



2019

## Pain Management Resource Guide for Caregivers of Children with Phantom Limb Pain

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Pain Management Resource Guide for Caregivers of Children with Phantom Limb Pain

by

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A Scholarly Project

Submitted to the Occupational Therapy Department

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Master's of Occupational Therapy

Grand Forks, North Dakota

May 2019

Approval Page

This Scholarly Project Paper, submitted by Micaela Monn, OTS and Amanda Steffen, OTS in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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December 10, 2018

Date

## PERMISSION

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## **ACKNOWLEDGEMENTS**

The authors would like to thank Dr. Lavonne Fox for her guidance throughout the development of this scholarly project. Her positivity and encouragement supported our learning and enthusiasm for helping children with phantom limb pain and their caregivers.

## **ABSTRACT**

Approximately 80% of children, under the age of 18, develop phantom limb pain within one year after receiving an amputation (Burgoyne, Billups, Jiron, Kaddoum, Wright, Bikhazi, Parish, & Pereiras, 2012; Krane & Heller, 1995). Research on treating phantom limb pain has been focused on the adult population and often includes the use of pharmacological interventions (Subedi & Grossberg, 2011). Because phantom limb pain can cause psychological and physical dysfunction, it can negatively impact a child's ability to engage in everyday life. Currently, no holistic treatment guides are available for caregivers to refer to when helping their child manage his or her phantom limb pain. The P.L.P. (Play Learn Persevere) is a resource guide created for occupational therapists to give to caregivers of children with phantom limb pain. This product is intended to be introduced by occupational therapists working in acute care settings with children who have undergone a unilateral amputation. The P.L.P. is designed to help caregivers manage their child's phantom limb pain by using the physical and psychosocial activities provided in the resource guide.

## **CHAPTER I**

### **Introduction**

Approximately 80% of children, under the age of 18, develop phantom limb pain within one year after receiving an amputation (Burgoyne, Billups, Jiron, Kaddoum, Wright, Bikhazi, Parish, & Pereiras, 2012; Krane & Heller, 1995). Phantom limb pain is caused by the brain sending signals to the missing limb. Because the limb is missing, it cannot send feedback to the brain to tell it to stop sending these signals. The result is pain felt in the missing limb, which can range from moderate to severe (Burgoyne et al., 2012; Wilkins et al., 2004). The psychosocial impact of phantom limb pain can include anxiety, depression and post-traumatic stress disorder (PTSD) (Khan et al., 2016). No caregiver-directed interventions currently exist for children and their caregivers to perform at home after discharge from the hospital, outpatient or rehabilitation setting. A caregiver-directed resource guide was developed to help families manage their child's phantom limb pain once home from the hospital. The P.L.P implementation process begins with the occupational therapist reviewing the P.L.P with the caregiver at the hospital pre-discharge. The caregiver will then be able to confidently use the P.L.P. at home to reduce their child's phantom limb pain in the absence of a skilled therapist.

Several factors could influence the application of the Play Learn Persevere (P.L.P.) product. Because phantom limb pain is not experienced by all, this product might not be applicable to every child. There are various tasks within the product and the feasibility of each largely depends upon the needs of the child. The product contains modifications to provide relief for both children with unilateral upper extremity amputations and lower extremity amputations.

Because phantom limb pain affects both the body and the mind, the product includes tasks to address both the child's physical and psychosocial needs. Each task can be completed in an under an hour, making implementation convenient for busy families. Step-by-step instructions and visual aides are provided to create a user-friendly guide that can be easily understood by caregivers.

The Ecological Model of Human Performance (EHP) was used to guide the development of this product. The EHP consists of four components; person, task, context and performance (Dunn, 2017). The product focuses on increasing the child's performance range within their natural context, such as home or school. Each activity within the product targets one or more of the following EHP intervention strategies: establish/restore, adapt/modify, create, prevent and alter (Dunn, 2017). Activity instructions include suggestions for which contexts the activity could be used in, as well as which person factors are being addressed. The person factors include sensorimotor skills, cognitive skills and psychosocial skills (Dunn, 2017). It is the hope of the authors, that this resource guide will empower caregivers to address the pain management needs of their child in the absence of a skilled therapist.

### **Key Terms and Concepts**

1. **Coping Skills/Mechanisms:** The way we deal with stressful situations. These can be effective or ineffective (The Free Dictionary, 2018).
2. **Intact Limb:** The limb (either arm or leg) that was not amputated (The Free Dictionary, 2018).
3. **Mind-Body Connection:** Our thoughts, feelings and emotions can affect our body's physical functioning. The health of our mind can positively or negatively impact the health of our body (The Free Dictionary, 2018).

