



Step by Step Through Year One

You may be the parent(s) of a new-born child amputee or the parent(s) of a child that has recently undergone an amputation due to an illness (such as cancer) or an accident. While you will face unique issues in your new journey (depending on how your child came to be an amputee), many experiences are similar to those experienced by other amputee families. In the beginning, amputation, and the issues surrounding it, may feel overwhelming, a little frightening and even intimidating.

In this article we aim to take you through several stages that are commonly experienced by new amputees and their families. However, it is important to bear in mind that each family's experiences are unique and may vary from those outlined in this article.

Step One – Feelings and Reactions

New-born Child Amputees

(referred to as “congenital amputations”)

A congenital amputation may present itself during an ultrasound that an expectant mother undergoes. While this, in some ways, gives you time to begin to adjust to the news and to do initial research into amputation, you still have very strong emotions to deal with. Knowing in advance that your child will be born missing a limb can sometimes place an added worry in the minds of expectant parents, on top of all the usual issues that pregnancy presents.

Because amputations are often hard to detect on an ultrasound (as the limb may be hidden from view or it may just not be clear) it is more likely you did not know in advance that your child was going to be born

with a congenital amputation. The amputation was something you learned of at birth. In either case you may experience many feelings at this time – sadness, anger, frustration, worry and guilt or blame.

These feelings and emotions are **very normal**. As parents you may also search for answers to explain why this happened to your baby. Unfortunately, there are no real answers to these questions. Most professionals agree that congenital amputations are rarely the cause of anything that can be pin-pointed (unless a syndrome is also involved). During these early, and perhaps challenging, days it will help to talk about your feelings. Knowing you are not alone in facing these concerns and issues is important. The CHAMP Program can help with wonderful resources like the Matching Mothers Program.

At the end of the day, celebrating the birth of your beautiful baby will become your main focus – you may be surprised at how resilient you are. Looking towards the future and what you can do to help your child is a positive approach.



Child Amputees Due to Illness or Accident

Your child may recently have undergone an amputation, due to illness or because of an accident, in which case you and your child will be coping with many difficult issues. Having your child hospitalized to undergo an amputation is an extremely frightening experience.

Young children do not express emotions and feelings in the same way as adults do so it may be hard for you to gauge exactly how your child is feeling. Children, especially very young children, may not understand why an amputation is necessary – perhaps even thinking it is happening because they did something wrong. It is important to explain, in very simple terms, to your child why an amputation is necessary. Your child will experience many feelings and emotions and may go through varying stages of denial and acceptance. Some children quickly accept the amputation, while others need more time to adjust. Commonly children may feel shock, anger, depression and sadness. Sometimes children cannot express these emotions verbally but may show you through their actions how they feel. Your child may seem to be angry with you or become quiet and withdrawn. Having said that, children are extremely resilient and adaptable. Parents often tell us how amazed they are by their child's "let's get on with things" attitude. Children commonly want to get back home to a normal life as quickly as possible.

During this time, even though as parents you will be experiencing many of the same emotions as your child, you need to present a positive and united front to your child. Your actions and reactions will affect your child's attitude. Children pick up on what they sense around them and react accordingly. When parents see amputation as a tragedy and react negatively, children tend to do the same thing. Your own emotions and concerns need to be expressed – allow time for yourself to work through your feelings.

Step Two – Early Days (first weeks and months)

In these early days, together with a team of professionals, you will develop a "plan of attack" for the future. Where you live – whether in a city or town or in a more remote rural area – may have a bearing on the approach that is decided upon. Here we provide you with a general idea of the process you will go through, but keep in mind that the approach you and the team of professionals involved in your child's care decide to take will be very individualized to best suit your needs.

In your journey as parents of an amputee child you will encounter many medical/rehabilitation professionals along the way and you may feel a little intimidated starting out. To make the best use of the time during your appointments with these professionals, it is a good idea to write down any questions you can think of in advance of your appointments. You do not want to forget anything. Taking notes during these meetings that

you can refer back to later is also helpful – with so much information coming your way these notes can be reviewed when you have more time. At the start of your journey you will experience many different emotions

and, at times, may be confused so taking notes can certainly help you to keep all the information straight. Remember there is no such thing as a stupid question – all the professionals you encounter are there to help you. Only by having your questions answered will you feel comfortable about the care your child receives.

