RECOGNIZING & RESPONDING TO NEEDS
OF
A PERSON WITH DISTRESSING BEHAVIORS
OR
COGNITIVE IMPAIRMENT

Suggestions to Consider

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Distressing behaviors 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 is cognitively impaired, emotionally distressed, or engaged in behaviors that are disturbing, can be very challenging. Some reasons for this difficulty in recognition and response are listed here, along with suggestions for assessment and intervention.

Needs are often unrecognized by caregivers, when there are distressing behaviors.

1. **Emotional pain and discomfort**: Distressing behaviors are often caused by an underlying anxiety or fear, especially in a person with moderate cognitive impairment. For example, a person may misinterpret an environmental cue, such as a chair in front of a window that looks like an odd and frightening shadow.
2. **Physical pain and discomfort**: Distressing behaviors are often caused by an underlying pain, physical discomfort or need, especially in a person with severe cognitive impairment. For example, joint pain, hunger, or needing to use the restroom can trigger calling out or grabbing people as they pass by. Physical pain is frequently under-treated among persons with cognitive impairment.

Needs are often unrecognized by persons with distressing behaviors and cognitive impairment.

3. Sometimes they don't know they have a need.
4. Sometimes they know they have a need, but they don't know what the need is.
5. Sometimes they 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. Sometimes they may be so used to pain, they don't recognize they have pain or discomfort, for example if they have diagnoses or disorders involving joints, swelling, rigidity, fractures, or if they have been sad or depressed for a long time.
7. Sometimes they recognize they hurt or are in pain, but they will say "no" instead of "yes" when asked. Sometimes they don't realize they said "no", and sometimes they are unable to understand the question and to respond accurately.
8. Sometimes they can't distinguish between physical pain and emotional pain.
9. Sometimes they 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.

Expressions or evidence of discomfort and 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, fearful, 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 or touching a part of their body frequently.
19. Grabbing with their hands, especially if they don't let go 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 activities.
25. Distressing behaviors of any kind. For example, frequent spitting by someone with severe cognitive impairment during tasks might suggest physical pain upon movement. Spitting when a caregiver walks by may suggest a need for help. When a 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.

When assessing for pain, the caregiver could:

26. Listen and watch carefully for expressions or evidence of needs, pain or discomfort.
27. Encourage a person to say more. For example, ask them questions or respond to what they say.
28. Listen very carefully for verbal meaning in a person's vocalizations.
29. Use words a person understands and has used in the past to indicate pain or other needs.
30. Use various words like "hurt", "pain", "bother you", "ouch?", "uncomfortable", "acting up" , "sore" to describe various types of pain, such as bone pain, muscle pain, surface skin sore, abdominal pain, stiffness, cramps, metal in a body part from a past fracture or treatment, or general discomfort.
31. Touch various parts of the body when asking if it hurts "here".
32. Use gentle pressure or stroking of body parts for verbal and nonverbal feedback.
33. If appropriate, gently move a joint or body part for verbal and nonverbal feedback.
34. Observe very closely for overt and subtle nonverbal feedback or evidence of discomfort or pain.
35. Assess the area a person seems to be identifying first, then search for discomfort in other areas.
36. Assess frequently, since pain levels can fluctuate.
37. Consult with a health care professional for a thorough examination and recommended treatments.

When responding to expressions of needs, a caregiver could:

38. Believe what a person says, even if it changes frequently and rapidly.
39. Be very calm and reassuring. For example, use words and stroke the person's back as appropriate.
40. Listen to a person's words and analyze the behaviors to figure out the person's feelings.
41. Respond to the person's feelings behind the words and actions.
42. Let a person know you are there for them.
43. Ask the person to tell you more, if appropriate.
44. Avoid trying to tell or convince a person they don't have the need expressed.
45. Use medications for pain as appropriate; adjust the medication when pain persists.
46. Offer solutions, such as "Would you like to go to the bathroom?", or "Would you like some tea?".
47. Keep analyzing the situation and attempting interventions until solutions are reached.
48. Be creative, patient, and tolerant.
49. Consult with a health care professional.

To prevent physical discomfort and pain, a caregiver could:

50. Assist with range of motion.
51. Help/encourage a person to shift position frequently.
52. Help/encourage a person to walk and to exercise frequently, as appropriate.
53. Use pain medication if appropriate before an activity of daily living.
54. Prepare body parts and joints for movement when shifting position.
55. Encourage a person to move their own body parts rather than you move them.
56. Tell a person every time you are going to move a body part.
57. Move a body part slowly, smoothly, and with warning.
58. Visit a while before moving a person's body part, when a person is waking up, or has been in one position for a long time.
59. Stop moving a body part if pain is present.
60. Help the person get plenty of rest throughout the day.
61. Consult with a health care professional.

To prevent emotional discomfort, a caregiver could:

62. Create a warm, upbeat, cheerful, safe-feeling environment.
63. Respond to a person's concerns immediately; nip discomfort in the bud before it escalates.
64. Match the space to a person's mood, such as a quiet space or stimulating space as needed or desired.
65. Create a variety of small manageable spaces.
66. Keep caregivers in sight of a person when necessary, so they can always feel help is nearby.
67. Make sure a person knows how to get help immediately when they want it.
68. Help the person avoid getting fatigued.
69. Match expectations and demands of the environment, task, and interactions to a person's abilities, desires, and needs.
70. Think about how a person spends the twenty-four hour day, and adjust it to better meet their preferred schedule and needs.
71. Show a person you love and enjoy them.