4. **Residual Limb:** The part of the amputated limb (either arm or leg) that remains after the amputation. This is also referred to as a stump (The Free Dictionary, 2018).
5. **Mindfulness:** Being in the present moment. Being aware of what is happening in the “now” and non-judgmentally accepting your thoughts, feelings and physical sensations (The Free Dictionary, 2018).
6. **Negative Self-Talk:** Your child thinking negatively about himself/herself or saying negative things about himself/herself (The Free Dictionary, 2018).
7. **Phantom Limb Pain:** Pain that feels like it is coming from a body part that is no longer there (The Free Dictionary, 2018).

Following this introduction is Chapter II, which contains an extensive literature review of current research regarding phantom limb pain and pediatrics. Chapter III addresses methodology, which describes the process the students used to design the scholarly project. Chapter IV is the product itself, which contains the resource guide for caregivers of children with phantom limb pain. An analysis of the product’s strengths, weaknesses and suggestions for improvement are described in Chapter V. The scholarly project concludes with a list of references used throughout the writing of the scholarly project.

## **CHAPTER II**

### **Literature Review**

#### **Introduction**

There is a lack of evidence regarding treatment of phantom limb pain within the pediatric population. Following an amputation, approximately 76% of children develop phantom limb pain in the residual limb (Burgoyne, Billups, Jiron, Kaddoum, Wright, Bikhazi, Parish, Pereira, 2012). For most children, this pain subsides within one year, however 10% continue to experience painful sensations after one year (Burgoyne, Billups, Jiron, Kaddoum, Wright, Bikhazi, Parish, Pereira, 2012). The brevity of the pain could be responsible for the lack of evidence for treatment during this time. Using a focused review, researchers determined that no randomized controlled trials on non-pharmacologic interventions for children with phantom limb pain had been conducted (DeMoss, Ramsey & Karlson, 2018). The authors found numerous research articles addressing phantom limb pain, but none specifically related to pediatric occupational therapy and a caregiver-directed pain management guide. The students found only one research study somewhat closely related to the topic of a caregiver-directed pain management guide. This was a home-based mirror therapy program designed for adults with phantom limb pain (Darnall & Hong, 2012). The program resulted in significant pain reduction after one month of using an instructional DVD. However, this study did not incorporate occupational therapists nor children (Darnall & Hong, 2012).

The literature review was conducted on topics related to pediatric phantom limb pain: definition of phantom limb pain, demographics and causation. The literature review identified

current best practices that provided the foundation for the development of a pain management resource guide for caregivers of children with phantom limb pain. The goal was to develop a guide, for caregivers, to help decrease their child's pain and increase their engagement in meaningful occupations.

### **Phantom Limb Pain - Pediatrics**

Phantom limb pain (PLP) is a condition characterized by neuropathic pain that stems from changes in the peripheral nervous system's axonal pathway, and is experienced by 45% to 85% of individuals following a limb removal surgery (Kuffler, 2018b). In other words, to compensate for the limb removal, the body forms new neuronal pathways to and from the central and peripheral nervous systems. As this process occurs, the individual experiences phantom sensations, either painful or non-painful, in the region of the body that was removed. The phantom sensations can occur for a brief period of time or develop into a troubling chronic condition with recurrent episodes of pain.

### **Demographics**

Approximately 20 million individuals within the United States are currently living with phantom limb pain (Kuffler, 2018a). Children are equally as susceptible to the unpredictable development of phantom limb pain as adults. However, research on this condition in the pediatric population is limited due to the misleading belief that a child's resilient nature will overpower the phantom phenomenon development. Early research revealed that 20% of amputees, under the age of 6, and 85.7% of amputees, over the age of 6, reported experiencing PLP (Wilkins, McGrath, Finley & Katz, 1998). Furthermore, Krane & Heller (1995) completed a chart review of children and adolescents, under the age of 18, who received an amputation between 1980 and 1990 at two tertiary-care hospitals in Puget Sound. Results from the chart review revealed



documented reports of PLP in 83% of charts (Krane & Heller, 1995). While 19<sup>th</sup> century research proclaimed there to be a high prevalence of phantom phenomenon post-amputation for youth of all ages, 20<sup>th</sup> century research asserts that the prevalence of PLP is actually less prominent in children under the age of 10 (Alexander & Matthews, 2010). The current trend in research is geared toward examining older children and adolescents in relation to amputation origins, yet, there is a dearth of literature on the domains of occupational therapy for children experiencing phantom limb pain.

The following section contains a comprehensive outline of amputation origins in relation to incidence, ethnicity, and location.

