

Life Care Planning for the Amputee with Chronic Pain

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Abstract. *Although amputation as a consequence of trauma will always result in short term pain, a few individuals with traumatic amputation go on to experience chronic pain that interferes with their quality of life. Pain in the amputee should be addressed using a team approach of health professionals who deal with a large number of amputees, since the problematic pain in an amputee is often associated with a pain generator that can be identified and improved. A pain treatment algorithm should be utilized and is provided with this article. Additionally, pain medication categories common for amputees are presented. Further, a well-fitted prosthesis will often result in a lessening of the amputee pain experience. Likewise, the emotional well-being of the amputee is usually inter-related with the pain experience, and counseling can be an important part of the team treatment plan. Functional outcomes should be utilized in determining if the amputee has achieved the ideal level of function, and the life care plan should take into account the expected outcomes for an individual's particular level of amputation. A functional outcomes checklist is provided to assist the life care planner in determining expected functional outcomes for various levels of amputation.*

Introduction

This article is presented to generally discuss problematic pain that is present in persons who have undergone acquired amputations. The majority of amputation cases in which a life care planner is involved will be work-related or traumatic in nature. Although the most common type of amputation seen in the United States is in an older person who also has dysvascular disease, it is less common for a life care planner to be involved in a case of amputation related to dysvascular disease. This review of amputation pain is most appropriate for the person who is younger and has sustained a traumatic amputation.

This article is intended to review the types of pain management techniques that are frequently used in the management of an amputee with chronic pain. It is not intended to discuss a treatment regimen specifically for pain. In addition, since many professionals who are life care planners are also case managers, the article should assist with better knowledge for case management of the amputee who has problematic pain.

The Issue

All adults who sustain a limb amputation will experience pain and phantom sensation, at least in the immediate post-operative period. In most adult amputees, this pain will subside and not impair the quality of their life or become chronic and debilitating in nature (Hompland, 2004; Meier & Weed, 2004). For those in which the pain becomes debilitating, the pain experience must be carefully described in order to ascertain whether it is one of four differing sensation phenomena that occur in adult amputees. The evaluation and differentiation of pain is important so that the amputee can be treated appropriately in an effort to successfully decrease or resolve the pain and to assure that it does not interfere with function and/or quality of life.

Definitions

Incisional or Acute Post-Amputation Pain

Pain occurs because the amputation has been performed and body tissue has been transected, including skin, muscle, nerves and bone. Each of these structures has pain fibers that will respond when these tissues are cut. While this is the most common pain present in the acute post-operative period, incisional pain usually subsides within the first three weeks of the amputation. Although an in-depth discussion of this topic is beyond the scope of this article, prolonged use of narcotics or synthetic narcotics for post-amputation incisional pain is to be avoided and should not be necessary.

Phantom Sensation

As previously stated, all adult amputees experience this sensation phenomenon, at least for some period of time following the traumatic amputation. Phantom sensation is the perception that the part of the limb that has been amputated is still present. Often, various parts of the “phantom” are felt to move or itch, with a feeling of being asleep or held in a peculiar position. This sensation typically resolves within a short time following the amputation but may be present to a greater or lesser extent for the amputee’s lifetime. Most frequently, phantom sensation decreases significantly and is not a bothersome problem. In many amputees with phantom sensation, the phantom foot or hand will “telescope” so that it moves proximally and eventually comes to be perceived at the end of the stump. Some amputees state they feel they may be going insane since they still feel the part of the limb that has been amputated (Van Dorsten, 2004). These individuals should be assured that this is a common sensation and an expected phenomenon and should diminish with time. The phantom sensation typically does not need to be treated and on occasion is utilized when training the amputee in prosthetic function.

Phantom Pain

Phantom pain is experienced in the part of the limb that has been amputated and can be perceived differently in individual amputees. Common descriptions of this pain include deep burning, as though someone is sticking a red hot poker into the phantom limb, extreme cold, squeezing or crushing (Meier & Weed, 2004). This type of pain can continue for prolonged periods of time or can present like an electric shock and only occur momentarily. Sometimes,

the phantom pain is constantly present and in other amputees, it may occur once a month or less. Phantom pain can be triggered by stress, a local source of pressure on the stump, as well as changes in weather or barometric pressure, and can be debilitating, affecting function and sleep.

Residual Limb Pain

Residual limb pain is pain that is felt to be present in the part of the limb that remains. It may arise from pathology that is present in the limb but is most often caused by poor prosthetic fit or the presence of a neuroma that may or may not be palpable. All nerves that are cut during the amputation form neuromas, so all amputees have neuromata present. However, the majority of neuromas are not painful or problematic and do not need any form of treatment. In addition, few of these neuromas are superficial enough to be palpated in the residual limb.

Most often residual limb pain is related to difficulty with prosthetic fit. With a poorly fitting prosthesis, unusual or abnormal forces are placed on the soft tissues, the nerves or the bones in the part of the limb that remains (Meier & Weed, 2004). Residual limb pain may also be caused by new bone formation. This new bone can grow into sharp or irregular bony edges that cause abnormal pressures in the stump when weight is placed on the prosthesis, and these pressures cause pain. In addition, residual limb pain can be caused by superficial neuromas that do not tolerate the pressure of an intimately fitting prosthesis. Residual limb pain may also be related to the formation of infected sweat glands or skin ulceration or friction from excessive socket pressures.

