

## FACT SHEET 7

# Hygiene, Phantom Pain and Phantom Sensation

Maintaining the health and wellbeing of you and your child with limb difference is very important. Ensuring that your child's physical health is positively managed is the key to maintaining good health and reducing preventable issues in the future.

This Fact Sheet provides information about: hygiene and residual limb care; phantom pain and phantom sensation; and, accessing support.

## Hygiene and residual limb care

Maintaining the health of your child's residual limb is extremely important. Hygiene is paramount to preventing problems.

If your child uses a prosthetic liner it must be washed / cleaned on a daily basis with a mild non-fragrant soap or cleaned with a damp cloth and left to dry. Stump socks should be changed and washed / cleaned daily.

Some children with limb difference can experience skin problems and breakdowns on their residual limb. This could be due to a number of different factors such as heat and perspiration building in the airless socket, bacterial or fungal infections, pressure or friction.

Some common skin disorders include: general irritation or rashes; dermatitis or allergies related to cleaning agents; skin products or prosthetic materials; skin swelling; cysts resulting from rubbing of the prosthetic limb against skin; scar tissue due to wound healing; and, breakdowns resulting from bacterial infection.

Parents and children should check the health of their residual limb on a regular basis and a small hand mirror can be helpful to achieve this. Ingrown hairs can pose a problem for some teenagers with limb difference so it is recommended that your child not shave or wax their residual limb.

If you have any concerns with regard to the maintenance of healthy skin or your child experiences any changes contact your doctor or Prosthetist immediately.

## Phantom pain and phantom sensation

Some children and young people that have an acquired amputation may experience 'phantom pain' or 'phantom sensation'. This means that the child feels and thinks that the lost limb is 'still there'.

Phantom pain or phantom sensation can last a lifetime or subside over time, and most persons who have lost a limb due to amputation will experience it at least once.

When only feeling, and no pain, is felt it is referred to as phantom sensation (eg. your child may experience pins and needles in the foot / hand that no longer exists or feel the need to scratch a shinbone that is no longer there).

Phantom pain and phantom sensation can range from mild to severe, brief to lengthy in duration, and can be very distressing for children and parents. It can be debilitating and draining, and should not be dismissed.

If your child is experiencing phantom pain or phantom sensation it is a good idea to let educators or others know that it is something your child may experience from time to time. That person may not have heard of it before so you may need to explain what phantom pain and sensation is to them.

If your child does experience episodes of phantom pain it is best that you discuss these issues with your health care providers so they can assist with developing a treatment plan for your child.

There are a number of alternative means for treating phantom pain including: massage; acupuncture; acupressure; and, hot / cold compresses. Your Prosthetist is often the best person to speak to about any pain or discomfort being experienced by your child and ways of addressing it.

Many Universities continue to carry out studies on phantom pain in order to better understand it and find more effective ways of managing it.

## Accessing support

If you or your child need assistance with hygiene and residual limb care matters, phantom pain or phantom sensation issues speak to your health care professionals as soon as possible.

If hygiene, phantom pain or phantom sensation is an issue you may want to speak to a Limbs 4 Kids team member who can assist you. You may also want to speak to another parent who has experienced what you are going through. If so, Limbs 4 Kids can connect you to a trained Peer Support Volunteer who you can speak to you. Visit our website or call us for more information and links to our online support.