#### **Amputation Incidence**

- Highest in the age groups of 1-5 and 13-17
- Higher occurrence in boys than their girl counterpart

#### **Prevalence by Ethnicity**

- Higher rate of amputations in white children (69.9%) than any other ethnicity (12%)

#### **Amputation Location**

- Children experience more upper extremity amputations than lower extremity amputations, opposite of their adult counterpart
- Finger and Thumb: 54%
- Toe: 20%
- Amputations proximal to the hand: 5.9%
- Amputations proximal to the foot account for the smallest unidentified percentage
- Above Knee Amputation (AKA) and Below Knee Amputation (BKA): 14.8% of all amputations
- Most BKAs occur in children above the age of 12 (68%)
- Most AKAs occur in adolescents between the age of 16-17 (49%)

(Borne, Porter, Recicar, Maxson, & Montgomery, 2015)

Caucasian boys between the ages of one and five are at the highest risk for sustaining an amputation. Children typically receive more upper extremity limb removals than lower extremity limb removals. Common amputation sites for the upper extremity include finger, thumb and proximal to the hand whereas common lower extremity amputation sites are toe, above knee, below knee and proximal to the foot. As children mature into adolescents, the prevalence of above and below knee amputations increases significantly. Although amputations are commonly associated with the youth Caucasian male demographic, they can occur in any age group, ethnicity and part of the body, as can the development of phantom limb pain.

### **Causation**

Identified causes of upper limb and lower limb amputations in children are trauma, infection, tumors, congenital abnormalities, vascular abnormalities, machinery, motor vehicle accidents, off-road transportation and caught between two objects (Borne et al., 2015). One study further analyzed amputation origins in relation to geographical location. Results revealed that pediatric amputations in rural regions of the United States typically result from farm injuries, lawn mowers and high-tension wires (Le & Scott-Wyard, 2015). Aside from the variation of amputation causes among geographical regions, an additional discrepancy has been identified between the cause of amputation and age of the child. For instance, younger children's amputations are often caused by doors, tools and household injuries whereas the common causes of amputations for older children are power tools, bicycles, fireworks, burns, and gunshot wounds (Le et al., 2015).

Children typically encounter phantom limb pain, the first time, immediately following the amputation, but some children don't sense it until days, weeks, months, a year, or more than a year following the surgery (Wilkins et al., 1998; Krane et al., 1995). When children and

adolescents develop the phantom phenomenon, they typically reencounter it on a daily basis, with an average rating of moderately painful, for approximately one year (Burgoyne et al., 2012; Wilkins et al., 2004). Although this condition typically subsides after one year, 10% of children and adolescents continue to suffer from the effects of painful and non-painful phantom limb sensations (Burgoyne et al., 2012). Children with persisting PLP episodes after one year typically report that they are either equally as painful and frequent as they were post-surgery or are less severe and less frequent. Whether the mild to moderately painful experience lasts a year, or longer than a year, it's far too long for children to be suffering from the unmanageable pain associated with the phantom sensations.

Wilkins et al. (1998) found that 69.7% of participants with amputations resulting from cancer, trauma, and medical conditions reported phantom sensations and 48.5% reported phantom limb pain. Painful phantom limb pain sensations reported by children and adolescents include, but are not limited to, tingling, throbbing, piercing, aching, discomfort, and soreness (Wilkins, McGrath, Finley, & Katz, 2004). This endured pain has potential to disrupt the child's engagement in occupations meaningful to the pediatric population, such as play, education, sleep and ADLs. This persistent pain also creates an unnecessary barrier to engagement that can further limit the child's participation. Participation areas at risk include academic performance, social interactions with peers and family and daily routines. As the vicious pain cycle repeats itself each day, the child's ability to perform functional daily living tasks with independence slowly diminishes.

### **Psychological Impact**

Wilkins et al. (2004) identified a difference among gender for triggers of phantom limb pain in children. The researchers found that girls experience greater psychosocial triggers in

comparison to their boy counterparts, who by contrast, experience higher rates of physical triggers. Additionally, boys in the study experienced greater difficulty identifying the trigger for each documented phantom limb pain incident than the girl participants. Aside from highlighting triggers and their causes, the researchers also sought to identify additional influences affecting the development of PLP. Interestingly, a higher rate of painful sensations was documented in winter months than summer months, alluding to weather as a contributing factor in the manifestation of this condition (Wilkins et al., 2004).

It is also not uncommon for post-traumatic stress disorder (PTSD) to be observed in the pediatric amputee, as well as in the child's primary caregiver (Khan, Javed, Rao, Corner, & Rosenfield, 2016). Likewise, depression and anxiety have potential to develop after an amputation, either discretely or jointly, adding to the challenge of this complex, debilitating condition. Khan et al. (2016) found that 35.5% of amputees reported experiencing anxiety whereas 28.3% reported experiencing depression.

Psychosocial implications can also manifest from the stigma, prejudice and discrimination children face after receiving an amputation (Calheiros & Conti, 2017). The ideal body image reflected throughout society leaves children with missing limbs as outcasts and an easy target for childhood bullying. Furthermore, the consequences of an accentuated disability can result in strong emotions, alienation by peers and friends, self-isolation and a distorted self-image (Calheiros & Conti, 2017). In a study by Calheiros & Conti (2017), 4 children with amputations between the ages of 9 and 12 reported their perceived body image to have a direct, negative impact on their participation in desired social groups or activities, thus diminishing their overall sense of self. The consequences of a distorted self-image, stemming from imbalances between the child and the child's environment, can further limit the child's ability to effectively

maintain control over the recovery and self-management process. To compensate for changes in the child's wellbeing after the onset of phantom limb pain, caregivers turn to healthcare professionals for assistance with treatment options.

