

The Road to Rehabilitation

Part 1 ■ Pathways to Comfort: Dealing with Pain & Brain Injury

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Brain Injury Association of America

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Creating a better future through brain injury prevention, research, education and advocacy.

BIA's *The Road to Rehabilitation Series* (Parts 1-6) was made possible through an unrestricted educational grant from Allergan, Inc.

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Introduction

Everyone has experienced pain at one time or another. Although most individuals find it bothersome, many of them are able to continue going about their activities of daily living (ADLs) despite the pain. However, for some persons, the pain they experience can be severe, causing a person to avoid some, most and/or all of their activities. This brochure will attempt to provide the reader with a greater understanding of pain and how it can be improved in an effort to assist individuals with more disabling pain who also are challenged with recovery from brain injury.

Pain can be viewed as either acute or chronic. Acute pain typically has a cause that easily is explained and usually improves as the physical cause is treated properly. In contrast, chronic pain persists beyond the expected healing time and continues despite appropriate physical improvement in the affected area of the body. Chronic pain affects millions of Americans and can disrupt job performance, as well as causing problems in relationships with family members and other individuals.

When chronic pain occurs in a person with brain injury, it can be very distracting and interfere with the focus and effort this individual needs to make in facing the many challenges of the recovery process. Approaches to pain management in persons with brain injury tend to be similar to approaches for individuals who have not sustained a brain injury. While this can be helpful for some individuals with traumatic brain injury (TBI), cognitive limitations following brain injury are wide ranging and are not always taken into account. If proper steps are not taken to account for each individual's specific limitations and strengths, there may be a substantial reduction in the effectiveness of the pain management approach.

Many people believe that the amount of pain they feel is related directly to the severity of injury or is a result of increasing physical problems at the site of injury. If the pain increases over time or spreads to other areas of the body, they may think their injury is becoming worse. However, this may not be the case, particularly if it is not supported by medical findings. Instead, the increasing and spreading pain may be associated with the impact of a number of other

factors including: (1) emotional functioning, (2) personality traits, (3) past learning experiences, (4) the way others respond to the person's behavior and (5) deconditioning from limited movement. Assessment of these other factors sometimes can be helpful in making recommendations to improve the person's control over the pain.

Types of Pain

Pain can be viewed as either *acute* or *chronic*. Acute pain usually has a cause that easily is explainable and well-defined (i.e., a blow to the head resulting in headache, swelling, discoloration or other obvious injury to the painful area). The amount of pain corresponds to the level of discomfort and it usually improves as the physical cause is identified and treated accurately. Although responses to acute pain vary from person to person, usually over time the report of pain and the person's response to it improves in relation to the improvement of the physical injury.

In contrast to acute pain, chronic pain persists beyond the expected healing time for a particular injury and/or illness. This means pain continues despite appropriate treatment and physical improvement in the affected area. Individuals with chronic pain typically show pain in excess of that which can be explained by physical causes alone. Not only can this pain be widespread, sometimes it may not make sense medically because it may not remain at the original site of injury nor may it stay in related areas of the body. In most cases, the pain and the disability it creates remain the same or worsens, rather than slowly and steadily improving as expected.

Pain and Brain Injury

A person who has sustained a brain injury faces many challenges. These challenges include returning to work or school, family responsibilities and social activities with newly acquired problems in thinking skills (i.e., cognition) as well as in physical and emotional/behavioral functioning. The difficulties a person with brain injury faces can be even greater when pain is involved. The pain can emerge as headaches, neck and shoulder pain, lower back pain and/or pain in other body areas. The pain may be so intense and bothersome that the person withdraws from work, family and social activities. Unfortunately, this could result in a situation that may be out of proportion to the degree of physical, cognitive and emotional consequences of the brain injury itself.

Pain experienced by individuals with mild brain injury may prevent them from attempting to return to everyday activities despite being ready for a gradual, safe return as a result of improvement in cognitive functioning. This not only serves to lengthen significantly the time before returning to activities, but it also may contribute to hesitancy and reduced self-confidence when later attempting to resume activities. In contrast to people with mild brain injury, individuals with moderate to severe brain injury may deny or minimize the effects of their deficits. For these people, pain may reduce both awareness of their deficits and their incentive to work on improving these deficits by causing them to focus too much on their pain.

