The War Amps

Parenting the Child Amputee

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Introduction

This booklet covers many of the issues parents encounter in raising a child amputee. The content is based on the work of the Child Amputee (CHAMP) Program, which was started by The War Amps in 1975.

It all started when War Amps members decided to explore how they might use their own experiences as amputees to help other amputees. Thus CHAMP was born from The War Amps philosophy of "amputees helping amputees," a tradition that continues as the program's hallmark.

The War Amps has maintained that the CHAMP Program be operated with a family feel and based on a positive approach to living with amputation that is summed up in what is called the Winner's Circle philosophy. These characteristics have been experienced by the thousands of families who have joined CHAMP through the years.

The CHAMP Program serves Canadian child amputees up to the age of 18 regardless of the cause of their amputation(s) – congenital, accidental or medical. CHAMP provides comprehensive support for families of child amputees. It offers financial assistance for artificial limbs and recreational devices, information on amputation and prosthetics, regional seminars, peer support and beneficial resources like this booklet.

The Winner's Circle Philosophy

CHAMP believes "It's what's left that counts!" Although child amputees have lost or were born missing a limb, the focus is on what remains and the abilities of the amputee. Through a simple but effective approach called the Winner's Circle philosophy, child amputees are encouraged to have a positive, open and winning attitude about their amputations. Being a part of the Winner's Circle, with other young amputees just like them, provides the support needed by Champs to accept their amputation and develop a "can do" approach to the challenges amputation brings.

Whenever a child amputee (Champ) overcomes a challenge, tries a new activity or sport or simply takes an optimistic approach to accomplishing their goals, they are true winners. This Winner's Circle philosophy runs through everything that the CHAMP Program does.

Familiar Feelings

The feelings identified here are the most common shared by CHAMP parents. It should become clear as you read that they are closely linked to each other. Acknowledging them is the only way to face the feelings and work through them. You will be able to focus on looking ahead and meeting the needs of your child with a realistic and positive outlook. Specific approaches and strategies for dealing with these feelings are shared throughout the booklet.

Grief

The grief over the loss of a body part experienced by an amputee or his/her parents, and the accompanying fear for the future, is sometimes compared to the grief of losing a loved one. It is common for parents to feel grief at the time of the birth of their child amputee, or at the time of an accident or illness that results in amputation.

Internationally renowned grief expert Elisabeth Kübler-Ross (1926-2004) identified the stages of grief as denial, anger, bargaining, depression and acceptance. Each person's experience of grief is different, and everyone does not go through the stages in the same way or to the same degree. Grief is an individual experience and, therefore, so is the type of support each individual needs.

Guilt

Guilt results when you blame yourself for your child's amputation. You may believe, for instance, that something you ate or drank or exposed yourself to caused your child to be born with an amputation. You may feel guilt believing you failed to watch over your child well enough and an accident resulted.

Shame

Concern over how others may perceive the child's amputation can cause feelings of shame in parents. This includes not just concern over what others will think about the child amputee, but about the reason for the amputation as well.

Shame associated with a child's amputation can manifest in many different ways. For instance, a mother may avoid bringing her child to playgroups because she feels her child is different. A father might bundle up his child in an effort to hide the amputation.

Blame

Blame can be felt inwardly and/or expressed outwardly.

A mother may blame herself for her child being born missing a limb, feeling there was something she might have done differently that would have prevented the amputation. The father or other family members may also feel this way.

Some parents look to blame the environment for the amputation – factors such as acid rain, fertilizers, pesticides, medications, radiation, pollution or even computers. It is only in very rare instances, such as the thalidomide crisis of the 1950s and 60s, that congenital amputation can be directly attributed to an environmental cause.

Looking Back

When a child has an amputation – whether it be congenital or as the result of an accident – it is common for parents to look back and wonder if the amputation could have been prevented somehow.

They subject themselves to countless questions, often beginning with "what if." What if I hadn't let his big sister look out for him? What if I had made her stay in the house when I was mowing the lawn? What if I had not taken that medication when I was pregnant? They are all questions that do not change the reality that amputation is now part of your lives.

Anger

Parents may feel anger over their child's amputation and its cause. When you feel anger, it can present itself in many ways, including resentment and arguing.

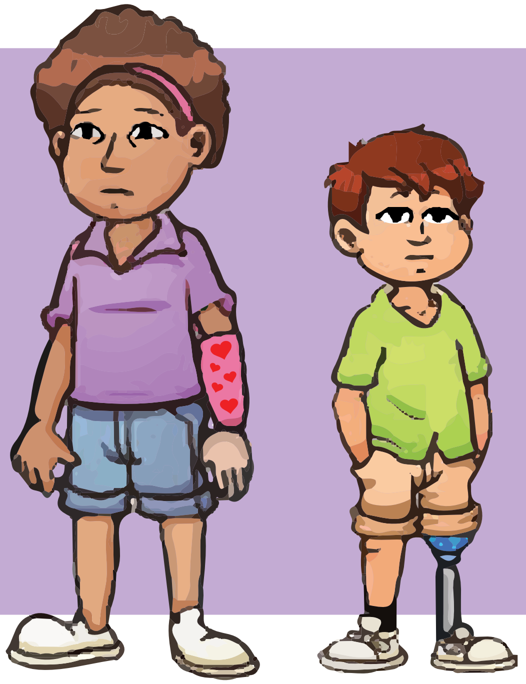
One parent may be angry at the other parent who was caring for the child when the accident that caused the amputation occurred, or because cancer, another possible cause of a child's amputation, runs in the other parent's family. You may feel that it is unfair this has happened to your child and you and be angry at the world.

Rejection

Parents expecting the arrival of a baby with 10 fingers and 10 toes may be shocked when their baby arrives missing a limb. They may not know how to react initially, and, as a result, withdraw from the situation and the baby. Rejection can be silent, with the mother, father or another family member trying to hold it inside.

Helping Parents through the Dirty Dozen

Since starting the CHAMP Program, The War Amps has been regularly approached to provide guidance to CHAMP families. The Association's collected insight and advice was put on video so that it could be shared with more CHAMP parents. The video identifies 12 primary issues that parents face in raising a child amputee, such as dealing with guilt. The War Amps terms these issues "The Dirty Dozen" and, in the video of the same name, deals forthrightly with the issues, leaving parents with an optimistic outlook for their children.



Another type of rejection comes in the form of denying the realities of amputation. A parent may focus blindly on finding a prosthesis that will give the amputee all the function she/he is missing from a natural limb, even when no such prosthesis exists. It can become more about making the amputee whole rather than addressing the realities of living with amputation(s).

Overprotection

It is a parent's natural instinct to protect their children, but the parents of an amputee may feel the need to safeguard their child even more. You may feel compelled to step in whenever your child is struggling or facing a challenge they really should learn to overcome on their own.

While done with the best intentions, being overprotective can inhibit the development of any child, leaving them without the skills they need to be self-sufficient.

Pity

When your child is born with an amputation or undergoes one due to an accident or illness, you may feel sorry for yourself, or other members of your family may feel sorry for you. You and/or family members may also feel and express pity towards the child amputee. Doing so gives the impression that there is something wrong with the child amputee, something *wrong* with being an amputee.

Such feelings can leave you and the child amputee feeling powerless and with a negative outlook on life. Amputees often say the comments they dislike most are ones like "Oh, you poor dear!" or "Let me do that for you," which imply amputees should be pitied or need to be looked after.

Worry

It is common for the parents of a child amputee to worry about how their child will cope now and in the future. A million questions may come to mind at once, even regarding experiences that are years down the road. Will my child be able to swim, ride a bike or play soccer? How will other people react to my child's amputation? Will my child be bullied? Will my child's self-esteem be affected by her missing arm? Will my child be able to drive a car? Will my child get to have a family of his own? Meeting other families who have experienced these same concerns helps you to move from worry to action that will benefit your child.

Frustration

With so many new terms to learn and unique challenges to grapple with, it is normal for new parents of a child amputee to feel frustrated and overwhelmed. You may find it frustrating to watch your child struggle to adjust to their amputation, or to go through the trial and error associated with finding the right prosthesis.

Dealing with new doctors, prosthetists and occupational therapists might also be a source of frustration, even if you realize they are there to help.

Doubt

Because you have entered an area that is completely new to you – amputation – you will encounter many medical and rehabilitation professionals, such as an orthopedic surgeon, physiatrist, prosthetist, occupational or physical therapist and social worker.

