

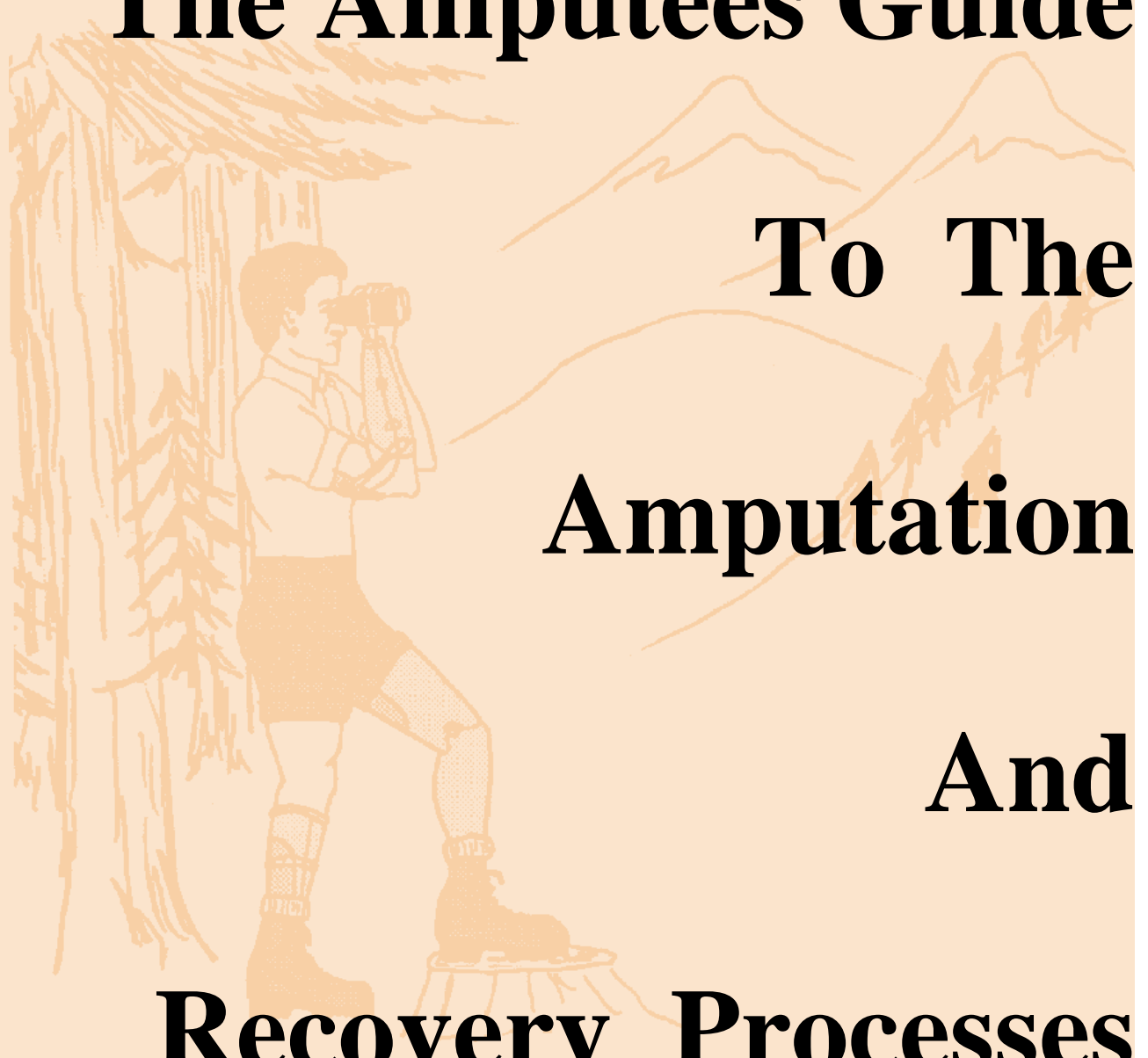
The Amputees Guide

To The

Amputation

And

Recovery Processes



by

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The Amputee's Guide
To The Amputation And Recovery Processes

Second Edition 1995

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INTRODUCTION

If you are about to have an amputation, you are about to experience a major change in your life. You will be in a very novel environment - the hospital - and will have to deal with new people, ideas, and language. You probably don't really know what to expect. You aren't likely to have a good idea of the sequence and types of events that will take place, of what you are going to feel, or of what is normal and what is not. You are probably worried about what can go wrong, how well you will recover, how long it will take, and lots of other things.

This guide has been prepared so you and your family will have a good idea of what to expect both before and after your amputation so you can participate in your own care and recovery. You will be living with your amputation for the rest of your life so you need to know what you are likely to experience, how to get along with one less limb, and what groups and literature are available to help you do it.

We don't expect most people to read every word of the guide. Look through it - pick and choose what you need to know now. Then hang onto it and read other parts as you need them. Share it with your family so they know what you are going through and what to expect.

The vast majority of people who have amputations do not know what to expect when they actually come to the hospital for an amputation. They know almost nothing about the surgery itself, what to expect in the way of length or difficulty in-recovery, or what they are likely to feel - either physically or psychologically. This can be a very upsetting and frightening experience. You probably won't know much of the vocabulary used by your health care team and other patients. A brief look through the "translation of terms" section will give you a hint of what to expect.

Most people who have amputations can and do make excellent recoveries. However, recovery is a slow and physically exhausting process which requires considerable patience and understanding. If expectations are unrealistic, considerable anger and frustration can be added to an already emotionally draining situation. If you have a good idea of what to expect and an idea of some of the concepts and words which will be used around you, you will be far more at ease. You will also have a much more realistic idea of how much recovery you can expect and how long it may take. This is invaluable in planning your future and guiding your family and friends.

It is vital to understand that your recovery can be prevented or slowed as much by a poor attitude as by your physical condition. Therefore, you should make every effort to understand what is likely to happen. It is especially important to read the sections on the psychological effects of an amputation and on phantom sensations. If you are not aware of normal reactions and feelings, you may upset yourself needlessly by thinking that something is wrong with you when you are actually reacting normally and are experiencing very normal feelings coming from the cut nerves.

Amputees are not rare. There are at least 26,000 living veterans who have had amputations as a direct result of military service and 10 to 15 times that number of civilian amputees. About twice as many males as females have amputations. Two major groups of people have amputations. Relatively young, healthy people who are hurt in accidents or who develop tumors and older people with chronic diseases that eventually cause such severe problems that a limb must be amputated to save the patient's life. The most common reasons for a limb to be amputated among adults are poor circulation and when medical or surgical treatment is unable to restore, reconstruct or salvage a damaged or diseased limb. Amputation is a reconstructive operation, part of a process to replace an irrevocably diseased or damaged limb with a more useful artificial one. The older group has more experience with hospitals, usually expects the amputation long in advance, and frequently knows other people in their situation who have had amputations. In other words they know pretty much what to expect and have a chance to prepare emotionally, financially, and socially for the event. The younger group almost never expects an amputation. Many are seriously hurt in motorcycle crashes, sports mishaps, or automobile crashes. Thus, many are from the group of relatively young people who, until the injury, believed they were immune to substantial harm.

Relatively young, healthy people can recuperate physically much faster than older, chronically debilitated people who have to overcome the remaining aspects of their chronic disease as well as the effects of the amputation. However, the younger group is almost never as psychologically prepared as is the older group, so differences between them can equal out quickly. All in all, the better shape you were in prior to your amputation and the more will power and effort you put into your rehabilitation, the quicker and more fully you will recover and return to your usual activities.

A few words about your mental state just before and after an amputation: You are under incredible stress during this time. Nobody thinks clearly when under stress. Many of the anesthetics used during the surgery leave your mind somewhat "cloudy" for days to weeks afterwards. Unfortunately, you can not recognize the change in your ability to think clearly.

Many prospects may appear bleaker to you than they would if you weren't under stress. Just before and after your amputation are not the times to make critical decisions! This guide can give you knowledge about what help is available and what you are likely to be able to do, but you may not make the best decisions for yourself based on this information. You ought to avoid major decision making for at least several weeks after your amputation and perhaps until you are well into your rehabilitation.

A few hints about working with your health care team: You are going to meet over a dozen professionals who are very important to you. Because you will meet so many so fast, because you are not really at your mental best just before and after the surgery, and because their roles are unfamiliar to you, it will be next to impossible to remember who is who. It really helps to write down the names and roles of the people you meet. You are very likely to be out of sorts due to the normal stress and exhaustion common following any major surgical procedure. This will be made worse by having to deal with people prodding you to do unfamiliar, somewhat scary activities that make you hurt. They may assume you understand why and how they want you to do something when you don't. Please have patience with everybody and ask questions. Try to keep as good a mood as possible. Your health care team understands that you are in pain, are going to be a bit grumpy, and may not be thinking too clearly for a while so they are ready to meet you halfway. Remember that you may have to work with these people for months. A good, friendly working relationship will speed your recovery and make your life in the hospital and rehabilitation center far easier.

This booklet is a general guide to what will happen, but the specific details of your own amputation and rehabilitation may differ somewhat from what you find in this book, depending on your individual needs and the health care setting.

Chapter 1

LIFE AND EVENTS ON THE WARD : BEFORE AND AFTER AMPUTATION

a. Overview

While you are in the hospital, your closest contact with health care providers will be with nurses. They play a key role in the coordination of your care. Registered Nurses (RNs) have at least several years of training and frequently have additional training and experience in their field of specialization such as orthopedic nursing. Nurses usually work in rotating shifts so you will not always have the same nurse. However, most of the same team will probably be present throughout your stay so you will have an opportunity to get to know most of them well. They are interested in all aspects of your life at the hospital - not just problems with your amputation. They know that all of your feelings affect your progress toward recovery.

When you have questions, do not hesitate to ask. You are not expected to arrive on your ward knowing its routines or understanding all of your medical problems. If you do not ask questions, you could cause yourself unnecessary anxiety and discomfort as well as slowing down your recovery. Nurses are very busy. They may not be able to come just after you call and sometimes may not be able to stay and chat as long as both you and they would like. The evening and night shifts are generally quieter. A more leisurely atmosphere exists during those shifts but they are more lightly staffed than the day shift so each nurse has to cover more patients.

b. Before surgery

You are likely to have blood tests and X-rays before your surgery. These may be done before or after your admission to the hospital. If you have questions about any of the tests, don't hesitate to ask. You have a right to know. You may be admitted to the hospital on the day of surgery, or, if you have medical problems that require evaluation in a hospital setting, you may be admitted one or more days before surgery.

Prior to surgery you will meet with a member of the anesthesia team. He or she will explain the anesthesia options available to you (general anesthetic, spinal block, etc.). With their help you will choose the type of anesthesia best for you.

You may also be visited, before surgery, by a Physical Therapist, an Occupational Therapist, a Prosthetist (someone trained to make and fit artificial limbs), or all of these. These health professionals coordinate your rehabilitation and will gladly answer you questions and concerns. They may not cover everything you want to know. The major cause of fear and worry is the unknown. If you have questions or don't understand what you've been told- ASK!

Just after being admitted to the ward, you will be asked questions about your medical history to help in planning your care and in preventing problems. For instance, information about medications you are taking or allergies you may have is extremely important. Any special concerns or needs you might have are important to mention so the health care team can help you go to surgery with as few worries as possible. The nurses and doctors need to know about any pain you have been having and what you have been doing to relieve it. Each person experiences pain differently and responds to it and to pain medications individually.

Surgical pain is very different from chronic pain. The best part about it is that it decreases each day and soon goes away completely. Many patients who have had severe chronic pain eliminated by surgery do not complain about post-surgical pain at all.

The Registered Nurses (RNs) on each shift normally try to talk to each patient about their progress. If you have any special concerns or requests, they will handle the problem on the spot or, if necessary, contact your doctor. The nursing staff tries to give each patient as much independence as possible. The idea is that the sooner you can get around on your own, the better you will feel and the sooner you will be able to go home. The nurses know that it is important to talk with you frequently about your progress because the best way to be sure the entire team, including you, is trying to reach the same goals the same way is to keep communicating.

Families and friends are especially important to anyone's recovery. Sometimes both the patient and staff forget that families are going through almost as much stress as the patient and need to talk things out too. When family members visit you, introduce them to the nurses and let them know who they will be talking with if they call the unit.

There are many diseases and germs in hospitals to which children have not developed sufficient resistance. For their own safety, they are usually not allowed on hospital's patient units. Additionally, children may not understand other patient's needs for rest and quiet. Unless approved by your doctor and the nursing staff, it's probably best to have children visit you after you have recovered sufficiently.

Hospital wards are not always the quiet places we perceive them to be. It may be difficult to get a complete night's sleep because of people passing in the hall or entering your room to give you medicine or monitor your "vital signs" (heart rate - pulse, blood pressure, and temperature). You will probably not be restricted to your room but, rather, will be encouraged to go the ward's lounge and possibly to eat in the hospital's main cafeteria or central patient eating area. The idea is to help you meet other patients, to help you learn your way around, and to begin to feel "at home" as quickly as possible.

c. After surgery

The most common general complication associated with amputation is infection. Even with modern sterile techniques and antibiotics, infections can occur, so good wound care is critical to successful healing. You play an important role in this vital aspect of the process as you do with all other aspects of your recovery.