The professionals you encounter along the way, either at the hospital or at a specialized centre, can include:

Orthopedic Surgeon – this surgeon performs the actual amputation surgery or does an assessment and examination of a congenital amputee. Recommendations will be made concerning any necessary rehabilitation therapy, prosthesis and physio or occupational therapy.

CHAMP can arrange a match for you with another family who has "been there" which often helps at this time. Whether your child is a newborn or had just undergone (or will be undergoing) an amputation another CHAMP family can provide you with the reassurance that while there may be challenging days, there is support along the way.

Nurses – nurses sometimes act as coordinators and will likely be the professionals you deal with most frequently at the beginning.

Physiotherapist – physiotherapists (PTs) work with amputees through the rehabilitation process, through exercise to improve muscle function and often help an amputee learn to walk with an artificial limb (gait training).

Occupational Therapist – occupational therapists (OTs) work with amputees to teach them how to use an artificial limb (such as a myoelectric arm) and can also teach them adaptive skills.

Social Worker – a social worker can help with family counselling and provide much useful information on resources available to child amputees and their families.

Prosthetist – the prosthetist is the professional who makes the artificial limb (prosthesis) – see Step Three.

Time to Go Home

For new-borns (congenital amputees) and their families, leaving the hospital and going home will be within the usual timeframe unless there are other medical issues being addressed. A plan for the future may be reached at this stage with the clinic team or a referral may be made for later. If at any point you are not sure what, if anything, should be your next step it is best to check with one of the professionals you have encountered along the way. Many children are fitted with a prosthesis at a very early age. For leg amputees a prosthesis is fitted when the child begins to pull himself/herself up, wanting to take those first tentative steps. Arm amputees can be fitted with a simple prosthesis at just a few months of age to help with balance while learning to sit up. An early fitting also allows the child to incorporate the prosthesis into their own body image.

Children who have undergone amputation surgery will go through a rehabilitation process. Following the amputation there will be a “healing phase” during which time the incision and surrounding tissue will recover. The clinic team will evaluate how soon it may be possible and advantageous for your child to be fitted with a prosthesis. Occasionally, though not a common practice, a temporary leg prosthesis is built right into a cast on an amputated limb so that the amputee can

start walking at the earliest possible time in the rehabilitation process. The healing timeframe can vary quite widely between a matter of weeks or even a couple of months or more depending on the type of amputation, how much scar tissue may be involved and how the limb has healed (part of that healing involves promoting stump shrinkage. Swelling is always an issue after surgery and bandaging the stump with tensors or using a stump shrinker helps with this). Therapy on the use of crutches or a wheelchair are done before the amputee leaves the hospital if those are required.



Step Three – Time to See The Prosthetist to Get a Prosthesis

The prosthetist (with the help of prosthetic technicians) is the professional who fabricates a prosthesis for an amputee. The clinic team, working with you, recommends the type of fitting appropriate (depending on the level of amputation) for your child and a prescription will be provided to the prosthetist. In many cases (especially in larger centres) the prosthetist attends a clinic right at the hospital at which the child and parent(s) and the other rehabilitation professionals are present. Sometimes you are referred to a certain prosthetic facility. It is important to remember that you have the choice of which prosthetic facility in your province you will attend to have your child fitted.

There are several steps to being fitted for a prosthesis:

- Measuring the limb
- Making a cast of the residual limb (some facilities use equipment to “scan” the shape of limb)



Photo: Smith Prosthetics

- Temporary prosthesis (for amputees still going through rehabilitation following an amputation while the shape of the limb continues to shrink and change shape – does not apply to congenital amputees)
- Fitting of the “Definitive” (for permanent use) Prosthesis

Arm Amputees

As mentioned earlier, a child can be fitted with a passive hand (with no function, see below) prosthesis as early as three to six months of age. This kind of arm would be a very simple fitting to get your child used to wearing a limb and help with balance as the child begins to sit. An older child (or as a congenital amputee grows up) will often be fitted with a different type of artificial arm, one that provides more function. A myoelectric arm, in which signals from muscles in the residual limb are sent via electrodes to the prosthetic hand to open or close it, is powered by a battery. A body-powered prosthesis uses a cable and harness system – by using shoulder muscles and movements the cable is pulled to open (voluntary opening) or close (voluntary closing) the hand. Making the right choice will ultimately depend on the desired level of function and the look (cosmetic appearance) of



the prosthesis. Different terminal devices (which replace the function of the hand) may also be recommended depending on the type of function preferred. It is not uncommon for a child to move from one type of device to another as he/she grows and needs change.

