such as "pins and needles", "bugs crawling", or "tickling" up and down her/his skin, or be extraordinarily painful or uncomfortable. A soft touch might feel like a hit, or like intense heat or cold. Alert this person that you are going to touch her/him before doing so. Anticipation can help her/him prepare emotionally and help her/his body to reduce the undesired sensation.
- 13. Minimize the number of times your hand leaves and returns to her/his body, since her/his body may have difficulty adjusting to the initiation of touch.
- 14. Use the palm of your hand rather than individual fingers when touching to minimize the number of contact points between your hand and her/his body. To complete your grasp on this person's arm, for example, wait until your palm has settled on this person's skin, then keep your fingers together and gently roll your fingers onto more of her/his skin to reduce the discomfort of initiating touch to new parts of her skin.
- 15. Use a gentle but firm pressure when touching, when light touch seems to be particularly uncomfortable. Avoid applying so much pressure that your touch hurts this person.

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment III. BODY LANGUAGE

### Look for ways to:

- Use my body to communicate with this person
- Avoid unintentionally communicating the wrong messages with my body
- Compensate for this person's sensory and cognitive changes by how I position and move my body

# A. Do I use my body to communicate with this person, such as using facial expressions and hand gestures with my words to help her/him understand?

- 1. Use all of your body to communicate.
- 2. Avoid relying simply on words or tone of voice to get your message across, since this person may depend on watching your lips, face, hands, and the rest of your body to interpret what is difficult to hear (due to normal age related hearing loss) or understand (due to brain changes).
- 3. Remind yourself that this person may respond more to how you appear than to how you sound, and more to how you sound than to the words you say.

### B. Is my body telling this person what I want it to say? Do I avoid gestures or facial expressions that could be misinterpreted? For example, do I raise my eyebrows rather than frown when I want to show concern?

- 1. Be aware of what your body is communicating.
- Watch this person to see if you are unintentionally communicating a message, or communicating in a way that distresses or confuses her/him. For example, a frown could be interpreted as anger or anxiety, rather than concern.
- 3. Avoid making your gestures so big they confuse or distract this person.

# C. Do my body, face, eyes, and words all match? For example, do I avoid moving too quickly while using soothing words and smiling?

- 1. Be consistent with your body, words, and voice, so they all communicate the same message and level of calmness and intensity.
- 2. Avoid confusing this person with mixed messages: be aware of your body, especially when you feel rushed, tense, irritated, or impatient.
- 3. Remind yourself that if you speak soothing words and smile while your body is tense and moving quickly, this person will likely respond to the tension in your body rather than your words or smile.

### D. Do I place myself so this person sees and notices me easily?

- 1. Quietly position yourself close to this person so she/he sees you before you speak.
- Approach and position yourself in the part of this person's visual field that is most effective for her/him, since there may be visual problems, or this person's brain may not be able to tell this person to notice everything in her/his visual field,
- 3. Approach and position yourself on this person's stronger side, particularly if one side of her/his body is weaker than the other side due to a stroke or damage to one side of the brain.
- 4. Approach and position yourself in front of this person, if both sides of her/his body are equal in strength.
- 5. Place your face at eye level with this person, whether she/he is standing, sitting, or lying down.
- 6. Avoid holding an object too close to this person's torso (i.e., too low in the visual field).

### E. Do I change positions and gesture slowly and as little as possible?

- 1. Remind yourself that this person is likely not seeing where objects are in space in the same way you are.
- 2. Move and gesture only when necessary, to avoid tiring her/him unnecessarily, even when this person can perceive relatively correctly.
- 3. Move and gesture slowly to make it easier for her/him.

### F. Am I at eye-level with this person, such as sitting to interact?

- 1. Stay at eye-level when interacting with this person, whether she/he is standing, sitting, or lying down, so she/he can see and respond to you more easily.
- 2. Sit rather than crouch, to show more respect and to feel more relaxed.

### G. Do I make and keep eye contact with this person?

- 1. Maintain eye contact with this person when interacting, so you can keep her/his attention.
- 2. Watch this person's eyes and face, so you can see more easily how she/he is responding to what you are saying or doing.
- 3. Use eye contact to show you are giving this person your full attention.
- 4. Show compassion and respect with your eyes.
- 5. Position yourself close to this person, so she/he can watch your eyes and face to better understand what you are saying, especially when she/he is hard of hearing or having difficulty processing your words.

### H. Do I touch this person while talking, when appropriate?

- 1. Remind yourself that all touch is a form of communication, even when it is careless or unintentional.
- 2. Touch this person as appropriate, to help her/him understand what you are saying or doing.