Residual limb pain usually does not enter the life of the amputee unless there is poor wound healing or, as stated above, improper prosthetic fitting. Residual limb pain may also be present if there is poor posture due to muscle imbalance, neuroma formation, bony overgrowth or other underlying nerve, bone or joint pathology, i.e., diabetic neuropathy, arthritis, etc. Often, residual limb pain is caused by unusual pressures on tissues as required by prosthetic use. Gradually increasing the prosthetic wearing time and careful skin inspection will permit increased wearing time, functional use, and comfort. If pain persists, often a prosthetic modification will help. As previously stated, on occasion, residual limb pain is related to neuroma formation when pressure is placed on the neuroma from wearing a prosthetic.

Usual or Anticipated History of Pain Following Amputation

For the adult who sustains an amputation, it is expected that there will be acute post-operative pain that often requires oral synthetic narcotic pain medications (Meier & Esquenazi, 2004). However, it should be expected that this pain will subside in the first week and be resolved by three weeks post-amputation. Often, phantom pain will begin within a few days of the amputation and increase to a maximum level for a few weeks and then also subside with or without the use of common medications such as synthetic narcotics, amitriptyline, gabapentin, dextromethorphan or Zonagan. By six weeks post-amputation in the traumatic amputee, most problematic phantom pain should subside and not interfere with the quality of life. Any pain that persists longer than six weeks from the amputation needs to be thoroughly evaluated and aggressively treated with an algorithm so that it does not persist for more than six months and, therefore, becomes chronic in nature. Once the origin of the pain has been identified, it can then be approached with a rational treatment algorithm (Hompland, 2004). Figures 1 & 2 provide accepted protocols for medical treatment of phantom and residual pain.

Figure 1, Reprinted with Permission
R. Meier and D. Atkins (eds.). *Functional Restoration of Adults and Children with Upper Extremity Amputation*, 337-351. Demos Publishing

