

RESPONDING TO DISTRESS, PAIN, AND NEEDS OF A PERSON

Suggestions of Verbal and Nonverbal Strategies Shelly Weaverdyck

Distressing situations and **emotional distress** are usually triggered by a physical or emotional **unmet need** or desire, including pain or discomfort. Recognizing and responding to **pain** or **discomfort** in a person who has brain changes, has **many cognitive needs**, is emotionally distressed, or whose behavior is creating distress, can be particularly challenging. (See **other CAIS Handouts** including “**#26 Emotions**” and “**#28 Movement with Less Distress**” for more details and information at <https://www.improvingmipractices.org>)

Some reasons for this difficulty in **recognition** and **response** are listed here, along with suggestions for how to understand and intervene or support this person.

NEEDS OFTEN UNRECOGNIZED

1. **Emotional pain and discomfort:** Distress or distressing behavior is often caused by an underlying anxiety or fear. For example, a person may misinterpret an object in the environment, such as a chair in front of a window that looks like an odd and frightening shape or shadow, so they might repeatedly call for help or strike out at the object or other people.
2. **Physical pain and discomfort:** Distress or distressing behavior is often caused by an underlying pain, physical discomfort, or need. For example, joint pain, hunger, or needing to use the bathroom can trigger refusal to get dressed, irritability, calling out, swearing, or grabbing people as they pass by. Physical pain is frequently under-treated among persons with many cognitive needs.

Needs are sometimes unrecognized by a person in distress because they:

3. **Don't know** they have a need.
4. Know they have a need, but they don't know **what the need** is.
5. Have pain or discomfort, but they **think it is some other need**. For example, they may think they have to urinate, when they actually have abdominal discomfort due to hunger or gas, or they may think they have stomach pain when they actually have a fractured hip.
6. May be so **used to pain** they don't recognize they have pain or discomfort until the level of pain changes (gets better or worse) and calls their attention to it. For example, if they have a diagnosis or disorder involving joints, swelling, rigidity, fractures, or if they have been sad or depressed for a long time they might see that as normal and not think of it as pain.
7. Recognize they hurt or are in pain, but they will **say “no”** instead of “yes” when asked. Sometimes, especially if they have difficulty understanding or producing speech, they don't realize they said “no”. They may be unable to understand the question or to respond accurately.
8. **Can't distinguish** between physical pain and emotional pain.
9. Don't recognize that the part of their body that is in pain is part of **their body**. For example, if their leg hurts they might think it is someone else's leg and not theirs.

EVIDENCE OF DISCOMFORT OR PAIN

Expressions or evidence of discomfort or pain (**emotional** or **physical**) may include:

10. **Saying they hurt**, are in pain, hungry, etc., especially if repeatedly or unexpectedly.
11. Saying directly or using **words** that **suggest** they are **afraid, angry, anxious**, etc. especially if repeatedly or unexpectedly.
12. Speaking frequently of physical or emotional pain, for example, in general or when referring to other people or animals.
13. Speaking frequently about a **particular body part** of their own or others’.
14. **Asking for help** repeatedly.
15. **Vocal outbursts**, for example, yelling, crying, swearing, moaning, “whining”, or whimpering.
16. **Changes in vocal outbursts**, for example, changes in volume, pitch, or frequency.
17. Overt **body expressions**, for example, striking, kicking, spitting, biting, or wringing hands.
18. **Holding, grabbing, or touching** a part of their body frequently.
19. **Grabbing** other people and objects, especially if their hands or fingers can’t be released easily.
20. **Subtle body changes**, for example, tightening, stiffening or tension in face, hands, other body parts.
21. **Facial** expressions, for example, wincing, frowning, grimacing, teeth clenching, tears.
22. **Eye changes**, for example, widening, darting, shift in gaze, closing eyes, blinking rapidly or frequently, staring without seeming to see.
23. **Resisting movement**, staying very still, or staying in one position.
24. Apparent **lethargy** or not wanting to do most tasks or activities.
25. **Distressing behavior of any kind**. For example, frequent **spitting** during tasks might suggest physical pain upon movement. Spitting when someone walks by may suggest a need for help. When this person spits frequently while sitting in a chair there may be discomfort in their mouth, such as loose fitting dentures, a sore, a fuzzy feeling from an infection or growth, dry mouth from side effects of medication, dehydration, something tucked in a pocket in their mouth such as food that wasn’t swallowed, a bad taste, difficulty in swallowing saliva, habits from the past, boredom, or pain elsewhere in their body.
26. See **CAIS Handout “#26 Emotions”** for more information and specifics.