After recovering from anesthesia, you will return to your "unit" (ward). You will be checked for possible problems such as bleeding from the wound site and will be monitored to make sure that complications are avoided. For the first 12 to 24 hours, you will have your blood pressure taken frequently and will be asked to cough frequently. Coughing clears mucous from your lungs and keeps airways open, helping to prevent fever and pneumonia. Depending on your type of anesthetic, you may be encouraged to drink fluids. If you have an intravenous infusion (IV), this will probably be stopped when the nurses are sure you can take fluids well or when IV medications have been stopped.

Ice packs are sometimes applied to the operated area over your bandage to reduce swelling and pain. You will probably not get any pain medication until most of the anesthesia is out of your system. You may be having pain when you are first settled back into your bed but once you are made comfortable it will probably subside. The nurses will watch you and give you medication as soon as they feel it is safe.

One of the big surprises for patients who have never had surgery before is how soon you are encouraged to get out of bed and move around. If you have had a leg removed, you may be in a wheel chair for a while. The odds are good that if there are no medical complications, you will be up by the day after surgery. The reality of recovery is that the longer and more you stay in bed, the longer it will take to recover and the more debilitated you will be. Thus, it is vital that you get up and start moving around as soon as possible.

The length of hospital stay following an amputation varies widely with the type of amputation, the age and general medical condition of the patient, the medical care setting and other factors. If good outpatient services are available, you could be discharged after only a few days. Your rehabilitation will begin in the hospital, but will extend long beyond your hospital stay. This rehabilitation may be undertaken on an outpatient basis with you staying in your own home and going to the places you must to receive your rehabilitative help or you may go from the hospital to a rehabilitation center where you will stay until you are able to undertake more of your own care.

Patients and staff get to know each other well. The patients also get to know each other quite well and develop many friendships. Talking with other amputees can be very helpful. You can share experiences and get a good idea of what to expect. There are many people in the hospital to work with and talk to. Being open about any problems - either physical or those you feel may be "in your mind" - will help you achieve the good attitude toward your recovery which is vital to progress. Support is available through psychologists, social workers, ministers, and other health care specialists as necessary. It is important to know that you are never alone in what you are going through and that the health care team wants to help you as much as possible.

Chapter 2

SURGERY

a. History and safety of amputations

Amputations have been common throughout the known history of humanity. The earliest "recorded" amputations took place about 36,000 years ago in Spain and France. One such record is an imprint of a hand with finger amputations found on a cave wall in Gargas, Spain. In Egypt, artificial arms have been found buried with 2,000 year old mummies. Military reasons for amputation have been common throughout recorded history. Thus, health care providers have more experience with how to perform amputations and how to rehabilitate amputees than with most other surgical problems.

Modern anesthetics are very effective and permit surgeons to carry out the amputation painlessly, carefully, and gently with minimal harm to tissues of the stump.

b. Preparation for surgery

The most frightening part of an amputation is usually the surgery itself. In fact, with modern anesthetics, surgical techniques, and antibiotics, the surgery is not a life threatening procedure unless a very rare reaction to the anesthetic takes place or the patient is seriously weakened by other injuries or severe chronic disease. Pain during the surgery is virtually never a problem and can be well controlled afterwards.

(1) Anesthesia: Anesthesia is provided by an Anesthesiologists or Anesthetists. These health care providers are trained to keep you comfortable and "unaware" during you surgery. As mentioned earlier, you will probably be visited by a member of the anesthesia team prior to surgery. You will be asked questions about your medical history, allergies, previous surgery and other things; knowledge of which will allow your anesthesia to be as safe as possible. During this time, you should ask questions about the different types of anesthesia that may be suitable for you as well as their advantages and disadvantages. There are numerous anesthetic techniques and a member of the anesthesia team is well qualified to discuss these with you. Some types of anesthetic wear off very quickly. Some allow you to remain awake but not feel pain in the limb undergoing surgery. Your options may be limited by your medical condition. In any case, your anesthesiologist or anesthetist can advise and guide you as the two of you determine the best and safest anesthetic technique for you.

It takes a while for the effects of anesthetics to wear off. The effects and time to wear off depend on how long you were "under", the type and amount used, and your basic physical condition. Just after surgery various members of your health care team will keep insisting that you cough and keep asking you about it. They are not just trying to annoy a sick person. They are insuring that you can take in enough air to speed your recovery and avoid complications.

(2) Level of amputation: The location of the amputation along a limb is referred to as its "level". Many amputees are surprised at the distance above the apparent site of the problem at which the limb is amputated. Many factors go into the surgeon's decision about where along the limb to cut. The four most important are:

(a) The seriousness of the problem itself: In chronic illness conditions, the problem causing the amputation may be far more extensive then it looks from the surface. In some cases, bones can be "soft" a foot or more above the site of an apparent skin breakdown. In accident cases, the bones and tissues may be destroyed well above the level where problems show at the surface. So, if the limb was amputated just above the level at which the problem showed on the surface, the limb would never heal properly and no weight could ever be put on the residual limb stump - thus preventing reasonable rehabilitation. Enough blood must reach the end of the stump to permit healing and continued health. So the point along the limb where blood flow drops below adequate may determine the level of amputation.

(b) The level at which the skin and near surface tissues can survive as part of a flap: The "flap" is the part of your skin and near surface tissues which are used to cover the end of the amputation site. There must be sufficient blood supply in nearby tissue and skin so that the flap gets enough blood to live. If parts of the flap die, you will have to have further surgery to correct the problem. This delays your recovery and could cause very serious illness.

(c) The newer types of artificial limbs work best with certain lengths of limbs. A residual limb (stump) which is too long or short will interfere with good control. The best length of limb for a prosthesis which will provide you the maximum movement and control with the minimum of discomfort will help determine the level of amputation. As you will learn, the wearing and use of a prosthesis is a real skill, so it is important to include your future use of a prosthesis in the decision. The residual limb (stump) must be appropriately padded to minimize rubbing of bones against the end of the limb and maximize your ability to control the prosthesis. There are many types of prostheses which allow a variety of levels of control and sustained movement. The type you are most likely to need in your daily life will play a role in determining the type of amputation done.

(d) The surgeon will do everything possible to save the knees and elbows because the remaining limb is far more useful and rehabilitation is quicker with these joints functioning.

c. The operation itself:

Because amputations are usually very straight forward, the operation usually takes only a few hours. An amputation is a careful procedure in which a flap is carefully designed (if one is to be used), and the limb is gradually cut away. As blood vessels are exposed, they are either tied off or a special heater "melts" the ends of the vessels. Thus there is almost no actual blood loss. The end(s) of the bone(s) are carefully shaped and padded with muscle, subcutaneous fat and skin to optimize the fit and comfort of your ultimate prosthesis. Then the wound is closed as much as appropriate and wrapped-up. Sometimes, especially when the blood supply to the "flaps" is less than ideal or in the case of pre-existing infection, it is safest to leave the stump "wound" partially or even completely open to avoid complications. In those cases in which this technique is used, the wound may be closed at a second surgery or may be allowed to close on its own "by secondary intention". This is the safest technique to use in certain cases. Even amputation wounds left completely open will close and heal. Remember, mother nature has been healing people for far longer than medical science and in many cases does it better than doctors and nurses.

This guide is not intended to make you an expert in all of the varieties of amputations. Most are very similar and differ only in technical aspects. The figures on the following pages illustrate typical lower extremity amputations and are provided to give you an idea of what the stump and underlying bones will look like. Your amputation may well look similar to one of these, though the appearance and length of your stump may be somewhat different.

Remember that the muscles in your stump once went to the lower part of your leg. When you make some simple leg movement, you may have considerable spasm (short series of cramps which can be painful) in the remaining muscles because they no longer bear the weight or have the attachments they used to have.

d. "Leakage" of the wound:

All large cuts tend to drain fluid. You will be told what the normal leakage looks like and when to call the nurse if it is not right. A tube leading to a collecting bag may be placed into the amputation site to help drain off excess fluids so they don't collect beneath the skin. The tube will probably be removed in the first several days following your surgery.

Figure 1

Below-the-Knee (B.K.) Amputation

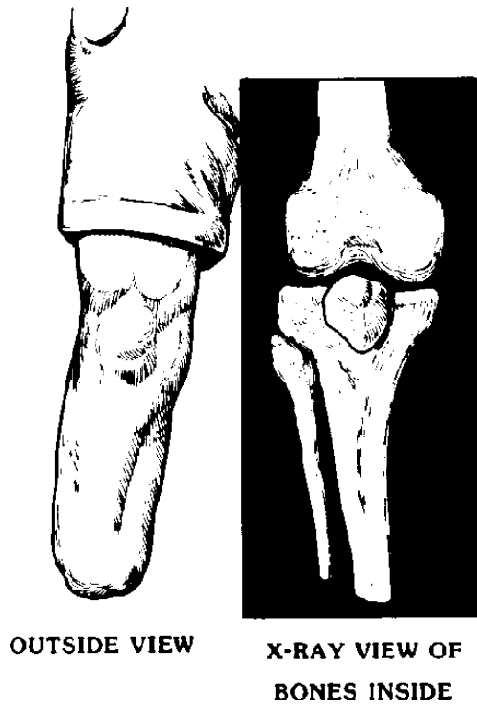
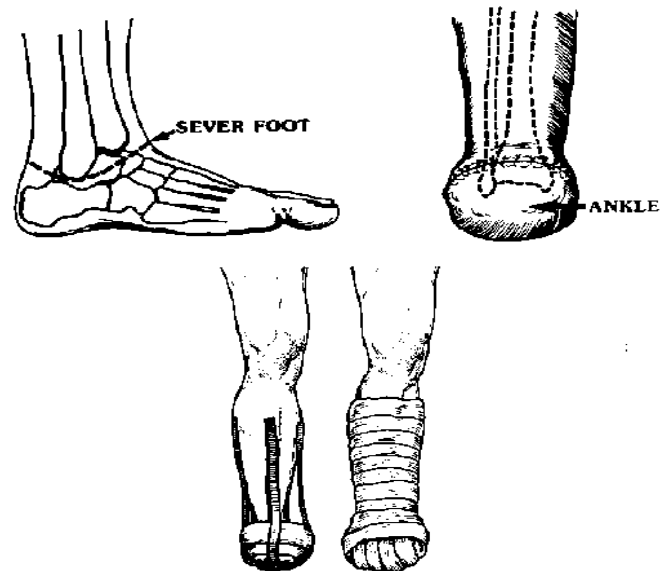


Figure 2

Syme's Amputation at the Ankle

Temporary bandage for the Syme's amputation.



Chapter 3

HEALING AND PAIN IN THE RESIDUAL LIMB

a. Healing

Regardless of the amputation's type or level, healing depends greatly on the disease which led to the amputation. Amputations which usually require relatively little time and trouble to heal are those resulting from mutilating accidents, local tumors, and problems which happened at or before birth. Relatively slowly healing amputations with greater likelihood of complications are those resulting from poor circulation, prolonged chronic illness, or diabetes.

Healing takes longer the older you get. Older patients have relatively more difficulty fighting off infections and the general level of strength and condition is relatively lower for older people than younger. For example, it takes longer to heal from a tooth extraction when you are 35 than when you are 25 years old. Thus, if you are relatively elderly and in poor physical condition due to long standing medical problems and lack of exercise, you can expect a relatively long healing period. A young adult in excellent shape both physically and mentally who was not otherwise seriously injured during the accident which caused the need for an amputation might expect to heal in weeks to months.

b. Pain in the residual limb

As we understand it, the purpose of pain is to act as a warning to protect us and make us aware of disease and damage to our bodies. Pain is also important because it triggers both the brain and body (which really act as one) to mobilize the very complex system of healing which includes the use of tissue proteins, hormones, vitamins, etc. Thus, when you are urged to eat well, it is not just to keep you happy and healthy but also to promote quick healing. Most pain sensors are near the skin's surface but some are in muscles and other tissues. Pain is also a protection for ongoing healing. This is probably the largest cut you have ever had. In spite of it's size, it will heal similarly to small cuts you have had in the past.

When you press on, or irritate a small cut, it hurts. The same thing happens with your stump until it heals. Once the stump heals, the mission of the pain is completed so it should stop until the stump is harmed from either the inside or outside. You can expect the stump pain to gradually decrease after the operation until it eventually goes away. Unfortunately, this is not always the case. For a very few people, it remains moderately severe and for many it comes and goes as internal and external problems occur.

Until they heal, the nerves from the skin and muscles which were either cut or disturbed during the amputation are especially sensitive to chemicals released by bruised or cut tissues. If the stump is bruised significantly, these nerves can become incredibly sensitive to pressure and changes in blood flow within the stump, so considerable pain can be produced by even a minor bump or some changes in position. As healing progresses, the nerves become less sensitive. The stump may remain more sensitive than the rest of the body indefinitely.

Two common problems related to pain and healing in the stump are (a) the formation of neuromas and (b) poor stump pad position. Occasionally, when cut nerve ends heal, the ends grow into a convoluted ball called a neuroma. This can act like a short circuit in an electrical system and send pain messages to the brain which are not actually related to any damaging event in the stump. If the stump is not formed well or is not properly wrapped and shrunken, it will hurt when pressure is put on it. You and your health care team will keep very careful track of problems as you heal so they can be taken care of as needed. It is occasionally necessary to perform repeat surgery on some part of the stump or remove a neuroma, so do not be surprised if you have to make a brief trip to the operating room sometime after your initial healing period.

As you get older, you tend to get cramps at night both in your intact limbs and in the stump as well. These can be successfully treated with a variety of medications including calcium and muscle relaxants depending on the underlying cause.

