

Caregiver's Guide to Supporting a Loved One Experiencing Pain

This guide aims to equip you with the necessary knowledge and skills to support your loved one experiencing pain. This resource offers suggestions for communicating with someone about their pain, strategies for assisting during their pain management journey, self-care strategies to reduce caregiver burnout, and suggestions for being a pain equity advocate.



STARTING THE CONVERSATION

The person you care for may be suffering from pain in silence. Below are tips for initiating a conversation with them so you can begin to offer support on their pain management journey.

Prepare Yourself. If the topic of pain is new to you, it is important to learn more prior to having a conversation with your loved one. Check out [BelieveMyPain.com](https://www.believethepain.com) to access information and resources about pain.

Create a Safe Environment. Try to talk in a space that is comfortable and familiar. Pick a time when neither of you are busy or distracted. Consider reducing the number of people involved in the conversation.

Know How to Identify the Signs. Sometimes it's difficult for someone to convey that they are in pain – especially if their ability to communicate is impaired. There are signs that can indicate if your loved one is experiencing pain:¹

- A person in pain may become tense, depressed, angry, or resistant.
- They may shout out, sigh, or groan.
- They may frown, grimace, or clutch and guard a particular body part.

The individual may express pain in ways not mentioned above. You should be on the lookout for any behavior change that could signal pain and discomfort.

Believe Them. It is important you believe the person in pain when they express their pain experience. Do not dismiss or diminish how pain impacts their life.

Be Patient. One conversation may not be enough. Remain patient and express to your loved one that they can share their pain experience with you on an ongoing basis.

Offer Support. Encourage the person you care for to seek help if their pain is impacting their quality of life. Offer support on their pain management journey as an advocate.

BEING AN ADVOCATE

Navigating the healthcare system can be confusing and scary, especially alone. You can support someone experiencing pain by being an advocate for them.

An advocate is someone who is there to support a patient through their pain management journey. An advocate cannot make care or treatment decisions for a patient unless they are a legal guardian, an assigned health care proxy or have another form of legal permission. As an advocate, you must remember to keep all health information about the patient you are supporting confidential.

Support can take different forms. Ask the person experiencing pain what level and type of support would be most helpful to them. Then determine the appropriate level of support you can offer based on your capacity, ability, and skillset.



Below are examples of the types of support you could offer as an advocate.

● Help with finding a healthcare provider

This type of support could look like checking your loved one's insurance status, researching in-network providers and physician profiles, and asking other friends and family members what providers they use and would recommend.



Review and share the [Your Roadmap to Treating Your Pain](#) resource for more information about seeking care for pain.

Help with preparing for an appointment

This type of support could look like helping the person you care for fill out any forms the doctor's office sends in advance, offering to provide transportation to their appointment, and making sure they are equipped with the right information to share with their healthcare provider during the appointment.

Relevant information to have at an appointment includes:

- Medical history, including family health history, past diagnoses, and past procedures.
- Up-to-date list of your loved one's medications, over-the-counter drugs and supplements.
- Summaries from past medical appointments



Describing and Documenting Your Pain for Care, a resource which includes a pain questionnaire and daily pain tracker.

Help communicating with a healthcare provider

This type of support could look like helping the person experiencing pain to create a list of questions and concerns that they may have about their condition and treatment options before their appointment.



Review and share the How to Advocate for Yourself in Medical Settings resource with your loved one, which is a step-by-step guide on effective communication with a healthcare provider.

Offer to accompany them to their medical appointment and be there for support in the consultation room.

Remind them to take notes at their appointment (or you may want to write notes if you are present). Ask the provider if they can provide a summary and action points, information on how to reach the doctor in an emergency, and how to get timely answers to questions that aren't urgent.

Before your loved one agrees to any significant procedure or treatment for pain management, like epidural injections or nerve blocks, recommend that they ask for a second opinion. This is particularly important if they feel like they have not been listened to, their concerns have not been addressed, or they experienced any sort of discriminatory or biased treatment by their healthcare provider.