You may, especially at first, doubt your abilities to make the best decisions for your child. You may feel uncomfortable with or intimidated by the professionals you will now deal with, particularly when they use terminology that is unfamiliar to you.

Getting Started

As the parent of a child amputee, you are embarking on a new journey. In the beginning, amputation and the issues surrounding it may feel overwhelming, frightening and intimidating. Remember, many other families have walked the same road before you and you will benefit in a very positive way from their experiences – experiences covered throughout this booklet, along with specific resources to assist you on your way.

Congenital Amputation

Congenital amputation refers to amputation or malformation of a limb that is present at the birth of a child. You may wonder why, when a child is born missing a limb, we refer to it as a congenital *amputation* since some people suggest that a child born missing a limb does not have an amputation because no surgical or traumatic removal of a limb has occurred. The War Amps refers to all missing limbs as amputations to simplify things and because in the end, all children missing limbs are dealing with similar issues.

Most often, parents learn of their child's congenital amputation at the time of birth. Sometimes, however, the amputation is picked up during an expectant mother's ultrasound. Knowing in advance about your child's amputation may allow you to begin to adjust to the news and to do initial research into amputation and the support services available to you, but it may also place an added worry in your minds on top of all the usual pregnancy issues.

Either way, you may experience many feelings at the news that your child is missing a limb. Mixed with the joy of your child's birth may be shock, anger, frustration, worry or guilt. These emotions are normal. It is important to seek the support you need in dealing with these strong emotions. During these early days, it will help to talk about

"Amputees Helping Amputees" Through Peer Support

CHAMP offers support to amputee families from others who have "been there."

Annual regional CHAMP Seminars bring amputees and their parents together, while providing practical and concrete information on many aspects of living life as an amputee. Seminars are positive, information-packed weekends where lifelong bonds are made in the CHAMP "family."

The Matching Mothers Program and Junior Counsellors provide support from other parents and older members of CHAMP who have tremendous experience and insight to share with others.

For more information on CHAMP Seminars or The War Amps peer support programs, contact CHAMP. You can also visit CHAMP Online via waramps.ca or champ.waramps.ca for more information.

your feelings. Knowing you are not alone in facing your concerns is important.

Children with congenital limb malformations may require surgery or other medical treatments to improve their function, therefore, comments under the "Acquired Amputations" section may also be relevant. Parents may become anxious and stressed as they consult with medical professionals. Parents want to make the *right* decision to have the *right* procedure done at the *right* time. They want to provide their children with the best possible outcome, and making the decisions to achieve that is not easy or straightforward.

The CHAMP Program can help parents face the new realities of living with amputation. Through the Matching Mothers Program, you can connect with experienced families who have faced similar situations.

Parents of congenital amputees may also search for answers to explain why their child was born with an amputation. The fact is that there are usually no clear answers. Current research indicates that the reason for or cause of the vast majority of congenital amputations is unknown and unpreventable, although in some cases a child is born with a known syndrome of which amputation is one of the effects. Some families choose to consult with a genetic counsellor, particularly if a syndrome is involved, and if they wish to know the possibility of future children being born with a similar condition.

Parents are encouraged to adopt a *forward-looking* approach to dealing with their child's amputation, with the focus on how to meet the needs of the child amputee now and into the future. Too much time spent looking back, and focusing on issues and situations that cannot be changed, takes time and energy away from parents that they could otherwise use to actively and positively promote their child's adjustment to amputation.

Although you will naturally have questions about your child's care and future in these early days, it is a time to celebrate the birth of your baby. You can relax knowing the resources and support will be there as you need them.

Acquired Amputation

Acquired amputation refers to amputation where a child's intact limb is removed. There are two basic categories of acquired amputation: 1) amputations that result from traumatic injuries from accidents, and 2) amputations that are necessary to treat disease or illness.

Parents of children who have recently undergone an amputation or are facing one in the near future have countless questions and concerns. They are also focused on helping their children through this difficult and life-changing experience, so strong emotional and practical support from family and friends is crucial during this period.

Children express their feelings in a way different from adults, so it may be difficult to gauge exactly how your child is feeling about the amputation. Like their parents, they may experience many of the familiar feelings outlined earlier, such as shock, anger and depression. They may not understand or accept that an amputation is even necessary, or may think they are being punished for having done something wrong. Young children often do not know how to recognize their feelings, much less talk about them. They often express them through their actions. They may become angry at their parents or others, or become quiet and withdrawn or fearful.

Some children quickly move forward while others need more time to adjust. There is no right way to deal with the knowledge that you are now an amputee or are about to become one. What the amputee feels one day may be different the next. Most children, however, think in very practical terms and want to get back to doing what they were doing before their amputation as quickly as possible. Parents will need to help them adapt to the changes that the amputation brings. Some may be short-term adjustments, while others will be long-term ones. Generally, children adjust to amputation much more quickly than adults, and parents are often inspired by just how resilient and adaptable their children are.

Sometimes multiple surgeries, or revision surgeries, are required over months or years. Reviewing each procedure in age-appropriate language with your child will help lessen his/her fears.

During the initial days and weeks, parents need to remember to: allow their child to work through the emotions and the dramatic physical changes, knowing that moods and outlooks may fluctuate; seek the support and advice of appropriate professionals as they need them; and seek support from other people who have had similar experiences and know about amputation.

During this time, parents will be experiencing many of the same emotions as their child, but they need to present a positive and united front to their child. Children sense what is going on around them and they will react accordingly. Your actions and reactions will affect your child's attitude. If parents see amputation only in the light of tragedy and negativity, the child will do the same. Your own emotions and concerns need to be expressed and it is important to allow yourself time to work through them – but do so away from your child.

The Rehabilitation Team

In the initial weeks and months following your child's birth or amputation, you will consult with various professionals to develop a "plan of action" for your child. You may work with just a few professionals or many, depending on your child's needs. Some may be a part of your lives for a short time (e.g., surgeon), while others will be a part of your lives for the long term (e.g., prosthetist).

Where you live (whether in a city or in a more remote rural area) will have a bearing on the approach that is best for your family. Depending on your situation, you may meet the rehabilitation professionals in the hospital or rehabilitation facility, as an outpatient of these facilities, or at a prosthetic centre. Some parents are comforted by having a team of professionals so involved in their child's care, while others can feel intimidated by it.

It can take time to get accustomed to interacting with a variety of professionals. A couple of simple ideas can make the experience easier and more productive. For example, make the best use of the time during your appointments and ease any discomfort by writing down any questions you have in advance of appointments. You do not want to forget to ask about an issue, and remember that there is no such thing as a stupid question! Also, taking notes on the information being shared with you during these meetings is a good idea. That way you can refer back to them later when you have more time to digest it all and perhaps when you are more relaxed. Remember that you are your child's best advocate; only with your active participation and by having all your questions answered will you feel comfortable and confident in the care your child is receiving.

The professionals involved in your child's care are instrumental in helping you to set and meet your child's rehabilitation objectives. The general roles of many of the professionals you will encounter are described here (in alphabetical order), but the specific responsibilities of each will vary within rehabilitation teams. In addition to those covered here, you may also seek the services of other health care professionals such as dieticians, massage therapists and chiropractors.

Nurse

Nurses provide medical care to patients dealing with acute and long-term illnesses, diseases or injuries. While your child is in the hospital or rehabilitation centre following amputation, nurses oversee his/her daily care – they monitor vital signs, administer pain medication, bandage the residual limb and assist with all your child's daily needs. They also teach you and/or your child self-care techniques you will need to know before leaving the hospital.

Nurses work mainly in hospitals, but in rural areas they also have prominent roles in the community, attached to a health centre or general practice, and in residential homes, schools and hospices. They often have roles in educating the public about good health.

Occupational Therapist

The occupational therapist (OT) provides training to individuals with physical, mental or social challenges in functional tasks including activities of daily living, work skills and leisure skills. OTs assess a person's ability to perform activities and design appropriate treatment to address their needs, with the goal of increasing an individual's independence, confidence and control.

OTs teach amputees adaptive skills and practical solutions for daily living. A few examples are teaching an arm amputee to carry out daily tasks in a new way with or without a prosthesis, including specific skills like eating with a knife and fork; recommending assistive devices to make activities easier for a leg amputee, such as grab bars for balance in the shower; or determining what devices are required by an amputee to drive a car.

Oncologist

Oncologists specialize in the diagnosis and treatment of cancer. They remain a part of your child's rehabilitation team throughout his/her treatment for the disease. After an amputation due to cancer, treatment may continue for weeks, months or longer.