Cramps or apparently spontaneous severe jerks of the stump can occur at any age. They are frequently related to fatigue and overuse of the residual limb. When they aren't, you should ask your health care provider about the problem. The prosthetic may not be fitting properly or you may need special training or muscle relaxants to ameliorate the problem.

Infections arising from skin irritation on the residual limb or from an infection that has spread from an area elsewhere in the body can cause severe stump pain. Because the stump may not have normal circulation, it can be more difficult for the body to fight off infections near the end of the stump and medications take longer to work or are not as effective as they might otherwise be. Thus, don't allow an irritation to become infected. Take it seriously and take care of it!

If you do not use your residual limb, it will get progressively weaker from lack of exercise and your bones will get softer and easier to damage. This leads to easy bruising as well as pain from the muscles and bones. This can be a very real problem and there is no quick cure for pain resulting from damage to weakened bones. Prevention is the best approach. Keep your limb in good physical shape and you will avoid most of the pain problems and disabilities that come with disuse.

Occasionally the end of the bone in the stump develops tiny spurs which may cause irritation of adjacent muscles and severe pain with movement. They may have to be removed surgically.

We have surveyed over 7,000 amputees. Over half of them report that they are bothered by stump pain at least a few times per year. It is incapacitating for a few but is simply an intermittent, endurable annoyance for most. The pain is frequently affected by the weather and physical exhaustion. Common pain medications and surgery have a mixed record of helping relieve stump pain unless a specific problem can be identified and corrected. The underlying cause of the pain can be exceedingly difficult or impossible to determine so the "trial and error" method of selecting a treatment is sometimes required to find the best remedy. Frequently, nothing helps or the drug side effects are worse than the stump pain. The best thing to do in these cases seems to be to "grin and bear it". Some amputees slide slowly into alcoholism or become drug addicts as they attempt to self-medicate their pain. There is no need for this to happen!!! Your physician can refer you to pain specialists who can decrease the intensity of most cases of stump pain and help you learn to live with the remainder. Another common type of pain related to amputation seems to come from the part of the limb which has been removed. It is called "phantom limb pain" and is discussed in the next chapter.

Chapter 4

SENSATIONS FROM THE PART OF THE LIMB THAT WAS REMOVED **(PHANTOM LIMB SENSATIONS)**

a. Overview

One of the biggest surprises after an amputation can be discovering that sensations still seem to come from the missing limb and that sometimes its movement can apparently be controlled. Just after amputation, the phantom can feel so real that fresh (very recent - new) leg amputees occasionally try to stand up and walk away. Occasionally, the missing limb feels as though it is in a very uncomfortable position. Nearly all amputees report that they can sense the shape of the amputated limb for at least a few months after amputation. This "shadow limb" is called the phantom and the feelings coming from it are called phantom sensations. Many continue to sense it all of their lives. In addition to the sense of shape, virtually all amputees report various feelings such as itching, warmth, twisting, etc. which seem to come from the limb. These feelings may change with time of day, fatigue, weather, and other factors. The great majority of amputees report that these feelings are painful at least occasionally.

b. Phantom sensations

Feelings which appear to come from a limb which is no longer attached can be quite upsetting. It is important to understand that phantom limb sensations occur among virtually all amputees and that phantom limb pain is well recognized by the medical community. Your doctor and other health care providers will not think you're crazy if you tell them about a problem you are having with a portion of a limb that is no longer there. In order to understand how it is possible to feel something that isn't there, it is necessary to understand how the body is "wired" to feel things. Figure Three shows a diagram of how the brain and body are wired together to pick up feelings from your body. The upper rear portion of the brain contains a structure similar to a hard-wired telephone switchboard which is called the sensory (for feeling) homunculus (for "little person"). It is shaped very much like a person and has a place for each nerve coming from your body surface.

Thus, if you tap your right little finger, a signal which starts in the nerve endings in the finger runs through your hand, up your forearm, past your elbow, along your upper arm, into your neck, and eventually winds up at the corresponding right little finger in the homunculus. The homunculus is not part of your conscious brain. It is essentially a switchboard.

We do not think it can learn or change much after early childhood. It has no way of knowing where the signals reaching it actually started from. When you bump your elbow, you very often feel pain in your fingers and hand. This is because the nerve which carries signals from your hands and fingers passes just under your elbow and is shocked when you bump your funny bone nerve. The homunculus does not know the signal actually started in your elbow so it tells the conscious portion of your brain that the feelings came from the fingers and hand. Because it cannot learn, the pain in your hand continues although you consciously know that only the elbow was hit. This pathway is illustrated on the left side of Figure 6. Feelings which seem to come from one part of the body but are actually from another part are called "referred feelings".

Another way the homunculus becomes confused is illustrated by the feelings of cold and pain in the forehead which occur when you eat very cold ice cream. The nerve "wires" from the roof of the mouth run close to those from the forehead. This kind of cross-talk between nerves is similar to what happens when you are on the phone and hear another phone conversation in the background. Signals from one nerve are passed to another. The homunculus has no way of knowing that the transfer has occurred so, even though you know you haven't been eating ice cream through your forehead, the homunculus still reports the forehead as being cold and painful. A third way the homunculus is fooled about the starting place of signals occurs when a nerve is cut during surgery or by an accident. The raw end of the nerve is very sensitive to any kind of stimulus. Chemicals from cut or bruised skin can make it much easier for the nerve end to fire off a signal. Any minor pressure or other stimulus is enough to send a powerful signal to the homunculus.

The homunculus has no way to know that the nerve has been cut and no longer runs from the area it used to serve so it reports the feelings as coming from that area instead of the spot where the nerve was cut. Thus, the stimulus causing the feeling may not be where you feel it. If a limb is amputated, the three ways to confuse the homunculus discussed above still work. The homunculus still has no way of knowing that the limb is missing even though you know perfectly well that it is gone. Anything which causes the nerves which once served the amputated limb to start a signal will cause a sensation which seems to come from the phantom limb. The "lightening bolt" hitting the left middle finger shows that when the end of the finger is stimulated, a signal travels through a series of nerves to a part of the brain (called the homunculus) which has a part for receiving signals from each part of the body. If the nerve serving the finger is hit as it traverses the elbow (instead of the finger being shocked), the signal follows the same path to the same place in the brain. So, the brain still thinks the finger has been hit and "feels" it there.

If the signal had started at the right elbow - in the stump of an amputated limb - the signal would still travel to the right middle finger part of the brain so the body would feel pain in that finger even though it is not there. You can not consciously convince the brain that the finger is not there and the wiring does not change much as the years go by.

c. Phantom pain

Pain which seems to come from one part of the body is frequently caused by problems in another part of the body. A common example is a person with a nerve pinched in the low back who feels pain running down the leg instead of in the low back. The signal starts in the back, but since the nerve is supposed to come from the leg, the homunculus reports it (refers it) as coming from the leg. If that leg was amputated, the pain would still seem to come from the same location on the "phantom" because little corresponding change occurs in the homunculus when the leg is amputated and it cannot learn. This system was illustrated on the right side of Figure Three.

Painful feelings which appear to come from the amputated portion of the limb are called phantom pains. Some typical ones are illustrated in Figure Four. They may be burning, stinging, cramping, shooting, twisting, or other unpleasant sensations. They are always stronger versions of the painless phantom sensations. There is no reason to think that those amputees who report phantom pain are either exaggerating normal phantom sensations or have anything wrong with their minds. We have received over 7,000 responses to questionnaires sent to amputees inquiring about problems with phantom pain. Over 80% of the respondents said that they had enough phantom pain to cause them real problems for at least a week every year. Most have episodes of pain which last anywhere from a few seconds per year to several weeks at a time, with several to many episodes per year. Some people have continuous pain which varies in amount from almost none to excruciating over the course of the year. About half of the amputees who report phantom pain seem to be able to associate changes or onset of their pain with some change in themselves (such as stump irritation, exhaustion, back pain, or stress) or outside themselves (such as changes in humidity).

It is important to note that two amputees who describe their phantom pain as being identical in frequency, severity, and type of feelings may report entirely different events which change the pain. For most amputees, phantom pain is worst just after amputation while the stump is healing. However, it is not likely to go away permanently. A few amputees report that the severity does not decrease after stump healing, but, rather, persists throughout life. Almost none of the respondents to our surveys reported that their phantom pain went away completely with the years after amputation. Thus, you will probably have some phantom pain. It may be enough to trouble you from a few times per year to almost all of the time. The amount of pain is likely to vary from almost negligible most of the time to severe once in a great while. You may be able to predict what causes your phantom pain to become worse and take measure to avoid the worst of it. Many amputees are afraid to talk about their phantom pain with their health care providers for fear of being thought to be crazy. Some reported that their health care providers either told them outright or strongly indicated that anyone who felt pain in a limb no longer present had mental problems and should see a psychiatrist.

Figure 3

How pain can be felt in a part of the body different than where the pain "signal" started.

When your finger is touched (lightning bolt), a signal travels along nerves past your elbow, through your spine to your brain. The signal goes to a part of your brain (the homunculus) corresponding to your finger. You can send a signal to the same part of your brain by bumping your elbow (hammer) because the brain can't tell where it began. This is why your fingers tingle when you bump your "funny bone". The nerves and brain don't change much after an amputation so you still feel your hand when you start a signal in the stump.

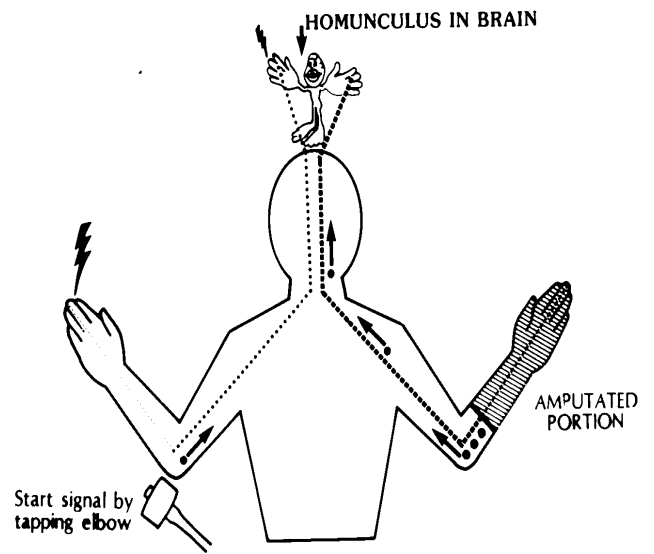
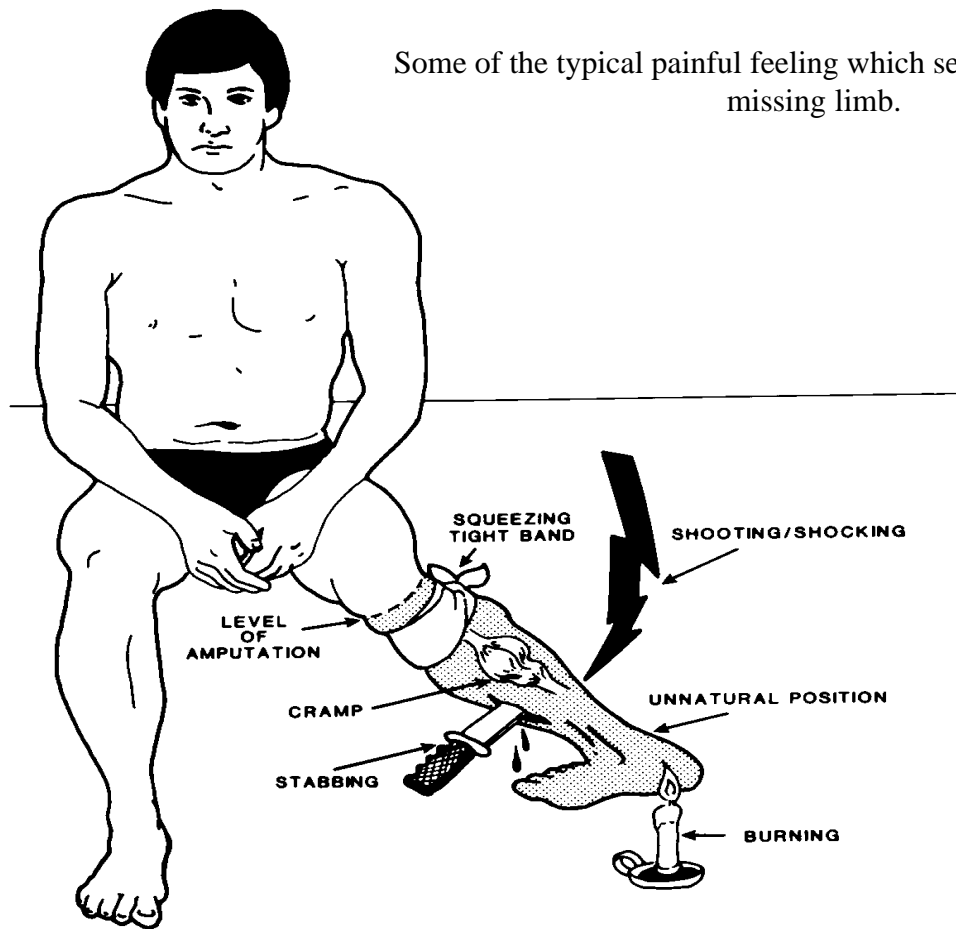


Figure 4

Phantom Limb Pain

Some of the typical painful feeling which seem to come from the missing limb.