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- 3. Touch this person's body part, when talking about the body part (e.g., when asking her/him to lift an arm or when asking if she/he is in pain).
- 4. Use touch to communicate comfort and reassurance and to help calm her/him,
- 5. Use touch to keep this person's attention.
- 6. Touch this person to feel her/his reaction to what you are saying or doing (e.g., stiffening or increased tension in a body part).
- 7. Before touching, remind yourself that this person may be particularly sensitive to touch. Your touch might send sensations such as "pins and needles", "bugs crawling", or "tickling" up and down her/his skin, or be extraordinarily painful or uncomfortable. A soft touch might feel like a hit or like intense heat or cold.
- 8. Watch this person to see how she/he responds to touch. If she/he is very sensitive to touch, then avoid touching or try touching using the palm of your hand with gentle sustained firmness.
- 9. Remind yourself that discomfort with touch may be unpredictable. Each part of this person's body may have a different level of sensitivity and discomfort. The presence and degree of sensitivity or discomfort may also change from one moment to the next. Watch this person's face and body constantly and listen to what she/he says to recognize evidence of the level of sensitivity or discomfort with touch at this time.
- 10. Go slowly enough to allow this person time to prepare for your touch.
- 11. When touching, minimize the number of times your hand leaves and returns to her/his body, since her/his body may have difficulty adjusting to the initiation of touch.
- 12. Use the palm of your hand rather than individual fingers when touching to minimize the number of contact points between your hand and her/his body.
- 13. Use a gentle but firm pressure when touching, when light touch seems to be particularly uncomfortable. Avoid applying so much pressure that your touch hurts this person.

### I. Do I model the task and positive behaviors?

- 1. Remind yourself, that this person may be able to better understand what to do by watching you, rather than listening to your words.
- 2. Show this person how to act or do a task.
- 3. Do the task with this person (e.g., wash her arm while she is also washing her arm).
- 4. Model the task for her/him (e.g., sit beside her/him and wipe a placemat while she/he wipes another placemat).
- 5. Avoid expecting this person to act a certain way or perform a task when you are doing something different. For example, during a meal, sit down and eat your meal at the same time she/he is eating. Have the food already at the table, so that there is less need for you to stand or walk around.
- 6. Remind yourself that this person's feelings may reflect events and the feelings expressed in the environment. If the environment around this person is calm and comfortable, she/he will more likely feel calm and comfortable.
- 7. Avoid mirroring this person's emotional state, particularly if she/he is anxious or distressed. Look and sound calm and in control to communicate reassurance.

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment IV. APPROACH

### Look for ways to:

- Introduce a topic, activity, or request in a way that helps this person feel positive about it
- Set an upbeat, cheerful, relaxed, and comfortable emotional tone
- Prevent anxiety, uncertainty, or frustration in this person

## A. Do I build trust with this person, for example by conversing, before mentioning a task such as bathing or getting dressed?

- 1. Focus on helping this person feel comfortable and relaxed with you.
- 2. Remind yourself that this person may not consciously remember who you are.
- 3. Remind yourself that she/he may have an emotional response to you based on previous experiences with you.
- 4. Use specific strategies to build this person's trust in you.
- 5. Converse in a friendly tone.
- 6. Spend time with her/him.
- 7. Smile and touch her/him reassuringly.
- 8. Mention the task to be done only after you feel she/he trusts you.
- 9. Invite her/him to do the task by your tone and phrasing, rather than simply requesting or demanding.
- 10. Say that you'll do the task together.

## B. Do I avoid embarrassment about private activities, such as inviting this person to use the toilet only when we are alone, so that other people don't hear me ask?

- 1. Remind yourself that this person may have enough social awareness to be embarrassed when her/his privacy is compromised, even if she/he appears to be nonverbal and unaware.
- 2. Consider others' embarrassment when this person's private activities or information are exposed.
- 3. Talk with this person only in private about personal hygiene, etc., and keep all other private activities, conversations, and information out of sight and hearing of other people.

## C. When appropriate, do I avoid telling this person about the whole task, such as a shower, and suggest one step at a time, such as "let's walk to the bathroom"?

- 1. Remind yourself that the idea of some tasks, such as taking a bath or shower, may feel too confusing to this person.
- 2. Avoid overwhelming this person by presenting the whole task all at once, since she/he may feel anxious about a task, have difficulty understanding all the steps, or be unsure how to begin.
- 3. Suggest one task step at a time in a relaxed friendly way.

