

LIVING WITH PARALYSIS

Pain Management



CHRISTOPHER & DANA
REEVE FOUNDATION
TODAY'S CARE. TOMORROW'S CURE.®

First Edition 2019

This guide has been prepared based on scientific and professional literature. It is presented for the purpose of education and information; it should not be construed as medical diagnosis or treatment advice. Please consult a physician or appropriate healthcare provider for questions specific to your situation.

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Pain Management

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INTRODUCTION: HOW PAIN AFFECTS LIFE

Pain is a frequent problem for many individuals living with a spinal cord injury (SCI) and can interfere significantly with daily life. There are many types of pain associated with SCI with varying frequency, duration, severity and location, including areas where there is little or no feeling.

Although pain after a SCI can be complicated and difficult to treat, it is most often related to nerve damage from the injury or musculoskeletal problems that arise from living with a SCI. By identifying the mechanism for the pain and targeting each selective mechanism with treatment options, pain can often be managed and reduced enough to improve your quality of life.

For many, a holistic approach that includes a combination of exercise, medication, stress reduction, or alternative treatments, such as acupuncture, can help relieve SCI pain. Each individual is the best judge of his or her own pain. It is important to understand your pain and work with your doctor to explore a variety of treatments that can help you manage your pain and improve your daily life. With new discoveries in pain management being made every day, there is a lot of hope for additional treatment options in the future.

Acute pain can be caused by a specific injury or an unidentifiable source that may not be localized to the area of the issue. Chronic or long-lasting pain persists beyond a normal healing or recovery time (often longer than three months) and is usually associated with a SCI.

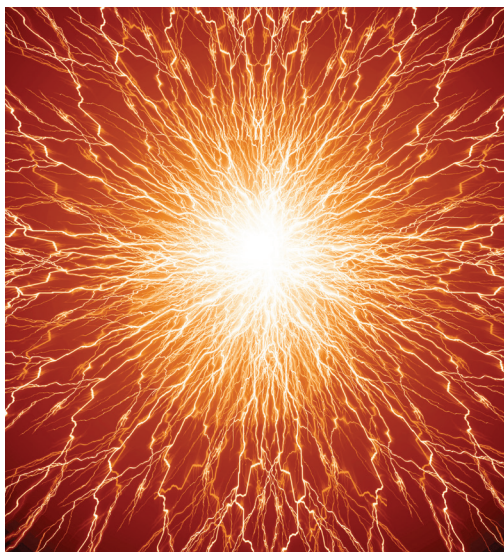
Nurse Linda says... *“It can take months for central neuropathic pain to develop after an injury. Be sure to contact a doctor if pain starts years after injury as it might be due to referred pain or a new medical problem.”*

TYPES OF PAIN

To choose the best treatment for pain, it is important to understand the type of pain you are experiencing. Pain location, severity, duration, circumstance and other key factors are used for diagnosis and development of the most comprehensive pain management plan. The amount and type of pain may be different for each person, so it is important to discuss your specific pain with your doctor.

Neuropathic Pain

When the spinal cord is damaged, the signals that inform your brain how your body feels can be misunderstood or amplified in intensity from the area around your injury. This abnormal communication can cause neurogenic pain (also referred to as central neuropathic pain, central pain syndrome or deafferentation pain) at and/or below the level of injury where you have little or no feeling. Often described as a burning, aching or tingling sensation, the mechanisms at play may be different depending on the type and extent of injury to the spinal cord. In central neuropathic pain, however, the ability of the



central nervous system to interpret even normal sensations has gone awry; therefore, medications that target the spinal cord and brain, at sites where pain is processed, are a mainstay of therapy. Worsening of bowel and bladder problems, including urinary tract infections, can heighten preexisting neuropathic pain often without being able to localize the problem to the source of inflammation or distension.

Peripheral neuropathic pain is associated with damage and/or inflammation of the peripheral nervous system. Because most trauma does not spare the structures around the spinal cord, peripheral neuro-

pathic pain syndromes often occur together with central neuropathic pain after trauma. On the other hand, secondary pain syndromes will often accompany the primary pain syndrome; these include peripheral neuropathic pain syndromes, including new onset pain syndromes from nerve injuries above the original level of SCI.