The greater the deficits sustained from the brain injury, the greater the emphasis will be on family members to participate in the reduction of pain behaviors in the person with brain injury. An individual who has sustained a brain injury may face a variety of cognitive and/or psychosocial limitations including:

- A lack of awareness of deficits
- A lack of insight into the effect a particular impairment may have on everyday functioning
- Reduced attention and/or concentration
- Decreased short-term memory and learning, sequencing, judgment and reasoning
- Decreased initiation
- Apathy or indifference
- Impulsivity
- Anger and/or irritability
- Impatience and/or frustration

- Restlessness
- Withdrawal
- Suspiciousness and/or distrust of others
- Reduced self-awareness

These limitations may serve to restrict the person's ability to carry out recommendations for managing the pain consistently and reliably. Generating a list of cognitive and psychosocial impairments and making the necessary treatment adjustments is important. A professional experienced with individuals with brain injury will be very helpful in this regard.

Success in the management of chronic pain depends in large part on the person's understanding of the pain and his/her incentive and drive to improve the pain. As a result, when dealing with individuals with brain injury, it is necessary to take into consideration the individual's specific limitations. First, the individual must understand the source of the pain. The pain should be explained in a manner that compensates for any cognitive deficits. Explanations should be provided in brief, concrete sentences that utilize more than one modality (i.e., verbal statements and visual aids). The specific cognitive strengths and weaknesses of the individual also should be considered in these explanations to improve understanding and potential cooperation. An understanding is needed of the benefits of treatment and how the treatment plan will help achieve these benefits.

It also is important to note that some pain medications can exacerbate cognitive deficits in attention, memory and other areas. Minimizing and, if medically feasible, eventually eliminating use of narcotic medications will allow the person with brain injury to maximize his/her potential to participate successfully in a pain management program.

Arranging for a neuropsychologist to provide instruction to pain management specialists on the relevant effects of the person's brain injury on his/her treatment will be important. Some questions that need to be answered include: *Can the person with brain injury focus long enough to participate in a pain program? Can the person recall the behavioral and physical exercises? Can the*

person follow an exercise sequence? Can the person follow the logic of the treatment plan? Are there any significant personality or emotional factors that need to be accounted for? Additionally, the neuropsychologist may help the person with brain injury and his/her family to: (1) understand possible obstacles to participating successfully in a pain management program, (2) outline steps for compensating for cognitive limitations when working with pain specialists and (3) help establish appropriate incentives for the person with brain injury to enhance participation in the pain management program.

Individuals with brain injury are not all the same—each person presents his/her own unique combination of strengths and weaknesses. Tailoring pain management interventions to meet the specific needs of each individual will be important for success.

How Pain is Measured

Pain may be measured in different ways. One common way is to have the person rate the pain on a scale of zero to ten, both at rest and when performing different activities. The individual also may be asked to perform certain physical tasks to test his/her capability to carry out each task with the reported pain. Unfortunately, none of these ways of measuring pain provides an unbiased, objective measure since they rely on the person's own perceptions of the pain.

In addition, pain felt from a particular injury can vary from person to person as a result of different tolerance levels to the same degree of injury. These differences in pain tolerance are associated with a variety of biological, psychological, social and emotional differences among people. The variability of pain tolerance from person to person and the lack of an unbiased way to measure pain complicate the professional's understanding of the person's pain and can lead to disagreements between the person experiencing the pain and the treating professionals. In cases of disagreements, professionals may request psychological and functional capacity evaluations. These evaluations help to: (1) increase the professional's understanding of the person's pain complaints, (2) increase the functional difficulties that may result from the pain and (3) identify how best to treat and manage the person's pain.

Chronic Pain Syndrome

Chronic pain is believed to involve a variety of factors, including psychological components. Some individuals have observed that chronic pain begins as physical pain that has failed to resolve or has become worse. The person then develops unhealthy ways to deal with the physical pain, creating problems in daily functioning or making existing problems worse. The person then can develop "chronic" pain that cannot be explained medically. More recently, chronic pain has come to be viewed as a complex experience or syndrome involving sensory, cognitive, motivational and emotional components. For example, psychological influences such as increased daily stress, a perception of having little control over events in one's life and lower levels of psychological well-being have been associated with more frequent pain episodes and sometimes a greater severity of pain.

Sleep and appetite disturbances—along with the side effects of excessive pain medication—intensify the disability that results from chronic pain. As time goes by, the person may become depressed and preoccupied with normal changes in bodily functioning and may worry about experiencing new illnesses. The individual can develop a tendency to view all activities in terms of how much pain will be experienced. This can lead to a cycle of helplessness and despair, often accompanied by anger toward professionals who never seem to be able to cure the pain. In turn, professionals lose patience with the person with persistent pain who appears to have limited medical justification for these complaints. Pain becomes the main focus of the person's life. Interests and social activities are given up, resulting in withdrawal from family and friends. Isolation from others can contribute to the development of alcohol and medication abuse. Pain can become an excuse to allow the person to avoid stressful activities and conflicts. The whole process can become cyclical and result in a greater focus on pain, less support by family and friends and greater isolation and dependence.