### D. Do I offer options this person can understand, so she/he can make choices?

- 1. Frequently assess this person's ability to recognize and choose among options.
- 2. Adapt your approach and presentation of options to this person's ability to choose among options.
- 3. Simplify your presentation of this person's options when she/he is making a choice, especially as she/he becomes increasingly confused and less able to understand multiple or abstract options.
- 4. Remind yourself this person can make choices and express preferences even when very severely impaired.
- 5. Try to be creative when discerning what she/he might want or need.
- 6. If this person is nonverbal, encourage her/him to point to what she/he wants.
- 7. List specific options available. For example, say, "Would you like eggs, cereal, or a muffin for breakfast?" rather than "What would you like for breakfast?"
- 8. List fewer options at a time. For example, say, "Would you like eggs or cereal for breakfast?" rather than "Would you like eggs, cereal, or a muffin for breakfast?"
- 9. Another strategy is to present each option as a "yes/no" choice. For example, say, "Would you like eggs for breakfast?" and then, regardless of her/his response say, "Would you like oatmeal for breakfast?" in order to better understand what her/his desires might be.
- 10. Show this person the options rather than simply naming them. For example, show her/him eggs and cereal to make the options more concrete and visible.
- 11. Help this person feel or taste the options, if she/he is unable to see or recognize objects. For example, put a small taste of each option in her/his mouth and watch for her/his response to each option.

### E. Do I suggest a refreshment or fun enticement to help this person participate?

- 1. Remind yourself that this person may not see the need for the task; may need other incentives to complete the task; may wish to avoid the task, or may feel overwhelmed when faced with the task.
- 2. Give her/him a reason to do the task: for example, bathing in order to look good for visitors.
- 3. Distract her/him with another desire: for example, anticipating coffee and a donut after the bath, or eating pie during the bath.
- 4. Reduce the focus on the task itself: for example, talk about the pie she/he is eating during the bath.
- 5. Make it easier for her/him to participate: for example, by joking or rhythmically singing when walking to the bathroom.

# F. When appropriate, do I rhythmically sing or march to a place, such as the bathroom or dining room, to help this person walk and participate?

- Remind yourself that when trying to perform a task such as walking, this person's brain impairment may make it more difficult for her/him to respond to verbal requests or instructions, or to "talk" her/his own way through a task (i.e., give her/himself verbal instructions).
- 2. Make use of the parts of the brain that use nonverbal processing: for example, by singing rhythmically or providing music with a beat to help her/him move to the music.
- 3. Walk or march with her/him in a rhythmic way to model and to perform the task together.

### G. Do I laugh, joke, and use humor in a concrete, emotionally supportive way?

- 1. Remind yourself that this person will likely create and respond to humor, regardless of her/his level of functioning.
- 2. Use humor to make a situation fun or more tolerable.
- 3. Use humor to help this person feel good.
- 4. Adapt your humor to this person's level of functioning and understanding.
- 5. Keep the humor focused on the task or immediate situation.
- 6. Avoid jokes that have to do with the past.
- 7. Avoid complex jokes with puns or complicated scenarios.
- 8. Avoid "put down" jokes that tease this person or any ethnic group.
- 9. Avoid jokes that rely on objects and events that aren't present or concrete: for example, "What do you call a cow with no legs?" She/he may respond, "You don't call (i.e. shout for) a cow," rather than be able to give or understand the answer (i.e. ground beef).

## H. Do I stay calm, whatever else is happening, even for example, when we are being silly together, or when this person is angry or frightened?

- 1. Remind yourself that you can have a direct effect on how this person is feeling at the moment.
- 2. Remind yourself that sometimes this person might mirror your emotions.
- 3. Help this person feel relaxed and comfortable by creating a relaxed and calm tone in your interactions.
- 4. Even when you are joking or being silly with her/him, be calm, loving, and respectful.
- 5. When this person is anxious or angry, avoid mirroring her/his anxiety or anger in your face and movements.
- 6. Respond with calm reassuring facial expressions and body movements, including raised eyebrows rather than a frown of concern that could be misinterpreted.
- 7. Respond with words and a tone of voice that affirms the person without increasing or mirroring her/his emotion, such as: "Yes, I can see why you might feel that way," rather than: "Well, I should say so, that was just terrible of him to do that!"

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: V. OBSERVATION

### Look for ways to notice and recognize:

- How this person is feeling
- How well this person is understanding
- What this person is trying to express
- Evidence this person is going to be frustrated, anxious, or angry
- Evidence this person may engage in a distressing behavior
- How to best respond to this person's feelings and behaviors

# A. Do I watch this person carefully for nonverbal and verbal feedback, so I can note how this person is feeling, and anticipate or respond to frustration and anxiety?

- Remind yourself that since your goal is to help this person feel comfortable and content, her/his feelings are more important than the task you are performing (e.g., when bathing, it is more important for this person to feel good than to be clean. If she/he needs to be clean, then find a way to help her/him be clean and still feel good).
- 2. Focus more on this person and her/his feelings than on the task.
- 3. Face and watch this person at all times, even when performing tasks, such as speaking on a phone, rinsing out a washcloth, or talking to someone else.
- 4. Listen to the words this person is using and to the volume and tone of voice to better understand her/his feelings.
- 5. Listen to any changes in the tone and volume of this person's voice (whether or not words are used) that might indicate emotions, pain, or change in her/his level of understanding.
- 6. Watch for subtle changes in this person's body or vocalizations, and respond immediately to the beginning signs of possible frustration or anxiety.

