



**Assessing Pain in Your Family Member with Dementia:
A Toolkit to Support Caregivers**



**Weill Cornell
Medicine**



**College of
Nursing**



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Overview of Toolkit

Pain is common as we age and can affect function and quality of life. It is important to identify pain, understand the experience of pain for each person, and address it before it becomes a serious problem. Most older adults are able to let people know when they have pain so it can be evaluated and treated. However, family members of people with dementia are often faced with challenges in both recognizing pain and achieving effective pain management.

Caring for a family member with dementia can be stressful and frustrating. One of the most challenging aspects is coping with disruptive and disturbing behaviors. It can be difficult to identify causes of changes in behavior. A large body of research demonstrates that unrecognized pain often leads to behavior changes in adults with dementia. Pain is one cause of disruptive behavior, although not the only cause.

As a caregiver, you can cope with these challenges by learning skills that help you to identify pain in your family member and communicate key information to his or her health care provider. This process can help you ensure that your family member does not suffer from unrecognized and undertreated pain.

Recognizing pain in dementia requires different knowledge and skills depending on the severity of cognitive impairment. Those able to speak and relay what they are experiencing need a different approach from those who are unable to communicate their discomfort. This toolkit will provide the information you need to recognize pain across the course of cognitive decline.

The content in this manual is based on the best available research evidence and best practices in recognizing and managing pain in people with dementia. It is built on an extensive review of the research literature and input from caregivers. Key resources are provided at the end of the manual for those who want more information.

Overview of Pain in Family Members with Dementia

A. Pain in Dementia: Why Does it Matter?

PEOPLE WITH DEMENTIA ARE AFFECTED BY PAIN

You may be wondering why it is important to identify and treat pain in your family member with dementia. There is clear evidence that untreated or even under-treated pain can have many negative consequences on people with dementia. It can:

- ▶ contribute to depression, anxiety and cognitive impairment,
- ▶ interfere with physical activities and therapies,
- ▶ interfere with sleep and nutrition,
- ▶ lead to disruptive behaviors that make it hard to provide care and to engage in meaningful activity,
- ▶ increase likelihood of hospitalization and institutionalization.



PAIN IS COMMON IN OLDER ADULTS INCLUDING THOSE WITH DEMENTIA

Pain has been reported by more than 50 to 70 percent of community-dwelling older people and up to 90 percent of people living in long term care facilities. Given these high numbers, it is likely that your family member will experience pain problems at some point. Pain is often unrecognized, so being aware of how common pain can be is the first step in identifying it. There are different types of dementia (such as Alzheimer's disease, Lewy Body dementia, Frontotemporal dementia), and pain may be experienced and expressed a little differently depending on the type of dementia. In *Module 3*, we will discuss strategies for increasing awareness and recognition of pain in dementia.

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Overview of Pain in Family Members with Dementia *(continued)*

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Common Conditions that Cause Pain

Understanding that underlying health conditions can cause certain types of pain, such as neuropathy (or nerve-related pain) from diabetes, can help you identify the type of pain when it occurs. You aren't expected to diagnose conditions or pain, but it helps to be aware that many medical conditions that occur frequently in older people can be associated with pain.

There are three main types of pain that may occur in your family member.

1 ***Pain caused by tissue injury to muscle, bones, joints or soft tissue***, such as low back pain, arthritis, pressure ulcers or old fractures, ***or by injury to internal organs***, such as kidney stones, urinary tract or bladder infections or severe constipation. Musculoskeletal problems are by far the most common causes of pain in older adults. Tissue injury pain is usually well-localized and constant and described as aching, stabbing, gnawing, or throbbing. Pain related to internal organs may be present in a larger area of the body and described as dull, deep cramping or sharp stabbing pains; it may also be accompanied by other symptoms such as nausea, vomiting or sweating.

2 ***Pain caused by injury to or dysfunction of the nerves and/or brain***, such as shingles, diabetic nerve pain, or a ruptured disc (i.e., sciatica). These pain conditions are often hard to recognize, particularly in people in the more advanced stages of dementia who can't describe what they are feeling. Nerve-related pain is often described as electric shock-like, tingling, burning or pricking. It can cause unusual sensations, such as when a light touch causes a disproportionate amount of pain, tingling feelings, shock-like sensations, or a sensation of worms under the skin.

3 ***Pain that has a mixed or difficult-to-understand cause***, such as complex regional pain syndrome, fibromyalgia, poststroke pain. Conditions such as these typically have different types of pain – both nerve-related and musculoskeletal-related – and in multiple locations. They may have symptoms out of proportion to any identifiable cause, can be widespread, and may involve stiffness and weakness.

So, there are many important reasons for ensuring we recognize pain and effectively treat it.

B. Why is it Hard to Recognize Pain in Dementia?

It can be challenging for people with dementia to communicate about pain. One of the most frustrating problems for people with dementia is the loss of the ability to clearly communicate thoughts and feelings. In early stages of dementia with mild or even moderate cognitive impairment, your family member may be able to communicate that he or she is having pain. But when cognitive impairment becomes severe in later stages of dementia, it becomes less likely that the person with dementia will be able to let others know that he or she is hurting, where he or she is hurting, and how bad he or she is hurting. Addressing these communication issues is key to increasing recognition of pain.