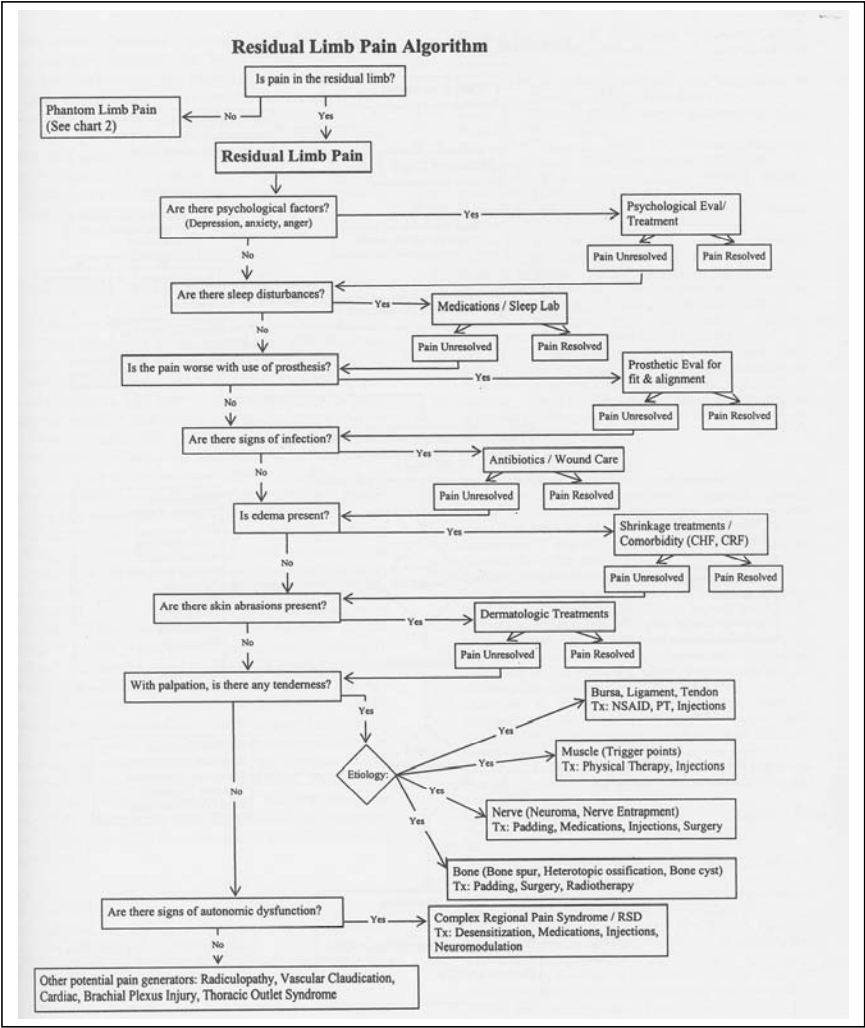
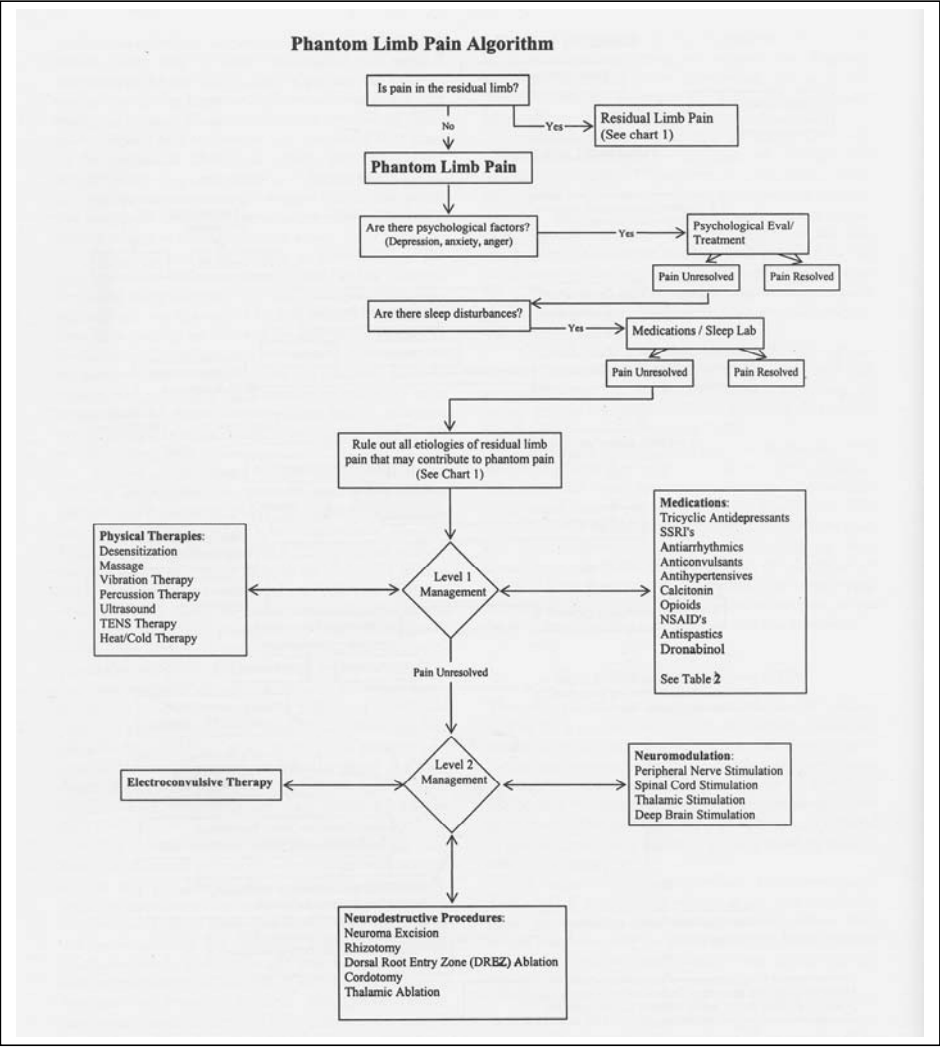


Figure 2
Reprinted with permission, R. Meier & D. Atkins (eds.) (2004). *Functional Restoration of Adults and Children with Upper Extremity Amputation*. New York: Demos Publishing



Treatment Algorithm

Whenever there is continuation of the phantom pain such that it decreases the quality of life or interferes with function, a physician who has expertise in working with amputees with pain issues should be involved in the evaluation and treatment of this type of pain (Meier & Weed, 2004). Many pain specialists have not treated persons with amputation and do not know the role that prosthetic wearing may play in pain generation.

The evaluation of the pain should include a very thorough history of the pain, its triggers, its location, and its response to prior treatment. Evaluation may include MRI of the residual limb to determine the presence of neuroma formation, bone or soft tissue causes. Electrodiagnostic studies may be helpful in identifying whether a neuropathy may be part of the pain problem (Meier, 2004).

Diagnostic blockade in long-term pain may help to demonstrate whether the pain is peripheral or centrally generated. Peripheral blockade can also assist in identifying a specific nerve that may be involved in pain generation. In addition, sympathetic blocks can assist in demonstrating whether there is a sympathetic component to the pain that is present.

Smoking

An important component of successful pain treatment is the cessation of any nicotine intake. A formal smoking cessation program may need to be instituted to include the modalities commonly used to stop smoking. In addition, it is important that the person also be removed from any environment that would expose them to second-hand smoke. Nicotine is a known pain generator and diminution of the pain cannot be expected if the individual continues to smoke. The use of Wellbutrin, hypnosis, nicotine patches and acupuncture can be appropriate in achieving a nicotine free lifestyle.

Sleep

Rapid eye movement (REM) sleep is a state of body rest that can produce endorphins. These endorphins can help diminish the pain experience. In addition, being rested enhances both the physical and emotional state of the individual. Improving the emotional state of the individual is essential to pain management, and both pain management and emotional management go hand in hand in the amputee.