There are several major components of *chronic pain syndrome*. These include a significant decrease in any kind of activity, as well as selective inactivity (i.e., claiming that certain tasks—usually unpleasant ones—are too painful to perform, while equally demanding, albeit enjoyable activities do not result in similar complaints of pain). Abuse of alcohol and medications can be common. Some reports have estimated that as much as 90% of individuals with chronic pain syndrome abuse alcohol and/or medications. Although any sort of medication may be involved, the narcotic, sedative and minor tranquilizer medications most often are abused.

Typically, these drugs provide little pain relief and increase the person's challenges in daily functioning by causing: (1) thinking and memory problems, (2) decreased activity, (3) increased bed rest and (4) inconsistent sleep patterns. These problems may be worse for people with brain injury who have less tolerance for these drugs. Individuals who grow dependent on narcotic medications take them regularly every three to four hours and show a classic pattern of awakening in the middle of the night when they have overslept their supply and go into low-level withdrawal. Narcotics and sedatives can be helpful in acute pain. However, daily consumption for more than two to four weeks encourages tolerance and dependence and, in the long-term, may help maintain the pain problem.

Another component of chronic pain syndrome is excessive use of health care resources, including multiple medical examinations and unnecessary surgery that prove to be of no lasting benefit. Psychological changes involving depression also are common. Depression is exacerbated by extended periods of inactivity and overuse of narcotics and sedatives. Overuse of narcotics and sedatives can result in memory and other cognitive problems that confuse these individuals, increase their anxiety and reduce their ability to cope with pain. The involvement of a work-related disability or a history of work difficulty prior to the injury may serve to decrease the person's motivation to improve the pain in order to escape an unpleasant work situation or avoid possible unemployment.

Finally, in some studies, the presence of an attorney in workers' compensation cases has been associated with failure to return to work after pain treatment. When issues of litigation and compensation are involved, the person's focus can change many times to having been "wronged" and to restoring his/her pride rather than focusing effort on adjusting to and improving present problems with pain.

Managing Chronic Pain

Acute pain requires minimal intervention and resolves naturally. Chronic pain syndrome can be a disabling diagnosis that may require multidisciplinary assessment and treatment. Many times, it never may be eliminated completely. As a result, pain management strategies are based on one ultimate and constant objective—the *reduction of pain, not its total elimination*. If the person experiencing the pain and all of the professionals who treat the individual do not make this the goal, frustration will grow, resulting in failure to coordinate treatment efforts in a successful manner. The treating professionals must make this the goal because treatment can break down if even one team member begins to alter treatment as a result of changing the goal to "elimination" of the pain. Also, if the person changes his/her expectations to complete elimination of the pain, odds are that the person will experience continued disappointment even though treatments may be reducing the pain significantly.

Always, the goal of chronic pain management is to reduce the pain and improve the person's ability to cope with the pain that remains. Never is the goal to eliminate the pain completely. Reasonable outcomes include:

- Decreased medication use
- Fewer physician visits
- Decreased attempts of seeking alternate physicians by both the individual with pain and the referring physician
- Fewer hospitalizations and emergency department visits
- Lower costs of maintaining pain care
- Improved flexibility
- Greater endurance
- Increased strength
- Improved functioning at home

- Improved interaction with family and friends
- Return to employment

The *disease model of illness* does not explain or provide an adequate basis for treating chronic pain syndrome given its reliance on a physical basis for the pain, while ignoring the psychological, social and legal factors that appear to contribute to chronic pain syndrome. As a result, other approaches to understanding and treating chronic pain syndrome have been utilized.

One common approach uses the *operant model of pain*. In this model, pain is viewed as a *learned behavior*. A psychologist or neuropsychologist with training and experience in behavior management can help professionals use this approach with the person with chronic pain. Other approaches help the person to identify inappropriate and unhealthy beliefs about pain and provide strategies to deal more effectively with pain behavior. Several techniques such as: (1) relaxation training, (2) hypnosis, (3) stress management, (4) attention-diversion strategies and (5) biofeedback may be used in conjunction with the operant model and other approaches.