DENIAL OR HIDING OF PAIN

Older people sometimes hide the presence of pain, and researchers have identified several reasons why this happens. As people with dementia lose cognitive function, they are less likely to process these factors, but it is still important to be aware of them.

- 1. Fear of the cause of pain.** Older adults may fear the underlying cause of the pain (for example, undiagnosed cancer or serious illness) and deny pain to avoid unpleasant diagnostic procedures and diagnosis.
- 2. Fear of losing independence.** Older adults may be afraid they will be hospitalized or institutionalized if they have challenging problems to manage, such as pain.
- 3. Don't want to bother a caregiver or distract a health care provider.** Older adults may believe their pain issues create a challenge or stress to their caregiver and thus avoid acknowledging its presence. A related concern is distracting their health care provider from focusing on other conditions they perceive as more important, such as treating their cancer or serious illness.

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Overview of Pain in Family Members with Dementia *(continued)*

- 4. Fear of medication side effects and addiction.** Some pain treatments, such as opioids, come with unpleasant side effects and in some cases can lead to a substance abuse disorder. Although most side effects can be managed and development of addiction is not common in those without prior substance abuse issues, these concerns may lead individuals to deny that they have pain or refuse treatment for their pain if it is found.

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Myths or Misconceptions about Pain with Dementia

A number of myths or misconceptions held by both caregivers and health care providers need to be addressed.

MYTH 1 ***If people with dementia don't say they are in pain, then they aren't in pain.*** This is a common misconception and contributes to false assumptions about what the person with dementia is experiencing. When someone has dementia, declining cognitive abilities can make it hard to convey their thoughts, feelings, and experiences. This does **NOT** mean they do not experience pain!

MYTH 2 ***People with dementia feel less or no pain.*** Some believe that because of cognitive loss, people with dementia feel less pain or can't feel pain at all. However, we know from research that this is not true. They feel the same pain sensation, but they may interpret it differently and express it differently. We also know that they have the same number of pain conditions as those who are cognitively intact. So, what does this mean in terms of understanding pain in people with dementia? It means that we should assume that people with dementia experience the same number and type of pain conditions as well as severity of pain as older people who are able to tell us what they are feeling.

MYTH 3 ***Pain does not exist if there are no physical or behavioral signs.*** Similar to Myths 1 and 2, the person with dementia may not show typical behavioral signs of pain, such as wincing, bracing or guarding a painful area when moving, or groaning. They may also not show signs that sometimes occur in individuals with acute pain, such as elevated heart rate and blood pressure and sweating. As a result, we cannot use these as the only indicators to determine whether a person is experiencing pain or not. There are other behavioral signs that may help identify pain that we will discuss in *Module 3*.

MYTH 4 ***Pain is a normal part of aging and just needs to be lived with.*** This misconception can be a detriment to identifying and treating pain in older people, including those with dementia. Although some pain conditions are more prevalent as we age, it does not mean that the pain should not be treated and managed to allow maximum function and quality of life.

MYTH 5 ***We don't know how to assess pain if the person with dementia can't tell us what he or she is feeling.*** Although identifying pain in people with dementia is a challenge, procedures to recognize pain and evaluate it have been developed and tested. This training program provides key information that can be used by caregivers to ensure their family member does not experience unrecognized pain.

Overview of Pain in Family Members with Dementia *(continued)*

C. Importance of Recognizing Pain and Treating It

- 1. The key to improving pain is recognizing it.** It is hard to improve pain if we don't know or expect that it exists. That is why recognizing the presence of pain is an important activity, one which you as caregiver will be primed to do after taking part in this training program. Many people with dementia do not receive pain treatment for existing conditions because of the misconceptions discussed earlier. Recognizing the possibility of pain is key to further evaluation that can help determine pain presence and develop a treatment plan.
- 2. Telling the difference between symptoms of dementia, pain, and other conditions.** Many of the behaviors that can be indicators of pain also resemble symptoms of dementia. In people with dementia, it is not uncommon for challenging behaviors, such as being disruptive, agitated, and resistive to be attributed to dementia. This often leads health providers to prescribe medicines that help control the behaviors but do nothing to manage the underlying pain. The behaviors could be related to unidentified pain or to other unmet needs that can trigger disruptive behaviors. Although it is not easy to determine the exact cause of behavior changes, the goal is to recognize pain when it exists or to eliminate pain as a cause of behaviors.
- 3. Pain is under-recognized and under-treated in people with dementia.** Failure to treat pain can lead to adverse consequences and decreased quality of life. As discussed in *Module 2*, untreated pain in older adults can have serious consequences, including delayed healing, worsening cognitive function, functional decline, and even death. Thus, recognizing pain is an important factor in preventing decline and impaired quality of life in the people with dementia. Although it may not be possible to eliminate all pain, the goal is to reduce pain to a level that does not interfere with important function and quality of life.

Recognizing Pain in Dementia

A. Important Role of the Caregiver

TRUST YOURSELF AND YOUR KNOWLEDGE

Trust yourself and your perceptions—you know your family member much better than the health care provider because of your extensive involvement and contact over time. You can stand up for your family member and be an important advocate for his or her care.