There is NO evidence or indication that amputees are any crazier (or more sane) than people who have not had amputations. (See the next chapter for further discussion). Most health care providers have learned that referred pain is a very common problem and that phantom pain is one example of it.

We now know what causes several descriptive types of phantom pain. For example, burning and tingling phantom pain is caused by decreased blood flow in the end of the stump, while cramping - squeezing phantom pain is caused by spasms in the stump. Unfortunately, we do not know what causes shocking - shooting phantom pain yet. Unless the treatment is related to the cause, it doesn't usually work. Most of the commonly used treatments for phantom pain do not have good long term success rates because they are not related to the underlying causes. In addition to asking the 7,000 amputees discussed above about their treatment experiences, we have surveyed many health care providers and have carefully reviewed the literature for rates of success of phantom pain treatments upon one year follow-up. All three sources give the same answer. Many treatments offer temporary help but (with exception of those discussed below) even the best usually last only a few months to a year. A few of the thousands of respondents were helped significantly for an extended period of time but each was helped by a different treatment. Surgery, solely for treatment of phantom pain, was not successful in any case. Do not become a victim by permitting an unknowledgeable physician to operate on you! Burning - tingling phantom pain is usually successfully treated by increasing blood flow to the residual limb. Cramping - squeezing phantom pain is usually successfully treated by decreasing muscle tension and spasms in the residual limb. Specific ways of accomplishing these changes include training you to control your own blood flow or muscle tension, use of muscle relaxing drugs, and electrical stimulation.

There is a substantial incidence of alcoholism among amputees as a direct cause of attempts at covert self-treatment of phantom pain. Drinking alcohol does appear to temporarily reduce awareness of phantom pain as it does for other types of pain. However, it is no more effective than other drugs which are probably safer and are definitely easier to control.

Chapter 5

PSYCHOLOGICAL REACTIONS TO LOSS OF A LIMB

There can be no denying that the loss of a limb is a major event in anyone's life. The limb has been with you throughout your life and you need it for normal functioning. As the fact of an amputation became clear, you probably thought about just what the limb does for you and your way of living. You know that you are going to have to learn to get along without it and are probably not sure just how well you will do. You are probably not sure about how much you will have to change your lifestyle (job, recreation, etc.) or what the loss of the limb will mean to your relationships with people who are important to you. You may be worried about the pain from the amputation itself at the time of surgery and after recovery. All of these worries are natural and produce normal, predictable reactions.

Everyone reacts in their own way. Some are bothered by one aspect of an amputation more than others. Some people don't worry much at all. Some are terrified by the prospect of losing a limb or of having to face the future without it. You have your own unique blend of worries and uncertainties and your own way of handling problems. The important thing is that everyone reacts! Some people feel that they must hide their feelings and are better at putting on a "happy face" than others, but inside, everyone reacts to their worries and fears.

It is very important for you to be aware that you are likely to experience some of the very normal reactions to the loss of a limb that other amputees have reported. If you think you are going "crazy", the stress and anxiety you can inhibit or prevent a recovery.

Some of the common reactions to amputation are discussed below. They are certainly not the only normal ones and you may not have all or even some of them. For your own health, if you feel you may be reacting more than you should or that your reaction is abnormal, ASK!!! Your health care team has worked with lots of amputees while you have only your own experience to guide you. They are used to handling emotionally related questions and can guide you to further sources of help in the cases where it is required.

When unexpectedly told that a limb is going to have to be amputated or waking up after an accident without a limb, a common first reaction is shock. People frequently either totally deny the need for the amputation or have such feelings as

"this can't happen to me" or "I won't let you do this to me." You may feel quite calm and believe that you are taking the entire thing very well. In time, many people start experiencing anger. It may be directed at themselves for getting into a state which requires an amputation or may be directed at others, including God and loved ones. It is normal to feel anguish and feel the need to cry out "why me?" This is a very normal "grief" reaction and the physical and emotional steps in the process are well known. They will be recognized by your health care team but may not be obvious to you. The reaction is similar to what a spouse goes through when the husband or wife dies. If you do not believe that the process is powerful, consider all of the spouses who get very sick or die just after the death of their loved one.

You need to recognize the anger, understand that it comes from frustration and from losing control of your life for a while, and try to let it out of your system. It's too late now to go back and change anything, so you may as well get on with your life. If you don't let yourself get over the anger, you can use up so much energy that you will have far less available for recovery.

Before the amputation, there is usually a "bargaining" stage where the patient tries to get God, the surgeon, or both to stop the amputation or remove the need for it. For most amputees, the physical need for the amputation is well understood and unhappily accepted as being vital. This generally does not stop the emotional reaction which leads to the bargaining process. Patients and their relatives may tell themselves that the problem is not as bad as it seems in spite of overwhelming, obvious evidence to the contrary. After "bargaining" does not work, a deep sadness and depression may set in. However, this normal emotional reaction makes everything look really bleak. Without realizing you are doing it, you may exaggerate the problems the amputation is likely to cause you in your daily life and emotional relationships. Depression drains your energy. You need all the energy you can get to recover physically and get on with your life. Your health care team recognizes the signs of depression and can help you get over it if necessary. The fact is that most people go through these stages of feelings but manage to get through them on their own. Almost everyone eventually snaps out of the sadness and reaches the acceptance stage of grief in which they face the facts, get the diseased limb out of the way, and get on with their lives.

All of the worries, concerns, uncertainties, and reactions discussed above, as well as the normal physical discomfort from an amputation, cause stress and anxiety. Everyone will suffer a different amount of stress and will express it in their own way. People in this situation are frequently short tempered and very grouchy. You should be aware that prolonged anxiety and stress cause very well known physical and emotional reactions. When you are under stress and are anxious, your body and mind try to get ready to defend themselves from an upcoming attack as best as possible. The body spends less energy digesting food and on curing infection because it is directing the energy so the muscles can fight off an attack. Blood pressure tends to go up so extra blood can get to the muscles. The muscles themselves tense up more than normal in preparation for fighting or running away. This costs you vital energy which you need for recovery. You may get headaches and body aches from the sustained muscle tension. You cannot fight off infections as well as you should, or digest food as easily as you could. You can expect to feel some anxiety. If you feel that you are more anxious than you should be, talk with your health care team about it. If there is a problem, they will help you deal with it.

At some point during your rehabilitation, you may get "really down", feel "blue", or depressed by the amputation and the changes it may mean to your life. It is helpful to remember that depression is a normal reaction if it doesn't grow so big it overwhelms you or prevents you from seeing that life can still go on and has a bright side. It will help a lot for you to talk with your rehabilitation specialists and other amputees so you develop a realistic idea of just what your limitations are likely to be. The actual number of activities important to you which you will not be able to do or will have to substantially modify may be far less than you think. It may be hard to believe, but things usually do not look quite so bad after some time has passed, so give yourself a chance to adjust. The more active you are in rehabilitation efforts and in thinking about and planning for the many alternatives available to you in the future, the faster the "blues" will disappear.

How we feel about ourselves, our "self-concept" or "self-image" continues to develop and change throughout our lives. It is certainly obvious that a serious event, such as an amputation, can disrupt and make some changes in self-concept. These changes can be either positive or negative depending on how the person deals with the loss. The self-concept which emerges after an amputation may include a greater feeling of strength developed in the effort to overcome the losses which have occurred. On the other hand, some individuals may turn to a dependent lifestyle using amputation as an excuse.

Another aspect of your "self-image" is what the image of your body means to you emotionally. Very "macho" people as well as those who are highly concerned with the attractiveness of their bodies to the opposite sex tend to have more problems adjusting if they believe that their image will suffer in the "eyes" of the people they feel a need to impress. Many people are afraid that they will not be as well respected by their peers and business associates because they are "crippled".

In fact, a large proportion of relatively young amputees make such good recoveries you can't tell that they have a limb missing. Many are as active in sports as they were before the amputation. However, the reality is that many people will react to you differently! Almost everyone does adjust to the new body image. For some the adjustment is slower and more painful than for others. You and those close to you will have to have the patience, strength, and understanding to adjust to your new body. An important part of developing a positive self-concept after amputation rests on your ability to adjust your value system. In other words, try to avoid comparing your current situation with what "used to be". You will probably make a mistake in your comparison. Following a lower extremity amputation, it requires a good deal more skill to ascend a set of stairs than it did to run a mile with two normal legs. Recognize the effort you put into your rehabilitation and take pride in it. The most successfully adjusted people seem to be those who can view their changed capabilities in proper perspective with more positive events in their lives and have a good sense of humor and attitude about it.

The effects of the previously discussed factors are different for each amputee. Each individual who undergoes an amputation will deal with it in a unique, personal manner. The amount of actual disability resulting from the loss of a limb depends upon how well the injured person handles the loss physically and emotionally. For example, research indicates there is no direct relationship between the extent of physical loss and the individual's emotional difficulties: the difficulties are more dependent upon the personality (including coping skills) of the individual than the type of amputation. One person with a "limited" physical loss may have greater adjustment problems than someone with a "major" loss. For help in reaching an accommodation with your feelings, you may want to read Kushner's book titled "When Bad Things Happen to Good People". The philosophy behind this book is highly controversial but many people feel that it gives you a basis for further thinking about your disability in relation to God and fate in general.

In summary, the way you handle your loss emotionally may have as much or more impact in determining how disabled you are in the future than the physical problem itself.

Chapter 6

PHYSICAL REHABILITATION

a. Overview

Rehabilitation after an amputation is a long process. If a leg or foot has been amputated (lower extremity amputee), most of your training in stump care and walking will be done by Physiotherapists / Physical Therapists (called P.T.s). These professionals have four or more years of training in helping people recover from a wide variety of debilitating problems. They are highly skilled in helping you learn to take proper care of your stump and in learning to walk with an artificial leg. You will be taught to take care of and wrap your residual limb (stump). You will be fitted with the artificial limb (prosthesis) most likely to help you develop a good way of walking (gait), carry out your daily activities, return to work, and participate in sports. If an arm or hand has been amputated (upper extremity amputee), you will probably work with an Occupational Therapist (called an O.T.). These professionals have four or more years of training in helping people overcome handicaps and disabilities. They are experts in such areas as teaching you to carry out all kinds of tasks with one hand or in modifying activities to make the best use of your prosthesis.

You will probably get to go home from the hospital as soon as you can get around by yourself safely - with or without an artificial limb. You will have to plan to return to the hospital or a local rehabilitation center very frequently for continued training and treatment.

One vital part of rehabilitation is extra care for the remaining limbs. An intact lower limb tends to take more of your weight at first. A remaining upper limb tends to take over much of the work done of an amputated arm or hand. The extra stress on these limbs may be more than they can easily take so you have to give them extra care and be sure not to over use them.

b. Extent of recovery

The extent of your recovery depends largely on your physical condition prior to amputation. If you were in good physical shape before the amputation, you will probably recover within a few months and be able to perform most of the

activities you did before your amputation. Many amputees who are in good physical condition play basketball, hike, hunt, swim, WORK, and do most of the other activities their peers do.

Extent and speed of recovery depends mostly on these factors:

(1) Your age and the length of the healing process. People heal more slowly as they get older. The more complex the amputation and its wound, the slower healing is likely to be.

(2) The extent of other medical problems associated with the amputation such as burns or diseases causing general debilitation such as diabetes or not enough blood supply to the limb (vascular insufficiency) all of which tend to lengthen the recovery process.

(3) Learning to use your prosthesis is hard work so your overall physical condition and health will play an important role in how quickly you can progress.

(4) How closely you follow the instructions of your physiotherapist. This is especially true of how much you do. It is easier to prevent problems than to cure them so don't overdo!

(5) How much you want to recover and learn to use your prosthesis. There is simply no substitute for determination. If you do not want to work at learning these difficult tasks, you will not get very far.

(6) There are many psychological factors which can speed up or slow down your recovery. Support from family and friends, various social and economic factors can play an important role in either speeding up or virtually stopping your recovery.

c. Post surgical dressings

Just after surgery any or all of the following basic types of dressings for your residual limb may be used.

(1) Rigid dressing: Just after surgery many patients are fitted with a rigid dressing (cast) to assure control of swelling and provide comfort. The end of the cast is made to take a simple training prosthesis usually called a "pylon" so training in standing and walking can be started immediately. A typical pylon is shown in Figure Five. This cast may have to be changed after several days or weekly because it becomes loose from the shrinkage of your residual limb. It is held on (suspended) by straps going to a waist or shoulder belt to hold it in place. These casts are normally designed to take only 1/4 of the body's weight or 30 to 35 pounds. Too much weight being put on the cast may result in a delay in healing or even cause the wound to open.

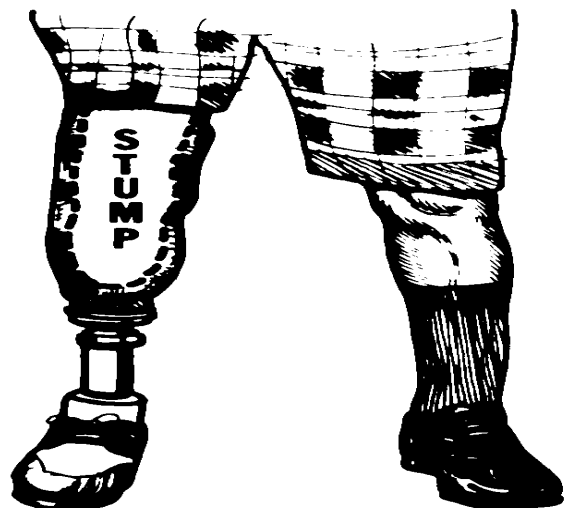
(2) Ace wrap: These elastic bandages are used to prevent swelling and encourage shrinkage of the residual limb as discussed above. Bandaging techniques will be demonstrated and must be followed very carefully. Wrapping is started as soon as possible even before complete healing.