### B. Do I watch this person's whole body for changes, such as tightening leg muscles, clenching fists, widening eyes, rapid eye movements, or brief frowns that suggest confusion, anxiety, or something else she/he is feeling?

- 1. Remind yourself that this person's body is always expressing emotions, level of pain, and the ability to understand what is being said or occurring, regardless of her/his level of functioning, even when she/he is nonverbal or lying still.
- 2. Note any changes or movement in this person's body during a conversation, activity or event. Such changes and movements can indicate a shift in emotions, pain, or possible confusion.
- 3. Pay particular attention to this person's face and eyes, which may be the most communicative part of her/his body.
- 4. Avoid focusing only on the face or eyes: watch her/his hands and entire body.
- 5. Touch this person's body to feel when subtle tightening and relaxing occurs.

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### C. Do I watch this person's eyes when we talk?

- 1. Remind yourself that this person's eyes may be the most communicative part of her/his body.
- 2. Watch for changes in this person's eyes, such as widening eyes, rapid eye movements, blinking, closing eyes, glancing off to one side or down or up, wincing, narrowing of eyes, sudden focusing on you or anther person or an object, or a brief frown between the eyes, that might indicate emotions, pain, or change in her/his level of understanding.

### D. Does this person seem comfortable and relaxed?

- 1. Focus more on this person and her/his feelings than on the task.
- 2. Remind yourself that since your goal is to help this person feel comfortable and content, her/his feelings are more important than the task you are performing (e.g., when bathing, it is more important for this person to feel good than to be clean. If she/he needs to be clean, then find a way to help her/him be clean and still feel good).
- 3. Watch for smiles and a relaxed face and body (i.e., all parts of the body are relaxed) showing contentment and comfort.

### E. Is this person responding positively to what I am saying or doing?

- 1. Listen and watch for this person's responses to what you are saying or doing.
- 2. Remind yourself that understanding this person's responses to what you are saying or doing are crucial to figuring out how to help her/him feel comfortable.
- 3. Face and watch this person at all times, even when performing tasks, such as speaking on a phone, rinsing out a washcloth, or talking to someone else.
- 4. Remind yourself that this person's positive response is more important than successful completion of a task.

### F. Does this person seem to understand me?

- 1. Remind yourself that communication with this person is successful only if she/he understands you.
- 2. Remember to watch her/him to make sure she/he understood you before going on to your next comment.

## G. Do I give this person enough time to absorb what I say and to then respond?

- 1. Pause often and long enough to allow this person to absorb and respond to what you do and say.
- 2. Pause often and long enough to allow you time to observe whether this person understood you and is feeling comfortable.
- 3. Pause between sentences, concepts, and tasks.
- 4. Keep your pauses only as long as necessary, so you don't disrupt the natural flow or rhythm of the task or conversation.

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## H. Do I change my own behavior or the environment in response to this person's reactions?

- 1. Respond immediately when you see or hear evidence of emotion (positive or negative), pain, or a change in level of understanding.
- 2. Nip this person's confusion, frustration, or distress in the bud, before it increases.
- Change your behavior or what you are saying by, for example, stopping, slowing down, reassuring, repeating yourself, using different words, or shifting to a new position, topic, or task.
- 4. Change the environment by, for example, removing that which is distressing, or adding positive alternatives such as tea and cookies.

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### Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: VI. DISTRACTION

### Look for ways to:

- Use distraction or diversion to help this person
- Compensate for and reduce inappropriate distraction for this person

# A. Do I know when distraction or diversion is helpful with this person, such as when she/he is looking for a dead spouse, or when she/he is performing a task that is easier to do when she/he isn't thinking about it?

- 1. Since each individual and situation is different, adapt your response to this person to fit her/his individual needs and desires at this particular time.
- 2. Avoid distractions unless distraction would be helpful in this particular situation.
- 3. Respond directly to this person's questions or concerns if possible. Use distraction when a direct response would be painful, harmful, or inappropriate; for example, if she/he would grieve when told the spouse she/he is repeatedly looking for is dead.
- 4. Use distraction if a direct response seems ineffective. For example, this person asks the same question over and over and seems unsatisfied with the response.
- 5. Distract when focusing directly on an issue or task is too difficult for this person. For example, provide a mild distraction if this person can perform a task such as getting dressed, tying her/his shoes, or swallowing medication more easily when she/he isn't thinking about it.
- 6. Use only as much distraction as is helpful. Using too much distraction can cause confusion. For example, if you are using distraction, such as conversation about this person's daughter to help this person perform a task more easily, then make as many comments as is necessary to prevent her/him from focusing attention on the task, but not so many that this person stops doing the task or gets confused.
- 7. Watch this person's responses to your interventions to discern whether to use distraction and how much is needed in a particular situation.