Facing these two situations at the same time – cancer and amputation – is difficult. In addition to answering your questions about the disease, the oncologist will also liaise with other members of the rehabilitation team to share how the cancer will affect your child's rehabilitation.

Orthopedic Surgeon or Specialist

Orthopedics is the medical specialty devoted to the diagnosis, treatment, rehabilitation and prevention of injuries and diseases of the body's musculoskeletal system. Orthopedic specialists/surgeons specialize in the care and treatment of malformations, diseases and injuries of the bones, joints and muscles.

The orthopedic surgeon performs the amputation surgery and any revision surgery that may be necessary later. You will meet with the surgeon beforehand to discuss the surgery, unless it is an emergency situation that makes this impossible. After the surgery, the orthopedic surgeon will oversee the healing of the amputee's residual limb and outline the amputee's rehabilitation needs. Once the work of the orthopedic surgeon is complete, any amputation-related care is usually overseen by another professional, such as a physiatrist.

Orthotist

The orthotist provides care to individuals with disabling conditions of their limbs or spine by recommending, fitting, fabricating and maintaining orthopedic braces that support or limit the movement of weakened joints or limbs. Some professionals are trained in either prosthetics or orthotics, while some are trained in both disciplines.

Amputees may sometimes require orthotic care for parts of their bodies beyond their amputations. For example, some amputees have been fitted with a support brace on their sound limb to provide protection and reduce the risk of injury, especially for active pursuits, or if their sound limb has also been weakened by disease or injury.

Physiatrist

The physiatrist specializes in physical medicine and rehabilitation and treats the whole body, assessing the physical, mental and occupational rehabilitation needs of the patient. The physiatrist does not treat the amputation as just a missing arm or leg but takes into consideration the overall effects of the amputation on the rest of the body and vice versa.

Following an amputation, the care of the amputee for ongoing amputation-related issues is often overseen by a physiatrist. It is the physiatrist who recommends physiotherapy and/or occupational therapy and is often responsible for prescribing the amputee's need for a prosthesis.

Physician

The physician is commonly referred to as a family doctor. The physician is the professional in charge of overseeing your general health.

It is imperative that the amputee's physician be familiar with all aspects of the care the amputee is receiving from other specialists and the strategies being followed throughout the amputee's rehabilitation. The physician needs all this information in order to take the amputee's full medical history into account when treating other health problems unrelated to the amputation and in order to recognize any changes in the amputee's health status.

Physiotherapist

The physiotherapist (PT) carries out individually-designed treatment programs to maintain, improve or restore physical functioning, alleviate pain and prevent physical dysfunction.

The treatment goals PTs establish are based on the person's physical diagnosis and evaluations of the person's functional abilities. Some therapies PTs use are therapeutic exercise, manipulations, massage, electrotherapeutic and other mechanical equipment and hydrotherapy. A few examples of how they assist amputees are sessions to build strength and range of motion in your residual limb following amputation; a conditioning program to increase your endurance to make using a prosthesis or other aids easier; gait training on how to utilize a prosthesis; or suggestions of mobility aids or adaptations that might be helpful around your home.

Prosthetist

The prosthetist is the professional who designs and fabricates prostheses for individuals with partial or total absence of a limb. The prosthetist takes all of the amputee's physical abilities and challenges, as well as his/her personal goals, into consideration in determining which components to recommend for the prosthesis. From there, the prosthetist custom designs and fits the prosthesis to meet the specific needs of the amputee.

The prosthetist remains an integral part of the amputee's life, as adjustments, repairs and new prostheses will be regularly required. Some prosthetists work in prosthetic clinics connected to a rehabilitation centre or hospital, while others provide prosthetic care through private clinics.

Psychologist

Losing a limb affects all areas of a person's life, and there are professionals to support the amputee's emotional and psychological adjustment to limb loss. A psychologist applies methods and theories of psychology with the aim to reduce psychological distress and enhance and promote psychological well-being. The psychologist often works as part of a multidisciplinary team to help individuals make positive adjustments as they face the life-changing experience of amputation. Specifically, a psychologist can help you and/or your child deal with how amputation impacts all areas of his/her life, help your child adjust to his/her new body image, provide specific coping skills, as well as offer family and couples counselling.

Social Worker

The social worker treats social functioning difficulties through counselling, therapy and referral to other supportive social services. Social workers are responsible for the day-to-day co-ordination of psychosocial programs, activities and professional services for individuals and their families, including those who are dealing with disease, injury and disability.

Social workers can help in numerous ways, such as by referring you to other agencies and community resources to meet your specific needs; helping to co-ordinate any financial assistance you need; putting you in touch with services related to housing, social support and family counselling; or suggesting meeting family and loved ones to discuss issues that arise from the amputation.

The Family Unit

When a child is born missing a limb or undergoes amputation due to an accident or for a medical reason, the entire family is affected by the experience, including siblings and other family members like grandparents, aunts, uncles and cousins.

It is important for the parents and child amputee to have the support of the larger family unit. In fact, in the early days following a child's amputation or birth, when the attention of parents is often taken up by the child amputee, it is often close friends or family members who play a leading role in sharing information about the child to other family and friends.

The child amputee will need appropriate support to deal with the physical and emotional experience of amputation, especially early on. Just as the amputee is learning to live with amputation, family members and close friends are learning as well. Family and friends need to learn how to assist parents in providing the support the child needs. Assistance should be provided in an encouraging and realistic way that does not overprotect the child, negate any of the child's feelings or over/underestimate the child's abilities. As mentioned previously in this booklet, connecting with other families who have already been through the same experience can provide tremendous insight to help families navigate these new waters.

As extended family members and friends spend more time with the child amputee, it is important for parents to explain the child's amputation in a straightforward and encouraging manner, which will set the tone for family and friends to follow. Family members and friends may mean well in some of the things they say and do, but when parents feel the comments and actions of family members or friends do not support their own views, it is important for parents to be firm and clear about the attitude and approach they want demonstrated around their child. For example, when family members treat the child's artificial limb with a healthy curiosity rather than pity, it helps the child develop an open and positive approach in dealing with questions about his/her amputation and prosthesis.

For cousins and other children who come into contact with the child amputee, although the parents of the child amputee can assist, the parents of the other children should ensure their children develop a positive and healthy outlook about the amputation – one that puts all the children, including the amputee, at ease.

As time goes by, the larger family unit will become increasingly confident about how to support the child amputee and his/her parents. Family members and friends ultimately realize they just need to treat the child amputee as they do other children in the family, which simply means they take into account all aspects of personality and physical characteristics in their interactions with each child.

Siblings

A child's amputation has the most impact on immediate family members – the parents and siblings of the child. The siblings of the child amputee naturally require special attention to help them deal with the amputation.

Just as parents and the child amputee experience a gamut of emotions, so too may the siblings of the child amputee. Children have active imaginations and can have many fears and concerns that they do not know how to express. They may feel sad and scared. They may worry about how their sibling will be able to do things. In the case of an accident, they may feel guilty, believing they did or thought something that caused their sibling's amputation. They may fear the same thing will happen to them or to one of their parents or another sibling. They may feel lonely and left out and resent that their parents spend so much time with the child amputee. They may withdraw and not talk about their own fears because they do not want to bother or worry their parents more than they already are.

It is important to discuss the cause of the child's amputation. If it was due to an accident, the sibling may need to be reassured about his/her own safety in the world. If the amputation was due to an illness or disease, like cancer, it is important to also discuss the illness or disease in terms appropriate for the sibling.

It is also possible that siblings may seem to be coping well at home, but are expressing negative feelings outside the home. In addition to your family and friends, it can be helpful for other individuals who interact with your children outside of your home to know that your family is dealing with this new experience of amputation. This includes individuals at your children's daycare or school, those involved with sports teams or other activities, and the parents of your children's friends. These people can be a great support to your family, and also recognize if your children are behaving uncharacteristically and make you aware of any concerns that arise.

Just as how you address amputation with the child amputee depends on the amputee's age, so does how you address issues with siblings. Only once children reach the age of two or three do they even notice that their brother or sister is missing a limb and, at that time, you can explain it in very simple terms. As the sibling gets older, you can expand on the details as appropriate.