Regardless of the preferred mode of treatment, a good pain management program usually includes several basic elements. First, chronic pain involves not only pain, but also several other problems such as depression, deconditioning, unhealthy learned responses to the pain, functional disability and dependence on medications. The presence of these other challenges may make it necessary to receive treatment from several different types of professionals in a coordinated manner. Receiving pain medications from a physician or heat treatments from a physical therapist may provide temporary relief from the pain. However, the other problems associated with chronic pain syndrome often result in the pain level returning to its initial level of severity. Thus, obtaining treatment from a multidisciplinary pain clinic or rehabilitation center or—if these are not available—a well-coordinated effort between the primary physician and other necessary professionals, likely will provide the best opportunity for success.

A second element involves managing emotional distress. Chronic pain commonly involves depression which can contribute to alcohol and other substance abuse, inactivity, loss of employment and poor self-esteem. Medication and psychotherapy can be very helpful in improving mood, enabling the person to participate more effectively in pain management

treatments and preventing some of the associated problems from developing. A third element consists of medication monitoring with the goal of eliminating unnecessary medications, particularly narcotics and sedative-hypnotic agents given their potential for abuse.

A fourth element involves efforts to increase exercise and activity level to combat deconditioning and its harmful effects on pain and overall functioning.

A fifth element involves a combination of *operant* and *cognitive-behavioral approaches*. This may include programs designed to increase healthy behaviors and reduce unhealthy pain behaviors. It also may include strategies to identify and replace inappropriate thoughts about pain, as well as relaxation training—possibly with biofeedback or hypnosis—to provide a sense of self-control and mastery over pain. Finally, it may include training in problem solving, communication skills, assertiveness and social skills.

A sixth element is emphasis on the impact family members and significant others can have on managing pain behavior. Teaching family and friends how to change specific ways they interact with their loved one who has sustained a brain injury in order to produce more healthy behavior cannot be emphasized enough.

For the person with brain injury, another element is the identification of cognitive deficits and their underlying causes (i.e., impaired memory, medication effects). Professionals then can take appropriate steps to improve and/or work around these limitations to allow the individual to maximize the benefits from the pain management program.

If the person with brain injury and pain is interested in returning to work and has the cognitive capacity to pursue this interest, a final element involves making professionals aware of past employment history along with obtaining aggressive vocational rehabilitation and follow-up.

Resources

The management of chronic pain in persons with brain injury requires multidisciplinary assessment and treatment. The team of healthcare professionals that may be involved in managing chronic pain in persons with brain injury includes:

- Physiatrists
- Primary care physicians

- Anesthesiologists specially trained in invasive procedures for the treatment of subacute and chronic pain

- Physical and occupational therapists

- Neuropsychologists or psychologists

- Neuropsychiatrists or psychiatrists

- Registered biofeedback technicians

- Insurance preapproval staff

- Nurses

- Social workers

- Nutritionists

This is a list of possible members of a treatment team and does not mean that all of these professionals are needed in all or even most cases. However, it is essential for the team to include a physician, neuropsychologist and/or other professional with an understanding of brain injury in order to provide guidance in working around the person's limitations from the brain injury. It also is very important that each professional involved in treatment establish short- and long-term goals before proceeding with specific treatments. Further, they should coordinate their efforts with all other treating professionals. This will be facilitated by active involvement on the part of family members who can make an effort to encourage communication among professionals.

Investigating treatment alternatives in the local area and ensuring that a coordinated effort is being made among all professionals providing treatment are two ways of enhancing the chances of success. Checking with the local hospital for a nearby pain treatment center or finding out if they have a behavioral medicine department that treats chronic pain in an individual with brain injury is a good start. Also, some insurance carriers have their own pain management programs and asking them about their plan may be helpful.

About the Authors...

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For additional information about dealing with pain and brain injury, contact BIA's Family Helpline at (800) 444-6443 or familyhelpline@biausa.org. Or visit BIA's award-winning web site at: www.biausa.org.

Distribution of these publications supported by the Defense Brain and Spinal Cord Injury Program (DBSCIP).

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For the individual with brain injury and his/her circle of support (i.e., family members, significant others, friends and co-workers) brain injury is a complex and often tumultuous journey. Although there are broad issues affecting ALL individuals with brain injury, both the road to rehabilitation and the outcome experienced by each individual are unique. In this series of brochures, BIA seeks to educate individuals and organizations about rehabilitation after brain injury. Some individuals with brain injury may face challenges in all of these areas, while others may experience problems with just a few of them. Regardless, the information in these brochures is crucial to provide those affected by brain injury, as well as the individuals and organizations treating them, with a basic understanding of the complex challenges following brain injury. For additional information about any of the topics covered in The Road to Rehabilitation Series, contact BIA's toll-free Family Helpline at (800) 444-6443 or visit their web site at www.biausa.org.