Appetite

A change in appetite and/or a history of weight change may indicate an altered emotional state of anxiety or depression. Both depression and anxiety can result in an increase or decrease of appetite that is then accompanied by a significant weight change. This change may also be seen in persons with Post-Traumatic Stress Disorder (PTSD) and should be monitored by a medical professional (physician, nutritionist, etc.) and possibly a psychologist or other qualified mental health professional.

Stress

An increased state of stress can increase the tension present in voluntarily controlled muscles and this increased muscle tension state can aggravate the pain that is experienced. Stress management or control is an important component of pain management in the amputee.

Depression

Pain and depression are often associated negative phenomena for the person with an amputation. Active counseling for the depression and the use of anti-depressant medication should be considered to help achieve a healthy emotional state and to be certain that the depression may not be contributing to the pain state. On the other hand, the presence of pain may be contributing to the depression. Again, these two issues go hand in hand and the health care professional may not be able to tell which was present before the other. Nevertheless, both issues should be monitored and treated appropriately.

Anxiety

Anxiety, like stress, can contribute to an increased state of muscle tension and may contribute to a heightened pain state. Anxiety may also be a component of PTSD which should be suspected when significant anxiety is present. Anxiety itself may be related to the loss of control that the amputee experiences when they do not have significant input into the need for an amputation. Re-establishing their locus of control through a comprehensive rehabilitation program is important in diminishing the amount of anxiety and depression that can be present following an amputation.

Post-Traumatic Stress Disorder (PTSD)

It is common for persons who have undergone the amputation of a limb to experience PTSD, a diagnosis that tends to be overlooked by the amputating surgeon and healthcare team. Many therapists and prosthetists are not familiar with the diagnostic criteria for this disorder so it may be uncovered lately or not discovered at all. In today's healthcare environment, few amputees are seen by health professionals other than the amputating surgeon, their prosthetist, and occasionally a physical and/or an occupational therapist. Few of these individuals are experienced in recognizing the symptoms and diagnostic criteria for PTSD.

The DSM IV-TR (APA, 2000) indicates that a diagnosis of PTSD should be considered when the patient displays a combination of the following symptoms: anxiety, depression, nightmares, flashbacks, decrease in short term memory and the feeling of loss of control over the decision processes related to amputation.

PTSD may also contribute to a heightened pain experience so it is important that the disorder be treated successfully as a part of any pain treatment program.

Categories of Pain Medications

A specific listing of the commonly used medications to treat pain in the person with amputation is outside of the scope of this article. However, excellent reviews of current medication used in the amputee with pain are found in an article by Oakes (2004) in the *Journal of Life*

Care Planning, and a recent book chapter by Hompland in Meier and Atkins' (2004) text titled *Functional Restoration of the Adult and Child with Upper Extremity Amputation*.

The following list includes the broad categories of medications that are often used either singly or in combination in an attempt to decrease amputee related pain. There are no scientific studies that show one medication is more effective than another. Also, while one medication or combination may work in one person with an amputation, another medication or combination may prove more effective in another amputee. Therefore, each amputee should be treated using a pain treatment algorithm in a step-wise fashion that moves from the less noxious medications to the more addictive and controlled substances. In general ascending order are some suggested broad categories:

Nonsteroidal anti-inflammatory: These medications have become quite popular in treating medical conditions that have an inflammatory component since they work to inhibit cyclooxygenase and therefore, inhibit the production of prostaglandin. While their use in inflammatory processes has been an accepted form of pain control, they have also begun to be used in almost any pain condition. Their major side effect has been gastric irritation but, again, they are currently in wide use for various pain syndromes. However, more recently, some of the COX2 inhibitors have been found to be related to stroke and cardiac problems, and their usage has been called into question, with some being removed from the market.

Antidepressants: Tricyclic antidepressants have long been utilized in the treatment of depression and, more recently, in chronic pain syndromes as well as phantom pain. Their most efficacious use appears to be for the person with neuropathic pain. Since many traumatic amputations and those amputations associated with diabetes may have an element of neuropathic pain, these medications have received wide use in persons with phantom pain. In addition, some of these amputees have an element of depression and the antidepressant effect may also be quite useful in these individuals. More recently, Selective Serotonin Reuptake Inhibitors (SSRI) have been utilized as antidepressant medications and also in the treatment of phantom pain.

Anticonvulsants: These medications have had a long history of use in both phantom pain and other neuropathic pain conditions. While phenytoin and carbamazepine have had long term usage, the most likely anticonvulsants to be utilized today are gabapentin (Neurontin), topiramate (Topomax) and zonisamide (Zonogran). There are proposed mechanisms for why these medications do decrease pain but no sure reasons for their effects are proven.

Antihypertensives: Propranolol and clonidine have been utilized with some success in treating phantom pain. They act centrally to change the serotonin levels or to decrease the sympathetic outflow from the central nervous system (CNS). Clonidine has had success in decreasing pain in the pain syndrome that seems to have high sympathetic tone in a person with an amputation.

Hormonal Therapy: Calcitonin has been utilized with limited success for treating phantom pain. It is a hormone secreted by the thyroid gland and although its mechanism of pain relief is unknown, it has been shown to increase the level of endorphins in humans.