UNDERSTANDING OR ASSESSING FOR PAIN

27. **Listen** and **watch** carefully for expressions or evidence of needs, pain, or discomfort.
28. **Encourage this person to say more**. For example, ask them questions or respond to what they say.
29. Listen very carefully for verbal **meaning** in this person’s **vocalizations**.
30. **Use words this person understands** and has used in the past to indicate pain or other needs.
31. Use **various words** like “hurt”, “pain”, “bother you”, “ouch?”, “uncomfortable”, “acting up”, “sore” to describe **various types of pain**, such as joint pain, muscle pain, surface skin sore, abdominal pain, stiffness, cramps, metal in a body part from a past injury fracture or treatment, or general discomfort.
32. **Touch** various parts of their body asking if it hurts “here” (if this person is comfortable with touch).
33. Use gentle **pressure** or slowly **move your hand** on body parts for verbal and nonverbal feedback.
34. If appropriate, gently **move** a joint or part of their body for verbal and nonverbal feedback.
35. **Observe** very closely for **overt** and **subtle nonverbal** feedback or evidence of discomfort or pain.
36. Assess the area this person seems to be identifying first, then search for discomfort in **other areas**.
37. Assess **frequently**, since pain levels can fluctuate.
38. Consult a **health professional** for a thorough examination and recommended treatments.
39. See **CAIS Handout “#28 Movement”** for more information and specifics about pain and movement.

RESPONDING TO EXPRESSIONS OF NEEDS

40. **Believe** what this person says, even if it changes frequently and rapidly.
41. Be **calm** and **reassuring**. For example, use words and move your hand on this person's back if they are comfortable with your touch.
42. **Listen** to this person's words and **analyze** behavior to figure out this person's **feelings**.
43. Respond to this person's **feelings** behind their words and actions.
44. **Let this person know** (verbally and nonverbally) you are there for them.
45. **Ask** this person to tell you more, if appropriate.
46. **Avoid** trying to suggest to, tell, or convince this person they don't have the need expressed.
47. Use **medications** for pain **appropriately**; adjust the medication when pain persists.
48. **Offer solutions**, such as "Would you like to go to the bathroom?", or "Would you like some tea?".
49. Keep analyzing the situation and attempting interventions **until solutions** are **reached**.
50. Be **creative**, **patient**, and **compassionate**.
51. Consult with a **health professional**.

PREVENTING DISCOMFORT AND PAIN

Physical:

52. Assist with **range of motion**.
53. Help or encourage this person to **shift position** frequently.
54. Help or encourage this person to **walk** and to **exercise** frequently, as appropriate.
55. Use pain **medication** if appropriate **before a task**.
56. **Prepare** parts of their **body** and joints to move when shifting position (See **CAIS Handout #28**).
57. Encourage this person to **move** parts of their own **body** rather than you moving them.
58. **Tell** this person every time you are going to move a part of their body.
59. **Move** a part of their body **slowly**, **smoothly**, and **with warning**.
60. **Converse** a while before moving a part of this person's body when this person is waking up, or has been in one position for a long time. This can help them shift focus and also **trust** you.
61. **Stop** moving a part of their body if pain is present.
62. Help this person get plenty of **rest** throughout the day.
63. Consult with a **health professional**.

Emotional:

64. Create a warm, upbeat, cheerful, safe-feeling, and safe **environment**.
65. **Respond** to this person's concerns **immediately**; nip discomfort in the bud before it escalates.
66. **Match the space** to this person's mood, desires, or needs, such as a quiet space or stimulating space.
67. Create a **variety** of small understandable and manageable **spaces** to match various moods.
68. Keep **someone** who **helps** this person **in sight** as much as necessary, so they feel help is nearby.
69. Make sure this **person knows how to get help** immediately when they want it.
70. Help this person **avoid fatigue**.
71. **Match** the **expectations** and demands of the environment, task, and interactions to **this person's abilities, desires, and needs**.
72. Think about how this person spends each half hour of their **twenty-four-hour day**, and help them **adjust** their time, activities, and social life to better meet their preferred schedule, desires, and needs.
73. **Show** this person you admire, respect, and enjoy them.