IDENTIFYING AND SHARING IMPORTANT INFORMATION

It should be clear that you, as your family member's caregiver, can be an important and essential team member in recognizing pain. Although caregivers often feel helpless, being part of the team by sharing information and observations, particularly pain-related behaviors, can be valuable and lead to improved pain care and quality of life.

ENSURING CONTINUITY OF CARE

As caregiver, you can help ensure that your family member's pain is recognized and managed when he or she transitions between settings. For example, if your family member is hospitalized or transferred to skilled care, you know best about how to recognize and treat pain. Sharing this information with the person doing the intake assessment and your health care provider is important to ensure continuity of current pain medications and treatments, as well.



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Recognizing Pain in Dementia *(continued)*

B. Information for Pain Identification

OVERVIEW

Health care providers gather information that can help determine if pain is present in people who cannot report it themselves. There are multiple ways a caregiver can have important input in this process. Providing information about the personality and behaviors of your family member and how he or she has changed over time is important in assessing pain. This module explains how the caregiver can help.

SELF REPORT

Because pain depends on the individual's unique physical, emotional, and social characteristics, the person with pain is the only one who fully knows what he or she is experiencing. Health care providers typically ask patients if they are having pain and gather key information about it (e.g., how bad it is, what it feels like, where it is located, how long it lasts, and how it is impacting physical and emotional function). Although cognitive changes in dementia can make self-report difficult, it is often possible to obtain reliable reports from individuals with mild to moderate cognitive impairment. Thus, you should try to get your family member to talk about his or her pain, although this may be limited to how bad the pain is. Of course this kind of self-reporting becomes more difficult as severity of dementia worsens.

- 1. Lack of report of pain does not mean no pain exists.** It only means that the person did not or was not able to report the presence or severity of pain.
- 2. Ask about pain in a simple way.** Simply asking if the person is experiencing pain with a yes or no response or a head nod or shake can be used.

3. **Use a standard pain scale.** A pain scale makes it easier for people with dementia to communicate their pain severity. A very good pain scale is a word scale that may include a “thermometer.” A pain thermometer is a scale that includes words describing pain severity alongside a thermometer. For those with cognitive issues, thinking about pain increasing as temperature rises on a thermometer can help them to report their pain. You can try to use the *Iowa Pain Thermometer-Revised* with your family member. A copy of the scale, along with instructions, is provided in the *Appendix A*. An alternative is a simple word scale that asks about no pain, mild pain, moderate pain or severe pain. This can be used if the person can’t use the *Iowa Pain Thermometer-Revised*.
4. **Clearly explain the purpose and use of the scale.** In using a pain scale with your family member, it is important to clearly explain the instructions, speak slowly, be sure the tool is large enough to see the words and numbers, and provide plenty of time to think about his or her pain and to select the right pain level on the scale.
5. **If unable to self-report, use other approaches.** Although many people with mild-to-moderate cognitive impairment can still self-report, it is unlikely that those with advanced dementia will be able to do this. In these circumstances, gathering other sources of information is essential.

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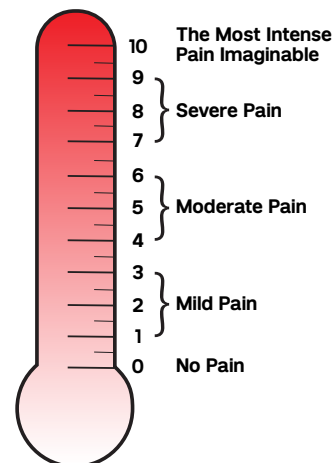
Iowa Pain Thermometer-Revised Scale

PAIN THERMOMETER USE:

Good for use with any older person, including those with mild to moderate cognitive impairment or who have difficulty communicating verbally. Have the patient point to the word on the thermometer that best shows how bad or severe their pain is NOW.

PAIN THERMOMETER SCORING:

Document the words that the older person points to on this tool. Evaluate the change in pain words selected by the elder over time to determine the effectiveness of pain treatments.



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Recognizing Pain in Dementia *(continued)*

IDENTIFY POTENTIALLY PAINFUL CONDITIONS AND PROCEDURES

Try to identify conditions and procedures known to be painful in older people. Understanding these conditions can help increase awareness that your family member might be experiencing pain. It also helps to decide if behaviors seen are potentially pain-related or due to other causes. Key points include:


- 1. Many conditions experienced by older adults can be painful.** Refer to *Module 2* for information on the various conditions or diagnoses to consider. Beyond pain diagnoses, other conditions can be painful. Think about things like severe constipation, bladder infection, lung infection, skin tears or infections, pressure points or sores, old fractures, joint stiffness from inactivity, tooth aches, and muscle spasms. These are some of the conditions that can be painful and you may think of others. Watch for things that could be causing pain such as a zipper or button causing pressure on tender skin, coffee too hot that may have burned tissue in the mouth, not having a bowel movement for a week. You may have information about your family member's medical history and conditions that are important to share with the health care provider.
- 2. More locations of pain may mean more pain.** Older adults often experience pain in many different parts of the body (on average 3 or more different locations), and this impacts the overall severity of pain and the person's overall functioning. Looking out for multiple sources of pain and sharing your knowledge of your family member's history and prior experiences can be important.
- 3. Procedures, treatment and activities can be painful.** Often the person with dementia must undergo procedures or treatments such as dressing changes, needle sticks, range of motion exercises, or tubing changes that can be painful. Think about what you might experience given the same conditions; this may help increase your awareness of activities that could be causing pain.

