

Appendix

Assessing Pain in Your Family Member with Dementia:

A Toolkit to Support Caregivers

Weill Cornell Medicine | The University of Iowa College of Nursing

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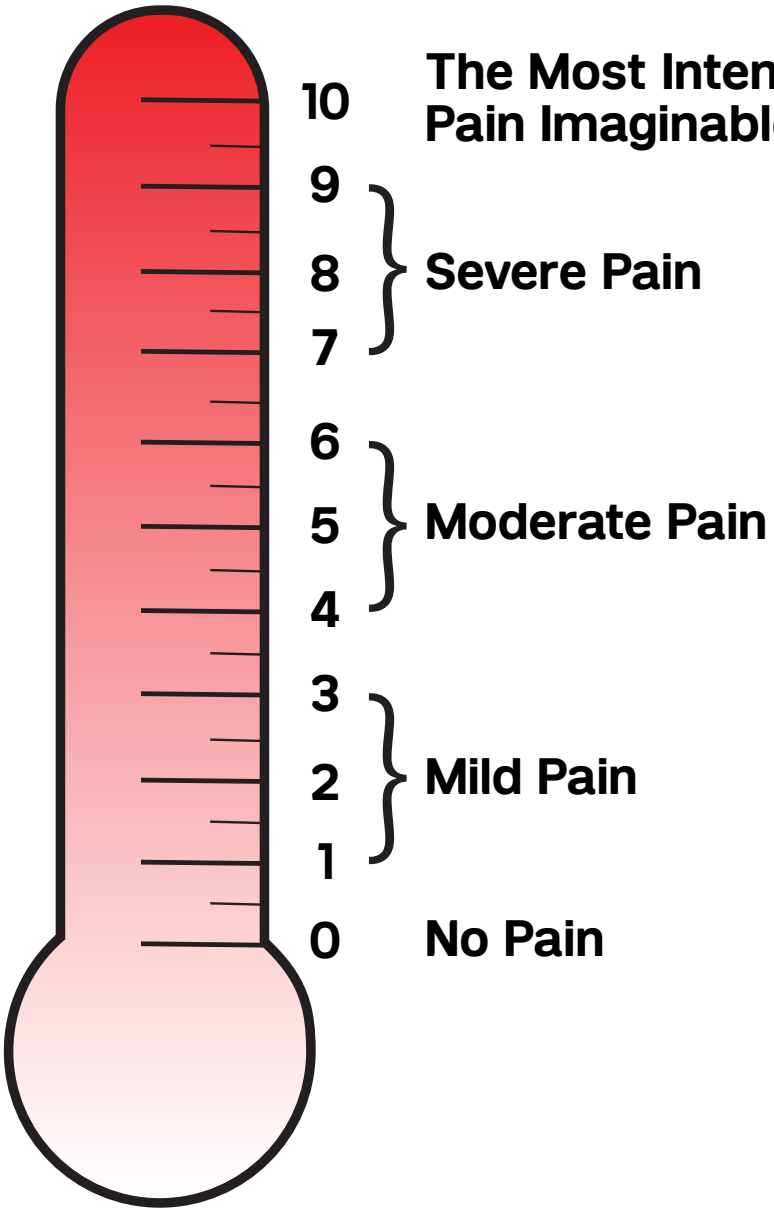
APPENDIX

A

Iowa Pain Thermometer-Revised

Iowa Pain Thermometer-Revised

Circle a number on the pain thermometer below that best represents the intensity of your pain right now.



Used with permission Keela Herr, PhD, RN, AGSF, FAAN, College of Nursing, The University of Iowa, Iowa City, IA, USA

Pain Diary

A Pain Diary is used to monitor pain over time, collect data on possible pain triggers, and provide information for a health care provider to make best treatment decisions. Document your family member's pain experience on the attached page once per day or any time you see a change in behavior or suspect a new or different pain problem. Bring the Pain Diary to the next appointment with your family member's health care provider. *See next page.*

Use the *Iowa Pain Thermometer-Revised* with your family member, if they *are able to provide a self-report* of their pain severity. See *APPENDIX A*.

Use the *PAINAD* with your family member, if they are *unable to provide a self-report* of pain. *See APPENDIX C*.

(continued)

Pain Diary

Date/ Time	**Pain Location** Note any areas causing pain	**Self-Report Pain Rating** (0-10)	**PAINAD Score** no self-report (0-10)	**What triggered the pain report or behaviors?**	**Treatments Tried** Medicine (specify drug and dose) non-drug treatment (e.g. heat, cold, exercise, massage, distraction, music, splinting)	**Pain Rating** 1hr after treatment (0-10)	**Additional Comments**

Pain Assessment in Advanced Dementia (PAINAD) Tool

PAINAD Tool				
	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 Frowning	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*	

* Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").

(continued)

APPENDIX

C Pain Assessment in Advanced Dementia (PAINAD) Tool *(continued)*

INSTRUCTIONS

Observe the older person both at rest and during activity/with movement. For each of the items included in the PAINAD, select the score (0, 1, or 2) that reflects the current state of the person's behavior. Add the score for each item to achieve a total score. Monitor changes in the total score over time and in response to treatment to determine changes in pain. Higher scores suggest greater pain severity.

