

SURVIVING A LOVED ONE'S CHRONIC PAIN

A guide for family and friends of pain patients.

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Editor's note: The following article is suggested as a handout to your patients' families or loved ones to help them understand what patients are going through and encourage them to communicate with them and provide support. This article is available online (at www.PPMjournal.com/Handout.pdf) as a printer-ready PDF to allow free unlimited printing of handouts.

This handout was inspired by a patient of mine who came into my office and inquired what resources were available for the family members of patients with pain to help them understand what their loved ones were going through. He discussed how his wife was frequently angry at him for not doing more physically at home while she was at work and how she often yelled at him. He felt guilty about it, but felt he did as much as he could tolerate. I was embarrassed to admit that I did not know of any handouts explicitly directed at spouses, family members, and other loved ones. After doing some research on the Internet, I discovered several very helpful publications, specifically Julie Silver's 2004 book, *Chronic Pain and the Family: A New Guide* (Harvard University Press) and the American Chronic Pain Association family manual, *ACPA Family Manual: A Manual for Families of Persons with Pain*, written by Penny Cowen (ACPA, 1998). I also found some helpful articles by Mark Grant, a psychologist in Australia, especially his "Ten Tips for Communicating With a Person Suffering From Chronic Pain," which is available on his website, www.overcomingpain.com. Mark was kind enough to allow us to summarize his suggestions here. As well, one of us (Whitman) has a website to help patients cope with chronic pain, and occasionally discusses family issues on it (www.howtocopewithpain.org). Much of what is in this handout is taken from these sources.

What was striking, however, is how little material there was oriented toward the family compared to the massive amount of

self-help material oriented to the patient with pain. In view of the profound effect the patient's pain has on the family and the equally profound effect the family's (and friends') responses have on the patient with pain, I found this troubling. I also felt that while Silver's book and the ACPA manual were very helpful, few family members would get them and fewer read through them. What was needed, I felt, was something brief and to the point. This is the result of that determination.

In putting this together, I would like to acknowledge the assistance of a number of people. First, I would like to thank Brenda Byrne, PhD and Judith Berman, MA, my colleagues at Margolis Berman Byrne Health Psychology in Philadelphia, for reading my initial manuscript over and making suggestions. Brenda especially was very patient in helping me revise question number 5, "How Should I Respond to My Loved One When (S)he's in Pain?" Thanks also are due to the members of the Pain Study Group in Chestnut Hill, Philadelphia. I especially want to thank Sarah Whitman, MD for organizing the group and for disseminating this handout to the members, as well as for her feedback and oversight for the section on medication, and Rebecca Tendler, for stressing the importance of having the section on medication co-authored by a physician with expertise in pain management. I would also like to thank neurologist Dr. Steve Rosen who generously contributed suggestions for section 12.

- David Kannerstein

1. What is chronic pain?

Chronic pain is pain which persists beyond the time usually required for the healing of an injury or illness. Some definitions set a specific time period; for example, pain which lasts longer than three months or longer than six months.

2. How is it different from acute pain?

Acute pain is what most of us are familiar with. It's what happens when you twist your ankle or burn your fingers on the stove. It's a signal that tissue damage is happening. While it may be severe, it is time limited and responds to appropriate treatment. Chronic pain is different. It may occur without ongoing tissue damage. This is what happens when nerves get injured (known as neuropathic pain). Examples include shingles (postherpetic neuralgia), diabetic neuropathy, and Reflex Sympathetic Dystrophy (RSD, also known as Complex Regional Pain Syndrome). It is difficult (or impossible) to imagine someone can be in severe pain continually if one has not experienced it. It's normal for you not to understand it if you haven't lived through it. It may also be hard to stand by and accept that your loved one's pain cannot be fixed or cured (although it may be eased and the suffering associated with it may be reduced). It may also be hard to accept that you cannot make it better.

3. How am I affected by their pain?

If you are in a close relationship (spouse, significant other, parent, child, sibling or even close friend) with someone with chronic pain, you are likely to develop a variety of negative feelings as a result. For example, you may feel guilty at times for not being able to help them more. You may feel angry at them if they are irritable or withdrawn. You may resent having to take over tasks they previously performed. You may feel depressed as a result of a withdrawal of affection or a decline in your sex life. You may get anxious about financial problems which result from your loved one's disability. You may feel stressed by the reactions of others. For example, relatives or neighbors may say "He (she) doesn't look that disabled to me" or "Should he (she) be taking that addictive pain medication?" In fact, both you and the family member in pain are victims of the pain problem, as are those others who are part of the family (and this applies to close friends too).

You may experience significant lifestyle changes. You may have to live on a reduced income or have to work harder to stay afloat financially. You may have to

spend time getting your family member to medical or other appointments if they can't drive. You may end up doing most or all household chores and child-rearing activities. You may have less time for friends and experience reduced social support.