Some tips to help address the issues siblings may face include:

- Encourage siblings to share all their concerns and to ask questions. By being open about the amputation and its cause and treatment (in age-appropriate terms), parents encourage siblings to adopt a similar open and encouraging attitude.
- Siblings may have many worries stemming from their brother or sister's amputation – worries about their brother or sister with the amputation, worries about themselves or worries about their parents or other siblings. Providing plenty of reassurance will help siblings feel less frightened and more secure.
- Siblings often get asked questions about their brother or sister's amputation by other children who are curious but who feel uncomfortable asking the child amputee directly. Siblings also need to learn how to respond appropriately to questions about the amputation.
- The medical and prosthetic appointments the amputee requires often means parents spend a lot of their time with the child amputee. Be certain to find some special time alone with other siblings, perhaps to share an activity they enjoy.
- When assigning household chores, divide them up according to each child's age and ability, including for the child amputee. By assigning the child amputee appropriate chores, you send the positive message that you view him/her as very capable and, thus, you increase his/her confidence. You also send siblings the message that you are not showing favouritism or providing the child amputee unnecessary privileges or allowances.

Grandparents

Grandparents are often the anchor of the family unit and, as such, play a significant role in helping the whole family adjust to the amputation. Children look to their parents for support no matter how old they are, and it is natural that the parents of a new child amputee will seek the support and guidance of their own parents.

Grandparents often experience emotions similar to those of the parents of the child amputee and go through the same stages of adjustment. In fact, sometimes grandparents have a greater difficulty coming to terms with a child's amputation than the parents do.

Grandparents who are dealing with their own reactions to the amputation should address their emotions as quickly as possible. The parents of the child amputee need their strong support at this time. In addition, grandparents have a strong influence on the child amputee and other children in the family. Grandparents should seek support from a trusted friend or counsellor, or may find keeping a journal helpful. The important point is for them to be open with the parents of the child amputee and to work through their feelings so that they can be there to support their family.

Grandparents who are more informed about the realities of amputation and artificial limbs feel more at ease with the amputation. They may gain that knowledge by asking questions of their grandchild's parents, doing their own research or by being actively involved in medical or prosthetic appointments for their grandchild. When grandparents have a greater understanding of amputation they naturally have more realistic expectations of the child amputee.

Grandparents provide support in many emotional and practical ways. Ultimately, their greatest support comes from them acting as grandparents. They allow themselves to be guided by a positive and supportive outlook for their grandchild who is an amputee; they balance their time and attention between all their grandchildren, neither paying too little or too much attention to the child amputee; and they learn that the amputation is secondary to all of the wonders and unique talents and abilities they will discover in their grandchild.

Questions, Comments and Stares

Amputation brings attention because it is generally visible, unlike many other disabilities or conditions. People are often curious when they see a person with a missing limb because they may not have met anyone with an amputation before, and they may sometimes be uncertain or nervous about how to act towards the amputee. Their curiosity and uncertainty may lead them to stare, avoid contact, make comments or ask questions.

The many questions that amputees, their family members or friends get asked range from those that show simple interest to those that seem silly or thoughtless. Comments can be positive, insensitive, kind, cruel, funny, pitying, admiring, rude, interested or even strange. Some parents are at ease right from the beginning and start answering questions about their child's amputation and handle them very directly. Many others feel more comfortable when they have practised their answers at home with their spouse, a family member or friend before the questions begin. Their answers then come more easily and naturally in public.

When some people stare, they try to do so in a way that they think won't be noticed (though you usually do notice), while others are more blatant. Young children in particular can be especially open and even point as their parents try to shush and stop them. Some parents take the initiative and go up to individuals who they notice are staring, especially children, and ask if they would like to ask any questions. Other parents prefer to filter out stares, or just smile in response, and only provide information when questions are asked.

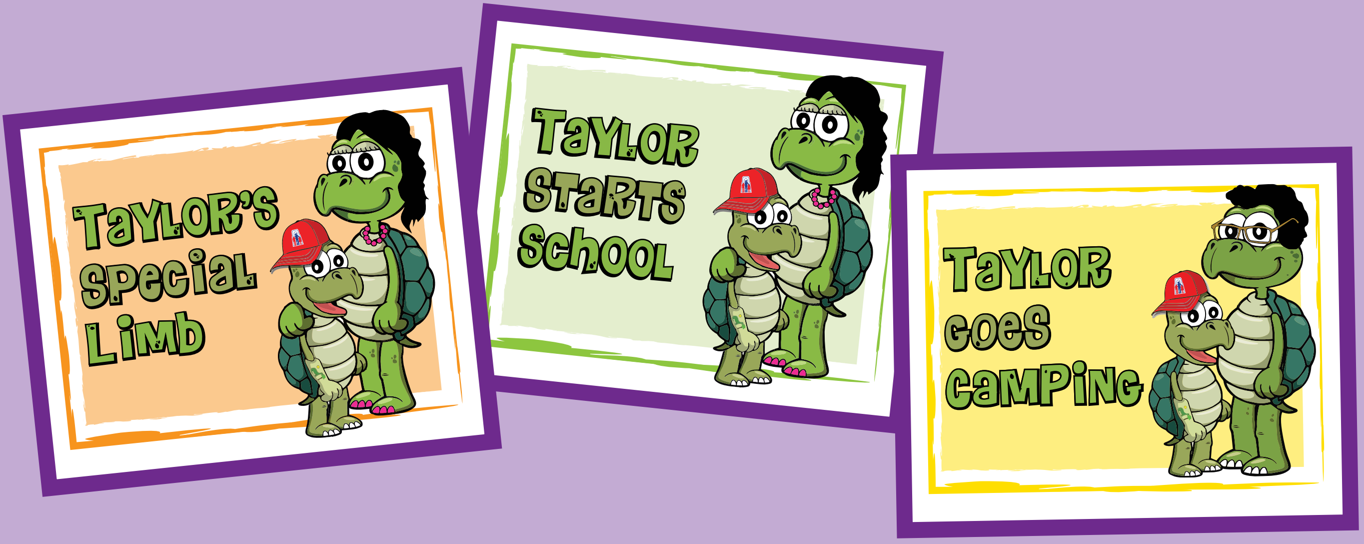
Some people underestimate the amputee's abilities and try to do things for him/her without even being asked. Some express pity in their comments, wrongly assuming that amputees are less capable than they really are. People may mean well when they try to help, or they do not see how their behaviour and comments are demeaning to the amputee. Many parents try, in a polite and direct way, to simply emphasize that there is no reason to feel sorry for the child amputee and that she/he is capable and accomplished. Hopefully, sharing knowledge of your child's capabilities will mean this one individual will know better how to react when they meet other amputees in the future.

Such situations are a part of life for an amputee, therefore, parents of child amputees need to develop an approach that feels right for them on how to handle such situations. Parents instinctively want to protect their children. They may even want to keep their child safe in the family cocoon and away from difficult experiences, but, of course, this is impossible. Simply put, those who live with amputation have the greatest responsibility to educate others about the realities of amputation and to advocate on behalf of the amputee until the amputee is able to do so him/herself. That is the only way that others who know little or nothing about amputation will become comfortable around it.

It is natural to have days when you feel frustrated, annoyed or even angry when you have negative experiences. You may not always feel like filling the role of educator and advocate. An overall open and relaxed approach to handling

Learning About Amputation Is Fun!

Parents are encouraged to have fun teaching their children about amputation. The War Amps has great storybooks featuring amputee characters that are popular with young Champs:



Other commercially published books with amputee characters include:

- *Harry and Willy and Carrothead* by Judith Caseley
- *Oliver's High Five* by Beverly Swerdlow Brown

Amputee dolls can also help promote positive attitudes about artificial limbs by reducing the complexity of amputation and artificial limbs. The Sew Able doll can put children at ease, which will, in turn, encourage them to ask questions. Amputee dolls can be useful as an educational tool, a counselling aid, a prosthetic model and, of course, a fun toy!

Sew Able Dolls (as seen at CHAMP Seminars)
Sew Dolling
PO Box 53
East Greenwich, Rhode Island 02818
401 398-0070
sew-dolling@cox.net
sew-dolling.com

all situations is very important. It is your attitude that provides the cue to family, friends and the public on how to act towards the child amputee. Children intuitively sense what is going on around them. They can take a negative reaction from someone and internalize it and begin to feel their amputation makes them inferior somehow. When parents positively handle negative situations, they teach their child amputee how to do so. Child amputees pick up on the positive and open attitude of their parents and adopt a similar healthy attitude about being an amputee. Still, it is important for parents not to ignore any of their feelings, including the sad or angry ones, and ensure they have ways to deal with them so that they can also maintain their healthy attitude.