### **Current Treatment Approaches**

Currently, there is no gold standard treatment protocol for phantom limb pain, however, the most common treatments involve a multidisciplinary approach. This multidisciplinary approach will be broken down throughout the next section which often includes a team of pharmacists, physicians, psychologists, physical and occupational therapists (Subedi & Grossberg, 2011).

#### **Pharmacological Treatments**

Medications such as opioids, anti-convulsants, anti-depressants, analgesics and anesthesia have been administered in the treatment of phantom limb pain. There have been mixed results in the efficacy of anti-depressants and anti-convulsants in treating PLP, thus more research needs to be done to determine their effectiveness (Subedi & Grossberg, 2011). The most common medications used are acetaminophen and non-steroidal anti-inflammatory drugs (Subedi & Grossberg, 2011). When considering medications, researchers suggest that the benefits outweigh the risks of developing an opioid dependence or the possibility of developing stomach ulcers and renal failure from long term anti-inflammatory use (Baron, Wasner & Linder, 1998). Despite the current opioid epidemic, more recent recommendations are limited regarding use of opioids for pediatric pain.

In 2016, the Center for Disease Control (CDC) created new guidelines for prescribing opioids to chronic pain patients, excluding those experiencing cancer, palliative or end of life care (Schechter & Walco, 2016). However, the CDC guidelines were only intended for

individuals 18 years and older, neglecting children and adolescents. Pediatric pain research could be sparse due to the ethical dilemmas many researchers face when conducting studies on such a vulnerable population (Schechter & Walco, 2016).

### **Surgical Treatment Approaches**

Surgical procedures are used as a last resort, while more holistic approaches are applied first. Surgeries include dorsal root entry zone lesions, rhizotomy, chordotomy, thalamotomy and neurectomy. These surgeries involve the removal or destruction of areas within the central nervous system (CNS). These invasive procedures have been shown to provide short-term pain relief, but many patients experience an increase in pain later on (Baron, Wasner & Linder, 1998).

### **Non-Invasive Treatment Approaches**

Among the less invasive approaches are transcutaneous electrical nerve stimulation (TENS), acupuncture, relaxation techniques and cognitive behavioral therapy (Subedi & Grossberg, 2011). Each of these are briefly presented in the following paragraphs.

TENS has been shown to decrease PLP in some patients (Baron, Wasner & Linder, 1998). The TENS unit applies vibratory stimulation to the peripheral nervous system through electrodes placed on the skin of either the residual or contralateral limb. In a study of 24 patients with PLP, the researchers determined that 75% of patients receiving TENS experienced a decrease in pain during the treatment session. TENS is non-invasive, portable and simple to repeat, making it a safe alternative to medications or invasive procedures (Baron, Wasner & Linder, 1998).

Relaxation techniques can include hypnosis, guided imagery and biofeedback. Hypnosis is a state of processing information using involuntary cognition rather than conscious efforts of thinking (Subedi & Grossberg, 2011). Guided imagery is the use of one's imagination and

perception of all senses to promote healing and relaxation. This is usually performed with a therapist who provides appropriate feedback as the patient describes what they are imagining or perceiving (Subedi & Grossberg, 2011).

Biofeedback is a self-regulatory method of controlling pain and other physiological responses through visual or auditory feedback. Mirror therapy is a visual example of biofeedback and will be discussed in greater within the next section (Subedi & Grossberg, 2011).

Acupuncture is a method used traditionally in Chinese medicine. Thin needles are inserted into the skin to stimulate certain parts of the body and this is thought to have an analgesic effect on PLP (Bradbrook, 2004).

Cognitive behavioral therapy (CBT) is a psychological approach that helps patients change faulty thinking and thereby, change their behavior and emotional response (American Psychological Association, n.d.). Authors, Moura, Faurot, Gaylord, Mann, Sill, Lynch and Lee (2012), completed a literature review on the mind-body interventions used to treat individuals with amputations experiencing PLP. The authors believed that the connection between the mind and the body was a crucial concept when understanding PLP and considering effective treatments. The authors point out that there is strong research supporting the belief that the brain can have powerful effects on the body's physiological response, and in turn, can reduce pain and stress. The authors discovered that hypnosis, biofeedback, guided imagery and mirror therapy all showed some promise in reducing PLP in the short-term and/or long-term (Moura et al., 2012).