Musculoskeletal Pain

There are two types of musculoskeletal pain that people living with a SCI may experience. One is a secondary pain syndrome caused by the overuse of the remaining functional muscles above or below the level of injury. Such problems can occur in the bones, muscles, joints, ligaments or tendons. Musculoskeletal pain above the level of injury is often caused by overuse, strain, arthritic changes or wear and tear on the neck, back, shoulders or arms from transfers, pressure relief maneuvers and wheelchair use. This pain may progress over time with repetitive use and age.

Central spasticity is another type of musculoskeletal pain. Spasticity is the uncontrolled, repetitive, involuntary contractions of skeletal muscles. Continuously contracted muscles can exacerbate preexisting pain including central and peripheral neuropathic pain.

Referred or Visceral Pain

Pain associated with the distension or irritation of organs such as distended or overfull bladder, constipation, kidney stone, ulcer, gall stone or appendicitis can cause abdominal or visceral pain often described as cramping or dull aching. For a person living with a SCI, the usual symptoms and location of pain may present in different forms than are typically associated with these medical conditions. The pain can be difficult to localize in individuals with any level of injury. If the source of the pain is below the level of injury where there is little or no feeling, the pain may present in another part of the body as a referred pain.

Psychological or Emotional Pain

Challenges in managing the emotional circumstances of living with a SCI can result in increased anxiety, stress and depression and can be associated with greater post-spinal cord injury pain.

Nurse Linda says... *“If one treatment doesn’t work, be open to trying another technique.”*

TREATMENT OPTIONS

With so many different causes, there is no single way to treat pain. Often it takes time to work out the right combination of therapy, medication and physiological treatments to find the best results. It is important to see a doctor who has experience working with SCI patients to ensure the correct diagnosis and care.

TREATING PAIN: PHYSICAL THERAPIES

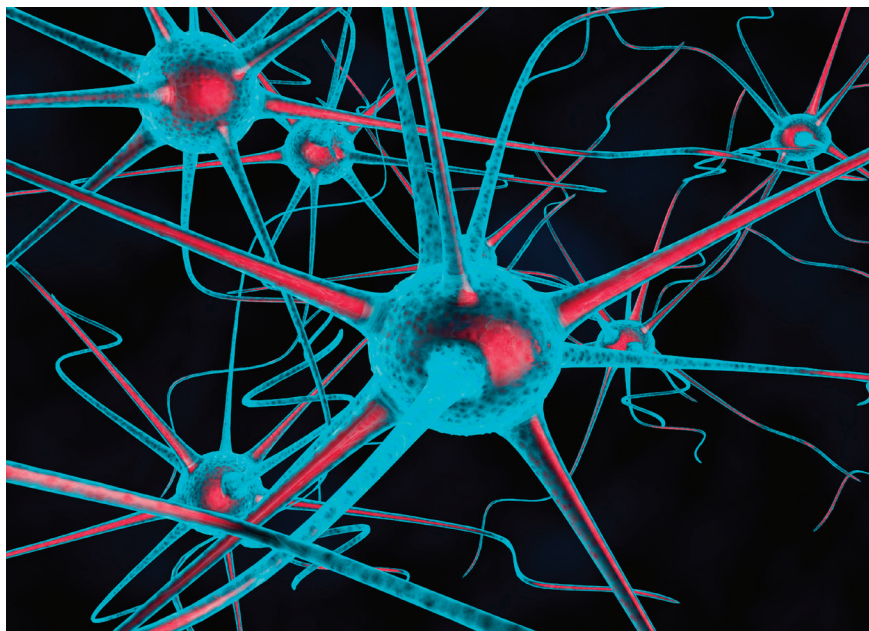
A variety of physical treatments can be effective in relieving musculoskeletal pain.

Exercise: Individuals living with SCI who underwent a regular exercise program showed significant improvement in pain scores, as well as improved depression scores. Even light to moderate exercise or aquatic exercise or therapy can contribute to an overall sense of well-being by improving blood and oxygen flow to tense, weak muscles. Strengthening weak muscles can also help improve balance and reduce musculoskeletal pain.