Parents need to be confident in handling these situations, but equally as important is teaching their child amputee how to also handle these situations. When children are infants or toddlers, parents handle the questions, comments and stares, but as the child gets older, they need to be prepared to handle these unavoidable experiences on their own. Preparing child amputees in advance will make the situations easier for them to handle. The seeds that parents plant now as their children observe their attitude towards amputation will grow and give the children skills to handle situations on their own.

It is better for parents to prepare the child at home than to have the child face questions for the first time in the playground. Other children will be naturally curious and will ask the child amputee questions about the amputation. If the amputee is unprepared for the questions or comments, they will be taken off guard, easily hurt and may feel there is something wrong with being an amputee.

You may, for example, ask your child, "What would you say if someone at the playground points to your little arm and asks you about it?" Then, discuss with your child what she/he would feel comfortable saying. A simple answer is often all that is needed for young children – a response like, "I was born missing my arm and I just do things my own way." You can also encourage your child to talk about their artificial limbs or any special devices they use for certain activities. For example, a child may say, "I have a special device to ride my bike. I can show it to you sometime." Explanations can be simple and straightforward early on, and more detailed as children get older.

Not only do parents need to be prepared to teach their children how to deal with questions and comments from the outside world, but they also need to be prepared for the ones the child amputee will ask them about the amputation. Some of these questions will pull at your heartstrings such as, "When will my hand grow big like yours?" It is usually when child amputees are around the age of 2 or 3 that they notice how they are physically different from others and begin to ask questions about their amputation.

Just as parents practice how they will respond to questions when out in public, they can also prepare for their child's questions before they begin. Such preparation will put them at ease so they are not taken off guard when the questions come. Some children only ask such questions once or twice, while others ask similar questions time and again. Repeating your affirming message will have a positive influence on the child amputee, as some children simply need more assurances than others.

To the question of "When will my hand grow big?," you might, for example, simply say, "Mommy and Daddy have two arms and two legs. You have two legs and a little hand. That is the way you were born, just as some people are born with eyes that need glasses. You are perfect just the way you are."

Artificial Limbs

In addition to adjusting to the emotional aspects of dealing with amputation, parents are introduced to the possibility of artificial limbs, or prosthetics, for their child. Some of the common questions parents ask follow below. There is much information available on the different options and approaches regarding artificial limbs. Parents seeking more information on this topic can obtain it from The War Amps National Amputee Centre.

Should we even have our child fitted with an artificial limb?

The vast majority of leg amputees use a prosthesis. The functional benefit of using a lower limb prosthesis is self-evident. Even very young children quickly grasp how the prosthesis will help them get around, but it does take time to adapt to wearing it. While some leg amputees with a very high level of amputation (such as the hemipelvectomy level) and high level bilateral amputations manage reasonably well with a prosthesis, they sometimes use a prosthesis in conjunction with other mobility aids like canes, or forego a prosthesis and use crutches or a mobility vehicle like a wheelchair instead.

For arm amputees, the decision should be made with long-term factors in mind. Functionally, arm amputees can manage to perform tasks with one hand or with the help of other parts of their bodies. Some amputees use a prosthesis regularly, while others use one for specific tasks or activities, such as at school or work, or for recreational pursuits. The sound limb will experience more strain because it will be used more to compensate for the missing arm. Although a prosthetic arm cannot replace the intricate function of the sound limb, arm amputees need to consider how to relieve some of that extra strain on the sound limb in order to keep it healthy throughout their lives. Prosthetics can play an important role in achieving that, as can daily living aids and adaptive techniques in managing tasks. Some amputees have appreciated the assistance provided by their prosthesis after they injured their sound limb and became almost totally dependent on others to have their basic needs met.

The following are a few key points to keep in mind. The level of amputation is a key determinant in a decision about whether to fit an upper limb amputee with a prosthesis – for example, many partial hand amputees, particularly those who have a functional wrist remaining, choose to not wear a prosthesis regularly, but instead opt for activity-specific devices, such as a custom device to play a musical instrument. The *function* provided by a prosthesis is crucial in determining whether a child will accept or reject it. If the prosthesis does not provide noticeable function to the amputee, the amputee is more likely to reject it. The complexity of whether or not to fit a prosthesis and what type to choose increases when amputees have very high level and multiple amputations.

What type of artificial limb is best for my child?

There are different prosthetic options to choose from and what is best for each amputee will vary. The choice of prosthetic components will be based on numerous factors: what the amputee wishes to be able to accomplish with a prosthesis; the age, size and weight of the amputee; the level of amputation; and even where the amputee lives (i.e., how close the amputee lives to the prosthetic centre to facilitate maintenance and repairs). The prosthetist takes all of these factors into consideration when she/he discusses options with you. Parents need to be open with the child's prosthetist about the kind of lifestyle the family leads and what they expect from a prosthesis. The prosthetist will then be in a much better position to advise the parents regarding the most appropriate prosthetic options, as well as what can be realistically expected.

Amputees and their parents must have realistic expectations about prosthetics. Artificial limbs cannot replace the function that a natural limb provides.

It is important to meet the needs of amputees at different times in their lives. One amputee, for example, requested an artificial arm that she could use for tasks on the family farm. She was fitted with a durable, cable-operated prosthesis with a work hook. Her needs changed as she was preparing to go to university and, at that time, she chose to go with a myoelectric prosthesis. The key was meeting her changing needs. The importance of being open with your prosthetist about your child's specific desires and needs cannot be overemphasized.

There are several key things to keep in mind when exploring with your child's prosthetist what particular components to incorporate into the prosthesis. First is *comfort*. The socket, into which the residual limb fits, must be comfortable and secure. If the amputee is not comfortable inside the socket, it does not matter what other great components are in the prosthesis, she/he will not want or be able to wear it. Second is *function*. The prosthesis must help the amputee function or accomplish certain tasks more easily or she/he will simply not bother with it. Third is *appearance*. The amputee has to be pleased with how the prosthesis looks or she/he just will not wish to wear it.

When is the right time to have an artificial limb fitted?

For congenital amputees, prostheses can be fitted at quite a young age, often when children are still infants. For the arm amputee, an initial fitting may take place just as the child begins sitting and crawling, at which time an artificial arm can help with balance. For the leg amputee, it is common to fit an artificial leg at the time a child begins to try to pull him/herself up to stand.

For amputees who lose limbs to illness or accidents, a prosthesis can be fitted within the first couple of months following amputation. The actual timing depends on numerous factors, such as how quickly the surgical incision is healing, the amount of scar tissue to heal, and whether there are other medical conditions or treatments like chemotherapy impacting healing. The initial prosthesis is usually a temporary or preparatory one, which allows for the fact that the residual limb continues to change shape in the months following amputation surgery.

Part of the healing process following amputation surgery involves shrinking of the residual limb, which takes place over months. Properly bandaging the residual limb and the use of tensor bandages or stump shrinkers reduces swelling and promotes shrinkage. This is a focus of amputee rehabilitation in the early weeks. Amputees also must follow an exercise regimen that will strengthen the residual limb and ensure issues like contractures (shortening of muscles) do not occur, as such issues can reduce prosthetic function. Leg amputees are also taught how to use crutches and/or a wheelchair by a physiotherapist before leaving the hospital. The medical team involved in your child's care maintains a close watch over your child's healing and will advise you when your child is ready for a prosthesis.

What is involved with a prosthetic fitting?

Prostheses are custom designed to each amputee. The process of fabricating a prosthesis can take several weeks and will involve numerous appointments with the prosthetist and others on your child's rehabilitation team.

The prosthetist will discuss with you which components she/he recommends based on assessing the amputee's needs (e.g., for an above knee amputee, this would include the type of socket, foot, knee and covering for the artificial leg). As the parents of the child amputee, you are a key part of this decision-making process.

The socket of the prosthesis, which covers the child's residual limb, must be intimately fit to the child. A close fit is obtained by taking a cast of the residual limb or using scanners to scan an impression of the limb. From there, the prosthetist makes a test socket that the amputee tries on; the prosthetist makes adjustments as needed and then proceeds to fabricate the final socket. Once the socket is fitting well and the chosen components are assembled and aligned properly, the prosthesis is often finalized with a cosmetic finish. The type of cosmetic finish is very much an individual choice, as shared under "How real will my artificial limb look?"

As prostheses are mechanical devices, they require ongoing repairs and adjustments. Children will require new prostheses regularly or the replacement of specific components, sometimes twice a year or more, as the socket and components wear out or need to be replaced to keep up with the child's growth.

How will we be able to pay for the artificial limbs my child will need?