### **Mirror Therapy**

A simple and cost-effective intervention for reducing phantom limb pain is mirror therapy. The mirror box was first invented by Dr. Vilayanur S. Ramachandran to relieve

phantom limb pain (Ramachandran, V.S. & Ramachandran, D.R., 1996). Dr. Ramachandran placed two mirrors on either side of a topless box. The patient places their existing arm into the box and the mirror creates the visual illusion that the missing limb still exists. According to Dr. Ramachandran, this illusion has a powerful effect on the brain, and it signals to the brain that the missing limb is now moving correctly. This provides the brain with feedback that it should stop sending signals to the missing limb, thus reducing the phantom limb pain. From this original study, Dr. Ramachandran concluded that the brain is more dynamic than hierarchical, and new pathways can be formed within two to three weeks of mirror therapy (Ramachandran, V.S. & Ramachandran, D.R., 1996). Dr. Ramachandran also concluded that the visual imagery of the mirror box allowed patients to unclench the feeling of a clenched phantom hand (Ramachandran, V.S. & Ramachandran, D.R., 1996). Many researchers have since used Dr. Ramachandran's idea of the mirror box to treat phantom limb pain and stroke. Two of these studies will be discussed within the next section.

More recently, occupational therapists have been using mirror therapy to improve upper extremity function in patients who have experienced a stroke. One study determined that an at-home mirror therapy intervention was successful in improving function for a 63-year old man who had recently suffered a stroke (Nilsen & DiRusso, 2014). An occupational therapist met with the man prior to beginning a 5-week mirror therapy intervention. Before the start of the intervention, the occupational therapist educated the participant on proper use of the mirror box based on relevant mirror therapy literature and modified to meet the participant's needs. The design of the program was participant-directed, but the occupational therapist stopped by the man's home once a week for thirty minutes to assess his performance, provide suggestions and answer questions. The participant engaged in 30-45 minutes of mirror therapy 4-6 days per week.



Three outcome measures were administered pre and post-treatment to assess pain and hand function. The results indicated that the participant experienced decreased pain, increased sensation and increased hand function at the end of the five-week program. The researchers concluded that mirror therapy can be successfully used by motivated clients within their home environment (Nilsen & DiRusso, 2014).

Another study was conducted to test the efficacy and feasibility of a home-based mirror therapy program, which the patients directed. The authors hypothesized that the majority of subjects would engage in patient-directed treatment (Darnall & Hong, 2012). Subjects were given a binder or a 7-minute DVD, both providing specific and consistent instructions on how to perform mirror therapy. Subjects were given a mirror, diaries and postage to mail in their diaries at month 1 and month 2. Subjects were instructed to engage in 25 minutes of mirror therapy per day. The study coordinator called each participant weekly to confirm that they were participating in the treatment. The results indicated that a patient can experience pain reduction between 15%-100% using a patient-directed mirror therapy treatment. The more educated an individual was, the more likely they were to self-direct treatment. The authors pointed out that severely depressed patients might fare better with in-person therapy directed by a skilled therapist to increase self-efficacy and motivation (Darnall & Hong, 2012).

## **Phantom Exercises**

One study implemented a phantom exercise program led by a physiotherapist to determine if phantom limb pain could be reduced both in the clinic and at home in the absence of a skilled therapist (Ülger, Topuz, Bayramlar, Şener, & Erbahçeci, 2009). Twenty individuals with traumatic amputations were divided evenly into the experimental group or the control group. The control group received a 4-week general exercise program and prosthetic training led by a physiotherapist. The experimental group met with a physiotherapist for four weeks and underwent prosthetic training as well but learned phantom exercises rather than general exercises. During the phantom exercises, the physiotherapist asked the participant in what position they were experiencing phantom pain and asked them to place the existing limb in the same position they felt the amputated limb. The participants were asked to move their limbs in opposite directions and return to the previous position. This exercise was repeated 15 times or until the phantom pain subsided. The participants were asked to repeat these exercises if the pain returned. All participants were discharged after four weeks and asked to continue the exercises on their own following a home exercise program. The researchers telephoned participants for a two-month follow up to determine compliance and changes in pain. Using a visual analogue scale, the researchers concluded that the pain among participants in the experimental group was reduced significantly after just four weeks of participating in the phantom exercises (Ülger, Topuz, Bayramlar, Şener, & Erbahçeci, 2009).

Current research regarding PLP is focused on adults rather than children, yet, the percentage of children that experience phantom limb pain after an amputation range from 20% - 85.7% depending on the age of the child. There is current research supporting the use of non-invasive PLP treatments caregiver-directed by adult patients. Based on this research, it

appears that implementing a similar PLP treatment guide for children and their parents, that is caregiver-directed in their natural contexts, could be of benefit.

### **Implications for Occupational Therapy**

The following definition and descriptors are from the American Occupational Therapy Association (AOTA, retrieved 8-10-19 <https://www.aota.org/Conference-Events/OTMonth/what-is-OT.aspx>, ¶1-4).