Substance P Medication: This medication (Capsaicin) is applied to the skin and is known to deplete substance P. Application to the skin will result in a burning sensation and appears to desensitize nociceptors, thereby producing analgesia.

Anti-arrhythmics: Medications with a sodium-channel blocking mechanism (Mexilitine, Lidocaine) seem to be successful in reducing problematic phantom pain. This blockade does appear to decrease pain through a CNS blocking mechanism. Lidocaine can be applied to the skin using a patch while Mexilitine is taken orally. However, Mexilitine may have an adverse

effect in patients with a history of heart rhythm blockade.

Muscle Relaxants: Both baclofen and tizanidine have been successfully utilized in treating phantom pain. Their effect on decreasing pain may come from the decrease in facilitation of the spinal motor neurons that also decrease spasticity. Often, these medications are utilized in combination with the tricyclic antidepressant and the beta-blocking medications where their effects may be synergistic.

NMDA Receptor Antagonist: The NMDA receptor may result in pain because it is hyperactive and may maintain neuropathic pain. Medications to treat this include amantadine, ketamine and dextromethorphan. Dextromethorphan has been undergoing trials for treatment of neuropathic pain in the diabetic and has relatively benign side effects.

Opioids: This class of medication has been utilized in virtually every type of pain. These medicines and their use are undergoing a change in medical thinking, if not societal thinking. Opioids have found a use for the person with phantom pain, especially for the short term. In some problematic cases of phantom pain, long term opioid use has found a place, especially if combined with some of the other categories of medications listed in this article. The issues of chronic opioid addiction are present but true addiction for the person with chronic and problematic phantom pain is seldom present. If these medications are to be utilized over a long period of time (more than three months), the person with problematic phantom pain should receive their pain treatment in a specialized pain treatment program and their medication usage should be closely monitored with frequent communication with the prescribing physician. Both OxyContin and Methadone appear to be the opioids most commonly used today for long-term pain relief. Both of these medications need close supervision when taken over a constant period of time.

Benzodiazepines: These medications have been utilized in the past as adjunctive medications in the treatment of chronic pain and the emotional effects associated with having chronic pain. These medications are fraught with their own side effects (depression, cognitive impairment) and should be avoided in the amputee who has long-term phantom pain. Other classes of medications are available for the treatment of the associated emotional effects of chronic phantom pain and associated changes in function and lifestyle.

THC derivatives: Some persons with phantom pain report good temporary relief when smoking marijuana. The purified form of the active ingredient, THC, is available in the prescription medication, Marinol. On occasion, some amputees with problematic phantom pain may find that Marinol is useful in decreasing their pain with a resulting improvement in their quality of life.

Chronic Pain

Chronic pain by definition is pain that is present daily for more than six months (National Institute of Disability and Rehabilitation Research, 1993). However, in the amputee with chronic pain, their pain may not fit the usual diagnosis since the pain may be related to a bio-mechanical or prosthetic cause that once altered will see the pain subside. The chronic pain in an amputee is often unlike chronic musculoskeletal pain. For the person with musculoskeletal pain there is seldom a known cause of the mechanism of pain generation. In the person with chronic amputation pain, the mechanism of causation can often be determined and, on occasion, decreased or eliminated. In chronic musculoskeletal pain, commonly used techniques for pain management are behavioral so the person can learn to be more functional in spite of the pain. In the person with chronic amputation pain, often the cause can be identi-

fied and altered so that the pain is more easily decreased or eliminated.

Surgical Solutions

If there is a palpable neuroma, redundant soft tissue, adherent scar, or abnormal bony edges, the first treatment for residual limb pain may be surgical revision of the stump. There are a number of amputating surgeons who do not know the most appropriate methods of reconstructive surgery for a person who must undergo an amputation. These problems of the stump are not best handled with prosthetic modifications, but better resolved with appropriate revision surgery. Trying to improve prosthetic function with prosthetic modifications rather than the best surgical reconstruction of the stump will result in function that is less than ideal, chronic pain, and recurrent stump problems. There is NO substitute for a well-formed amputated limb at the time of initial surgery and the preferred amputation surgery is reconstructive in nature, forming a residual limb that is most useful in motoring a prosthesis. In most cases of a transtibial or transfemoral amputation, the stump should be closed using a myoplastic technique that will form a cylindrical shape. It is the conical shape in a residual limb that is to be avoided and makes comfortable prosthetic fitting much more difficult.

Prosthetic Solutions

Prosthetic solutions to pain in the amputee are most easily achieved. However, often a prosthetist does not understand how the prosthesis may be contributing to the pain that is experienced. Today's prosthetists may have only six months in a prosthetic school followed by two years of work experience. They commonly are not familiar with many of the known causations of amputation pain but they should still be a part of the treatment team. A physician who has experience with amputation rehabilitation and amputation pain issues should be also be included in the treatment team.