You may experience intrusions into your life from outside agencies. For example, some insurance companies (primarily worker's compensation) may follow or film your family member. You may also be stressed by lawsuits, disability evaluations, or independent medical examinations (IME's).

You may also experience some positive outcomes, although this is less common. For example, if your spouse was controlling, you may actually have more freedom. If you have very strong needs to help others, you may feel good about helping your loved one. If you were experiencing intimacy with your loved one (including sex) as unwanted, a decrease in intimacy may feel positive. You may get additional support or sympathy from other family members. These positive outcomes can lead one (not always intentionally) to try to maintain the situation. These have been referred to as "tertiary gains." Being aware of these can help you identify more effective ways of dealing with problems in your relationship.

If you are the spouse of a patient with pain and you have children, you may worry about the effect of the pain on them. Children may blame themselves for their parent's pain. It is important to let the children know it is not their fault. They may also get depressed about the loss of attention and affection from the parent in pain or from the loss of activities due to financial limitations.

4. What do I do to take care of myself?

If any of the above applies to you, you are not alone! In addition to discussing things with your loved one's doctor, you may also benefit from talking things over with a therapist or counselor to help you cope better. In addition, consider the suggestions below.

- Try to maintain a healthy life style. Keep exercising (or start), socialize as much as possible, and eat right.

- Try to find others to help with the care of your loved one. This may be other family members or friends. This will allow you to take a break at times. (Your loved one may also feel less guilty if the burden does not all fall on you!)

- Try not to personalize your loved one's behavior. If they are grouchy or depressed, don't see it as an attack on you but as a reflection of their pain.

- Try to avoid being either too babying or too harsh toward your loved one. Remember they are not doing this on purpose and are suffering just as you are. Gently encourage them to function in spite of the pain and to do as much as possible for themselves.

- Look for support wherever you can find it. If there is a support group for loved ones of patients with pain, join it (or start one if there isn't already one). Don't isolate yourself from friends and family. Participate in your church, synagogue, mosque, or other religious or spiritual organization. If prayer (or chanting or meditation) is helpful, keep doing it.

- Learn as much as you can about your family member's condition and the available medical and other treatment options, and discuss them with your loved one when he or she is ready to talk about them.

Remember, this is a family problem, not just an individual one. Try to see it as one that you face all together, "we" — not "he" or "she"— will fight this together.

The following are some questions you may have about your loved one's pain.

5. Is it all in their heads?

Chronic pain is rarely imaginary (psychogenic) or simply a way for your loved one's psychological problems to come out. However, negative emotions such as depressed mood, anger, or anxiety can play an important role in making pain worse. For example, anxiety or anger can cause an increase in muscle tension leading to more pain. Post-Traumatic Stress Disorder (PTSD) causes one's nervous system to become very sensitive and can make it harder to recover from a physical injury. Certain types of personalities may find it more difficult to cope with pain and/or the losses and disabilities it brings. For example, many people get their self-esteem from working and cannot tolerate being disabled. This can make it difficult to treat their pain.

6. Could they be faking it, say, to get out of work?

Consciously faking pain to get out of something or to get a reward is known as malingering. While it does occur, it is rare. Most patients will feel very guilty about not being able to do the things they used to do, whether working at a job or doing chores around the house. Very few patients with pain get rewarded financially for their pain. Most suffer severe financial losses. Unconsciously producing symptoms to get rewards or get out of unpleasant things is called "secondary gain." It is

rarely the cause of someone's pain, although it sometimes may reinforce a negative situation. For example, someone on disability may fear vocational training because they are afraid to lose the income, in case it doesn't work out if they go back to work at a new job. For some, there may be positive outcomes that make it easier to accept one's situation. However, for most pain patients, the losses far outweigh the gains.

7. How should I respond to my loved one when (s)he's in pain? How much should I do to be helpful?

People in chronic pain seem most helped when those closest express concern for their suffering and offer help that is genuinely needed, along with encouragement for them to be as active as possible. Don't overdo sympathy or try to remove all obstacles and challenges from someone in pain. On the other hand, don't punish the pain sufferer by blame and hostility. If you are not sure how best to be helpful, you might ask the person in pain what kind of attention (s)he feels is most helpful and respectful.

There are a number of signs that you can look for. The following are some important ones.

8. How can I tell how he or she is doing?

Are they able to communicate? Can they speak clearly and audibly and does what they say make sense?

Are they aware of where they are, who they are, and what day it is? Are they able to stay focused and to remember things? Problems with memory and concentration may indicate depressed mood or medication side effects. Not knowing where or who they are, and what day it is, is known as disorientation. It is a serious symptom and should be discussed immediately with the patient's physician.