Occupational therapy is the only profession that helps people across the lifespan to do the things they want and need to do through the therapeutic use of daily activities (occupations). Occupational therapy practitioners enable people of all ages to live life to its fullest by helping them promote health, and prevent—or live better with—injury, illness, or disability (AOTA, retrieved 8-10-19 <https://www.aota.org/Conference-Events/OTMonth/what-is-OT.aspx>, ¶1-4).

### **Academic Preparation**

The Accreditation Council for Occupational Therapy Education (ACOTE) is the accrediting agency that sets the standards for both occupational therapy programs and occupational therapy assistant programs throughout the United States. Occupational therapy curriculums consist of science courses (gross anatomy and neuroscience); theoretical courses, geriatric and pediatric courses, mental health courses and physical disability courses. Students are also required to perform two semesters of fieldwork in a clinical setting where they are expected to evaluate and treat patients under the supervision of a registered occupational therapist (Masters in Special Education Program Guide, 2018). Upon graduating from an accredited occupational therapy program, students must pass the National Board for Certification in Occupational Therapy (NBCOT) exam to become a board-certified occupational therapist.

### **Pediatric Specific**

For purposes of this scholarly project, the focus will be on pediatrics. Common occupational therapy interventions include helping children with disabilities to participate fully in school and social situations, helping people recovering from injury to regain skills, and providing supports for older adults experiencing physical and cognitive changes (AOTA, retrieved 8-10-19 <https://www.aota.org/Conference-Events/OTMonth/what-is-OT.aspx>, ¶1-4).

Occupational therapy services typically include:

- an individualized evaluation, during which the child/family and occupational therapist identify the child's goals.
- customized intervention to improve the child's ability to perform daily activities and reach the goals.
- an outcomes evaluation to ensure that the goals are being met and/or make changes to the intervention plan.
- educate children, families, caregivers and communities on safety, health and wellness and engagement in meaningful occupations.

Occupational therapy practitioners have a holistic perspective, focusing on adapting the psychological, physical, emotional, social and environmental needs of the child and family (AOTA, retrieved 8-10-19 <https://www.aota.org/Conference-Events/OTMonth/what-is-OT.aspx>, ¶1-4).

The authors were unable to find literature regarding occupational therapy research specific to pediatrics and phantom limb pain. It could be obscure somewhere but through the use of several research databases none were found. Peer-reviewed journal articles were gathered using the University of North Dakota School of Medicine and Health Sciences, Harley E. French Library. Databases, such as, PubMed, Cinahl and PsychINFO were used as well as Google Scholar and the American Journal of Occupational Therapy.

However, AOTA has addressed the role of occupational therapy in treating individuals with amputations and/or chronic pain, which can both include phantom limb pain. When working with individuals who have undergone amputations, the occupational therapist works within an interdisciplinary team to assess the patient's goals and help the patient during the four phases of rehabilitation (AOTA, 2016).

1. The acute phase is focused on building an occupational profile, assessing the client's current functional status, and facilitating pain relief and desensitization of the residual limb.
2. The pre-prosthetic phase addresses preparation for the fitting of a prosthesis as well as the skills needed to complete daily tasks. During this phase, the OT will continue to work on de-sensitization, pain reduction and scar management.
3. The patient will receive their prosthesis during the basic prosthetic training phase. During this time, the occupational therapist will educate the patient on donning and doffing the device, as well as developing a schedule suitable to the patient's tolerance for wearing the prosthesis.
4. The next phase is the advanced prosthetic phase, during which, the occupational therapist will assist the patient in performing functional tasks with the new prosthesis. The main goal of occupational therapy with this population is to prepare the patient for community re-integration and engagement in daily tasks and desired occupations (AOTA, 2016).

According to Hill (2016), occupational therapists can play a vital role in pain management by assessing the client's needs and using interventions to enhance performance and decrease pain. Common interventions used in occupational therapy to address chronic pain focus on ergonomics, pacing, energy conservation, goal setting, stress management, environmental modification, relaxation training and coping skills (Hill, 2016). The author points out that chronic pain can negatively impact sleep, mood and relationships. Therefore, occupational

therapists can help patients with chronic pain by teaching them coping skills to enhance mood and sleep and increase participation in daily life routines (Hill, 2016).

### **Self-Management Plan**

The purpose of a self-management plan is to utilize a caregiver-directed approach to modify health outcomes for chronic conditions, such as phantom limb pain (Modi et al., 2011). Throughout the caregiver-directed process, patients adopt new health related routines and behaviors while simultaneously learning how to self-monitor their condition and overcome the challenges of living with a chronic condition (DeRosa, 2013; Modi et al., 2012). This holistic plan is formed by the client and occupational therapist in conjunction with family members and other healthcare providers. Together, they promote adherence and achieve the long-term outcome of pain management. This type of plan is beneficial for children post-discharge due to the freedom and control it allows the individual to have over decision-making and recovery in the home environment. Most importantly, as the child ages, the plan can easily be modified to elicit adherence over time.