The cost of prostheses run from a few thousand dollars to tens of thousands of dollars, depending on the level of amputation and the type of components required in the prosthesis. Prosthetic care carries with it a huge financial responsibility that continues through an amputee's life. The CHAMP Program is there to help. CHAMP covers the costs of new prostheses and repairs and adjustments that remain for CHAMP families after government funding programs and private insurance plans have been accessed. Contact CHAMP for detailed information on the financial assistance available through The War Amps.

How quickly will our child adapt to using a prosthesis?

Children who have undergone amputation surgery will go through a rehabilitation process that begins with healing of the residual limb. The time it takes the residual limb to heal can vary widely between a matter of weeks and many months depending on numerous factors, as mentioned under the question "When is the right time to have an artificial limb fitted?"

Once a prosthesis is fitted, patience and perseverance are required as the amputee becomes comfortable and confident with the prosthesis. Both arm and leg amputees need to build up tolerance to wearing the prosthesis; this is the case whether a child was born missing a limb or underwent amputation surgery. Keep in mind that the body's skin and tissue are not naturally capable of tolerating a prosthetic socket and sustaining all this new pressure. When first provided with a prosthesis, the amputee generally wears it for short periods of time initially and gradually builds up the wear time. This initial adjustment period can span weeks and months depending on many factors, including the level of amputation and physical condition of the residual limb.

CHAMP Newsletter – A Must-Read for All CHAMP Families!

The *CHAMP Newsletter* is a great resource that keeps CHAMP families in touch with each other and provides encouragement to young amputees, as they see what many great pursuits other Champs follow. The newsletter also features information on War Amps programs and services to assist amputee families, information on artificial limbs and amputee rehabilitation, counselling and peer support, and reports on valuable CHAMP events such as CHAMP Seminars.

Arm amputees need to be taught very specifically how the prosthesis can provide function. Task-oriented training emphasizing bi-manual activities is often carried out with an occupational therapist. Often, if the amputee does not perceive real functional benefit from the prosthesis, she/he will reject the prosthesis. Even amputees who choose to wear a prosthesis for cosmetic purposes usually report that the prosthesis also provides functional benefit, such as when it can be used as a lever arm to hold items against the amputee's chest.

Leg amputees usually immediately recognize the benefit of a prosthesis. Their residual limb must become accustomed to the pressures of weight bearing – that can take time. In addition, it is important initially upon receiving a prosthesis for the leg amputee to receive training from a physiotherapist in order to develop a good walking gait. Bad walking habits that the amputee develops early on are extremely difficult to break later and can cause the amputee to use more energy to walk and/or back problems. A good gait will benefit the amputee throughout life.

Learning to incorporate a prosthesis into the amputee's daily life is an exciting time with its rewards and challenges. Learning how the prosthesis will fit into one's life is an ongoing experience for the amputee. Each time a new activity is introduced, the amputee will need to determine how the prosthesis fits in.

How real will the artificial limb look?

Most young child amputees are more concerned with how their artificial limb can help them keep up with their friends than with how it looks. Amputees have their own preferences about how they wish their prosthesis to look – some amputees prefer not to cover the cool mechanics of the prosthesis, others opt for natural-looking cosmetic covers, and others choose bright colours and unique designs for their finishes, such as a favourite movie character or sports team logo. Personalizing their artificial limb is fun for many amputees. Ultimately, whatever appearance is chosen for a prosthesis, it is important to encourage the amputee to be proud of their prosthesis, since acceptance will help to build a positive body image.

It is often parents who wish for a prosthesis to be as lifelike as possible. Some parents believe that a natural look will make the prosthesis less obvious, which will result in fewer comments and questions when in public. Parents sometimes feel that a more realistic-looking prosthesis will be more readily-accepted by others. Although this thought is well-meaning, parents also need to develop openness about the prosthesis and feel positive about showing it off. While today there are very lifelike silicone covers available for a prosthesis, these are extremely costly and are not recommended for children, who quickly outgrow their prostheses. The more standard covers are, in fact, quite pleasing. Parents can familiarize themselves with the options so they have reasonable and realistic expectations about the appearance of a prosthesis. One final thought – pleasing does not have to mean natural looking; the bottom line is that acceptance of how a prosthesis looks by amputees and the public comes down to attitude.

Sports and Recreational Pursuits

A person's ability to participate in sports and other recreational pursuits is affected by amputation, and the degree to which one's ability is affected varies. Some amputees are able to participate with little adjustment, while others face significant challenges.

Some amputees use their everyday prosthetic limbs for sports or other pursuits, others use special equipment or recreational devices, others adapt how they participate in a sport, and some choose a specific position for a sport that works best for them (e.g., goalie). Many amputees participate in their regular school and community activities, while others get involved in recreational groups and teams specifically for people with disabilities (e.g., sledge hockey).

In many cases, when children are young they manage quite well at keeping up with their peers – even amputees with more than one amputation. As children get older, many sports become more competitive and are not as inclusive of varying abilities as they often are when children are young. Physical education classes at school may become more demanding, and amputees may notice that it is not as easy to keep up. There are always, of course, those amputees who are natural athletes who often excel competitively, just as there are such individuals in the non-amputee population.

Facing the physical reality of an amputation is more difficult for some amputees than others. It is necessary to be realistic about the physical challenges an activity may pose. It is frustrating and difficult for some amputees to accept that they cannot participate in certain activities in the same way that others without amputations can. It is important to stress that being realistic does not mean limiting child amputees or discouraging them from taking part in certain activities. The physical capabilities of each amputee are unique and quite often the extent of the amputee's abilities surpass even their own expectations! The message is simply to be cognizant that child amputees may go through challenges in this area and periods of adjustment as they grow.

Sometimes parents of child amputees wonder if they should push their child more to become involved in sports. It is generally important for everyone to be physically active in order to be healthy. Outside of that, however, is that some amputees are not that interested in sports and prefer other leisure activities. Some like being involved in sports in a different capacity, such as a team manager, others enjoy specific activities and clubs such as student council, band or art. The important thing is for children to take part in activities they enjoy.

The bottom line is that perseverance, ingenuity and determination go a long way to helping amputees reach new and exhilarating heights, whether painting a picture with their feet, skiing down a mountainside, playing a musical instrument or breaking world records on the track.

Starting School and Other New Adventures

There are numerous situations where a child amputee spends time away from the security of family, such as at daycare or school and while taking part in recreational and sports activities. Parents often initially worry how their child will manage. They worry about whether their child will be accepted and about the comments, questions and stares she/he will face about the amputation.

Heading to daycare or starting school is a very exciting time in a child's life, as the child gets a chance to spend time with so many other kids their age. Parents naturally want the experience to be positive for their children and to protect them from any harmful or negative situations. They worry about how their child amputee will be affected by reactions to their amputation and how they will handle situations. They fear their child will be teased or ignored by other children.

The best way to protect child amputees is to prepare them for the situations that *will* happen. More on this topic is shared in the section "Questions, Comments and Stares."

Most young children are very curious and the child amputee needs to be prepared for the reactions of other children towards the amputation. In addition to preparing their child to handle these situations one-on-one, many parents visit the daycare or school and make a presentation to introduce the child amputee to the class. This is an open and up front way of presenting amputation in a positive light and gives the children an opportunity to ask whatever questions they have about amputation. Such presentations answer many of the questions children have at one time and thus significantly reduce the number of individual questions that child amputees later get in the schoolyard. CHAMP has a Starting School Kit to help parents give a presentation.

Parents may also wonder how the personnel at the daycare or school or the recreational or team coach will deal with having a child amputee as part of their group. Again, parents want the experience to be a positive one for the child. Many parents visit the principal, teacher, caregiver or coach in advance of the child starting the activity to discuss the child's amputation. Parents often need to educate personnel about amputation and their child's abilities, as many daycares or schools have never had an amputee as part of their group. Parents can share advice on the general approach to take with regard to the amputation, as well as on how little or how much assistance a child needs in the classroom or activity and with self-care, such as with putting on coats and boots. Discussing the approach and expectations in advance will ease incorporating the child into this new setting. Arrangements can sometimes be made for a Junior Counsellor to give a presentation at a Champ's school. Junior Counsellors are older, experienced Champs who offer support and are role models to younger child amputees.

Personnel of the daycare, school or recreational group should be willing to maintain open communication with parents and to seek advice from those knowledgeable about amputation when situations arise that they are unfamiliar with. Teachers and adult leaders have a tremendous influence on young children, and their approach to a child's amputation can have a significant and lasting impact on the child's own attitude.