Help with record keeping

This type of support could look like assisting the person you care for in documenting and storing important information for their records.

Important medical information to document includes:

- Their pain management treatment plan, follow-up care information, and any health education resources their healthcare provider shares with them
- Healthcare providers' answers to questions that your loved one asks
- Doctor's and pharmacist's contact information
- All medications they are taking, including over-the-counter medicines and supplements
- Names and addresses of any healthcare facilities they will use

Ensure that the doctor's office has a list of family members and friends who are on your loved one's support team, along with their contact information. Also, include any details about their healthcare proxy, if applicable.

Help with medication management

This type of support could look like helping your loved one organize their medication regimen, such as the dosage of each medication, number of times each day they need to take the medication, and when the medication needs to be started and stopped. Supportive tools like pill organizers, dispensers, and cases can be found in a pharmacy.

You can support your loved one in adhering to any medication instructions given by their healthcare provider or pharmacist, such as not eating or taking certain medications that may interact adversely with their pain medication. You can also support by asking the healthcare provider or pharmacist about side effects of your loved one's medication and looking out for potential signs of adverse reactions.

Help with day-to-day tasks

Certain tasks that a person experiencing pain can do one day may be challenging the next day depending on their level of pain. You can support them with daily tasks like running errands, cleaning, grocery shopping, preparing meals, driving, and child-sitting.

Depending on the severity of their pain, more extensive support with activities of daily living (ADLs) may be needed like getting dressed, doing their hair, eating meals, using the bathroom, walking, and bathing.



CARING FOR THE CAREGIVER

You can't care for others if you are not caring for yourself. Caregiver burnout is a state of physical, emotional, and mental exhaustion. Causes of caregiver burnout may include unrealistic expectations, conflicting demands, and lack of control.

Signs of potential caregiver burnout include feelings of anger, frustration, anxiety, depression, hopelessness, denial, exhaustion and physical fatigue, personal health problems, inability to concentrate, irritability, and social withdrawal.

The good news is that there are strategies you can implement to reduce caregiver burnout:

Spread the responsibility.

Don't be afraid to ask for help from others. Create a list of ways that others in your social circle like friends and family can help you, and let them choose what they are willing and able to do. Make sure to check with your loved one first to ensure they are comfortable with involving others.

Set realistic goals.

Be honest with yourself about the type and level of support you can offer. Know when to say yes and no to requests.

Take care of your own wellbeing.

Make sure you are giving yourself breaks. Establish a sleep routine, try to remain physically active, and remember to eat and drink plenty of water. Also try to keep up with your routine health appointments.

Focus on what is in your control.

Many things in the pain management journey are out of your control. Remember that you are doing the best you can with the resources and capacity that you have.

Seek emotional and social support.

If you are struggling, reach out to your family and friends to share your feelings and ask for support. There are also caregiver support groups you can join and caregiving resources that you can explore, such as [Caring Across Generations](#).

Prioritize activities that bring you joy.

Remember to find time to engage in activities and surround yourself with people who make you feel restored.

+ TAKE ACTION

Join the mission to advance pain equity. As a pain equity advocate, there are many ways to get involved.

Become informed.

Use #BelieveMyPain pain equity tools and resources to expand your understanding and broaden your impact on the issue of pain equity. Resources include stats on pain inequities that Black people experience and education on how to identify and combat racial bias in pain treatment.



Keep the conversation going.

Share [BelieveMyPain.com](https://believemypain.com) content with your community and follow and share #BelieveMyPain on your social channels.