### **Conclusion**

Upon review of the literature, it was concluded that there is little to no research involving a caregiver-directed pain management resource guide for children experiencing phantom limb pain. However, the current evidence suggests that a caregiver-directed pain management resource guide could be feasible for adults experiencing phantom limb pain. The evidence also suggests that a guide consisting of non-invasive interventions such as exercise, mirror therapy and coping strategies could reduce phantom limb pain in adults. This scholarly project is proposing a resource guide to address both the physical and psychosocial implications of

phantom limb pain, appropriate for children and their families based on proven current treatment approaches used for adults but adapted to meet the needs of a child.

The P.L.P (Play Learn Persevere) product was created to fulfill that need and serve as a resource guide for the caregivers of children with phantom limb pain. The resource guide provides a manual with home-based interventions to decrease pain and increase engagement in meaningful occupations using a caregiver-directed approach.

Use of the Ecology of Human Performance Model lays the foundation for the P.L.P product. The Ecology of Human Performance (EHP) has been chosen as the theoretical base for this manual due to its five intervention options; establish/restore, adapt/modify, alter, prevent and create (Dunn, 2017). These intervention approaches are compatible with the goal of patient driven promotion of health within the community setting. This model is important to the development of the manual, as the resource guide addresses the wants, needs and priorities of the child and their families within their natural environment to support performance in desired tasks (Dunn, 2017). Furthermore, this model uses language that is understood by individuals outside of the occupational therapy profession which supports a multidisciplinary approach.

Chapter III addresses methodology, which describes the process the occupational therapy students used to design the scholarly project. This includes a description of the occupational therapy model and how findings from the literature review were used to guide the product design. Chapter IV is the product itself, which contains the resource guide for caregivers of children with phantom limb pain. The resource guide will be introduced by an occupational therapist prior to the child's discharge from the hospital, outpatient or rehabilitation setting. An analysis of the product's strengths, weaknesses and suggestions for improvement are described

in Chapter V. Recommendations for use of the product are also included in Chapter V. The scholarly project concludes with a list of references used throughout each chapter.

The table of contents for the product is as follows:

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## **CHAPTER III**

### **Methodology**

The P.L.P is a resource guide for occupational therapists to give to caregivers of children with phantom limb pain. This product is intended to be introduced by occupational therapists working in acute care settings with children who have undergone a unilateral amputation. Prior to discharge, the occupational therapist will review the resource guide, with the caregivers, to ensure comprehension. The hope is that those caregivers will use this resource guide as needed to help reduce their child's phantom limb pain once home from the hospital, outpatient or rehabilitation setting.

The OT students became interested in phantom limb pain after one of them learned of the phenomena while taking a brain and behavior course. Together, they chose to create a program plan based on children with phantom limb pain for a separate occupational therapy course. While developing the program plan, the students discovered that there was limited research addressing this population. This presented an opportunity for the students to create a resource guide for their scholarly project to address the needs of children with phantom limb pain.

According to the literature, there are no treatment guides for children with phantom limb pain that can be directed by the caregiver. A variety of research databases were used to develop the literature review. Peer-reviewed journal articles were gathered using the University of North Dakota School of Medicine and Health Sciences, Harley E. French Library. Databases, such as,

PubMed, Cinahl and PsychINFO were used as well as Google Scholar and the American Journal of Occupational Therapy.

After the literature was reviewed, the occupational therapy students identified the needs of the population and the current treatment approaches being used for phantom limb pain. It was found that only two home programs had been used to treat phantom limb pain and both involved adult participants. Using the literature, the occupational therapy students determined which interventions could be used with the pediatric population. Additionally, the occupational therapy students used the literature review to determine which interventions could be used by caregivers in the absence of a skilled therapist. The literature supports a mind-body connection involved in phantom limb pain. Therefore, the occupational therapy students chose to divide the product into two sections; physical interventions and psychosocial interventions. The physical interventions target the phantom limb pain itself, using visual imagery and phantom exercises. The psychosocial interventions address mental well-being through the use of coping strategies and mindfulness. Each section contains tasks/activities that the caregiver can help the child engage in to reduce phantom limb pain.

The Ecological Model of Human Performance (EHP) was used to guide the process and was described within the introduction of the product. EHP was designed to be used interprofessional to enhance collaboration, making it an appropriate choice for a caregiver-directed resource guide. Interprofessional teams include caregivers and family, which are an essential part of the team but often forgotten.