# B. When there is a distressing behavior, do I use humor and diversion instead of demands, argument, shame, or instructions to stop the behavior?

- 1. Respond to the feelings behind the behavior; then use humor and diversion if necessary to help this person meet her/his needs and feel comfortable.
- 2. Respond to her/his feelings before telling this person what to do. For example, avoid saying "stop" or "come here" first, since she/he may not be able to respond to instructions when emotions are strong.
- 3. Use humor to distract or to emphasize positive feelings as a method to reduce distress. Avoid focusing on the behavior, distress, or negative feelings since this might increase the distress. For example, avoid embarrassing her/him, asking why she/he is engaged in this behavior, or insisting that she/he stop the behavior.
- 4. Adapt your humor to this person's level of functioning and feelings at the time, so the humor is appropriately simple, concrete, and emotionally supportive.

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### C. Do I avoid calling this person's attention to her/his behavior?

- 1. Remind yourself that this person may be unaware of her/his behavior or may not be able to stop or modify it.
- 2. Discreetly distract this person, since calling her/his attention to the behavior may embarrass her/him and/or make it worse.
- 3. Avoid giving instructions or requests when this person is distressed, since she/he likely cannot process instructions at the same time she/he is focused on the behavior or is feeling strong emotions.

# D. Do I try to discern the feelings behind distressing words and behaviors, and then respond to the feelings rather than simply to the words and behaviors?

- 1. Examine this person's words and behaviors to discern the feelings behind the behaviors.
- 2. Respond to her/his feelings; for example, by soothing with reassuring words and touch.
- 3. Respond to this person's words and behaviors only if necessary in order to address feelings.

## E. During tasks, do I encourage this person to hold or use an item while I use a similar item, such as a comb or washcloth?

- 1. Offer this person a task object to use or hold to help orient her/him to the task and to what you are doing and to encourage participation in the task.
- 2. Encourage this person to hold a task object to reduce her/his tendency to grasp onto you or other objects in the environment.

# F. Do I get and keep this person's attention before speaking and throughout our interaction?

- 1. Remind yourself that this person may be easily distracted by other stimuli in the environment.
- 2. Be the strongest stimulus in the environment, both before and throughout your interaction with this person
- 3. Get and keep this person's attention through touch, (when appropriate), placing your face close to hers/his, speaking more loudly, or positioning yourself and contrasting with your surroundings so as to be more visible to her/him.

# G. Do I reduce distraction such as noise and clutter around me when I am talking to this person?

- 1. Reduce noise or irrelevant stimuli when getting and keeping this person's attention. For example, close the door, turn off the TV, radio, cell phone, or intercom. Remove her/him from crowded noisy spaces.
- 2. Reduce the visual clutter, such as the number of items in the bathroom, clothes in the closet, or items on the dinner table.
- 3. Avoid standing in front of a complex visual pattern. Position yourself so that when she/he is looking at you, she/he is looking away from groups of people, moving objects, excessive clutter, or patterned wall paper.
- 4. Avoid wearing excessively patterned shirts or blouses.

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## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: VII. CONSISTENCY

### Look for ways to:

- Keep my interactions the same and predictable as much as possible
- Have only one caregiver at a time interacting with this person

### A. Does the same caregiver help this person every day as much as possible?

- 1. At all times, as much as possible, have the same caregiver help this person.
- 2. Have the same caregiver help this person during the days or occasions the primary caregiver has time away from caregiving.
- 3. When a caregiver who is unfamiliar to this person must help her/him, provide the unfamiliar caregiver with information about the primary caregiver's routines, so that the unfamiliar caregiver can help perform the tasks in as familiar a way as possible.

### B. Does this person know what to expect from me?

- 1. Be predictable to this person as much as possible, even if this person doesn't seem to know or to be able to tell you what she/he expects from you.
- 2. Perform a task with this person the same way each time. For example, wash the same part of the body first each time.
- 3. Adapt a task to this person's current desires and needs only as much as necessary, so you can keep the task as familiar as possible.
- 4. If you do look different or need to perform a task differently, reassure this person and tell her/him who you are and what you are doing.
- 5. Tell this person what you are going to do before you do it.

### C. Do I use nearly the same words every time we do this task?

- 1. Talk about the task in the same way each time, once you have discerned what is the best way to help and communicate with this person.
- 2. Avoid introducing new words. Use words that are familiar and meaningful to this person every time.
- 3. If this person seems bored or annoyed by the consistency of words, vary them as necessary to increase interest and stimulation.

### D. Do I position myself in the same spot every time we do this task?

- 1. Choose a place in the room to regularly perform tasks with this person. For example, help this person get dressed on one side of the room and undressed on another side of the room.
- 2. When helping this person with a task, position yourself in the same spot relative to her/his body and visual field each time, so she/he gets used to where you are. For example sit or stand on her/his right side each time.