Physical therapy and rehabilitation: Time-honored techniques, such as heat, cold, exercise, and massage may be applied to increase function, control musculoskeletal pain, and help recovery. These techniques should be employed under the care of a therapist as using them at home may result in unfavorable consequences. People with spinal cord injury may not be able to feel extremes of cold or heat on their skin and may wind up damaging their skin. Stretching and range of motion exercises may help relieve muscle tension and painful joints.

Functional electrical stimulation (FES): Low-level computer-controlled electric current applied to the neuromuscular system.

Transcutaneous electrical nerve stimulation (TENS): Low-level electrical pulses delivered through the skin to nerve fibers block signals in muscles and cause numbness or contractions that aid in temporary pain relief.



Sore Nerve

Nurse Linda says... “sometimes combinations of drugs work better than a single medication. All medications can have side effects that should be discussed with your doctor. Medication effectiveness can change over time and may need to be adjusted. Do not discontinue using pain medication without speaking with your doctor.”

TREATING PAIN: MEDICATIONS

Anticonvulsants: Developed to treat seizure disorders, these drugs are sometimes prescribed for neuropathic pain. Gabapentin (Neurontin) and pregabalin (Lyrica) were shown to reduce neuropathic pain associated with SCI from baseline compared to placebo. However, at the high doses often needed to treat neuropathic pain, gabapentin and pregabalin may take away the tone needed to stand or walk. Carbamazepine (Tegretol) is used to treat a number of painful conditions, including trigeminal neuralgia.

Antidepressants/Anxiolytics: Selective serotonin norepinephrine reuptake inhibitors (SNRIs), such as venlafaxine (Effexor) and

duloxetine (Cymbalta), and some of the tricyclic antidepressants (TCAs), such as amitriptyline (Elavil), can be effective in the treatment of peripheral neuropathic pain. Some antidepressants, such as amitriptyline, can worsen the cardiac, bowel and bladder problems that follow a SCI and can therefore worsen central neuropathic pain. Your doctor can help you determine whether an antidepressant's effect on mood may outweigh some of these challenges.

Antispasmodic: Some anti-anxiety drugs such as benzodiazepines (Xanax, Valium) can act as muscle relaxants for central spasticity; they do not typically relieve central or peripheral neuropathic pain. The muscle relaxant baclofen can be taken orally or applied by an implanted pump (into the spinal cord) and may work when pain is related to central spasticity. Tizanidine (Zanaflex) is also commonly used to treat muscle spasticity. Botulinum toxin (Botox) injections are commonly used to treat local spasticity.

Local anesthetics: Topical medications such as lidocaine (Lidoderm) can treat neuropathic pain that occurs when skin is lightly touched (called allodynia). These topical agents are unlikely to be helpful in conditions such as central neuropathic pain, in which the source of the injury is in the spinal cord.

Medical marijuana: Reported by many as effective for neuropathic pain relief, marijuana appears to bind to receptors found in many brain regions that process pain information. The data on marijuana's effectiveness is not clear as there have been no clinical trials due to its legal status. Please check your local and state marijuana laws as marijuana and its derivatives are not legal in every state nor are they legal under federal law.

Non-steroidal anti-inflammatory drugs (NSAIDs): Medications such as aspirin, acetaminophen (Tylenol), ibuprofen (Motrin, Advil) and naproxen (Aleve) are often used to treat musculoskeletal pain. COX-2 inhibitors ("super aspirins"), such as celecoxib (Celebrex*), work by blocking enzymes which promote the production of hormones that cause inflammation, fever, and pain. Because a SCI can be associated with low blood pressure and dehydration, individuals should not take NSAIDs on a long-term basis.

* *Celebrex has a black box warning which is the strictest warning put in the labeling of prescription drugs or drug products by the Food and Drug Administration (FDA) when there is reasonable evidence of an association of a serious hazard with the drug.*

Opioids: Morphine, codeine, hydrocodone and oxycodone are narcotic drugs often used to treat various pain syndromes.

However, following a SCI, the effect of opioids on bowel and bladder problems can be significant and can worsen central neuropathic pain. In addition, narcotics tend to dull or mask pain and chronic use can worsen pain over time. Due to the risk for developing a physical dependency and the potential for withdrawal symptoms when discontinued, people given opioids should be monitored carefully. If you are taking opioids, do not just stop them on your own. Your health care provider will establish a withdrawal plan to avoid further pain complications.