Starting School Kit

When child amputees head off to daycare or school for the first time, parents are often concerned about how they will manage. Parents worry about how other children will react to their child's amputation. Young children are naturally curious and will ask questions. The Starting School kit is a great resource that gives parents the tools to give a presentation to a class or daycare, introducing the child amputee to his/her new group. The kit includes guidelines and tips on giving a presentation, a fun board game, a Taylor the Turtle storybook and other great resources.

Included with the kit is the CHAMP Resource Kit DVD, which includes three award-winning videos – *Just the Way I Am* is a puppet video that teaches young children how to deal with questions about amputation and the Winner's Circle Profiles, described in more detail on page 25, are a great inspiration. Contact CHAMP to obtain a Starting School Kit.

Bullying

Bullying is present in the school environment to some degree during the school years. Just as parents need to prepare child amputees to handle questions, they need to prepare them for the reality of bullying. While many child amputees do not experience bullying, it is a reality in society today that is getting much attention, so parents should be cognizant of it in relation to their child amputee.

Bullies often have negative feelings about themselves and they try to make themselves feel better by making others feel bad. They often pick on others who they perceive to be weaker or different somehow. For this reason, it is clear why the amputee with an obvious visible difference might be a target for the bully.

It is valuable for children to understand why bullies sometimes are the way they are – to understand that the bully is the person with the problem. Understanding that will not make the situation go away, so children need practical tactics to deal with bullies.

Developing a confident and positive attitude about amputation from a young age will help the child amputee thwart the bully. Confidence is seen as strength, so if an amputee demonstrates confidence, the bully may think twice before picking on them.

The amputee needs to learn to stand and speak up for him/herself – not in a goading or adversarial way, but firmly and with self-assurance. The amputee should remain as calm as possible and try not to react with anger, fear or tears. Admittedly, this is not easy to do in the presence of a bully. Still, it is important to teach children to handle such situations to the best of their abilities so they are not taken off guard should they occur. Bullies are seeking a reaction and, often, if they do not get the negative response they want, they give up and move on. Many incidents of teasing stop when the child confidently asserts that there is nothing wrong with being an amputee. Many amputees find humour can help to diffuse a less intense bullying encounter or an uncomfortable or awkward situation.

As children get older, and during adolescent and teen years, bullying can be difficult and complex. Peer pressure can also present itself in power games and cliques. Many teens who themselves do not bully feel pressured to say nothing when they see someone else being bullied. Children may experience direct insults or threats, or indirect issues such as being excluded from groups or activities, name-calling or the spreading of rumours.

Parents instinctively want to protect their children from such experiences, and many parents personally involve themselves in the handling of bullying situations. When bullying is serious and in any way physical, direct parental and school involvement is essential. It is advisable in lesser situations for parents to not become directly involved but instead to support their children and teach them to speak up for themselves with confidence and conviction. Just as children practice responses to questions about their amputations at home, they should practice how to deal with encounters with bullies. If there is a situation at daycare or school that parents are working on with their children, it is important to ensure the daycare or school personnel are aware of it, too, and that you also have their co-operation and support in addressing it as appropriate on their end.

Many amputees in high school and beyond report that when you build your confidence over time, bullying becomes less of an issue at this period. In fact, many amputees say their peers express admiration towards them.

To reiterate, bullies pick on people who are different, but differences are what make the world interesting, so continue to teach your children to be proud of their differences. It is an ongoing lesson they will continue to grow stronger from. Ultimately, strong self-confidence is the best defence against bullying.

Taking the Sting Out of Bullying

Some schools are implementing anti-bullying campaigns, and parents might suggest helping implement one if there is not one already in place. These are great ways to develop a positive, tolerant atmosphere in your child's school! A few helpful web resources include:

The Canadian Safe School Network
canadiansafeschools.com

bullying.org

Government of Canada – Get Cyber Safe
getcybersafe.gc.ca

The Teen Years

Whether a person is an amputee or not, the teen years present very specific challenges and milestones. By being aware of the issues and how their teen's amputation may affect the issues, parents of teenage amputees can support their teen in many positive ways.

Body Image and Dating

It is during the teen years when young people develop their individuality and establish their independence. At this time, friendships and peer pressure assert a great influence. Although we discuss body image in this section on teens, body image concerns can arise even earlier for some children. Children in the pre-teen and teen years often wish to be just like their friends in every way. They want to fit in and not be different. They are often very critical of themselves and focussed on their physical appearance.

It is not uncommon at this stage for child amputees who were self-assured as younger children to suddenly seem to lose their confidence and self-esteem. Children who were once open about their amputation may now try to hide it and refuse to wear shorts or T-shirts, which would make their amputation visible. They may even stop taking part in certain activities in which the amputation would be seen, like swimming at a pool party.

Parents can be reassured that these feelings are normal. Such feelings of embarrassment are simply a part of adolescence, and some amputees will experience the feelings more intensely than others.

Usually, by the time amputees reach their mid-to-late teens, most will once again become more comfortable with their amputation. One amputee who is now an adult summed it up like this: "When I was a young teenager I found I didn't have a lot of confidence in myself, whereas when I was a really young kid, I had kind of an attitude that if somebody didn't like me for who I was, that was their problem. And I got back to that attitude when I hit about 16 or 17. I became more comfortable and accepting of who I was."

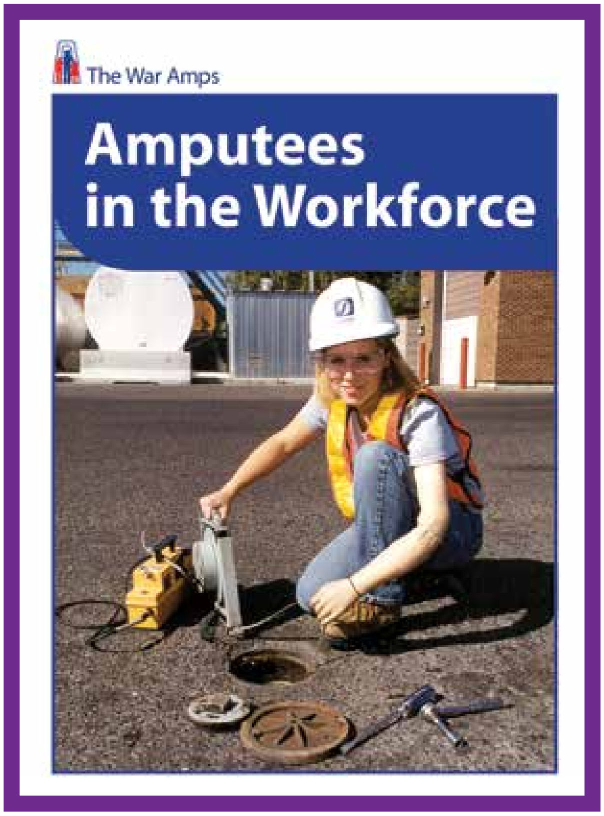
There are several key points to dealing with amputee body image issues. Firstly, although parents ache to make everything alright for their children, they must accept that resolving body image issues may just take time and the amputee may simply need to outgrow them. Secondly, body image issues become a problem requiring concrete action when amputees allow their feelings to keep them from participating in activities they like. And thirdly, seeking contact with other teen amputees to act as role models is often the best support for your teens; providing them with positive opportunities to interact with other teenage amputees allows them to have that connection they crave with people their own age who are just like them.

Directly linked to the issues of body image is dating. Young amputees may fear being rejected because of their amputation. Teen amputees who have become generally comfortable about their amputation in social situations may still feel uncomfortable when it comes to dating relationships. The truth is that some young people at this age are indeed superficial and would not date an amputee but the good news is that such individuals are a tiny minority. The positive experiences shared by amputees far outweigh the negative.

Older amputees have found that the support of close friends and family and interactions with other amputees who have had similar experiences is important in helping them navigate these waters. Hearing about and meeting adult amputees who are in intimate relationships and who are raising families of their own provides reassurance to parents and teenage amputees that this can be yet another normal part of life for them, too.

Employment

It is during a person's teen years when a lot of thought is given to career choices and many teens decide what career direction they would like to follow. Also, during these years, many teens take on their first part-time and summer jobs.