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### E. Do I move my body in a similar way every time we do this task?

- 1. Notice how you move your body and body parts when you help this person. Once you have minimized your movements, continue to move your body the same way each time.
- 2. Particularly note your hands and face. Position and move them the same way each time as much as possible.

### F. Is there only one caregiver helping this person at a time?

- 1. Remind yourself, that this person may have difficulty shifting from one stimulus or caregiver to another. Have only one caregiver at a time help this person with a task, to avoid confusion and anxiety.
- 2. Think of creative ways of interacting with this person, before considering bringing in additional caregivers to help with a task.

# G. If there are two or more caregivers, is there only one caregiver at a time that this person is noticing and paying attention to (i.e., the other caregivers are helping this person from behind, staying out of sight and not talking)?

- 1. Remind yourself that this person may have difficulty focusing attention on more than one caregiver and may have difficulty switching attention from one caregiver to another.
- 2. When more than one caregiver must help this person with a task, then have only one caregiver visible to her/him.
- 3. While one caregiver talks to this person and helps her/him from the front, have another caregiver help quietly and discreetly from behind, such as when helping this person change clothing.

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## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: VIII. CHARACTERISTICS

### Ask myself:

- Am I the best person to be helping with this task?
- Are there things I can change about myself to make this go more easily?
- Are there things I cannot change and therefore must compensate for?
- How do I feel about this person and about this task?

### A. Does this person recognize me as myself and not someone else?

- Watch this person to see if she/he seems to know who you are. Remind yourself that this
  person may recognize you even if she/he doesn't realize it or calls you by a different name.
  Look for evidence that she/he knows you by the way she/he acts and seems to feel. For
  example, she/he is consistently calmer with you than with other caregivers, or she/he
  relates to you in the same unique way as before her/his brain changes.
- 2. If this person calls you a different name or relates to you in an emotionally distressed way, examine yourself to see if you look, move, or act like the person she/he called you or seems to think you are. For example, if she/he calls you "mother", it might be that you look like her/his mother when she/he was a young person. Or if she/he seems to be angry with you, she/he may think you are a spouse or grandchild who previously hurt her/him.
- 3. Identify yourself each time this person sees you.
- 4. When this person first calls you by a different name, say your name once. Avoid correcting her/him when he/she calls you by a different name after that.

## B. Does this person feel comfortable with me or with the person she/he thinks I am?

- 1. Look for evidence this person is comfortable, for example, a relaxed face and body, smiling, words of contentment.
- 2. Look for evidence this person is uncomfortable, for example, a frown, tension, jerky movements, words of anger or pain
- 3. Help this person to feel comfortable, even if she/he thinks you are someone other than yourself.
- 4. If this person feels emotionally distressed or uncomfortable with you, regardless of whom she/he thinks you are, then help her/him to feel more comfortable.
- 5. If this person feels emotionally distressed or uncomfortable with you because she/he thinks you are someone else, make it clear that you are not that person. If that is not possible, then find a different caregiver with whom she/he is comfortable. For example, if she/he thinks a middle-aged child is a deceased abusive spouse, because the child looks like the spouse, then encourage the child to identify her/himself frequently, and to dress or wear a hairstyle different from the deceased abusive spouse.

### C. Does this person have strong feelings about me?

- 1. Look for evidence of strong positive feelings, for example stroking your arm or face, spontaneous smiles, eye contact, words of endearment.
- 2. Look for evidence of strong negative feelings, for example, tense face, raised hand or fist, words of anger.
- 3. If there are strong negative feelings, examine yourself and the ways you help this person to see if you can change in ways to reduce her/his negative feelings about you. If the required changes are not possible, then find a different caregiver.

### D. Does this person trust me?

- 1. Look for evidence this person trusts you, for example she/he tries to respond consistently and immediately to your requests even when she/he doesn't understand you.
- 2. Look for evidence this person doesn't trust you, for example widening eyes that appear fearful, pulling back, looking away, stiffening of body parts.
- 3. If this person doesn't trust you, examine yourself and the ways you help this person to see if you can change in ways to increase her/his trust in you. If the required changes are not possible, then find a different caregiver.

### E. Is my gender comfortable and appropriate for this person?

- 1. Look for evidence this person is uncomfortable with your gender, for example, using words that indicate a preference for a particular gender in her/his caregiver.
- 2. If this person has a preference for a particular gender in her/his caregiver, and you are not of that gender, then find a different caregiver.