Sometimes a regular prosthesis is not worn every day, but the amputee has devices only for certain activities and/or uses a variety of daily aids or develops their own adaptive techniques to carry out tasks. It’s important to familiarize yourself with the options and CHAMP can provide information on those.

Leg Amputees

The age, type of amputation and activity level of your child will influence the type of artificial leg fitted and the components chosen.

An **exoskeletal** prosthesis has a hard outer shell made primarily of plastics and laminates.

An **endoskeletal** or modular prosthesis has the tube or pylon frame that acts as a type of “skeleton.” A soft foam cover is usually applied over the prosthesis. The foam cover is shaped to match the remaining sound limb.

There are many different components – feet, ankles, knees, hip joints etc. which vary in complexity.

For more detailed information on prostheses and how they work, visit our website: waramps.ca or e-mail nac@waramps.ca



Learning to Use a Prosthesis

Physiotherapists and Occupational Therapists usually become involved to teach the child how to wear and use their prosthesis. They will use various activities during this training – some examples are:

Arm amputees can learn to open and close the terminal device and grasp objects; learn how to use a knife or fork or to hit or catch balls. Tasks are geared to the appropriate age level.

Leg amputees can learn how to put on and take off (doff and don) their prosthesis, to practise walking between parallel bars and with crutches (in the early stages), to manage stairs and walk on uneven ground.

Step Four – You Are Fast Becoming An Expert!

During the first year you will acquire a great deal of knowledge about amputation and deal with many professionals involved in your child's care. There is a great deal to handle and you may at times feel overwhelmed but this should not take away from your sense of accomplishment as you have navigated through previously unexplored waters with your family.

After that first year, you can reflect with pride on how far you and your child have come in your journey.

You must remember that children outgrow a prosthesis at a similar rate to which they outgrow their clothing, making adjustments or new fittings necessary.

Developing a good relationship and being open with your prosthetist is very important. By discussing your expectations with your prosthetist and clinic team the most appropriate prosthesis will be fitted. Do not feel overwhelmed – just learn as you go along and from the support and resources at your fingertips.

Stump care and skin hygiene are also very important to maintain. Your child has to build up a tolerance to wearing a prosthesis, usually that means starting out

wearing the prosthesis for a short period and gradually increasing the time. Your child may experience some discomfort, skin rashes or minor abrasions early on. It is important to be clear on what to expect. Persistent problems and areas that do not heal should be brought to the attention of your clinic team as they may indicate the current prosthesis is no longer fitting and changes are needed or possibly indicate other underlying issues.

As time goes by and your child goes through each development stage, new issues and concerns will arise. A good example is when your child first starts school or daycare and will meet many new children all at once. Other children will naturally be curious about an amputation and/or artificial limbs and will have questions. CHAMP has developed the Starting School Kit to enable parents to go into the classroom and give a positive presentation on amputation and artificial limbs. Also, when children enter their teenage years issues such as body image, finding employment and learning to drive will arise. As you and your child move through the stages of development, CHAMP is always there as a guide and has many resources available. All resources are provided to our CHAMP families at no charge, call CHAMP at **1-800-267-4023**.

Resources for you...

- **CHAMP seminars** – At a seminar, you can meet other parents and child amputees (Champs) and attend informative sessions. *A weight was lifted from our shoulders*, many parents have said after attending a Seminar.
- **Matching Mothers Program** – a match can be set up for many different reasons.
- **Resources and kits** like *CHAMP Newsletter* (automatically mailed to all Champs), the Starting School Kit, and Teen Talk videos are some of the free resources available to you.