BEHAVIORS

- 1. Behaviors are a way of communicating.** Because people with dementia often cannot tell us accurately what they are experiencing or when they are having pain, their behaviors can tell us important things. Certain behaviors or changes in behavior can be clues that require further investigation. As a caregiver, you play an important role in observing your family member's behaviors over time and recognizing changes that are important. Health care providers often rely on caregivers to help identify behaviors that might be related to pain.
- 2. Categories of pain-related behaviors.** Many different behaviors are potentially pain-related. It can be helpful to start with a broad understanding that the behaviors an individual with dementia might show can be unique to that person. Not everyone responds to or shows pain in the same way. However, there are categories of behaviors shown to be related to pain. The chart on the following page is a description of the different categories and examples of behaviors you might see in your family member.
- 3. Other factors that can affect behaviors.** Some pain medications and medical conditions can affect dementia-related behaviors. Family members who are taking sedatives or antipsychotic medications may not show pain behaviors—but it doesn't mean they are not in pain. For example, someone with Lewy Body dementia may have emotional outbursts that might be mistaken for pain or be overlooked as an indicator of pain. Another example is a person with delirium or fluctuating mental state whose behaviors might be attributed to the delirium, but are actually from underlying pain. Be aware of the medications and medical conditions of your family member and be vigilant in your observations and asking questions of your provider.
- 4. Observe your family member during movement.** Although pain-related behaviors can be observed any time, movement often increases pain behaviors. Observe your family member when doing personal care such as bathing, walking or transferring out of bed or to chair, or another activity that requires movement.

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Recognizing Pain in Dementia *(continued)*

 Categories of Pain-Related Behaviors	
Facial expressions	This category of behavior is particularly important. Frowning, grimacing, wrinkling of the forehead, and keeping eyes tightly closed are different facial expressions related to pain.
Verbalizations/vocalizations	This category of behavior can include different sounds or words that suggest pain including moaning, groaning, yelling out, being verbally abusive, and noisy breathing.
Body movements	Certain movements can suggest that pain may be present. Watch for rigid or tense posture, guarding or bracing a body part, increased fidgeting, restlessness, pacing or rocking, and changes in gait or mobility.
Interpersonal behavior changes	Changes in behavior can be associated with pain in people with dementia. These include aggressive behaviors, resisting care activities, and acting increasingly disruptive or more withdrawn.
Changes in daily living activities	Your family member may change his or her patterns or routines to avoid the possibility of pain. You may be the first one to recognize a change that is related to pain or some other condition that needs investigation. Watch for changes such as refusing food or a change in appetite, change in rest periods or ability to sleep, suddenly stopping common routines or activities, or increased wandering.
Mental status changes	This category includes changes such as increased confusion, irritability or crying.

REPORT FROM CAREGIVERS

You, as caregiver, serve as a surrogate for your family member. You can provide information that will help identify if he or she is in pain. Sometimes providers can miss important information because they are not familiar with patients' usual behavior and activities. Caregivers are often able to recognize the presence of pain.

Here's what you can do:



Describe what you see clearly. To be the most helpful, you should describe as clearly as possible what you have seen. This includes identifying specific behaviors or changes in behavior, noting when the behaviors occur, and observing if anything makes the behaviors get better or go away.



Capture behaviors on pain behavior tool. Capturing behaviors using a pain behavior tool helps with communication with the health care provider and adds to other information you gather. In *Module 4*, we will share one pain behavior tool that has been useful in capturing pain in people with dementia in different care settings.



Record your pain behavior information in a pain diary and or behavior chart. These are tools you can use to communicate with your family member's health care team. They are discussed in more detail in *Module 4*.

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Recognizing Pain in Dementia *(continued)*

TRYING PAIN MEDICATION

Using pain medications is an option when the health care provider is unsure if pain is present or if pain is the cause of behaviors observed. Often a trial of acetaminophen (e.g. Tylenol) will reduce pain-related behaviors and confirm that pain is present. Sometimes stronger medications are administered before ruling out pain as the problem. If the behaviors do respond to treatment, then causes other than pain for the behavior can be explored. Your provider will then gather information to determine the best treatment plan. You should have input in those decisions as an advocate for your family member.

C. Importance of Behaviors

KEY POINTS ABOUT BEHAVIORS

Remember that behaviors may be the only way your family member shows us he or she has pain. Behaviors are an important part of the puzzle in determining whether or not pain is present. It is important to take any verbal or nonverbal communication seriously, as this may be a message about hidden pain.

CHALLENGE OF BEHAVIORS

It is important to note that behaviors are not always related to pain. Unmet needs such as hunger, stress, fatigue, overstimulation, or anxiety can also lead to difficult behaviors. Careful evaluation of all the information you provide will help the health care provider differentiate pain from other causes of behaviors.

