

CARE Compass

Helping Navigate the Later Stages of Dementia



Learning to Assess Pain

This project was made possible by a generous gift.

The goal of the program is to help provide tools and information so that you can navigate the later stages of dementia. We hope that you find these videos and resources to be helpful and encouraging.

This program is designed to be a guide only for the compassionate care and support of your loved one and is not medical advice. If you have questions or concerns, always check with your doctor.

We also want to acknowledge that late-stage dementia can look very different from person to person. Sometimes the ideas we share may not work or work for a short time. That is okay. No one person is alike, and what works today may not work tomorrow. We hope to provide tools that can be options for you to try.

This guide contains links and other resources that may not be provided by the presenter but are added to the guide to provide additional information and support.

In the later stages of dementia, it is important to remember that communication can look very different. When our loved one is in pain, they may no longer say “I don’t feel well, or my head is really hurting,” instead of their actions. The way they breathe, the noises they are making, might be the way they communicate.

The Pain Scale is a way to help identify if your loved one might be in pain and a reminder that pain might look different as the disease progresses.

You can print out the one below and put it somewhere that is easily accessible to use when needed, or to help you navigate the later stages of dementia and the care for your loved one.

Pain Scale

Pain Assessment in Advanced Dementia Scale (PAINAD)

Instructions: Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

Behavior	0	1	2	Score
Breathing Independent of vocalization	Normal	- Occasional labored breathing - Short period of hyperventilation	- Noisy labored breathing - Long period of hyperventilation - Cheyne-Stokes respirations	
Negative vocalization	None	- Occasional moan or groan - Low-level speech with a negative or disapproving quality	- Repeated troubled calling out - Loud moaning or groaning - Crying	
Facial expression	Smiling or inexpressive	- Sad - Frightened - Frown	Facial grimacing	
Body language	Relaxed	- Tense - Distressed pacing - Fidgeting	- Rigid - Fists clenched - Knees pulled up - Pulling or pushing away - Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract, or reassure	
TOTAL SCORE				

(Warden et al., 2003)

Scoring:

The total score ranges from 0-10 points. A possible interpretation of the scores is: 1-3=mild pain; 4-6=moderate pain; 7-10=severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

Source:

Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc.* 2003;4(1):9-15.