Often, residual limb pain is created by excess pressure on the soft tissues or bones in the residual limb. In addition, there may be proximal body segment pain that is caused by the abnormal biomechanics of musculoskeletal use of the prosthesis. It is common for an amputee to establish muscle substitution patterns that create muscle and joint pain from abnormal use. This type of problem is best evaluated by a musculoskeletal physician, a therapist or someone trained in Aston Patterning. Aston Patterning is a means of improving muscle imbalance and posture that can be severely altered in the amputee who uses prosthesis (for additional information, visit http://www.astonenterprises.com/1-775-831-8228/Aston_Patterning.html). In addition, these abnormal body biomechanics can be corrected with a change in prosthetic alignment or prosthetic componentry. Because there is so much inter-relatedness with body biomechanics, the stump, and the prosthesis, these types of issues should be addressed using a multi-disciplinary team that is experienced with amputation rehabilitation.

Life Care Planning

Life care planning for the person with an amputation who is complaining of pain can be difficult for the experienced life care planner for a variety of reasons. Issues to be considered by the life care planner include:

1. How long has the pain been present?
2. Where is the pain located?
3. Has a diagnosis been made whether the pain is phantom pain and/or residual limb pain?
4. Has a diagnosis regarding the causation of the pain been made?
5. What treatments have been tried?
6. Is an experienced amputation pain treating professional involved in treating the amputee?
7. What was the pain treatment algorithm that was utilized?
8. Have all the commonly used pain medications described in this article been utilized? What dosages and length of time were the medications used?
9. Is the patient currently improving or on a steady pain regimen?
10. Have all the pain treatment modalities discussed in this article been tried?

It is important that the life care planner ask these questions of the amputee and his/her treating team (if the team is accessible) and review the medical records since, in this author's opinion, an accurate life care plan cannot be developed unless these issues have been addressed.

Physician Consultant for Your Life Care Plan

Most likely, the best consultant for your life care plan for the person with an amputation and long term pain is a physiatrist or anesthesiologist who has significant experience in working with problematic amputation pain. This consultant reviews prior pain evaluation and treatments and suggests whether the amputee whom you are evaluating has had an appropriate diagnosis and treatment regimen. The consultant can then provide the expected treatment regimens, their cost, and their likely outcomes for routine medical care, medication, supplies, equipment and aggressive medical care that should be incorporated into the life care plan.

Timing of the Life Care Plan for the Person with Amputation Pain

Based on published consensus conference information from the American Academy of Orthotists and Prosthetists, it is unlikely that a life care plan for an amputee with long term pain could be accurate if performed within twelve months of the original amputation date. An accurate prognosis for pain in the amputee is often delayed because most amputees, under the best of rehabilitation circumstances, will not reach a steady state until 12 - 18 months from the time of the amputation. This length of time to reach an ideal emotional and functional state is particularly true for the leg amputee. The arm amputee may reach a steady state a little sooner since they are not constantly putting weight on the prosthetic arm the way a person will using a leg prosthesis (American Academy of Orthotists and Prosthetists, 2004).

The Association of Amputation Pain and Functional Outcomes

One of the most difficult issues that will confront a life care planner in the person who has an amputation and long-term pain is a determination of the expected functional outcomes. Obviously, if the pain is associated with a lower level of function, then certain elements to

restore or assist with that function need to be included in the life care plan. This functional outcome will also likely affect work restrictions, return to work, potential for work or the need for vocational rehabilitation. There are few single limb amputees who sustain a traumatic work injury who are unable to return to some type of work. They may need job modification, re-training, further education or work hardening but they probably can return to work with or without prosthetic restoration.

The expected levels of function given a specific level of amputation have been enumerated in the rehabilitation medicine literature but are not commonly utilized in prosthetic education (Leonard & Meier, 1998). Most prosthetists do not use a standardized checklist to evaluate whether an amputee, with or without a prosthesis, has returned to the functional level that should be expected. However, it is important that the life care planner use these checklists to ascertain if the amputee has at least achieved the idealized functional outcomes expected for his/her level of amputation. If these idealized functional levels have not been achieved, the life care planner must be prepared to explain why this function has not been achieved and include services in the life care plan designed to help the client achieve the functional outcomes. It is suggested that life care planners use published outcomes to determine the client's functional levels as compared to what is expected for the various levels of amputation. Checklists for expected amputee function, with or without a prosthesis, follows:

Unilateral Below Knee

1. Ambulation with prosthesis on all surfaces
2. No gait aids
3. Independent in donning and doffing prosthesis
4. Standing up to two continuous hours
5. Walking up to two continuous hours
6. Gets up from kneeling
7. Return to recreational activities (hunting, fishing, golfing, jogging, skiing), if performed prior to amputation
8. Return to previous work
9. Comfortable with falling techniques
10. Performs cardiovascular conditioning program safely
11. Drives
12. Shops
13. Performs housework, gardening, home maintenance
14. Independent in Activities of Daily Living (ADL)
15. Knows how to purchase correct footwear
16. Can inspect skin and nails for remaining foot
17. Ascends and descends stairs step over step
18. Can run (if patient desires and has adequate cardiopulmonary reserve)