Use of Pain Behavior Tool

A. Why Use a Pain Behavior Tool?

PROVIDE CONSISTENT COMMUNICATION

A pain behavior tool provides a valid and reliable way to observe and record pain-related behaviors. A standard tool offers words to describe what you are seeing, ensures you are monitoring key behaviors, and provides a consistent way to communicate your observations. A tool provides key information to add to the assessment and examination completed by the health care provider.

OFFER CLEARER ASSESSMENT OF CHANGES

Because the pain behavior tool categorizes behavior into levels and converts it to a score, it is easy to note subtle changes in behavior that may indicate changes in pain levels. It can also help evaluate your family member's response to pain relief strategies.

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Use of Pain Behavior Tool *(continued)*

B. When Should I Use the Tool?

WHEN TO USE A PAIN BEHAVIOR TOOL

It can be beneficial to use the tool on a regular basis, such as weekly. There are three times when the tool can be particularly helpful in providing important information.

- 1. At a regular time.** A good approach is to set up a regular time to use the tool, such as weekly during morning bath and dressing. This establishes what is “normal” for your family member and makes it more noticeable when there are changes that might be related to a developing pain problem. Finding a time that will be easy to remember and include in your care activities is helpful.
- 2. When possible pain behaviors occur.** In addition, any time you notice behaviors that are disruptive or bothersome, or a change from usual behavior, you should use the tool. The purpose is to determine if pain is leading to the behaviors.
- 3. After treatment for pain.** It is also important to use the tool after you treat suspected pain, such as after a medication dose or after use of an ice pack. The goal is to see if the treatment improves the pain behaviors identified by the tool.

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use the tool on
a regular basis

C. What Should I Do with the Information?

WRITE IT DOWN

Keeping a record to share with your family member's health care provider can have an important impact on the decision-making and treatment planning. Record the scores from the pain behavior tool along with any other relevant information.

- 1. Record the day and time of the observation and the pain behavior tool score.** Note what your family member was doing when you completed the tool. Were you watching while your family member was lying in bed resting? Or were you observing during physical activity, such as during bathing, dressing, turning in bed, or walking?
- 2. Record treatments you use and follow-up with another observation of pain behavior when the treatment has had time to improve suspected pain.** For example, most medications reach their peak effect between 30 minutes and an hour after taking them. So, observing pain behaviors one hour after medications will help evaluate your family member's response to treatment.

USE A PAIN DIARY OR BEHAVIOR CHART

Many people find using a pain diary or pain behavior chart can be helpful. There are a variety of options available. *Appendix B* shows one tool that captures key information in a pain diary. You can make copies of the tool and complete it over time.

- 1. Shows patterns over time.** Recording information repeatedly can show when there are changes in behaviors and identify patterns of activity that might be causing those behavior changes. It can show worsening symptoms or improvements in pain by capturing trends in the pain behavior scores.
- 2. Easy to communicate.** Using a pain diary makes sharing of information with your family member's health care provider easier and more meaningful. *Appendix D* shows a chart that can be used to record pain behaviors to watch trends over time. The provider can look for and find patterns.

Use of the Pain Assessment in Advanced Dementia (PAINAD) Tool

A. What is the PAINAD?

PAIN BEHAVIOR ASSESSMENT TOOL

The Pain Assessment in Advanced Dementia (PAINAD) is a pain behavior assessment tool that was developed to help health care providers recognize pain in patients with dementia who are unable to communicate their pain experience. It asks providers to observe the person with dementia and record selected behaviors on a scale.

B. Why the PAINAD?

ONE OF MANY

You might be surprised to know that there are more than 20 tools that have been developed to identify pain in people with dementia. There are many similarities and differences in these tools, but several have the strongest testing to ensure they are measuring the right behaviors in a way that makes them easy to use. The PAINAD is one tool that has good research support and has recently been tested with family caregivers. This makes the PAINAD a good choice to use in observing and recording behaviors in your family member.

EASY TO USE

The PAINAD is pretty easy to understand, provides clear definitions of behaviors, and is easy to score. Our purpose is to provide a tool that you will be able to use after limited training.

C. How to Use the PAINAD?

- 1. Illustration of the PAINAD Tool.** On the next page is a copy of this assessment tool with a printable copy in *Appendix C*. As you can see, it looks simple. However, it is important to understand each behavior and how to rate the different levels of the behavior. Descriptions of each behavior and different levels of the behaviors follow in the next section.



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	

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Use of the Pain Assessment in Advanced Dementia (PAINAD) Tool *(continued)*

- 2. Explanation and definition of each behavior.** Now let's look at each behavior on the PAINAD. How would you determine if your family member is showing these behaviors and at what level? Refer to *Appendix C* for a printable copy of the definitions for each behavior identified in the PAINAD.

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

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Use of the Pain Assessment in Advanced Dementia (PAINAD) Tool *(continued)*

Body Language *(continued)*

- 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.