### F. Am I comfortable with this person in general?

- 1. Examine your own feelings before, during, and after you help this person with a task.
- 2. Remind yourself that your feelings may have a strong effect on the comfort level and emotions of this person, and on her/his behavior and ability to function. For example, she/he may become too upset to be able to understand you well, or your distress may prevent you from being able to focus on this person enough to be helpful.
- 3. If you are uncomfortable, explore possible reasons for your discomfort, for example, discomfort with death due to a recent loss of a loved one, or with this person's sexual behavior due to your earlier or current experience with sexual abuse.
- 4. Avoid talking to this person about your discomfort.
- 5. Talk about your discomfort with someone you can trust to see if you can change your own feelings of discomfort.
- 6. Change the conditions that make you uncomfortable, if the changes do not affect this person in a negative way.
- 7. If the required changes to make you comfortable are not possible at this time, or if you need more time to change your feelings, then find a different caregiver until you are able to feel comfortable with this person.
- 8. If the required changes to make you comfortable are not possible at any time, then find a different caregiver.

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### G. Am I comfortable with this person today?

- 1. Examine your own feelings before, during, and after you are with this person or help this person with a task today.
- 2. Remind yourself that your feelings may have a strong effect on the comfort level and emotions of this person, and on her/his behavior and ability to function. For example, she/he may become too upset to be able to understand you well, or your distress may prevent you from being able to focus on this person enough to be helpful.
- 3. If you are uncomfortable, explore possible reasons for your discomfort, for example, you are in a rush or you are emotionally vulnerable or tired today.
- 4. Avoid talking to this person about your discomfort.
- 5. Talk about your discomfort with someone you can trust to see if you can change your own feelings of discomfort.
- 6. Change the conditions that make you uncomfortable, if the changes do not affect this person in a negative way. For example, reduce the number of tasks for today.
- 7. If the required changes to make you comfortable are not possible today, then find a different caregiver until you are able to feel comfortable with this person.

## H. Am I comfortable doing this task with this person? For example, am I comfortable seeing this person without clothes or drooling while eating?

- 1. Examine your own feelings before, during, and after you help this person with a task.
- 2. Identify the tasks or aspects of tasks that change your feelings about this person. For example, bathing and dressing, or helping this person eat when she/he has trouble swallowing.
- 3. Identify how your image of this person is changing and how you feel about that. For example, you are uncomfortable seeing your distinguished father drool while he eats in public.
- 4. Talk about your discomfort with someone you can trust to see if you can change your own feelings of discomfort, embarrassment, guilt, disgust, anger, or frustration.
- 5. Change the task to avoid aspects that make you uncomfortable, if the changes do not affect this person in a negative way. For example, eat with your father in private and do other activities that aren't embarrassing when with other people.

### I. Am I comfortable with this person's dependency?

- 1. Examine your own feelings before, during, and after you help this person with a task.
- 2. Identify your feelings about this person's dependency. For example, notice how you feel about your distinguished father becoming incontinent.
- 3. If you are uncomfortable with this person's dependency, talk about your discomfort with someone you can trust to see if you can change your own feelings of discomfort, embarrassment, guilt, disgust, anger, or frustration.
- 4. If you are unable to change your feelings over time, find a different caregiver to help with the tasks that are upsetting to you.

# J. Can I avoid letting my anger or sadness about this person's behavior affect my ability to help?

- 1. Examine your own feelings before, during, and after you are with this person or help this person with a task.
- 2. Monitor your own physical and emotional health to see how you are affected by your caregiving with this person.
- 3. Notice how often or how strong your feelings of anger and sadness are about this person's situation or condition. For example, record the times you become impatient, irritable, tearful, or raise your voice angrily when she/he is or is not present.
- 4. Watch this person to see if your feelings are affecting this person. For example, see if this person pulls away from you, becomes rigid, or appears fearful or tearful.
- 5. Record the times your feelings of anger or sadness seem to affect this person.
- 6. If your feelings affect this person frequently, change your feelings, or find a different caregiver.
- 7. If there is an occasion when you physically or emotionally harm this person, for example you strike this person, raise your voice, or say words that hurt her/him, then immediately talk to someone you can trust, and find a different caregiver until you emotionally heal enough to help this person safely.

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: IX. ORGANIZATION

### Look for ways to:

- Organize my time, the task steps, and the task items
- Be efficient, but appear relaxed and calm to this person