Unilateral Above Knee

1. Ambulation with prosthesis on all surfaces
 2. No gait aids
 3. Independent in donning and doffing prosthesis
-

4. Standing up to two continuous hours
5. Walking up to two continuous hours
6. Gets up from kneeling
7. Return to recreational activities (hunting, fishing, golfing, jogging, skiing), if performed prior to amputation
8. Return to previous work
9. Comfortable with falling techniques
10. Performs cardiovascular conditioning program safely
11. Drives
12. Shops
13. Performs housework, gardening, home maintenance
14. Independent in ADLs
15. Knows how to purchase correct footwear
16. Can inspect skin and nails for remaining foot
17. Ascends and descends stairs step over step
18. Can run (if patient desires and has adequate cardiopulmonary reserve)

Below Knee, Below Knee (Bilateral Below Knee)

1. Ambulation with prosthesis on all surfaces
2. May (or may) not use gait aids
3. Independent in donning and doffing prostheses
4. Standing up to one hour
5. Walking up to one hour
6. Return to work at same or modified job
7. Comfortable with falling techniques
8. Performs cardiovascular conditioning program safely
9. Drives and shops
10. Performs light housework and light outdoor activities
11. Independent in ADLs
12. Ascends and descends stairs one step at a time

Below Knee, Above Knee (Bilateral)

1. Ambulation with prosthesis on all surfaces
 2. Use of gait aids
 3. Independent in donning and doffing prostheses
 4. Standing up to one hour
 5. Walking up to one hour
 6. Return to work at same or modified job
 7. Comfortable with falling techniques
 8. Performs cardiovascular conditioning program safely
 9. Drives and shops
 10. Performs light housework and light outdoor activities
-

11. Independent in ADLs
12. Ascends and descends stairs one step at a time

Above Knee, Above Knee (Bilateral Above Knee)

1. May use wheelchair or prostheses in combination for ambulation
2. Wheelchair accessible housing

Unilateral Below Elbow

1. Dons and doffs prosthesis independently
2. Independent in ADLs
3. Changed dominance including writing, feeding, and other ADL, if indicated
4. Independent in one-handed activities
5. Drives independently with or without adaptation
6. Trained in kitchen, automotive, laundry, outside home maintenance and light housework
7. Wears prosthesis during all waking hours
8. Uses prosthesis for bimanual activities at least 25 percent of daily activities

Unilateral Above Elbow

1. Dons and doffs prosthesis independently
2. Independent in ADLs
3. Changed dominance including writing, feeding, and other ADL, if indicated
4. Independent in one-handed activities
5. Drives independently with or without adaptation
6. Trained in kitchen, automotive, laundry, outside home maintenance and light housework
7. Wears prosthesis during all waking hours
8. Uses prosthesis for bimanual activities at least 25 percent of daily activities

Bilateral Below Elbow

1. Dons and doffs prostheses independently
 2. Independent in ADLs
 3. Changed dominance including writing, feeding, and other ADL, if indicated
 4. Drives independently with adaptation
 5. Trained in kitchen, automotive, laundry, outside home maintenance and light housework
 6. Wears prostheses during all waking hours
 7. Uses prostheses for bimanual activities the majority of time for daily activities
 8. Bidet for enhanced toileting independence
 9. Needs back-up set of prostheses
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Below Elbow, Above Elbow (Bilateral)

1. Dons and doffs prostheses independently
2. Independent in ADLs
3. Dressing tree for ease of dressing activities
4. Changed dominance including writing, feeding, and other ADL, if indicated
5. Drives independently with adaptation
6. Trained in kitchen, automotive, laundry, outside home maintenance and light housework
7. Wears prostheses during all waking hours
8. Uses prostheses for bimanual activities 100 percent of daily activities
9. Has back-up set of arm prostheses for essential function
10. Bidet for enhanced toileting independence

Mid-length to long Above Elbow, Above Elbow (Bilateral Above Elbow)

1. Dons and doffs prostheses independently
2. Independent in ADLs
3. Dressing tree for enhanced independence
4. Drives independently with adaptation
5. Trained in kitchen, automotive, laundry, outside home maintenance and light housework
6. Wears prostheses during all waking hours
7. Uses prostheses for bimanual activities for 100 percent of daily activities
8. Back up set of prostheses for essential function
9. Bidet for enhanced toileting independence

Bilateral Short Above Elbow, Above Elbow or shoulder disarticulations

1. Fairly dependent in ADLs and all other essential daily activities
2. Needs attendant care depending on prosthetic functional abilities
3. Needs back-up set of prostheses
4. Dressing tree for enhanced independence
5. Can drive with appropriately modified vehicle
6. Needs significant home modification for safe ingress and egress from the building
7. Bidet for enhanced toileting independence

If the amputee has not achieved the above levels of expected function, the life care planner must develop a plan in consultation with appropriate experts that includes the costs associated with achieving the idealized function as well as costs related to not achieving the idealized function (i.e., reduced or less than expected function). In the author's opinion, any amputee who has not achieved these general functional skills must have an experienced and knowledgeable physiatrist involved who can assist the client in achieving this expected level of function. The life care planner and physiatrist should have obtained an excellent under-

standing of the reasons the amputee has not gained idealized function in performing appropriate life care planning.