- 3. How to use and score the PAINAD.** When using the PAINAD, being consistent helps identify changes over time.
- ▶ Observe your family member for three to five minutes during an activity such as bathing, turning, dressing, or walking.
 - ▶ For each item in the PAINAD, select the score that reflects your observation – a 0, 1, or 2 for each of the five behaviors.
 - ▶ Add the scores for each of the five items for a total score. PAINAD scoring ranges from 0 to 10, with a higher score suggesting more severe pain.
 - ▶ After each use of the tool, look at the total of the previous score you recorded. An increased score suggests an increase in pain, while a lower score suggests pain is improving.
- 4. Interpreting PAINAD scores.** PAINAD scoring ranges from 0 to 10. 0 means the person feels no pain and 10 means pain is likely severe. The question is, at what score is pain present and how can we tell how bad the pain is?
- ▶ Scoring a 2 suggests pain is present; it should trigger further evaluation and perhaps pain treatment.
 - ▶ The higher the score, the worse the pain.
 - ▶ We watch for increases and decreases of score on the PAINAD to see if pain levels are responding to treatment.
 - ▶ Because people are different in how they may express pain in behaviors, it isn't possible to rate pain as mild, moderate, or severe. But we can know that it is getting better or worse.

being consistent
helps identify
changes over time

(continued)

Use of the Pain Assessment in Advanced Dementia (PAINAD) Tool *(continued)*

D. Other Behaviors Not on the PAINAD

- 1. Other behaviors.** The PAINAD does not include all behaviors that could be related to pain. In particular, it does not capture changes in activities, interpersonal interactions, and mental status. These may also be important, but will not be captured in the PAINAD. This tool focuses on behaviors that are easy to note during direct observation and are not based on knowledge of the person's typical patterns of behavior.
- 2. Unique to your family member.** You may be aware of other behaviors that your family member shows when experiencing pain. For example, you may notice that your family member stops engaging in playing bingo each afternoon or is crying at unusual times or refuses to go for daily walks that have been a part of his or her regular routine. These are examples of changes that could be related to pain. You should write down and report any other behaviors that you believe may be related to pain in addition to the PAINAD behaviors. These can be included on the Pain Diary as "other unique behaviors."

this tool focuses
on behaviors during
direct observation

Effective Communication with Providers

A. Establishing a Good Relationship

1. Ensuring that your family member receives the best care possible requires a partnership between your family member, you, and the health care provider. It is important that you establish a good relationship with your family member's provider. You need to be an active participant, especially when your family member is unable to advocate for himself or herself.
2. If the health care provider uses terms you don't understand, ask questions. Often, health care providers use medical jargon that you may not be familiar with. You should expect to receive information in a manner that you can understand.
3. Ask the provider to slow down and repeat if necessary. Because time for the meeting with the health care provider is short, the interaction may seem rushed. Do not hesitate to ask additional questions to ensure you understand instructions or what information is requested by the provider.



B. Preparing for Appointments and Communication

BE FOCUSED AND PREPARED

One way to make the best use of the limited time with your provider is to be well-prepared with information and key questions.

1. **Review your notes.** Don't expect to have time to sort through all of the notes you have kept. Organize your information and decide what you need to share about your family member's pain before you get to the health care provider's office.

(continued)

Effective Communication with Providers *(continued)*

- 2. Make sure you provide facts.** Pull together copies of the *Pain Diary*, the *Pain Behavior Chart*, and your notes of the related information that will help the provider evaluate if your family member is in pain. Be prepared to provide background information. The behavior chart (*Appendix D*) can help the provider visualize what has been happening with your family member's behavior and possible pain. *Appendix E Medication List* provides a tool for keeping track of all medications your family member is using currently. This is important for any appointment with a health care provider. A tool that will help you prepare for your provider visit is available to print in *Appendix F*.
- 3. Convey information in the fewest words possible and stick to pertinent information.** It is easy to get distracted by talking about various items of interest and telling stories. It is best to try to be as brief and focused as you can and share information on your most important priorities. If one of those priorities is pain, gathering the information discussed earlier including PAINAD scores and related information will help your provider a great deal.
- 4. Share pain diary/behavior chart and your details regarding your family member's pain.** Bring copies of the pain diary pages and behavior chart. A document that can show the changes in pain behavior scores over time is available in *Appendix D*. This will make it easy for the provider to visualize what has been happening with your family member's behavior and possible pain.
- 5. Make a list of questions you have related to your family member's pain problem.** Following are some questions you may want to ask:
 - ▶ What additional information should I be gathering that could be helpful in planning care for my family member?
 - ▶ What ideas do you have about what might be causing my family member's behavior? Could it be pain?
 - ▶ What can I do at home to help address my family member's pain?
 - ▶ How can I communicate information related to changes in my family member's condition most effectively?

- 6. Call the provider office if a new pain problem, worsening pain or severity of pain is a concern.** It is okay to contact the provider when you have concerns about your family member's pain. Call the provider's office to discuss your concerns and options.

Add questions you want to ask the provider using the tool in *Appendix F*.

C. Making the Most Use of Appointments

MAKE THE BEST USE OF YOUR APPOINTMENT TIME

How you use the time with your family member's health care provider will impact your ability to be an effective caregiver. You need input and guidance about how to ensure your family member receives the best care possible.

- 1. Make specific requests for input and follow-up.** It is useful to structure your time with the provider to ask for input on the information you have prepared and how you can be most helpful.
 - ▶ Ask questions and take notes.
 - ▶ Repeat back what you think you understand.
 - ▶ Ask for written instructions, if needed.
 - ▶ Be sure you understand follow-up recommendations.