Are they sleeping at night for the right number of hours? Sleeping too much or too little may indicate depression or anxiety. Insomnia can also result from being in a lot of pain. Has their appetite increased or decreased, or have they gained or lost weight? This can also be a sign of depression. Weight gain may also result from taking certain medications and/or a reduction in activity.

Do they appear depressed? Do they look sad or do they seem "slowed down"? Are they frequently grimacing, crying, groaning, or otherwise indicating extreme distress? Do they appear anxious or irritable? Have they maintained their relationships with family and friends or have they

become withdrawn?

Have they increased use of tobacco or alcohol? Are they overusing prescription drugs? Do they appear 'out of it' or intoxicated? Are they using street drugs of any kind, including marijuana, cocaine, or amphetamines (speed)?

If the answer to any of the above is "yes," these concerns should be discussed with the patient's physician and, if he or she is seeing one, their therapist.

9. What treatments are there for chronic pain?

There are numerous medical and other treatments which can help patients with pain live happier and more productive lives. Sometimes complete pain relief can't be reached, but reducing suffering and increasing a patient's functioning can almost always be accomplished. As a loved one of a patient with pain, you need to be aware of these to help your loved one get the appropriate treatment. As every patient is different, this information is not meant as medical advice, but to give you a sense of the range of treatments.

Let's start with medications. There are many medications which can be helpful in making your loved one's pain more tolerable. You and your loved one should be aware of both common and serious side effects from any medication being taken.

NSAIDs: For mild to moderate pain and inflammation, a Non-Steroidal Anti-Inflammatory Drug (NSAID) may be recommended. This includes over-the-counter medicines like aspirin, Advil and Motrin (forms of ibuprofen) and prescription drugs like Rufen (ibuprofen), Toradol (ketorolac), Naprosyn (naproxen), and Inderol (indomethacin) as well as many others. Tylenol (acetaminophen) operates on pain like a non-steroidal anti-inflammatory, but does not reduce inflammation.

Narcotics: For more severe pain, narcotics (opioids) are often prescribed. These include drugs such as hydrocodone (Vicodin), morphine, hydro-morphine (Dilaudid), and oxycodone (as in oxycontin). Narcotics may be short acting (taken every 4-6 hours) or longer acting (12-24 hours). They may be in the form of a patch put on the skin, such as Fentanyl in the Duragesic patch. A non-opiate which works much like narcotics is tramadol (Ultram) which is also available combined with acetaminophen (Ultracet).

Antidepressants: Some medications used to treat depression are useful to help with pain, and 2 types of antidepressants are most effective. These are the tricyclic antidepressants, including Elavil (amitripty-

line) and Pamelor (nortriptyline); and the dual-action antidepressants, including Effexor (venlafaxine) and Cymbalta (duloxetine). Another class of commonly prescribed antidepressants, the SSRIs (Selective Serotonin Reuptake Inhibitors) are generally less effective in treating pain, but they may work for some people. Examples include Prozac, Zoloft, Paxil, Celexa, and Lexapro. Antidepressants are helpful in treating the depression that patients with pain may develop, but they treat pain even without accompanying depression.

Anticonvulsants: Medications used to treat seizure disorders may be used in treating pain, especially nerve pain. They include Neurontin (gabapentin), Tegretol (carbamazepine), and Topamax (topiramate).

Others: Other drugs used to treat pain include muscle relaxants like Soma (carisoprodol) and Flexeril (cyclobenzaprine). Medication to help improve sleep is often used, as patients with pain often have difficulty sleeping. These include Ambien and Lunesta. In addition to oral medication, patients may use creams on the skin.

Procedural interventions can also be useful to decrease pain. For example, patients may receive injections, including trigger point injections or spinal injections such as nerve root blocks and facet blocks. Anesthetic and/or steroidal medication may be used in injections. Radiofrequency procedures can sometimes provide longer-term benefits than steroid injections.

10. Will my loved one get addicted to his or her medications?

Many patients with pain and their families worry about addiction to medication. Much, although not all, of this concern is the result of confusion about the meaning of terms like "addiction," "dependency," and "tolerance." The American Pain Society's definitions are paraphrased below.

Addiction: Addiction is a disease with genetic, psychological, social, and environmental factors influencing its development and symptoms. It consists of behaviors such as poor control over drug use, compulsive use, continued use despite harm, and craving.

Physical Dependence: Physical dependence is when the body is used to a certain medication or drug, and withdrawal symptoms occur when the drug is stopped or decreased in dose.

Tolerance: Tolerance means that the body gets less effect from a certain dose of a medication or drug, or needs a higher dosage to get the same effect.