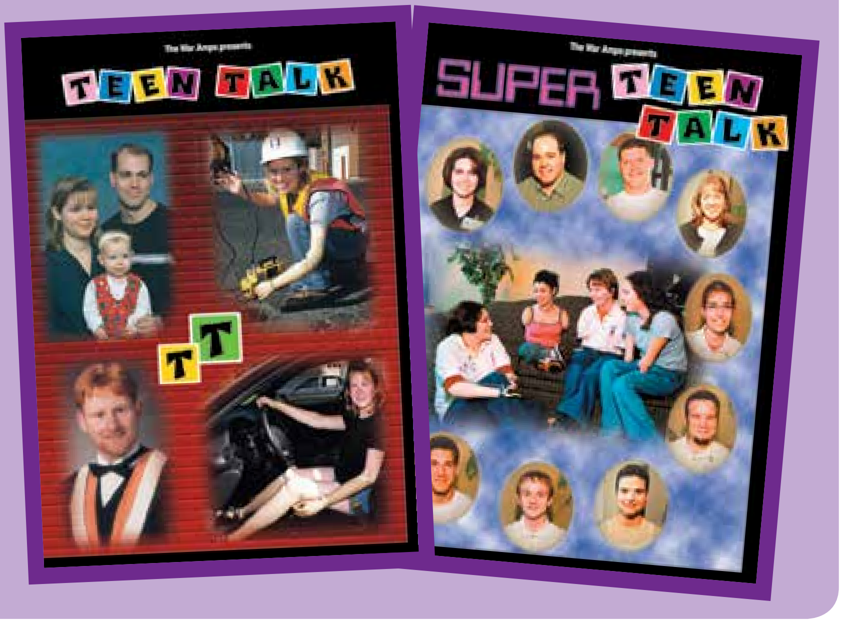


Teen Talk and Super Teen Talk Videos

A great resource for pre-teens, teens and parents is the Teen Talk DVD. In it, the teenage amputees and young adults share their insights and experiences on topics common to teen amputees, including:

- *Amputees and the School Years*
- *Relationships and Body Image*
- *Amputees Join the Workforce*
- *Amputees Go Driving*

The Super Teen Talk DVD, geared towards amputees with multiple amputations, is also available. In it, Super Champs (members of CHAMP with multiple amputations) discuss their unique challenges and, in addition to discussing the same topics as those in the Teen Talk DVD, also discuss becoming independent and living on their own.



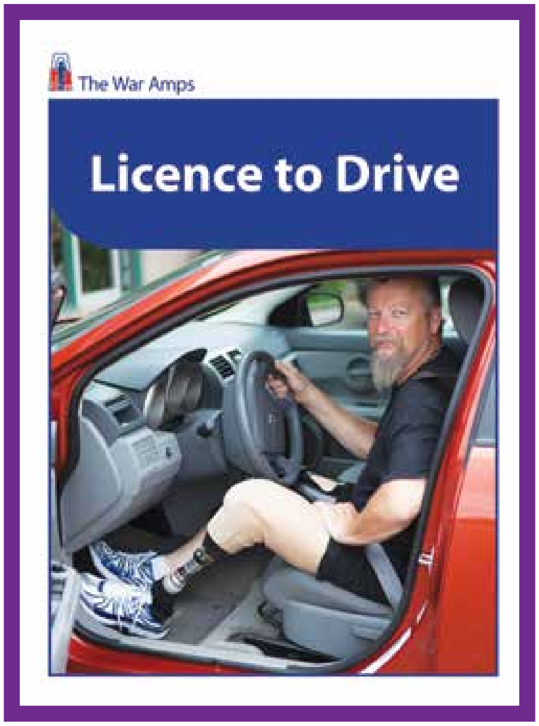
Amputees are always pushing the limits when it comes to their physical achievements and one should never say never when considering the types of careers that an amputee might follow. It is important for each amputee to realistically assess his/her physical capabilities when considering possible career options.

A great resource for teen and young adult amputees who are about to enter the job market for the first time and/or who are considering their future career is the *Amputees in the Workforce* booklet. Some of the topics it covers are: choosing a career, dealing with employer prejudice, disclosure about the amputation and special equipment and accommodations on the job. The advice in the booklet will help make getting a job a positive and exciting prospect for the amputee. The booklet can be obtained through The War Amps National Amputee Centre.

Driving

Getting a driver's licence is an important milestone that is eagerly anticipated by most teens. Driving is also a practical means of independence and mobility for many amputees.

Driving is a privilege and a responsibility that brings with it many rules and requirements including those that pertain to individuals with disabilities, including amputations. Since driving is under provincial regulation, requirements can vary from province to province, and oftentimes amputees report varied experiences within the same province.



The *Licence to Drive* booklet contains information to help amputees take this exciting step. The booklet outlines the process to follow in obtaining a licence, the documents that may be required during the process, the many types of vehicle adaptations that are available and the locations where you may obtain driving devices and have them installed. The booklet can be obtained through The War Amps National Amputee Centre.

The fact is that with the many types of vehicle adaptations available, driving is possible for the vast majority of amputees.

Conclusion

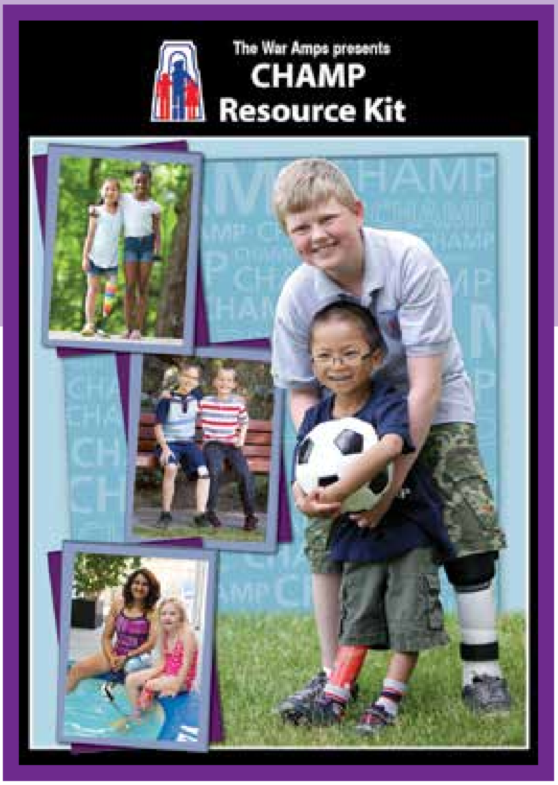
The parents of child amputees are not alone in dealing with the challenges they face in raising their child. With the right support, parents are able to meet the challenges head on and in a positive way.

Remember that the CHAMP Program and the National Amputee Centre have many resources available to help you and your child through the many stages of childhood and the teen years. These are free of charge to members of the CHAMP Program and include:

- CHAMP Seminars
- Counselling – Matching Mothers and Junior Counsellors
- Inspirational videos, including those in the CHAMP Resource Kit and Teen Talk DVD
- Starting School Kit
- Information booklets, including *Amputees in the Workforce*, *Licence to Drive* and *Pain and Phantom Limbs*

The Inspirational Winner's Circle Profiles

The War Amps produces Winner's Circle Profiles that are shared with the public. Each three-minute profile depicts a specific Champ who represents the Winner's Circle philosophy. These videos provide encouragement and inspiration to the public and to CHAMP families. You will find a compilation video of the Winner's Circle Profiles included in the CHAMP Resource Kit.



Glossary

"Amputees helping amputees" – the cornerstone of The War Amps tradition. Through peer support and counselling, amputees share their experiences with others.

Acquired amputation – a limb(s) is removed/lost due to a traumatic accident or an amputation that is necessary to treat a disease or illness

Amputee – a person who has had all or part of a limb(s) removed or is born without part of a limb(s)

Amputation – removal of all or part of a limb(s) due to injury, disease or illness

Champ – a member of The War Amps Child Amputee Program

CHAMP Program – The War Amps program for Canadian child amputees

Congenital amputee – a child born missing a limb(s)

Health-care professionals – a team of professionals involved in caring for an amputee (see descriptions of each profession starting on page 7 of this booklet)

Junior Counsellor – experienced member of the CHAMP Program who volunteers and shares their valuable insights with younger Champs and their parents

Prosthesis – an artificial limb

Prosthetist/Prosthetic Technician – professional who designs and fabricates artificial limbs

Residual limb – the part of the limb remaining after the amputation

Revision surgery – surgical alteration of the residual limb to improve function or appearance

Socket – the part of the prosthesis (artificial limb) that fits around the residual limb

Sound limb(s) – limb(s) that does not have an amputation

Thalidomide – medication prescribed in the 1950s and 60s that resulted in congenital amputations

Winner's Circle philosophy – Champs are encouraged to accept their amputation(s) and develop a positive approach to challenges.