KEEP PROVIDER INFORMED OF ANY CHANGES IN CONDITION

If you notice changes in your family member's behavior or are having challenges in your caregiving activities, do not hesitate to contact the provider.

making the best
use of your
appointment time

(continued)

Effective Communication with Providers *(continued)*

D. Tools to Share Information

Here are some ways you can help identify pain and some tools that are helpful to capture and communicate important information about your family member.

1. **Iowa Pain Thermometer-Revised: Appendix A.** This pain scale can be used to obtain self-report of pain if your family member is able to do so.
2. **Pain Diary: Appendix B.** As a reminder, the pain assessment diary gathers key information on pain and related information to guide treatment decisions.
3. **PAINAD Tool: Appendix C.** The *PAINAD* is the tool that identifies and scores behaviors relate to pain.
4. **Pain Behavior Chart: Appendix D.** The chart is designed to record pain behavior scores over time. This will be helpful to recognize small and big changes that need to be evaluated.
5. **Medication List: Appendix E.** Always bringing a list of current medications, including over-the-counter medications, is essential. Keep this list up-to-date and bring to each appointment.
6. **Preparing for Health Care Provider Visit: Appendix F.** The resources is designed to help plan your meeting with your family member's provider. Complete in advance using information gathered in the other tools provided.

using tools to help
identify pain and
share information

E. Being a Strong Advocate and Caregiver

BE AN ADVOCATE

Learning how you can help your family member shows your commitment to advocate and be the best caregiver you can. You have information, tools, and resources to help you advocate for your family member.

ASK FOR HELP

The responsibilities as caregiver can be overwhelming and there are many supports available to help you ensure your family member gets the best care possible. Don't hesitate to reach out to your family member's provider and to other support groups and organizations available to help you on this journey. Below are helpful resources to support you as a caregiver:

- ▶ **GeriatricPain.org**, See *Caregiver Section*
geriatricpain.org/caregivers-and-patients-0
- ▶ **Health in Aging Foundation**
www.healthinaging.org/health-aging-foundation
- ▶ **AARP**
www.aarp.org/caregiving/
- ▶ **National Alliance for Caregiving**
www.caregiver.org/

Your state or local county Office for the Aging can also provide you with links to caregiver resources.

Key References

- Booker, S., Bartoszczyk, D., & Herr, K. (2016). Managing pain in frail elders. *American Nurse Today*, 11(4); 1-9.
- Herr, K., Zwakhalen, S. & Swafford, K. (2017). Observation of pain in dementia. *Current Alzheimer Research*. 14(5), 486-501. doi: 10.2174/1567205013666160602234526 PMID: 27335035
- Herr, K., Coyne, P., Ely, E., Gélinas, C. & Manworren, R. (in press). Pain assessment in the patient unable to self-report: Clinical practice recommendations in support of the ASPMN 2019 Position Statement. *Pain Management Nursing*.

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Appendix

**Assessing Pain in Your Family Member with Dementia:
A Toolkit to Support Caregivers**



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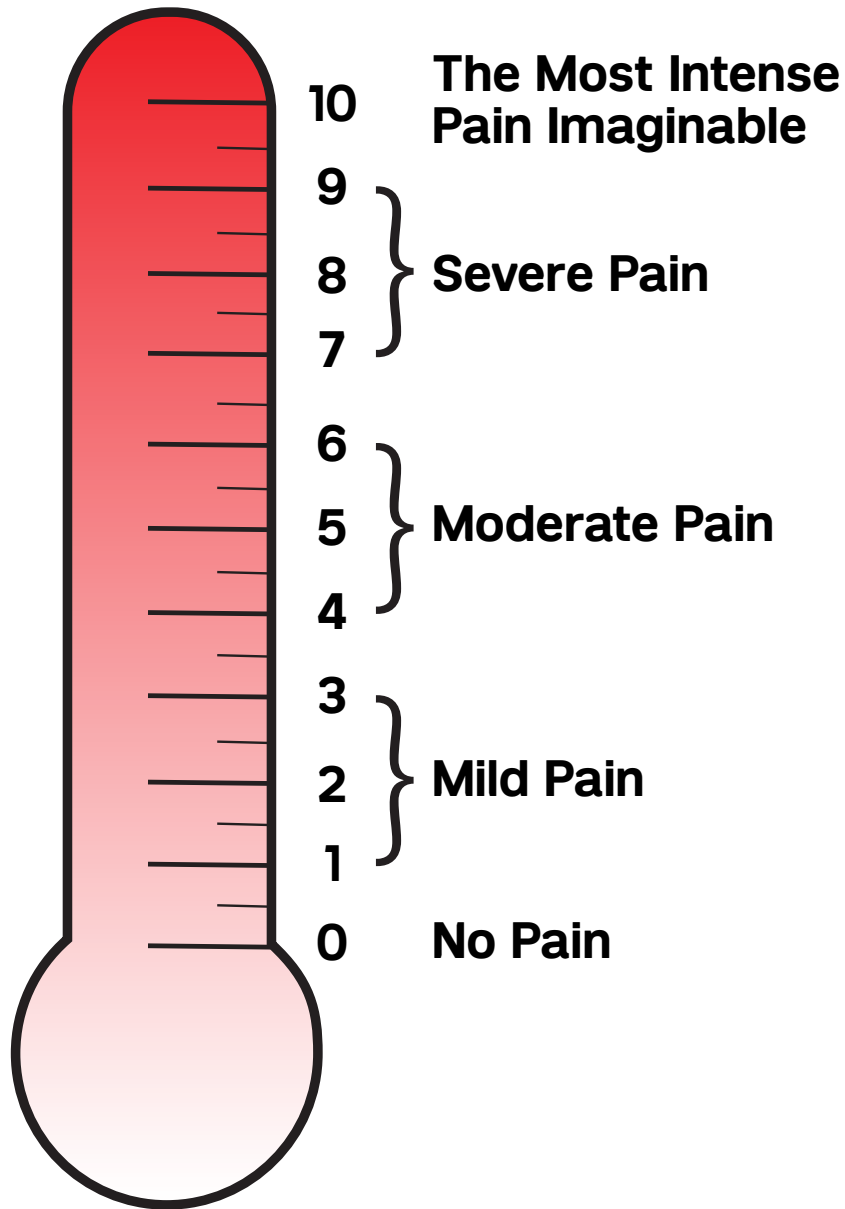
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Iowa Pain Thermometer-Revised