(3) JOBST compression pump: These air filled sleeves (similar to blood pressure cuffs) place constant, equal pressure on all sides of the residual limb to shrink it rapidly and to shape it appropriately.

(4) Stump shrinkers: These are elastic stockings used before your final prosthesis is made and adjusted. When you are not wearing your prosthesis, you will wear a "stump shrinker" or tensor bandage if there is a possibility that your residual limb will swell. They are frequently worn at night as well as during the day. Initial shrinkage and shaping take about six weeks to three months depending on your response and condition.

Figure 5

Temporary artificial leg for below-the-knee amputees



d. Residual limb (stump) care

Residual limb care is a vital function which must be done correctly for the rest of your life. Just after amputation, the stump must be wrapped to help it shrink to its optimal size and shape as well as to avoid painful and dangerous swelling. You can not be fitted properly with a prosthesis unless the stump has been correctly taken care of and swelling is under control. The general objective of stump care is to insure that your stump can be easily fitted with a prosthesis and you will have the physical capacity to operate it.

In order to be fitted for and use a prosthesis successfully, you will have to shape your stump into a cylinder with the help of proper wrapping techniques, keep it free from swelling, infections, sores, wounds, and irritations.

(1) Skin and joint problems: Chronic skin disorders and stump contractures (where the muscles and tendons shorten up due to disuse so that a joint is bent and cannot be straightened) can be long, painful processes to overcome. So you must do all that you can to keep this from happening. You can cause the muscles and tendons to shrink up and shorten so much that you cannot straighten your limb or use the joint by developing bad habits such as sitting with a BK (below the knee) stump bent. Allowing the stump to hang down causes the same problem. You will be given detailed instructions on how to avoid problems. You will also be given exercises to help avoid problems and to strengthen your muscles. If you follow them carefully, you should avoid most complications. The most important positions to avoid are illustrated in Figure Six.

(2) Residual Limb Hygiene: While wearing the prosthesis, fresh air is not able to get to the end of the stump and moisture cannot evaporate. This is particularly true if the prosthesis is one of the suction-socket types discussed later. The lack of air circulation may promote skin infections and abrasions which may keep you from wearing the prosthesis. Daily use of a prosthesis puts your skin under a lot of stress which can cause the skin to break down or become irritated very quickly if you are not careful.

You will be instructed on how to care for the prosthesis, the special stump socks worn with most prostheses and, especially, for your skin. Each evening the limb and the prosthesis must be washed with warm water, dried with a soft towel, and powder or corn starch must be applied. Stump shrinkers and socks must be changed and washed daily. These items are delicate and must be hand washed, dried on a flat surface (rather than hung on a clothes line or dried in a dryer). The key is to keep you and your equipment clean and dry. It only takes a few days to cause skin damage which can take months to heal.

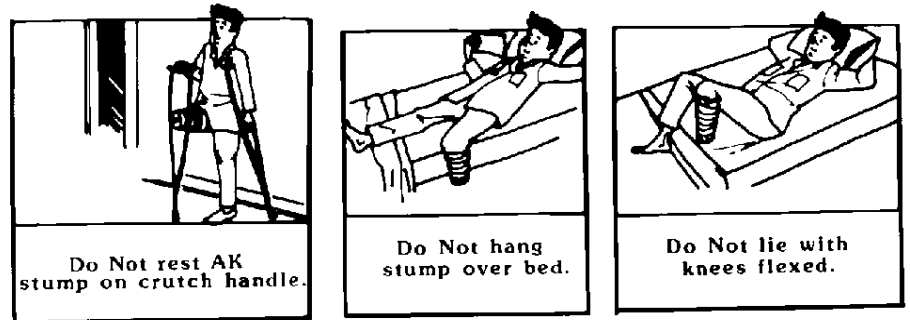
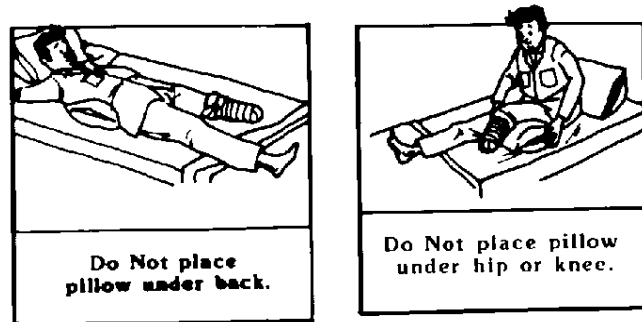


Figure 6

Positions new amputees should avoid

Figure adapted from one appearing in "Limb Prosthetics", 4th edition, 1979, published by Hanger, Inc. of St. Louis, MO.



(3) Wrapping and bandaging: When the residual limb has started to heal, bandaging is important to prevent swelling (edema) and assure that the limb is properly shaped. Only after the limb has become stable in size will you be able to be measured for your final prosthesis. Both you and, if possible, a close family member will be instructed in the proper application and correct pressure of the various bandages. The initial swelling (edema) decreases rapidly but edema usually lasts from six months to a year so expect lots of changes in your limb and prosthetic socket.

When the residual limb has healed and is relatively stable in size and shape, you will be measured for a final prosthesis. As soon as your stump is healed, you will be instructed in stump wrapping. This is necessary to prevent swelling and properly shape the stump. The stump is shaped by wrapping an elastic bandage around the stump using just the correct amount of tension and pressure. The limb is usually rewrapped every two to three hours in order to allow the stump to be exposed to fresh air and to adjust the bandage's tension.

e. Pre-prosthetic exercise program:

The object of an exercise program is to insure that you have the best physical ability you are capable of in order to operate the prosthesis safely and to walk efficiently.

If you do not use a part of any limb for a month or so, it may change so much it may never be useful again. The muscles literally shrink to almost nothing while the tissues which connect the muscles to the bones (ligaments and tendons) will shrink to match the shortest length they can be. Thus, if you keep your knee bent for a month or so, the tissues will shrink up (called a contracture) and may never be able to stretch out again. You will have to learn how to avoid these kinds of problems and to strengthen your residual limb so that it can take on the task of using the prosthesis when you are ready.

Walking with a crutch will probably be your first "functional" activity. You may have to start walking between two parallel bars until your balance has improved enough for you to safely use crutches. Muscle strength and endurance are important. The exercise program will be developed especially for you depending on your current condition and problems as well as your needs. Resistive exercises, pulley and mat exercises, push-ups, sit-ups, balancing, hopping independently on the unaffected limb, and crutch exercises are important to increase your confidence, strength, endurance, and especially, safe control of the prosthesis.

f. Prosthetic training

(1) The initial "training" artificial limb: The artificial limb you will use to walk or assist you to grasp items is called a prosthesis. Soon after amputation most people are fitted with a training or trial prosthesis. This is a very simple device to use so you can walk normally or carry out many of the functions of your hand. A typical pylon (training prosthesis) was shown in Figure Five. As soon as the residual limb is stable (measurements are unchanged for about two or three weeks), an expert in making and fitting artificial limbs (called a "prosthetist") will measure you and build a prosthesis to your exact needs and shape. Modern prostheses may be made from a variety of materials or combinations of materials. The best choice of materials for your prosthesis is determined by many factors. For someone who wants to engage in vigorous sports, material strength is an important consideration. For a frail individual, the weight of materials might be a greater concern. Your prosthetist can help you decide on the materials most suitable for the construction of your prosthesis. The process begins by creating a plaster mold of your residual limb; then a plastic socket for the limb is created from the mold. This socket is then fastened temporarily to an adjustable temporary leg for beginning of training in walking. Adjustments may have to be made occasionally before the leg is finished.

Please note that you can not bear weight on the end of your residual limb! If you did, the bone at the bottom of the stump would crush the skin flap and destroy it. Your foot is probably eight to ten inches long by three or so wide. The bone at the bottom of the stump is probably less than an inch by an inch. The weight is simply too concentrated for the skin to be able to take it.

(2) Steps and timing: It takes time to learn to use any kind of a prosthesis. You must be patient and learn each step in the process. Skimping on time and rushing now will slow down your eventual recovery and cause you considerably more pain than caused by the training itself. You can expect training to take anywhere from two weeks to two months if you are in good physical condition. It will be proportionately longer the further your physical condition is from good.

(a) The objectives of prosthetic training and care are to insure that you achieve the skills needed for using your prosthesis in daily activities, that you develop an efficient gait (way of walking), and that the prosthesis provides the best possible

function, comfort, and appearance.

(b) You will have to learn to care for your prosthetic device properly.

(c) You need to develop the balance, coordination, and motor skills to perform activities of daily living with your prosthesis.

(d) You have to learn how to put on the prosthesis correctly. You will be taught to develop correct habits in putting on and using the prosthesis so that it will always be second nature for you to do it right.

(e) You will learn how to put on and use special socks that go on over the end of your residual limb (stump socks). Some people have to add stump socks during the day in order to maintain total contact with the prosthesis. As your residual limb changes over time, stump socks may have to be added to maintain correct contact with the socket.

(f) Your body's weight is borne on different parts of the prosthesis depending on the type of amputation. In the below-the-knee prosthesis the weight is borne on the large tendon below the knee-cap and the flares of the shin bone. In an above knee prosthesis, weight is distributed evenly over the skin surface area and to a lesser extent on the buttock muscle.

(g). Artificial legs (lower extremity prostheses)

A wide variety of artificial limbs are available. Which one is best for you depends on many factors including your overall health and physical condition, the condition of your stump, what type of activities you want to perform while using the limb, the type and level of amputation, and most importantly, which works best for you! For example, an older person would need a safety knee and a much lighter prosthesis than a very active, younger person. Your stump and your prosthetic needs continue to change throughout your life so you may occasionally have to make corresponding changes in your prosthesis. You may occasionally have to change sockets as your residual limb shrinks or as the socket wears out.

After the optimal set of parts comprising the prosthesis have been selected for your needs at your particular stage in recovery, your prosthesis has to be aligned especially for you. This means, that it must be adjusted so it works as much like a real limb as possible. This takes a lot of tinkering and adjustment over a period of weeks or even months. Don't expect it to be perfect at the first attempt. Work with the prosthetist so you get your prosthesis working as well as possible.

Your artificial limb will not move like your leg did prior to amputation. This is especially evident for above-the-knee amputees because the lower limb swings like a pendulum. It develops momentum of its own which must be controlled. You need to learn to do this. Several newer types of prosthesis have computer controlled motions. They work by having motion sensors on your leg and back which provide information about your gait to the computer so it can adjust motion in the prosthesis. These work well but are new and expensive.

(1) General types of prostheses:

(a) Endoskeletal with foam cover: The basic weight is through a socket onto a steel or strong plastic rod which is covered with soft foam for cosmetic purposes.

(b) Exoskeletal with hard plastic laminated socket: This looks like a plastic arm or leg. Many are so realistic that even close observation cannot distinguish between artificial and real in either looks or function. Color can be arranged to suit the individual. There are a variety of ways to attach the prosthesis to your residual limb. Which prosthesis is used depends largely on the type and level of amputation, the health of the residual limb, and the use to which you will put the prosthesis. For example, a prosthesis intended for tramping in heavy woods is different from one used around the house or office.

(2) Attachment: Artificial limbs have to be attached in some way so they will not fall off or twist while in use and so they will provide enough stability for you to carry out the tasks at hand in safety and comfort. The common types of lower extremity prostheses and methods of attachments are detailed below. Figures Seven and Eight show typical artificial limbs for BK (below the knee) amputees. They are held on by various types of straps and wedges. Figure Nine shows a typical leg for a Syme's amputation which is held in place by closing a window to complete a circle around the residual limb. Figure Ten shows prostheses for above the knee (AK) amputees. They are held on by a combination of straps. Figure Eleven illustrates a very different method of holding on an artificial leg. This is the "suction" socket which is held in place by contact between the stump and the prosthesis. This "air tight" seal holds the limb on the same way a suction cup dart is held to a wall. This type of socket can only be used after the residual limb has been stable for a year or so. No socks are worn with this type of limb so considerable adjustment is required.

As mentioned above, the socket is made to your specifications from a plaster mold. It is modified to avoid excessive contact with your particular tender areas. Computer aided fitting of sockets is now coming into use. This has the advantages of easier modification to your needs and remembering your exact specifications so molds of your leg do not have to be kept for manufacture of future sockets.

(a) Types of sockets (which your stump fits into):

(i) Sockets for above-the-knee amputees:

Suction socket: Strapless model discussed earlier which is held on with a vacuum.

Semi-suction: Similar to (i) above but a little looser.

QTB: Weight is borne on the pelvis seat.

(ii) Sockets for below-the-knee amputees:

Traditional total-contact above-the-knee: prosthesis discussed earlier (either solid or soft versions).

PTB - weight borne on the knee cap's tendon.

PTS - supracondylar suspension for below-the-knee amputations, has an above the knee wedge.

(iii) hip disarticulation - for those with no actual residual limb because the limb was removed at the hip joint.

(iv) hemipelvectomy - when the entire limb and half of the hip bone are removed.