In other words, addiction always in-

volves abuse of a substance. Physical dependence and tolerance do not. If your loved one uses narcotics or benzodiazepines (e.g. Ativan or Klonopin) regularly, they may become dependent and may develop tolerance for them. By themselves, these are not signs of addiction. If your loved one is not abusing the medication, notice whether or not the medication is improving his or her functioning. Can they do more? Are they more cheerful? These are signs of appropriate use of medication.

Patients who are not getting adequate relief may complain and demand more medication — this may look like the behavior of an addict. This is sometimes called “pseudo-addiction.” So how can you tell real addiction? If your loved one repeatedly says (s)he has lost prescriptions, gets the same medication prescribed by different doctors, gets prescriptions filled in different pharmacies, or gets medication off the streets — all to get more medication than is prescribed — then this may be addiction and needs to be discussed with the doctor.

11. What questions do I need to ask the doctor?

You should go with your family member to the doctor at times and understand what the overall treatment plan is. Ask the doctor what medications are prescribed, in what dosages, and how often. You should also ask what the medication does (for example relieve pain, combat depression, help with sleep, etc.), what the possible side effects are, and how you will know if your loved one is taking too much or too little? A doctor (or physical therapist) can also help you understand what the appropriate level of activity is for your loved one, given his or her physical limitations.

12. What else helps besides medication?

Many other techniques have been found helpful with pain. Physical therapy includes exercise and other treatments. Exercises can focus on strengthening, flexibility, and aerobic or cardiovascular functioning and must be tailored to the individual to be effective. Other treatments include heat, cold, Transcutaneous Electrical Nerve Stimulation (TENS), ultrasound, and massage.

Assistive devices like braces, canes, telephone headsets, and orthotics can help reduce pain. So can making adjustments in seating arrangements at home or work. Adjusting the placement of computer keyboards, for example, can help re-

duce repetitive strain injuries.

Surgery is an option when it can address a specific cause of the pain. For example, some individuals with herniated discs or spinal instability may need spinal fusions (fusing vertebrae together) or discectomies (removal of the disc). Less invasive surgical options are now available to help stabilize the spine without undergoing a formal fusion. Surgery may also be used to implant pain-relieving devices such as dorsal column stimulators or spinal medication pumps. Patients' and families' coping strategies are important determinants of successful outcomes in these surgeries, and psychological evaluation is generally important to maximize non-medical coping strategies and chances for the success of the proposed implants. In addition to spinal surgery, other surgery may be indicated to relieve nerve compression (in the wrist or elbow, for example).

Alternative medicine includes a wide variety of approaches which can be helpful to many patients including chiropractic, acupuncture, the use of herbal and other nutritional supplements, traditional techniques including yoga, Tai Chi, qigong and many more. These should be seen as working with — and not as opposed to — medical treatments, and their use should be discussed with the physician. (Many herbs, for example, can interact with medications.)

Psychological interventions can also be very helpful for many patients with pain. Therapists help individuals change negative thinking styles and behaviors. This is especially crucial if the patient with pain has developed significant emotional disturbances. These interventions may also help with decreasing pain or increasing the patient's tolerance for pain through “mind-body” techniques including hypnosis, meditation, biofeedback, guided imagery, progressive muscle relaxation, breathing techniques, and other relaxation approaches. Additionally, they may help the patient identify and stick to an appropriate activity schedule.

13. How do I communicate with my family member?

(Adapted from Mark Grant, “10 Tips for Communicating with a Person Suffering from Chronic Pain” at www.overcoming-pain.com.)

Listen. Pay attention not only to what your loved one is saying, but to their non-verbal communication and how they're saying it. They may be reluctant to talk about how they feel but give indications in their behavior.

Be genuine. Don't pretend to be interested in their feelings if you're not.

Believe. Accept that their pain is whatever they say it is. Don't tell them it can't be that bad.

Accentuate the positive. Repeat and summarize what they say and ask questions that show you're interested. Avoid hurtful comments like “You'll just have to live with it.” Ask questions which help patients get in touch with their strengths, like “What helps you get through this?” Remember the idea of positive reinforcement; when your loved one acts in a more positive manner, reinforce this with praise and attention. When they act more aggressively, don't pay too much attention. Acknowledge they feel bad and wait for an opportunity to reinforce the positive.

Be aware of your nonverbal communication. Remember that you can also communicate rejection, not only through the words you choose but also by how you say them — your tone of voice and volume, for example. You also communicate by facial expression (frowns, sneers, gestures, putting hands up to indicate “enough!”), and by eye contact (looking away).

14. Conclusion

We hope the information in this handout will be useful. Remember, dealing with severe pain can be overwhelming for both patients and those who care for them. This handout is not intended to substitute for the expertise of a professional when needed. Before the burden becomes too great, speak with a professional therapist — psychologist, clinical social worker, or psychiatrist — with experience in the field of pain management. The more involved you get, the less helpless you will feel! ■

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