### A. Do I organize my time to avoid the need to rush through a task?

- 1. Remind yourself that planning your entire time with this person and the multiple tasks to be performed will save time and frustration for this person and for yourself.
- 2. Establish goals and priorities for your time with this person. Discern this person's own goals first, even when she/he doesn't state them or doesn't seem to know them.
- 3. Identify your own goals and priorities for this time with this person, after you consider this person's goals.
- 4. Plan your time and schedule of tasks to allow enough time to get the most important tasks done, so that the goals of this person and yourself will most likely be met.
- 5. Remind yourself that organizing each task and preparation for each particular task will save time and frustration for this person and for yourself.
- 6. Discern goals and priorities regarding this task. Consider this person's own goals first, then your goals. For example, during a shower or bath this person may want to feel relaxed, pain free, and luxurious, while you simply want this person to be clean.
- 7. Plan your time for the task before you approach this person with a task to be performed. Allow enough time to get the most important parts of the task done so that the goals of this person and yourself will most likely be met.
- 8. Plan for the tasks and the tasks steps that are most challenging, to occur when this person is best able to perform them, For example, plan to do the most difficult tasks when she/he is less fatigued or frustrated, or do the most appealing task steps first to entice her/him to begin the task and to be better able to understand and perform the more challenging task steps.
- 9. In your planning, allow enough time to approach this person leisurely and calmly to prepare her/him emotionally for the task.

### B. Do I plan the task steps ahead of time?

- 1. Break the task down into smaller task steps.
- 2. Note which task steps this person can do easily and which are challenging.
- 3. Plan how to best encourage this person to independently perform the easy task steps, and plan how to make the challenging task steps easier.
- 4. Remind yourself that this person's comfort is more important than her/his independent performance of a task step. If she/he can do a task step, but is physically or emotionally uncomfortable doing it, then assist or perform the task step for her/him.

## C. Do I do most of the task preparation out of this person's sight, for example, collecting and arranging the task items?

- 1. Remind yourself that this person might become tired or confused easily when there are many steps or items to a task.
- 2. Reduce the amount of distraction for this person by preparing for the task out of this person's sight and hearing. For example, collect and organize task items, such as washcloths and basins before you enter this person's room.
- 3. Arrange the task so this person sees and hears only those task steps in which she/he can directly participate.

### D. Do I focus more on this person and less on the task or product?

- 1. Remind yourself that this person and her/his feelings are more important than the task you are helping her/him perform.
- 2. Consider this person's own goals first, then your goals. Discern this person's goals even when she/he doesn't state them or doesn't seem to know them.
- 3. At all times, watch and listen to this person to see how she/he is reacting to what you are doing and saying.
- 4. Immediately change what you are doing or how you are doing it, when you see or hear negative reactions.
- 5. Modify the task, the timing of the task, or duration of the task to accommodate this person's preferences, needs, and timing.

## E. Do I move quickly and quietly when I am out of this person's sight, but more slowly on the parts of the task where this person sees me?

- 1. Be efficient, but appear relaxed and calm to this person.
- 2. Perform quickly, efficiently and out of this person's sight and hearing, the task steps that are not meaningful or helpful to this person.
- 3. When you are with this person, perform the task steps slowly enough for her/him to participate, to understand what you are doing, and to remain relaxed and comfortable.

## Cognitive Impairment Intervention Protocol (CIIP) for Caregiver Interactions with a Person with Cognitive Impairment: X. PREVENTION

### Look for ways to:

• Prevent distress, confusion, or anger, rather than simply respond to them when they occur

### A. Am I nipping distress or confusion in the bud, rather than letting it escalate?

- 1. Watch this person at all times so you can see immediately when she/he is beginning to get confused or upset.
- 2. Watch all parts of this person's body, especially her/his face and hands to see evidence of beginning distress or confusion.
- 3. Respond immediately to any distress or confusion, before it gets worse. For example, remove the cause of the distress or confusion, or get her/his attention and offer appropriate reassurance, pain relief, or distraction.
- 4. Monitor the emotional tenor of the environment. Keep it upbeat and relaxed. For example, make light conversation, smile frequently, sing, or joke in a relaxed way.
- 5. Anticipate and prevent situations where tension, confusion, or distress might occur. For example, avoid contact between this person and another person that might be distressing to her/him.
- 6. Prevent confusion and anxiety by creating a supportive, informative environment and by giving this person the emotional support and information she/he needs or wants.
- 7. Be visible to this person at all times, so she/he can feel more secure and less alone, or see you when she/he needs help.

# B. Do I apologize or reassure immediately when I see this person getting angry or anxious?

- 1. Reassure or apologize as appropriate when this person becomes irritated or anxious.
- 2. Avoid asking this person why she/he is upset.
- 3. Avoid drawing this person's attention to her/his behavior, or dwelling more than briefly on her/his feelings, until she/he is relaxed and can think more clearly again.
- 4. Remove the source of the anger, whether it is in the environment, such as an annoying sound, or an internal condition, such as pain or discomfort.
- 5. Stay with this person until she/he is relaxed and comfortable again.

# C. Do I notice subtle hesitations and try to gently coax or encourage this person when she/he is performing a task?

- 1. Watch this person closely while she/he is engaged in a task.
- 2. When you see her/him hesitate or appear confused, respond immediately with encouragement, information, reassurance, or praise.
- 3. Be visible to this person at all times, so she/he can feel more secure and less alone, or see you when she/he needs help.

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