(b) Types of suspensions (specific ways of attaching the limb to you):

(i) Below-the-knee:

PTS supracondylar prosthesis suspended by supracondylar flares

Wedge suspension

PTB - traditional plastic laminated hard socket worn with soft petite liner, kick strap, and pelvic band suspension.

Auxiliary straps and bands such as thigh lacers.

Supracondylar straps

Thigh lacers

(ii) Above-the-knee: Weight is borne on the Ischial tuberosity and suspended with Silesian bands or pelvic bands with steel hinges.

Figure 7

Artificial leg and foot with strap support for below-the-knee amputees

This leg has a strap which holds it just above the knee. The strap provides both stability and strong thigh support.

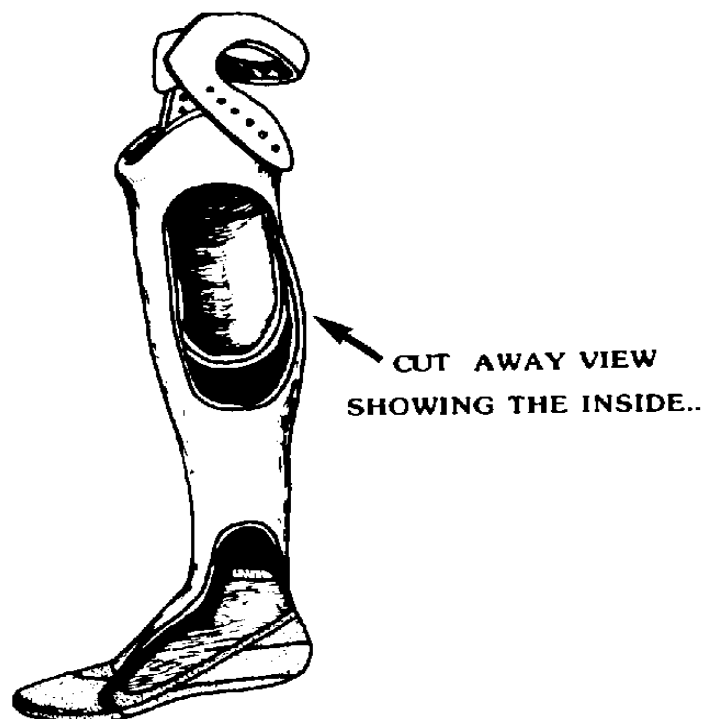


Figure 8

Artificial leg and foot for below-the-knee amputees with a "thigh lacer" for support and stability

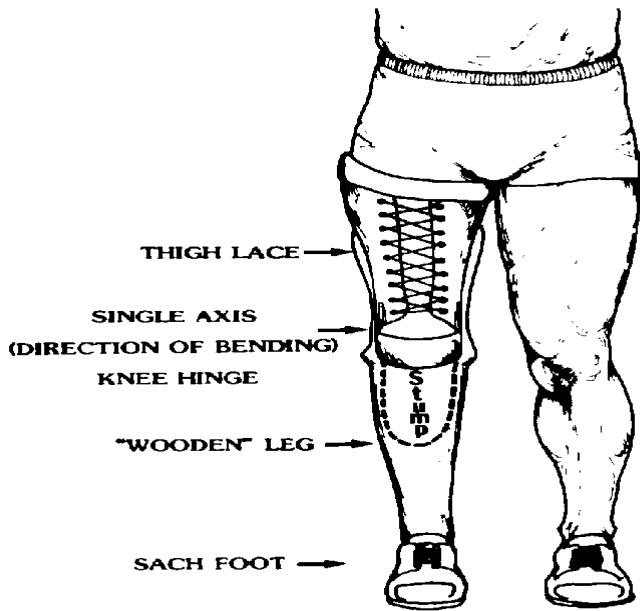


Figure 9

Artificial foot for Syme's "at the ankle" amputees

This leg has a hinged "window" which allows room for the ankle and heel to get inside the prosthesis. Once the residual limb (stump) is inside, the window is closed for support and stability during walking.

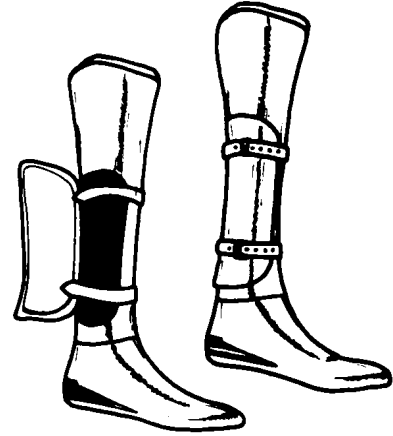


Figure 10

Strap methods for attaching an artificial limb for above-the-knee amputees

For some amputees, a shoulder and chest strap is needed to keep the leg in place. Others do well with just a hip belt.

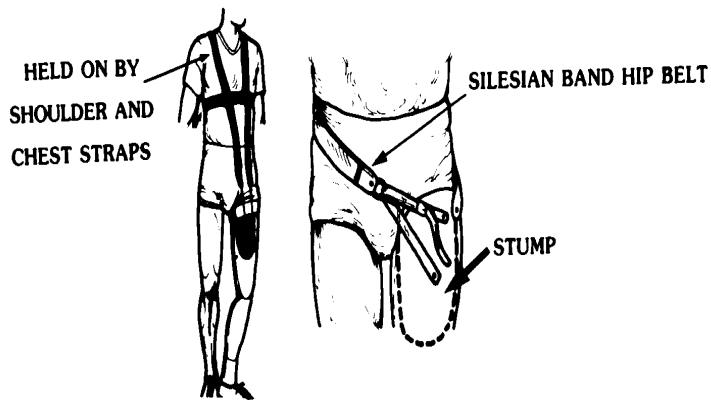
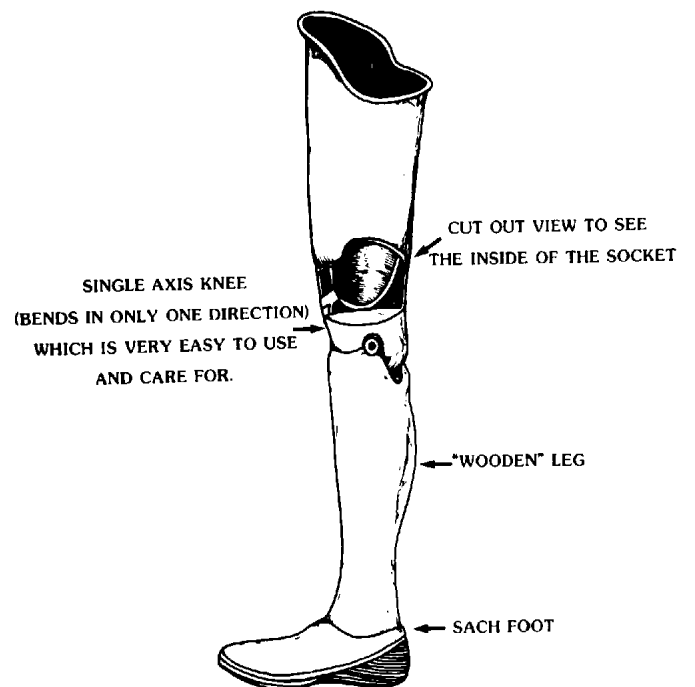


Figure 11

Suction socket method for attaching an artificial limb for above-the-knee amputees

This "suction socket" is held in place by the suction created between the residual limb (stump) and the prosthesis rather than by belts or straps.



(c) Percutaneously (through the skin) implanted prosthetic holders: The idea of these devices is that weight was meant to be borne by your bones so a strong metal rod is implanted into the end of the bone that is at the bottom of your stump and clamped in place. It has several "arms" that go from the end of the rod protruding from the bone out through your skin to a jig that a regular artificial limb can be attached to. The system has the great advantage of avoiding all of the problems with sockets. While they have been tried off and on since World War II, they are currently only experimental devices because of the high rate of infections getting into the bones along the rod "arms" that go through the skin. These infections are difficult or impossible to stop and can be deadly. Our laboratory and others are working on ways to solve this problem but the studies have not been completed yet. Thus, it is unlikely that you will be offered such an attachment system at this time.

(3) Knees: The knees shown in the following illustrations are all "single axis". They can only bend one way - forward and back - rather than rotating in and out the way human knees do. This is a simpler system to learn to use but does make walking on uneven surfaces more difficult. There are many types of artificial knees. They range from those which take a lot of energy to use but give a great deal of stability (such as the hydraulic knee) to those which take little energy to use but are not as stable (such as the single axis knee). You and your health care team will have to explore the alternatives as your rehabilitation progresses. You may go through several types before finding the best one for your own needs. Typical types of knees include:

(a) Spring extension - assist: No stance control, lighter weight for older or weak people with little stamina.

(b) Hydraulic unit: Swing phase control to the heel rise. Accommodates differences in high speed to produce more normal gait.

(c) Constant Friction: No moving parts and much more control demanded of the patient. Stance phase control only with constant friction. Stays locked until heels rise. Doesn't buckle. Better for older people.

(4) Feet: If you think about the movements your foot and ankle have to make while you are walking - especially if the surface is sloped or uneven - you will realize that the foot must be flexible to accept the changes in angle of the leg as you move through a step, must be able to adapt to a variety of uneven surfaces, and must provide support for the entire leg. Artificial feet are being improved all of the time. Figures Twelve and Thirteen illustrate the basic principles of these feet. The Veterans Administration (VA) has recently developed the "Seattle" foot which provides such natural support and movement, it is almost as good as the real one.

Different prosthetic feet are available. Each can take on basic shoe styles. A variety of special shoe styles such as elevated heels up to two and a half inches in height also are available. It is far easier and safer to walk in a relatively flat shoe. Typical types of feet are illustrated in Figures Twelve and Thirteen. They include:

(a) SACH - solid ankle cushioned heel - an all wood foot shaped like a human foot with a cushioned heel, bumpers, toe-break, and single axis ankle joint. This is a very durable foot.

(b) SAFE - stationary ankle flexible endoskeletal - more flexibility for walking on uneven ground. Needs occasional maintenance.

(c) Four-way - Inversion/eversion as well as flexion. Moves almost like a human foot. However, the more moving parts, the more up-keep, wear and cost.

h. Learning to move using an artificial leg:

Learning to walk again is a slow process which requires considerable time and patience. Problems vary with each patient depending on age, general health, and extent of amputation. Some patients can learn to walk with a few lessons while others take between several weeks and months and continue to improve throughout the first year. You do not have to be hospitalized during this period and can usually be treated as an outpatient.

Figure 12

Details of a "SACH" foot

("SACH" is an acronym composed of:

S = Solid; A = Ankle; C = Cushioned; and H = Heal)

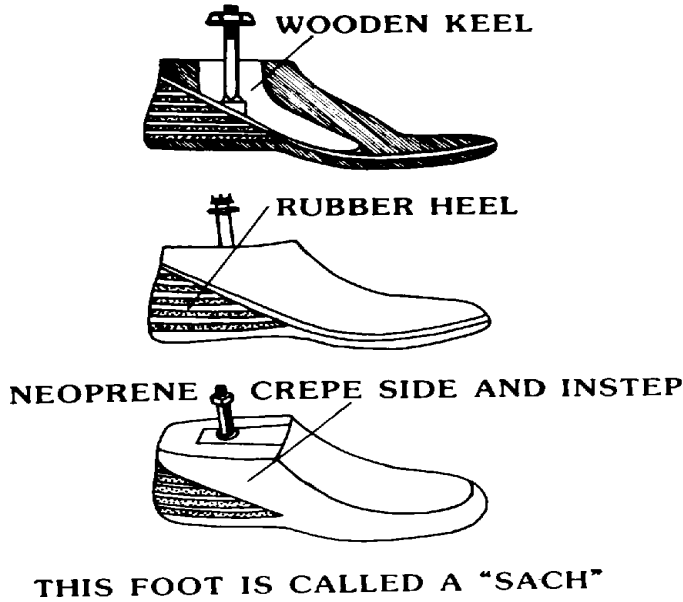
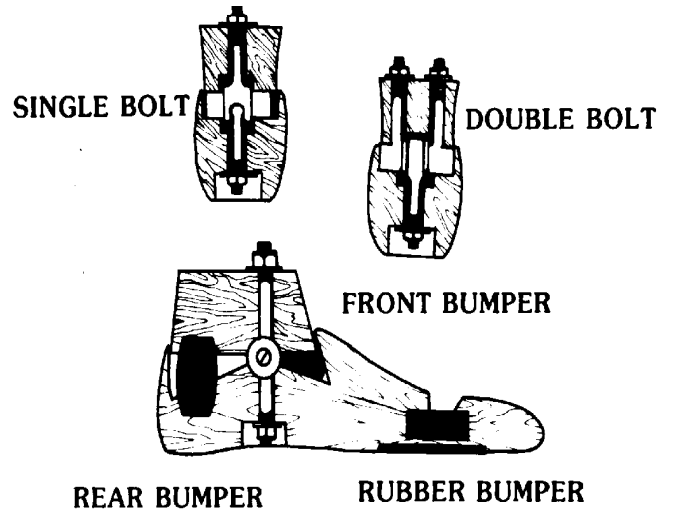


Figure 13

How an artificial foot replicates the motion of a real foot



Below the knee (BK) amputees become better ambulators than others because the knee joint has been preserved. It requires approximately three to four times more energy for an above the knee amputee to walk than it does for a person with normal legs.