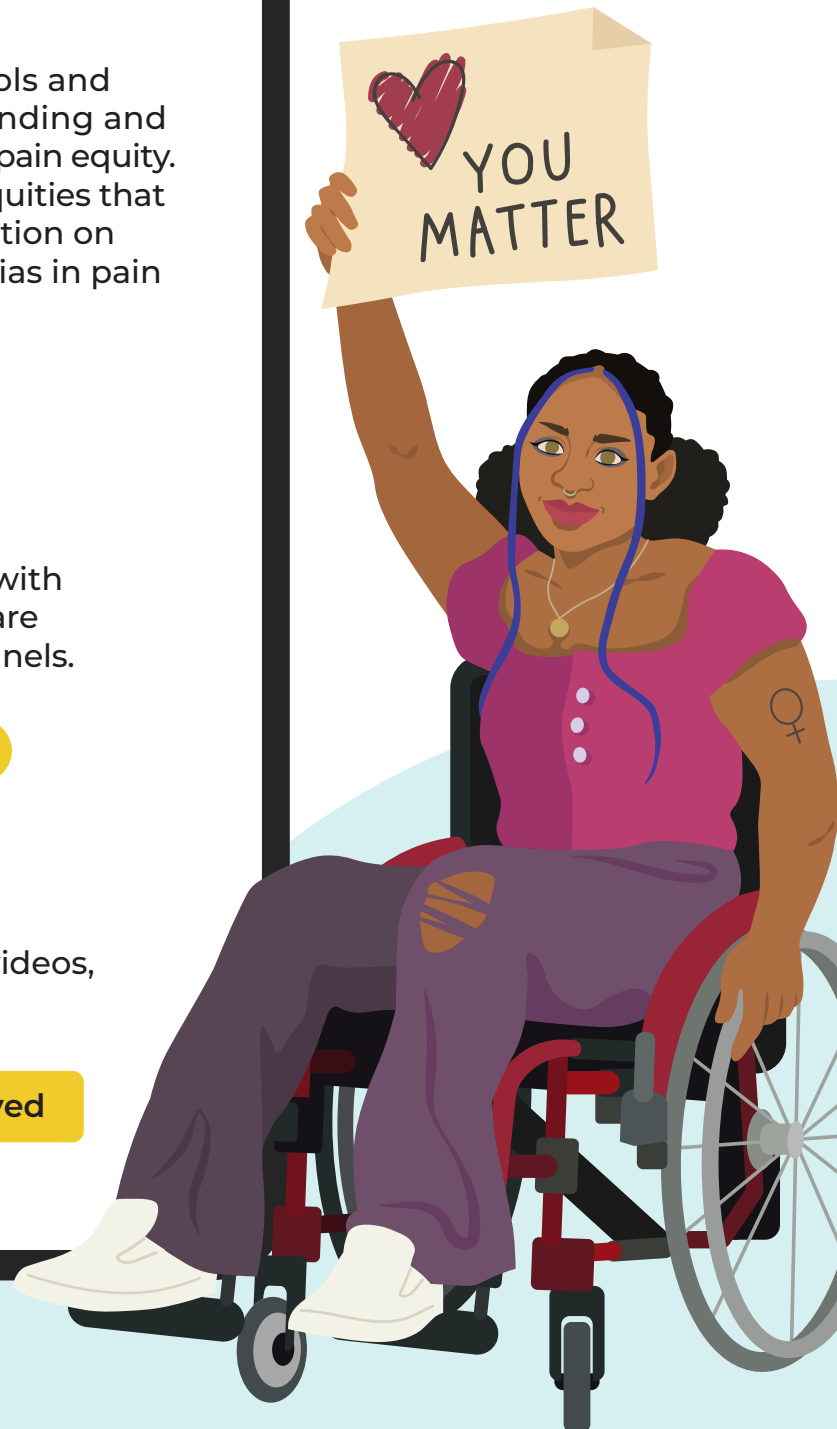
SHARE RESOURCES



Stay involved.

Join our mailing list for updates on partnership initiatives, roundtable videos, personal stories, and more.

[BelieveMyPain.com/GetInvolved](https://believemypain.com/GetInvolved)



References

- [1] Nabli, J. E. (2021, February 16). Recognize Non-Verbal Pain Cues. Parentis Health. <https://parentishealth.com/recognize-non-verbal-pain-cues/>