i

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)

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)

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

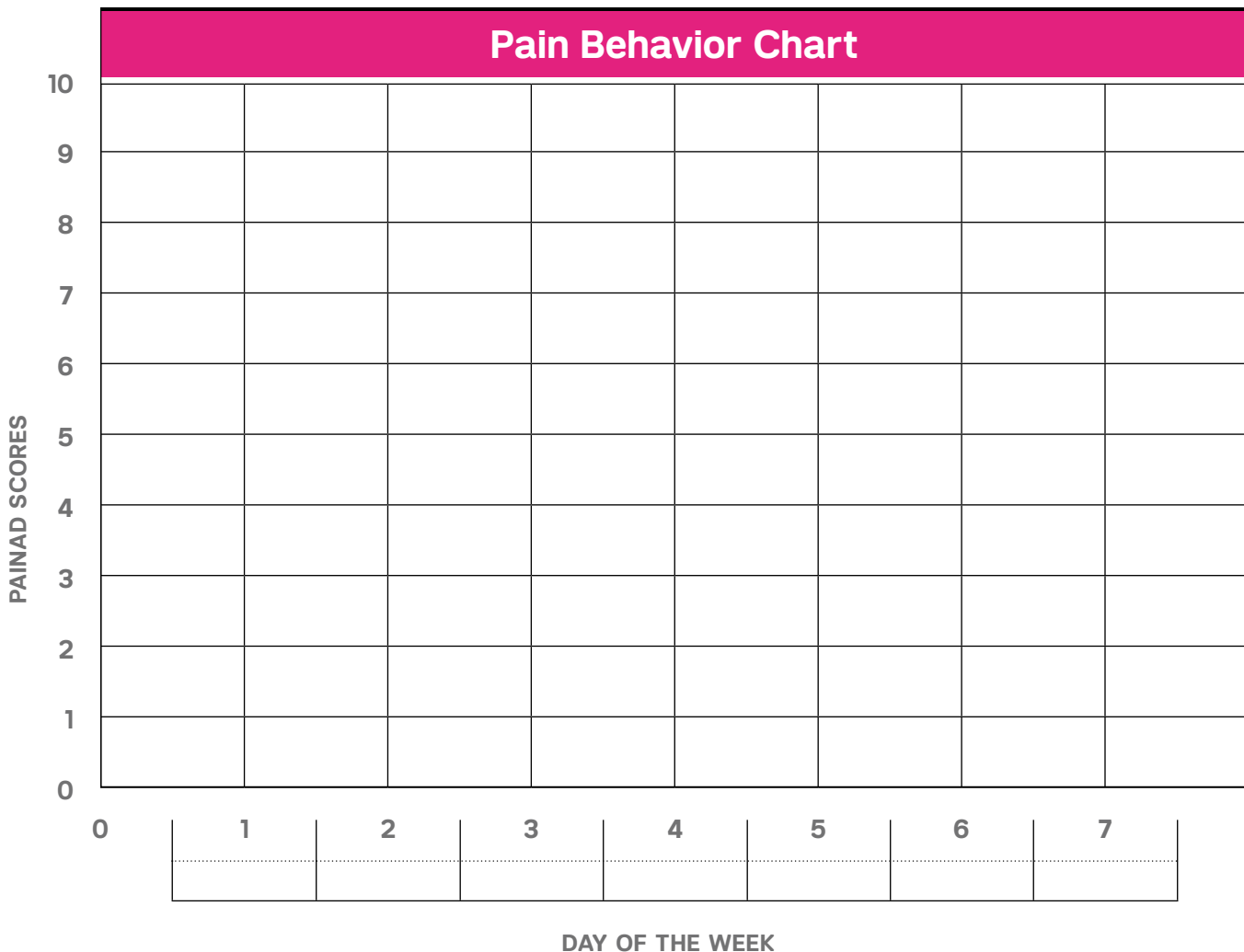
The chart below can be used to plot the PAINAD scores on each day over the course of a week to show trends in pain behavior.

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

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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)

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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