Your training for walking with a prosthesis will probably start on the "parallel bars". This is a pair of adjustable rails set slightly more than shoulder width apart at about hip height. Most of your weight is supported by your arms while you learn to control and put weight on your prosthesis. Walking is only one of the movements you must master. In order to be independent, you will have to learn to rise from a chair, to shift your weight and balance, to go up and down stairs, ramps, and hills, and, of vital importance, how to fall safely and then get up again.

i. Use of artificial hands and arms: Upper extremity prosthetic care and training:

You will probably work with an Occupational Therapist (OT) to learn about prosthetic hygiene, how to put on and remove your prosthesis, parts of the prosthesis, routine maintenance, and use in activities of daily living including self-care, work, and leisure. You will learn how to clean the prosthesis, how to adjust the stump socks which go between your residual limb and the prosthesis, and how often to clean your residual limb. You will practice putting on and taking off the prosthesis with and without help (when possible). The type of prosthesis and your abilities will determine whether it is possible to do it alone.

Your ability to adjust to wearing the prosthesis for extended periods of time (called "tolerance") involves your attitude toward the prosthesis as well as your body's ability to bear the strain. You will probably begin by wearing it for half an hour after which your stump will be inspected for signs of irritation. If none are noted, it will be put on again and you will wear it for another half hour. This may be repeated until you can wear it for two hours without irritation. If irritation does occur, the prosthesis must not be reapplied until the redness clears up. Do not be surprised if you have several one or two-day pauses during your training. If you allow an irritation to get bad by ignoring it and keeping a "stiff upper lip" you may cause severe skin and muscle damage which can take weeks to months to heal.

Training begins with learning to control the prosthesis's movements and operations. The basic movements are frequently learned in the first session. As you develop skill in controlling your prosthesis, you become ready to begin learning to use the prosthesis for the activity you want to carry out. For example, to grasp a jar, hook "fingers" must be perpendicular to the table or vertical. Prosthesis awareness and skills are readily learned by using the prosthesis in activities which require two hands such as cutting meat and tying shoes. Necessary acts which have to be carried out frequently for a comfortable, normal life are called "activities of daily living". The particular activities chosen depend on your needs and interests. You will have to learn to recognize and deal with the limitations of your prosthesis. If you do not take the time to learn to work with the device and adapt to its limitations, you may decide not to use one at all which would limit the range of activities you can carry out. This could unnecessarily make you a cripple. The type of prosthesis chosen and the training you get depend not only on the type of amputation and your physical abilities but also on the types of activities you need to carry out. A prosthesis worn just for looks (cosmetic appearance) is very different from one used to put parts together in a factory. Figure Fourteen shows a typical prosthetic hand. Figure Fifteen illustrates how a typical below elbow (BE) artificial hand and arm is held on and controlled.

Some prostheses are partially powered by batteries. They are controlled by tensing various muscles in your residual limb and shoulder so they are called "myoelectric prostheses". They are more complex and expensive than most and have problems with reliability, performance of many tasks, weight availability of parts, and repair. Some of the very new prosthetics are computer controlled. The computer helps regulate the amount and type of motion the arm makes so it matches the motion you wish to make better than one with a simple joint can. Some of the prostheses are capable of different grip strengths. They can signal you in various ways to let you know when you are gripping strongly enough to pick up a raw egg without dropping it but not so hard that it is crushed. They are more cosmetic, eliminate the need for harnessing, and require less energy and movement to operate. There is still some question as to whether the electrically powered hand is more functional than the muscle powered one. Your treatment team will do a careful evaluation of your needs and abilities. Then they will recommend the type of prosthesis most likely to meet your needs. Each amputee has to decide based on individual experience.

Quite frankly, most women do not use functional upper extremity prosthesis. They tend to stick with cosmetic ones largely because they don't like the looks of a pair of hooks sticking out the end of their sleeves. This is really unfortunate because the newer types of prostheses can be both very functional and relatively cosmetic. It is true that they don't yet look and act like a living hand but they are coming closer. Restricting yourself to a cosmetic hand puts severe limits on the types of work and recreational activities you can do.

Figure 14

Example of a functional prosthetic hand

Figure 14 is adapted from one appearing in "Limb Prosthetics", 4th edition, 1979, published by Hanger, Inc. of St. Louis, MO, USA.

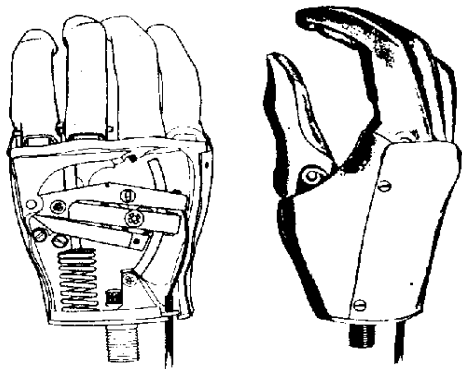
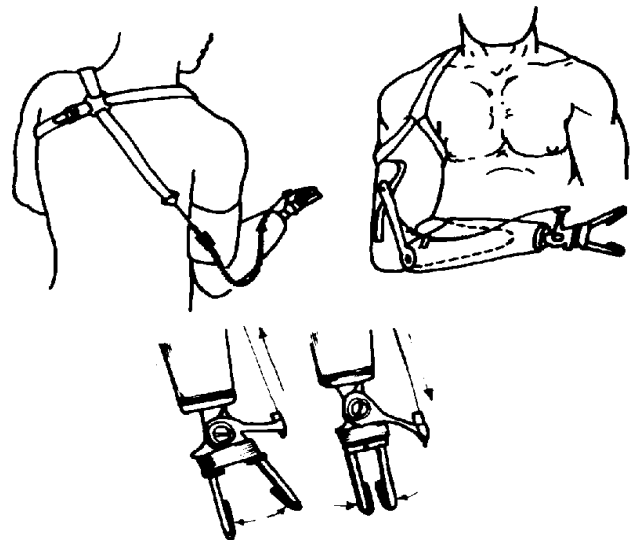


Figure 15

Attachment and use of a typical below-elbow prosthetic



j. Pain in the fully healed residual limb

"Stump" pain and phantom pain are very common even after the residual limb has been properly shaped, has healed properly, and has been properly used with a prosthesis for years. Pain in the residual limb is frequently caused by using the prosthesis too much, by skin problems related to the prosthesis, or by changes in the limb which come with age. As discussed earlier, your physician can usually help relieve almost all stump pain. See chapters three and four for extensive discussions of mechanisms underlying and treatments for phantom and stump pain.

Chapter 7

LIVING WITH AN AMPUTATION

a. What can't you do?

You can do almost anything you want to regardless of the type of amputation you have if you are in good physical health and condition. Numerous amputees sky dive, do distance swimming, mountain climbing, hiking, fishing, etc. However, you are limited by the differences between a natural limb and prostheses. This is especially true of the amount of activity you can do without causing problems in the residual limb. There is a real limit to how much irritation your skin can take from the pressure, sweat, and twisting of the socket. So, do, but don't overdo. You have to learn your limits.

b. Planning for your return home after the amputation:

Start planning before you have your amputation! Your ability to move independently may, at least temporarily, be quite different after your amputation than before it. You need to plan how you will get around your home, neighborhood, and work environments. This is probably the first time you and your family have faced this situation. You can get help from many professionals, especially Social Workers, Disablement Resettlement Officers and representatives of amputee groups, who know what is likely to happen and can give you guidance about what to expect and where to get help in changing your life style and living environment.

You have to plan for any changes needed in your home including the doorway, bathroom, bedroom, and kitchen. Apparently minor activities such as getting out of a deep armchair and a bathtub suddenly become events. It is much easier to trip and fall when learning to use a prosthesis so it is critically important to change or move anything you can trip over or slip on (such as highly waxed floors). Plan as soon as possible for changes in your occupation. If you will not be able to work as a result of the amputation, get help as early as possible in looking into disability allowances, etc. This is not only to stabilize your economic situation but to help reduce your level of stress. You can't concentrate on rehabilitation if you are worried "sick" about your family's economic survival.

c. Keeping up your health to keep your mobility and independence:

It takes slightly more energy to walk with some prostheses than with normal limbs. Older people tend to notice this more than relatively young folks. This increased energy expenditure, along with pain and irritation, can limit how far you can walk. Double amputees can expect considerable trouble with long hikes. If you find that you are really having problems, you may need a different type of prosthesis or to have your adjusted significantly. If you have difficulty getting onto trains and buses, you may be able to get a mobility allowance (frequently available from such sources as the US Veterans Administration and the British Government) to help you adapt a vehicle to your needs.

Because it is less convenient, and sometimes more painful, to move around and be normally active, many amputees tend to adopt a more sedentary life style than typical of others of similar age. This is potentially dangerous for amputees because decreased activity leads to weakened muscles and decreased vascular flow in the residual limb. If the limb begins to waste away, numerous problems set in quickly.

Of special importance is that the skin breaks down easier, bruises and infections heal slower, the bones break easier, and the prosthetic's fit changes more quickly and radically. The overweight that comes with obesity quickly adds extra strain on the skin - socket interface and changes the fit of the socket. The extra strain on the spine and joints accelerates the development of osteoarthritis and other problems. A regular exercise program is vital to continued good health and ability to use your prosthesis. You and your physiotherapist can work together to design a program which avoids putting extra strain on your residual limb while providing an interesting variety of activities. Promising yourself that you will regularly do a strenuous program of boring, repetitive physical exercises is not likely to be kept up for long.

Probably the best way to keep fit is to identify leisure activities that interest you and do a variety of them so you don't get burned out on any one. Many activities do not require extensive use of the lower extremities and can still be done by almost anyone with normal upper extremities. These include archery, swimming, rowing, canoeing, sailing, riding, and crafts such as wood working. Almost all amputees can walk for varied distances over a variety of terrains without damaging themselves.

d. Getting the help, training and support you need:

The saying "no one is an island" goes for amputees as well as for everyone else. If you are in good health and condition, you need not be more dependent on others than you were before the amputation. If your health and condition have deteriorated due to age, disease, disuse, etc., you will need correspondingly more help.

However, when you first have your amputation, you are not likely to be aware of what techniques exist to make your life easier (such as tying a shoe lace with one hand or adapting an automobile) or what you can do to make your life as effective as possible and reduce your limitations. The next chapter lists the major organizations who can help you help yourself. It also lists some of the written material which can provide information and direction. Too many amputees suffer needlessly because they don't make the effort to find out what techniques and help are available. There is no need to make your life more difficult than it has to be.

e. Will your residual limb ever be "normal"?

Not entirely. The blood supply to the end of the limb will probably never grow back entirely. Blood carries all of the heat to your limbs. Because less blood is flowing through the end of the limb than is normal, most amputees find that the end of the stump is usually colder than the rest of the limb. When it is very cold out, the limb is more easily effected than the rest of the body. Your stump will probably also always be more sensitive to touch, rubbing, etc. than other parts of your body. This means that it could be damaged more easily than you might expect.

f. Life-long changes in you and your prosthetic

Your residual limb will continue to change. It swells every day as you use it and it gradually shrinks with age. It will change in overall configuration as you alter the amount and type of use which you put your prosthesis to. As you age, the way you move, especially your gait, changes naturally. All of these factors effect how well your prosthesis fits. Prosthetics are machines. Just like any other machine, they get out of whack and break with time and use. They need to be kept up properly and tuned up. The newer devices have computers, muscle tension and motion sensors, computer controlled joints, tiny motors, etc. You can expect them to give you and your prosthetist more problems and have more "down time" than relatively simple mechanical prosthetics.

Between the changes in your body and in the prosthetic, you can expect to have to have the prosthetic adjusted and repaired at apparently random intervals. A common problem is that people who have been very comfortable with a socket for years gradually become aware that it no longer fits properly or is becoming irritating and painful. They have the socket replaced with an identical one and are surprised when it doesn't work out. You will have to be remeasured every few years at most and can expect to keep changing various components of the prosthetic as the years pass.

Because your body changes over time, the way your prosthesis fits changes. This can result in changes of several inches in the length your prosthesis has to be so that your legs are the same length. The importance of having a prosthetic limb of the correct length can not be overstated. If you walk with a tilt for several years, you will cause undue strain on your back, pelvis and your other leg. This can lead to far worse osteoarthritis in your hips and spine than you might otherwise

experience. These are major, disabling problems which can be ameliorated but not fixed, so don't let them start.

g. Critical final points

(1) You must take proper care of your residual limb and of your prosthesis! It is a real bother and impingement on your time to keep changing stump socks, cleaning a prosthesis, caring for your socket and etc. when nothing seems to be wrong. Unfortunately, it only takes a few days of slacking off for terrible sores to develop which can take months to heal.

(2) You can not overuse your prosthesis and get away with it. The price of overuse is crippling pain, sores and disability that can last for months. You can easily become unable to use your prosthesis for months after a single "binge" of overuse.

(3) You change with time and things randomly go wrong with you and your prosthesis. This means that you must have an excellent, continuing working relationship with your health care team - especially your physician and prosthetist. You need to be able to tell them when something is just starting to go wrong - not wait until you become disabled or need surgery to fix what would have been corrected with a simple adjustment.

(4) You are ultimately responsible for how well you live with your amputation. There is simply no way to duck the responsibility. Others, especially your health care team and your family, can give guidance and encouragement but, in the end, it's all up to you.