Life Care Plan Needs Associated with Amputation Pain

Primary Care Rehabilitation Physician

All persons with an amputation should be followed on a regular and periodic basis by a knowledgeable rehabilitation physician (physiatrist) who can monitor function, prosthetic issues, pain, and mobility aids that would be useful for the individual amputee. The rehabilitation physician should also be utilized to specify work restrictions, determine maximum medical improvement (MMI) and assist the vocational rehabilitation counselor and employer in returning the amputee to the workplace. If return to the prior job is not reasonable, then the rehabilitation physician should be useful in helping to develop a vocational rehabilitation plan, in conjunction with a qualified vocational counselor.

Pain Specialist

Amputation rehabilitation physicians will treat the pain that is present in the person with an amputation. On occasion, a pain specialist may also be included in the program for pain management; however, often, an anesthesiologic pain physician does not have experience with pain in the person with an amputation and does not differentiate the type of the pain the amputee experiences. In addition, the typical anesthesiologist does not know what prosthetic issues may contribute to the pain or how altered body mechanics can influence the pain that is experienced. Usually, a pain specialist without rehabilitation training will not understand or treat the “entire picture” for the amputee with difficult pain.

Pain and Associated Medications

Contemporary management of problematic pain involves a number of medications that may be used in an “off-label” manner. Many of these medications are costly and have been provided in a shotgun manner instead of being utilized in the context of a pain treatment algorithm. This shotgun approach is to be avoided since it often confuses the pain picture and does not permit the clinician to identify which medication or combination of medications is being useful.

As mentioned earlier in this article, see the recent review of these medications in a previous issue of the *Journal of Life Care Planning* (Oakes, 2004).

Psychologist

Most persons who have sustained an amputation and who experience problematic pain need to be involved with a knowledgeable psychologist/counselor who understands the relationship between the amputation, pain, altered body image, altered function and change in life roles for the amputee. The psychologist must have more skills available than just counseling and no pain interventions should be attempted unless the emotional well-being of the individual is being addressed and the person has achieved some control of the anxiety, depression,

sleep pattern and anger management. The therapist also should be versed in hypnosis, Eye Movement Desensitization and Reprocessing (EMDR), and PTSD therapy since these often are particularly useful adjuncts to counseling the amputee with pain and the sole reliance on mood altering medications. Biofeedback may also be effective with many amputees. Obviously, it should be determined by the treatment team whether the signs of PTSD are present and to what severity they occur.

Invasive Procedures and Blocks

There are a variety of block procedures that are now commonly used in pain management for the person with an amputation. The most common procedures include a peripheral nerve block to determine which of the peripheral nerves may be involved with pain generation. Often, a sympathetic block is also performed to determine if there is a sympathetic element in the pain generation. It may be important in the leg amputee to determine if back pathology, in addition to the amputation, may be creating the pain experience.

Spinal Cord Stimulator

Spinal cord stimulation has been used in an occasional patient with long-term pain associated with an amputation. However, the author has not had a patient who required this procedure. For additional information on this topic, the reader is referred to Kumar, Toth, Nath & Laing, 1998.

Pain Pump

In some patients, pain medication may be more safely and effectively delivered using the epidural route. For the rare patient with intractable pain, a pain pump may improve the quality of life for the very difficult pain patient. The author has not had any patient who has required this form of treatment.

Other Surgery

On occasion, further surgery may be indicated to improve the pain that is "felt." This surgery can be performed for the amputated extremity if there is a bone spur, a neuroma or some other local anatomic disturbance that is causing the pain.

For the person with a leg amputation and associated low back pain, back surgery may need to be considered. However, usually this low back pain can be treated successfully with medication, prosthetic modifications and body posture correction.

Chronic Pain Program

Most chronic pain programs are not of value for the person with an amputation. Chronic pain is most often related to the musculoskeletal system and not to the limb amputation. These chronic pain programs are usually of short-term duration and are not designed to address the multiple complex issues involved in a limb amputation, its resulting pain and dysfunction.

Conclusion

Pain is present in all adult amputees with an acquired amputation, at least in the immediate post-operative period. Problematic pain is present in only a few persons with amputation; however, for some few amputees, pain is significant enough that it interferes with their quality of life and their functional abilities. It is essential to categorize the type of pain that the amputee experiences in order to appropriately aim the treatments that are available. A treatment plan should be developed using a pain treatment algorithm presented in this article that moves from more conservative elements to more aggressive treatments. The life care planner should consult with an experienced physiatrist to assure that the amputee has achieved the idealized or expected level of function and can support the prosthetic recommendations that are often an essential and expensive part of the life care plan. Life care planning for the person with an amputation should not be completed until the individual has recovered from the amputation and has gained maximum function from comprehensive rehabilitation. This recovery often takes a minimum of 12 months from the onset of the amputation. If the amputee has not achieved the idealized functional outcome expected for his/her level of amputation, and is not pain free, the life care plan should include strategies to achieve the desired outcomes or provide an alternative plan based on continued pain and lowered level of functional outcome.

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About the Author

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