Note: Behavior observation scores should be considered in conjunction with knowledge of existing painful conditions and report from an individual knowledgeable of the person and their pain behaviors. Remember that some individuals may not demonstrate obvious pain behaviors or cues.

ITEM DEFINITIONS

Breathing

a. Normal breathing is effortless, quiet and rhythmic.
b. Occasional labored breathing means periods of harsh, difficult, or wearing respirations.
c. Short period of hyperventilation means intervals of rapid, deep breaths lasting a short period of time.
d. Noisy labored breathing may sound loud, gurgling or wheezing when the person inhales or exhales. Breathing appears strenuous or wearing.
e. Long period of hyperventilation means rapid, deep breaths lasting a considerable time.
f. Cheyne-Stokes respirations are rhythmic waxing and waning of breathing from very deep to shallow respirations with periods when breathing stops completely.

Negative Vocalization

a. None means speech or vocalization that has a neutral or pleasant quality.
b. Occasional moans or groans are mournful or murmuring sounds, wails or laments. Groaning is characterized by louder than usual involuntary sounds, often abruptly beginning and ending.

c. Low level speech with a negative or disapproving quality means muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining or sarcastic tone.

d. Repeated troubled calling out occurs when a person uses phrases or words repeatedly in a tone that suggests anxiety, uneasiness, or distress.

e. Loud moaning or groaning are mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning means louder-than-usual inarticulate involuntary sounds, often abruptly beginning and ending.

f. Crying is expressing emotion accompanied by tears; it includes sobbing and quiet weeping.

Facial Expression

a. Smiling or inexpressive. Smiling means upturned corners of the mouth, brightening of the eyes, and a look of pleasure or contentment. Inexpressive refers to a neutral, at ease, relaxed, or blank look.

b. Sad means an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.

c. Frightened means a look of fear, alarm, or heightened anxiety. Eyes appear wide open.

d. Frown means a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.

e. Facial grimacing is a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body Language

a. Relaxed means a calm, restful, mellow appearance. The person seems to be taking it easy.

b. Tense means a strained, apprehensive, or worried appearance. The jaw may be clenched. It should not include any muscle spasms.

(continued)

APPENDIX

C

Pain Assessment in Advanced Dementia (PAINAD) Tool *(continued)*

Body Language *(continued)*

c. Distressed pacing is activity that seems unsettled. The person may seem fearful, worried, or disturbed. The pacing can be slow or fast.

d. Fidgeting is restless movement. It could mean squirming or wiggling in the chair. The person might scooch his chair across the room. Repetitive touching, tugging, or rubbing body parts can also be fidgeting.

e. Rigid means stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and inflexible. It should not include any muscle spasms.

f. Fists clenched means tightly-closed hands. The person may be open and close them repeatedly or hold tightly shut.

g. Knees pulled up means flexing the legs and drawing the knees up toward the chest. Overall troubled appearance. It should not include any muscle spasms.

h. Pulling or pushing away occurs when the person is resisting care. He or she is trying to escape by yanking or wrenching free or shoving you away.

i. Striking out can be hitting, kicking, grabbing, punching, biting, or another form of personal assault.

Consolability

a. No need to console means the person appears content and feels a sense of well-being.

b. Distracted or reassured by voice or touch occurs when the person is upset, but the behavior stops immediately when the person is spoken to or touched.

c. Unable to console, distract or reassure occurs when the person is upset and no amount of verbal or physical comforting will help to calm them down.

Reference: Warden, V, Hurley AC, Volicer, V. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *J Am Med Dir Assoc*, 4:9-15. Developed at the New England Geriatric Research Education & Clinical Center, Bedford VAMC, MA.