Chapter 8:

FURTHER INFORMATION

This brief introductory guide cannot supply all of the details you will need to be fully informed about amputations and attendant problems. The best source of information about the amputation itself and your immediate rehabilitation is your health care team. After you leave the hospital, information is more difficult to come by. You may also feel alone and isolated in attempting to deal with your problems. Since you are not an expert on amputations, you may not know what is normal or what is important. You may feel hesitant to "bother" your physician very often with what may be minor problems. With rare exceptions, your physician will not be an amputee and you may not know any other amputees, so you may have difficulty communicating your feelings. This further increases feelings of isolation. You also may not know where to get information on ways to further your rehabilitation. It really helps if you can contact other amputees or organizations interested in working with amputees. Some literature is available which may be of help in furthering your rehabilitation and in letting you know what kinds of problems to expect. We have included most of the readily available publications that we know of.

a. Organizations:

1. British Limbless Ex-Service Men's Association (BLESMA):
Frankland Moore House, 185 High Road
Chadwell Heath, Romford, Essex RM6 6NA, England
Phone: 081-590 1124

2. National Amputation Foundation (NAF):
National Amputation Foundation; 73 Church Street
Malverne, NY 11565, USA Phone: (516) 887 3600

3. American Amputee Foundation (AAF):
PO Box 55218 Hillcrest Station; Little Rock, Arkansas 72225; USA
Phone: (501) 666-2523

4. The Amputee Association of Northern Ireland
Enterprise House, Balloo Ave, Bangor BT19 7QT, Northern Ireland
Phone: 0247 271525

5. US Veterans Administration
Central Office 810 Vermont Ave. N.W.
Washington, D.C. 20420; USA

6. Paralyzed Veterans of America
7315 Wisconsin Ave. Suite 300W
Bethesda, MD 20014; USA

7. Disabled American Veterans
807 Maine Ave. S.W.; Washington, D.C. 20024; USA
Phone: (202) 554-3501

8. National Association of the Physically Handicapped
76 Elm St.; London, OH 43140
Phone: (614) 852-1664

9. National Information Center for the Handicapped (US)
1201 16th St. N.W.; Washington, D.C. 20036
Phone: (202) 833-1460

10. National Handicapped Sports and Recreation Association
4105 E. Florida Ave.; Denver, CO 80222
Phone: (303) 757-3381

11. National Association for the Limbless Disabled, 134 Martindale Rd, Hounslow, Middlesex, TW4 7HQ.; England
Phone: 01-572-5337.

12. Disabled Living Foundation
380 Harrow Road, London W9 2HV; England Phone: 01-289-6111

13. War Amputees of Canada
(Helps both children and adults, need not be war related)
2277 Riverside Drive Suite 207
Ottawa, Ontario K1H 7X6, Canada Phone: (613) 731 3821

14. Amputees de guerre Quebec
606 Cathcart St. Suite 530; PO Box 11027, Station Downtown,
Montreal, Quebec H3C 4W6, Canada Phone: (514) 398-0759

b. Literature intended to help amputees help themselves:

Much of this literature is available from amputee organizations. Most large public libraries can borrow books from other libraries at no cost to you.

1. Survivor

Consumer Survival Kit; Owings Mills, Md. 21117; USA

2. Single Handed (A guide for getting along with one hand) edited by B. Garee 1978 Accent Special Publications Cheever Publishing, Inc.

P. O. Box 700; Bloomington, Ill 61701; USA

3. Amputee's Guide: Above-the-Knee

by A. Alexander (1978); Medic Publishing Co.

P. O. Box 0; Issawuah, Washington 98027; USA

4. Amputee's Guide: Below-the-Knee

by A. Alexander (1978); Medic Publishing Co.

P. O. Box 0; Issawuah, Washington 98027; USA

5. A Manual for Below-Knee Amputees

by A. Muilenburg and A. Wilson; P O Box 8313 Houston, TX 77004

6. A Manual for Above-Knee Amputees

by A. Muilenburg and A. Wilson (address as above)

7. How to get behind the wheel: Information for amputees wishing to drive a car: UK Forum of Driving Assessment Centres

Banstead Mobility Centre, Damson Way, Queen Mary's Ave, Carshalton, Surrey SM5 4NR, England. Phone: 081 770 1151

8. Guide for the Disabled: Booklet from the Automobile Association (British) covering hotels, guesthouses, and farm houses catering to the needs of the disabled driver. 5 New Coventry St., London, W1V 8HT, England. Phone: 01-930-2462.

9. Physical Fitness: Sports and recreation for those with lower limb amputation by Bernice Kegel, Journal of Rehabilitation Research and Development Clinical Supplement 1, 1985. Office of Technology Transfer, Veterans Administration Medical Center, 50 Irving St, NW Washington, DC 20422, USA

(Excellent source of information for activities and groups)

10. Which Benefit (British)

Booklet from the DHSS available from the Social Work Department covering all current DHSS benefits available.

11. Disability Rights Handbook

Disability Alliance, 25 Denmark St., London WC2H 8NJ, covers many aspects of disability.

12. Various publications from the US National Information Center (funded by the US Government)

308 Mullen Library; The Catholic University of America
Washington, D.C. 20064

13. On the Road to Recovery - General Information for Patients with Lower Limb Amputations

by J. Dayan and E. Moore 1981; Burke Rehabilitation Center
Available through the National Amputation Foundation

14. Strong at the Broken Places by Max Cleland 1980
Berkley Books of New York

15. The One Hander's Book: A Basic Guide to Activities of Daily Living by Veronica Washam 1973; John Day Company of New York.

16. Directory of Information Resources for the Handicapped
compiled by the staff of Ready Reference Press 1980 published by Ready Reference of Santa Monica, California

17. Limb Prosthetics published by the J. G. Hanger Corp. 1979; Albany, GA 31701

18. Pocket Guide to Federal Help for the Disabled Person (American)
write to: Office of Information and Resources for the Handicapped
U.S. Dept. of Health, Education, and Welfare Washington, D.C. 20201

19. Care and use guide for the below-knee amputee
American Academy of Orthotists 717 Pendleton Street, Alexandria, VA 22314; Phone: (703) 836-7118

20. Hygienic problems of the Amputee
American Orthotics and Prosthetics Association
719 Pendleton Street, Alexandria, VA 22314

21. Information booklet for patients and relatives regarding amputation
Camberwell Health Authority, Dulwich Hospital, East Dulwich Grove, London, SE22

c. General literature of interest:

When Bad Things Happen to Good People by Harold S. Kushner 1981 Schocken Books of New York

d. Literature in the scientific press intended mostly for other scientists and health care providers rather than being directed toward amputee patients:

Much of this information may be too technical for the average reader to understand completely but may be of interest for finding out about specific areas of interest.

1. Driving after Amputation: Information for professionals

UK Forum of Driving Assessment Centers

Banstead Mobility Centre, Damson Way, Queen Mary's Ave, Carshalton, Surrey SM5 4NR; Phone: 081 770 1151

2. Amputation Surgery and Lower Limb Prosthetics

Edited by G. Murdoch and R. Donovan, Blackwell Scientific Publishers, London, 1988.

3. Sherman, R.: Phantom limb and stump pain. Chapter in (R. Portenoy, ed.) Neurologic Clinics of North America 7(2): 249-264, W.B. Saunders Co., Publisher. 1989.

4. Sherman R, Arena J: Phantom Limb Pain: Mechanisms, incidence, and treatment. *Critical Reviews in Physical and Rehabilitation Medicine* 4: 1-26, 1992.
5. Sherman R: Phantom limb pain: Mechanism based Management. *Clinics in Podiatric Medicine and Surgery: Pain Management* 11: 85 - 106, 1994. Saunders, Philadelphia, 1994.
6. The psychological rehabilitation of the amputee by L. Friedmann
Charles C. Thomas Publisher, Springfield, Ill., 1978.
7. Occupational Therapy for Physical Disabilities by Trombley, K. and Scott, A. Published by Williams and Wilkins of Baltimore
8. Report to the Veterans' Administration Department of Medicine and Surgery on service connected traumatic limb amputations and subsequent mortality by Hrubec, Z. and Ryer, R. *Bulletin of Prosthetic Research* 16: 29-53, 1979.
9. The challenge of pain by Melzack, R. and Wall, P.
Basic Books, N.Y., 1983.
10. Pitetti, K, Snell, P, Stray-Gundersen, J, Gottschalk, F: Aerobic training exercises for individuals who had amputation of the lower limb. *JBS* 69A: 914 - 921, 1987.
11. Haber, W: Reactions to loss of limb: physiological and psychological effects. *Annals of the New York Academy of Sciences* Volume 74, pages 14-24, 1958.
12. Pearson, H: Better health for the amputee. Published by BLESMA (address in preceding section).
13. Karacoloff, L: Lower extremity Amputation: A guide to physical therapy management, Aspen Systems, Rockville, MD, 1985.

Chapter 9

DEFINITION OF TERMS

Abrasion: rubbing off the skin leaving a "raw" area.

AE: Above the elbow amputation

AK: Above the knee amputation

Alignment: Relative position of socket to the heel/foot the prosthesis

Dynamic alignment - Position of socket stump during motion

Static alignment - Initial position of socket to stump

Alignment apparatus: Adjusts the prosthesis so that the gait is as normal as possible.

Ambulation: Walking

Amputation: Surgical removal

Anterior: Towards the front

Axilla: The depression in the armpit

BE: Below the elbow amputation

BK: Below the knee amputation

Cadence: Rhythm of walking

Check socket: A test socket to evaluate the initial fitting of the socket, the material is usually clear to allow visual inspection for problem areas

Chronic pain: Pain which lasts for at least six months

Condyle: A rounded bump at the end of the bone

Contracture: Tightening of muscles, tendons, and ligaments around a joint causing decreased motion.

Delayed primary closure (DPC): When the amputation site is closed 3-5 days after surgery

Dependent: Hanging down (Not usually used to mean needing others).

Distal: A direction - end part of the limb relatively away from the trunk of the body (also see "Proximal")

Edema: Swelling (usually of the residual limb)

Elastic wrap: Elasticized bandage used to prevent swelling and encourage shrinkage of the residual limb

Endoskeletal: Soft outer finish with an interior support

Exoskeletal: Hard outer support and finish

Extension: Unbending or stretching

Femur: The thigh bone

Fibula: Smaller of the two bones in the lower leg

Flexion: Bending

Flexion contracture: Inability to extend through the to normal range of motion

Gait: Speed, rhythm, and style of walking

Inferior: Below or directed downward

IV: Intra-venous - usually refers to a thin plastic line run from a bag into a vein through a needle which is kept in the skin for up to several days at a time. Blood can be sampled through this tube and antibiotics and other medications can be run in through it.

Lateral: Away from the midline of the body

Mature: Usually refers to the residual limb that has stabilized in volume and shape (usually within one to two years after amputation)

Medial: Toward midline of the body

Modular Limb: A type of artificial limb based on a central pillar (pylon) which normally contains at least one joint such as a knee. It is surrounded by plastic foam to imitate the contours of a normal limb.

Occupational Therapist: An expert in upper extremity rehabilitation.

Oedema: Swelling (of the tissues with fluid).

PAM: A very temporary artificial limb used with someone who has just had an amputation so they can practice standing and some walking. It is held to your stump by an inflatable sleeve and contains a rod (pylon) which acts as a leg and foot.

Patella: Knee cap

Phantom sensations: The normal "ghost" image and feelings which seem to come from the part of the limb which was removed

Phantom limb pain: Pain which seems to come from the portion of the limb which was removed. These are painful phantom sensations.

Physiotherapist: (A physical therapist) The therapist that gives you exercise and trains you in how to walk properly.

Pistoning: Stump slipping up and down in the prosthesis

Ply: Thickness of stump stocking material

Posterior: Behind or towards the rear

Prosthesis: Artificial limb

Prosthetist: Person who constructs and fits artificial limbs

Proximal: A direction - part of the limb close to the trunk of the body

PTB: Patella tendon bearing - a type of below-knee prosthesis. Takes your weight on the relatively insensitive area just below the knee.

PTS: Patella tendon supracondylar - a type of below-knee prosthesis suspended by femoral condyles

Pylon: Metal shaft inside the prosthesis. Also: temporary, simple prosthesis

Residual limb: The part of the limb remaining after the amputation (commonly called the stump)

Revision: To surgically do the stump over again, usually results in a shorted length

SACH foot: Solid ankle cushion heel - type of artificial foot in which a foam heel imitates normal ankle movements.

SAFE foot: Solid ankle flexible (endoskeletal) - type of artificial foot

Shrinker: An elasticized prosthetic sock used to prevent swelling and to encourage shrinkage of the residual limb

Shrinking: Usually refers to swelling going down in the residual limb rather than decreased amount of muscle

Skin breakdown: Any bleeding or disruption of the normal skin surface (e.g. blisters and sores)

Slip socket: Protects a tender stump against chafing

Socket: The part of the prosthesis which fits around the residual limb

Soft insert/liner: Cup shaped form which fits inside the permanent B/K prosthesis

Soft socket: Soft lining built into a socket to provide cushioning or permit muscle function

Stump: The residual limb or the end of the residual limb

Suction socket: A way of holding on an artificial limb using air pressure rather than straps

Superior: Above or upwardly directed

Supracondylar: Above the condyles

Suspension: How the artificial limb is held on

Symes amputation: A type of amputation at the ankle

Tibia: Larger of the two bones in the lower leg

Tubercle: A small protuberance on a bone, usually forming an attachment point of a muscle

Volume changes: Swelling or shrinking of the residual limb

Wedge: Triangular insert which helps hold some BK prostheses in place.

Weight-bearing area: An area of the residual limb able to tolerate pressure and stabilizing forces

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