In addition to the medications listed above, clinical research with new drugs continues to open the possibilities for new treatments.

MEDICATION SAFETY TIPS

- ✓ ***Keep an up-to-date medication list***
- ✓ ***Be aware of potential interactions and side effects***
- ✓ ***Report all prescription, over the counter, and recreational drugs that you take to your health care team***
- ✓ ***Follow proper dosage***
- ✓ ***Safely dispose of old or unused medication***
- ✓ ***Securely store all medications from theft and children (consider using a lock box)***
- ✓ ***Maintain an open dialogue with your physician about medication use and effectiveness***
- ✓ ***Do not share your medication under any circumstances***

TREATING PAIN: TRANSCRANIAL STIMULATION

Transcranial stimulation: A rapidly evolving extension of age-old practices to stimulate muscle nerves, transcranial stimulation is being studied and sometimes is used to treat musculoskeletal pain. However, the two types below are less often used therapies and are not always reimbursed by insurance companies.

- **Transcranial electrical stimulation (TCES):** Electrodes applied to the scalp allow electrical current to stimulate the underlying cerebrum and may be useful in reducing chronic pain.
- **Transcranial magnetic stimulation (TMS):** Electromagnetic pulses applied to the brain can potentially reduce post-SCI pain over long-term use.

Nurse Linda says...“Surgical procedures are challenging for everyone. Careful consideration should be taken to weigh possible benefits with potential risks and cost.”

TREATING PAIN: SURGICAL INTERVENTIONS

Surgery should be considered only if other non-surgical treatment options have failed. Surgical interventions can relieve pain by attempting to reverse structural problems or by destroying or disconnecting the site of abnormal nerve activity. This type of treatment is permanent and the consequences should be carefully considered with your health care practitioners.

Intrathecal pumps: To treat neuropathic pain using morphine or muscle spasm-related pain using baclofen, a pump can be surgically placed under the skin in the abdomen to deliver the medication directly to the spinal cord and nerve roots.

Surgical nerve blocks: To interrupt the relay of neuropathic pain messages between specific areas of the body and the brain, several types of surgical nerve blocks can be used. These interventions can be associated with worsening pain in a proportion of individuals.

- **Rhizotomy:** This procedure severs the nerve roots in the spinal cord.

- **Cordotomy:** Often used to treat pain associated with terminal cancer, this procedure severs bundles of nerves within the spinal cord.
- **Sympathectomy:** A procedure in which a portion of the sympathetic nerve trunk in the thoracic region is destroyed.
- **Dorsal root entry zone operation (DREZ):** Electrodes can be used to selectively destroy neurons in a targeted area of the brain or spine that correspond to the person's pain.

Surgical stimulators: To treat nerve root damage, a high frequency, low intensity nerve stimulator can be surgically placed to encourage nerve function and reduce neuropathic pain. Depending on the location and extent of injury, placement of these devices can be challenging.

- **Spinal cord stimulation:** Electrodes are surgically inserted within the epidural space of the spinal cord. The individual triggers a pulse of electricity to the spinal cord using a small box-like receiver.
- **Deep brain stimulation:** Considered an extreme treatment, it is used for a limited number of conditions for surgical stimulation of the brain, usually at the thalamus.

Nurse Linda says... *“While not proven effective through scientific research, alternative treatment options can offer additional opportunities to explore pain relief.”*



TREATING PAIN: ALTERNATIVE OPTIONS

Many have found pain relief through other treatments. While the data to support their use is still being generated, the risks associated with these treatments are generally low.

Acupuncture: Dating back 2,500 years to China, acupuncture may boost natural painkillers (endorphins) through the application of needles to precise points on the body. This controversial yet popular technique is a noninvasive treatment for musculoskeletal pain.