Pain Behavior Chart

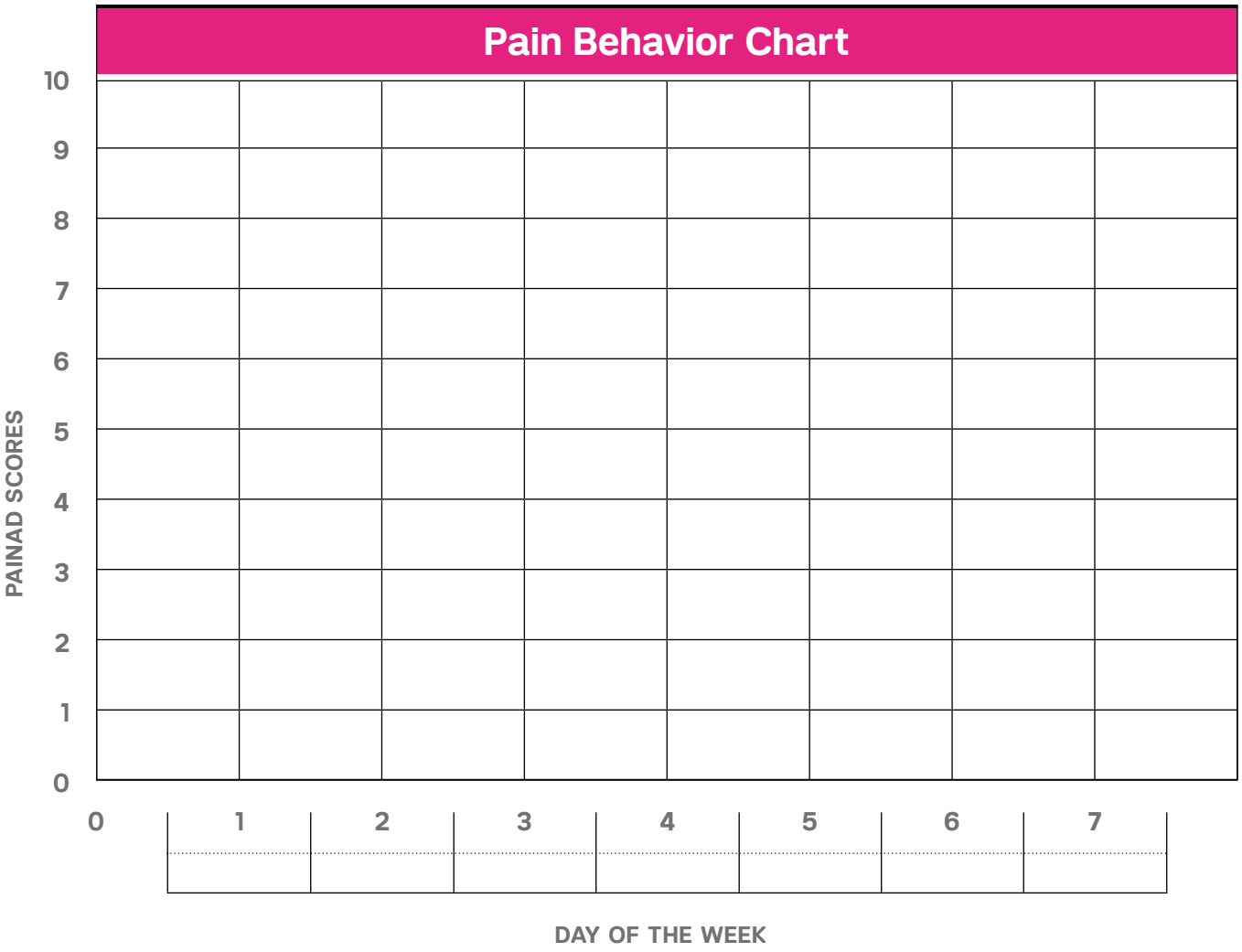
The chart below can be used to plot the PAINAD scores on each day over the course of a week to show trends in pain behavior.

For each day of the week (listed along the bottom of the chart as 1-7), place a dot or an X on the line that represents the PAINAD score for that day. So 1 is the first day of the week recording PAINAD scores and 7 is the end of one week.

You can start any day of the week, but add the dates at the top and write under the day number which day of the week you are recording to show when you started recording PAINAD scores.

For example, if you start plotting PAINAD scores on Tuesday, you would write Tues under the "1" on the left side of the chart.

List the dates and day of the week you are recording PAINAD score here:



Medication List

A Medication List is used to monitor use of medications and any reactions that need to be reported to your family member's primary care provider. Record all medications your family member is taking and include the information listed in the columns.

Take the Medication List to the appointment with your family member's health care provider.

Medication List

Medication Name *(ex. Gabapentin)*	**Reason for Taking** *(ex. neuropathic pain)*	**Dose/ Strength** *(ex. 600mg)*	**Frequency** (check all that apply)					**Provider Prescribing** *(ex. Dr. John Smith)*	**Additional Information** (include special instructions, side effects, allergies, precautions, etc.)
			Morning	**Noon**	**Evening**	**Bedtime**	**As needed**		

Used with permission from Keela Herr, PhD, RN, and GeriatricPain.org

Preparing for Health Care Provider Visit

Health care provider name:

_____

Appointment date:

_____

I plan to take the following items to my appointment with my health care provider:

☐ Pain Diary ☐ Pain Behavior Chart ☐ Other: _____

☐ Complete "Preparing for Health Care Provider Visit Tool"

I want to remember to ask the health care provider the following questions:

1. _____

_____

_____

2. _____

_____

_____

3. _____

_____

_____

4. _____

_____

(continued)

APPENDIX

F

Preparing for Health Care Provider Visit *(continued)*

I want to remember to share the following information with the health care provider:

1. My major concern(s): _____

2. Major changes noted in my family member: _____

3. Other information: _____

Date/Time of next appointment: _____

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The toolkit and training materials were developed by a multi-disciplinary team with expertise in pain, nursing, geriatrics, psychology, and education. This work was supported by a National Institute on Aging (NIA) Alzheimer's Disease and Related Disorders (ADRD) administrative supplement to grant P30 AG022845-15S1.

Disclaimer: Draft, not for circulation


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