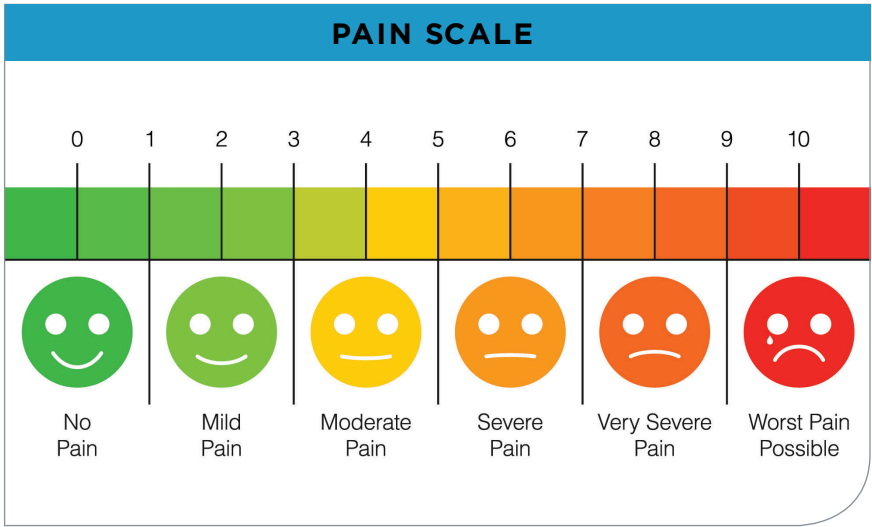
Biofeedback: Using a special electronic machine, the individual is trained to become aware of and to gain control over certain bodily functions, including muscle tension, heart rate, and skin temperature. The individual can then learn to effect a change in his or her responses to musculoskeletal pain, for example, by using relaxation techniques.

Hypnosis: First approved for medical use in 1958, hypnosis is used to control physical function or response to the amount of musculoskeletal and neuropathic pain an individual can withstand. Through acting on chemicals in the nervous system to slow impulses, this visual imagery therapy uses guided images to modify behavior by changing perceptions of discomfort.

Laser Therapy: Low-powered or cold lasers are believed to have anti-inflammatory effects, help repair tissues, and release pain-relieving endorphins to reduce musculoskeletal and neuropathic pain.

Magnets: Usually worn as a collar or wristwatch, the use of magnets as a treatment dates back to the ancient Egyptians and Greeks. While it is often dismissed by skeptics, proponents offer the theory that magnets may effect changes in cells or body chemistry, thus producing musculoskeletal and neuropathic pain relief.

Nurse Linda says... *“Pain can lead to inactivity which results in increased or additional pain. Ironically, gentle movement can reduce pain. Psychological strategies are an important part of every pain management plan. Less stress equals less pain.”*



TREATING PAIN: PSYCHOLOGICAL HELP

Psychologists trained in pain management can help with a variety of distraction and relaxation techniques proven to be effective in reducing the intensity and impact of pain.

Cognitive-behavioral therapy: Learning to think differently about your pain can lead to changes in brain activity and, in turn, your experience of musculoskeletal and neuropathic pain. There are a wide variety of coping skills and relaxation methods available.

Counseling: SCI elicits major adjustments in relationships, lifestyle, work and self-image. Both individual counseling and support group participation can provide important help with identifying desired goals and increasing pleasure and meaning in daily life. Counseling can also help reduce the anxiety and depression associated with musculoskeletal and neuropathic pain.

TIPS FOR CAREGIVERS

- ✓ *Watch your loved one for potential symptoms of worsening pain. Warning signs include increased withdrawal, fatigue, low appetite, trouble sleeping, mood changes, irritability and lack of energy.*
- ✓ *Remain aware of your own physical and mental health. The stress and anxiety felt by caregivers can also be very intense. Be sure to:*
 - *Reach out to other caregivers—share, learn and know you are not alone*
 - *Schedule down time—value yourself; find balance and recharge*
 - *Be an advocate—speak up to be sure needs are met*
 - *Ask for help—feelings of frustration and isolation can lead to depression*
 - *Empower yourself and your loved one—honor opinions and take charge of the situation*

For more caregiver resources, visit

ChristopherReeve.org/living-with-paralysis/for-caregivers

Nurse Linda says... *“Chronic pain is not hopeless. Learning to control your pain takes time and effort but the results are worth it.”*



PREVENTION & SELF-CARE: TIPS TO PREVENT WORSENING PAIN

Overall health and lifestyle habits can have a big impact on pain. If you are rundown, stressed, suffering repeated urinary tract infections, or not getting enough sleep, pain can get worse or harder to treat.

Treat medical problems: Urinary tract infections, bowel problems, skin problems, sleep problems and spasticity can make pain worse. Keep yourself as healthy as possible to help reduce pain.

Maintain a healthy lifestyle: Good diet, healthy weight and regular physical activity can reduce pain and stress while improving your mood and overall health. Safe and appropriate exercise can be enjoyable and distract you from pain.

Focus on emotional health: Stress, depression, and other emotional upsets can make pain worse. Proper counseling, medication and relaxation techniques can help you manage tension and cope with chronic pain to improve your quality of life.

Distract yourself: Distraction is one of the best methods for coping with chronic pain. Participating in fun and meaningful activities can help you feel more in control of your life, especially when pain is at its worst. When you are bored and inactive, you tend to focus more on your pain, and this can make your pain feel worse.

Keep a record: Since everyone's pain is a little different, keep a record of what makes you feel better and what makes pain worse. It is important to understand the things that influence your pain to find effective ways to reduce it.

Get a wheelchair seating evaluation: Poor posture and improper wheelchair technique can cause serious pain problems. A physical therapist trained in wheelchair seating can evaluate your positioning and teach you proper propulsion (pushing) techniques.

Refrain from alcohol use: Using alcohol as a pain reliever can lead to alcohol abuse, dangerous interactions with medications and other serious issues. Be mindful of the potential problems alcohol can cause.

Nurse Linda says... *“It is important to find a physician, psychologist or physical therapist who is familiar with SCI and pain management. Another alternative is to seek help from a pain specialist or multidisciplinary pain clinic.”*

HOW TO TALK TO YOUR DOCTOR ABOUT PAIN

Everyone experiences pain differently. The quality and quantity of information you give your doctor is crucial to finding the correct treatment.

Be specific: *Use as much detail and description as possible to describe your pain. Keep a pain diary to note pain timing, intensity, location, severity, duration, and what makes the pain better or worse.*

Be honest: *Although some health topics may be uncomfortable to discuss, it is important to be frank and honest and use whatever words best communicate what you are experiencing.*

Be patient: *It may take some time to find the right combination of treatments to reduce your pain. Do not stop a pain medication or treatment without consulting your doctor. Sometimes discontinuing a treatment plan suddenly can make the pain worse.*

CURRENT PAIN RESEARCH

Current research in neuroscience will lead to a better understanding of the basic mechanisms of pain and to superior treatments in the years to come.

“*There is much hope on the horizon for new treatments for chronic pain following SCI, particularly in the area of central neuropathic pain. A growing body of research has identified not only specific mechanisms of pain to target but also new ways to better deliver drugs whose analgesic effects are known. An area of progress has been in the classification of different pain syndromes that individuals with chronic SCI endure. This has allowed us to move towards a more personalized approach to choosing new therapies.*”

Christine N. Sang, M.D., M.P.H.

Associate Professor of Anaesthesia

Harvard Medical School

Director, Translational Pain Research

Brigham and Women's Hospital

RESOURCES

If you are looking for more information on pain management or have a specific question, Reeve Foundation Information Specialists are available Monday through Friday, toll-free at 800-539-7309 from 9 am to 5 pm EST.

The Reeve Foundation maintains a fact sheet on pain management resources. Please also see our repository of fact sheets on hundreds of topics ranging from state resources to secondary complications of paralysis. Below are some additional resources on pain management from trusted sources:

PAIN RESOURCES

American Chronic Pain Association (ACPA)

www.theacpa.org/

Craig Hospital: Pain Management

craighospital.org/resources/pain-management

Model Systems Knowledge Translation Center: Pain After Spinal Cord Injury Fact Sheet

msktc.org/sci/factsheets/pain

U.S. Pain Foundation

www.USBainFoundation.org

PAIN MEDICINE

American Academy of Pain Medicine (AAPM)

www.painmed.org

PAIN RESEARCH

Brigham and Women's Hospital: Translational Pain Research

www.paintrials.org

International Association for the Study of Pain

www.iasp-pain.org



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Learn more today!

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This project was supported, in part, by grant number 90PRRC0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201.

Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions.

Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.