Using the five intervention strategies offered in this model, caregivers can apply pain reduction techniques within their child's natural contexts. The strategies include establish/restore, adapt/modify, alter, prevent and create. Two other models were considered

before choosing EHP. Occupational Adaptation (OA) was considered for its' focus on the client as an agent of change. However, focusing on adaptation alone limited the type of activities we could provide to caregivers. Person Environment Occupation (PEO) was also considered, because it allows you to target more than one element using the P-E-O transactions. While both of these models are valuable, they do not offer the array of intervention strategies that EHP does. Understanding that each child is unique, providing caregivers with five different intervention approaches allows them flexibility to choose what is most appropriate for their child. Application of the EHP model can be seen throughout the product within the next chapter.

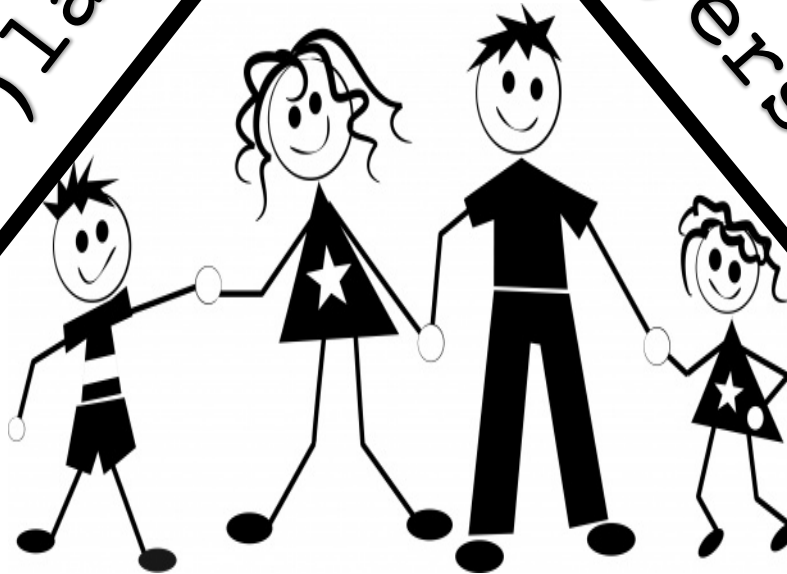
## **CHAPTER IV**

### **Product**

The purpose of this product is a resource guide to assist caregivers in helping reduce their child's phantom limb pain. This resource guide will be provided by an occupational therapist prior to the child's discharge from the hospital, outpatient or rehabilitation setting. The resource guide begins with an introduction to the product itself and how it can be used to help children with phantom limb pain. It then contains a terminology page that defines occupational therapy terms for the caregiver. The Ecological Model of Human Occupation was used to guide the development of this produce and is explained after the terminology page. The remainder of the product is divided into three sections; physical interventions, psychosocial interventions and caregiver resources. Section I provides several activities to address the child's physical limitations caused by the phantom limb pain. Section II provides psychosocial activities to enhance the child's coping skills in relation to the phantom limb pain. Section III offers a list of online resources, including support groups and extra activity ideas that caregivers can use with their child. The product in its entirety is in the following sections.

(P)lay

(P)ersevere



(L)earn

**An occupational therapist's  
guide for caregivers to  
reduce phantom limb pain  
(PLP) in the affected child**

**Micaela Monn & Amanda Steffen**

**Masters of Occupational Therapy Students**

**University of North Dakota Occupational Therapy Program**

**May 2019**

**Advisor: LaVonne Fox, OTR/L, PhD**

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Dear Caregiver,

Welcome to the Play, Learn, Persevere (P.L.P.). If you are reading this, you are caring for a child between the ages of 6 and 12 whom is experiencing phantom limb pain from a unilateral amputation. This resource guide should have been provided to you by your child's occupational therapist before discharge from the hospital, outpatient or rehabilitation setting. Phantom limb pain is caused by the brain sending signals to the amputated area. Because the amputated area is gone, there is no way for a response to be sent to the brain to tell it to stop sending signals. This can result in painful sensations, called phantom limb pain.

This is a resource guide for caregivers to help decrease your child's pain and increase their participation in everyday life. Understanding that each family and each child is different, we have included a variety of tools and activities to help you along your journey. The tools provided in this guide are meant to be safely used in a variety of settings to accommodate your family's needs.

Several factors could influence the application of the Play Learn Persevere (P.L.P.) product. Because phantom limb pain is not experienced by all, this product might not be applicable to every child. There are various tasks within the product and the feasibility of each largely depends upon the needs of the child. The product contains modifications to provide relief for both children with unilateral upper extremity amputations and lower extremity amputations. Because phantom limb pain affects both the body and the mind, the product includes tasks to address both the child's physical and psychosocial needs. Each task can be completed in an under an hour, making implementation convenient for busy families. Step-by-step instructions and visual aides are provided to create a user-friendly guide that can be easily understood by caregivers.

This guide is divided into three sections.

- **Section I** contains activities to address your child's physical needs, such as pain and discomfort.
- **Section II** contains activities to address the child's psychosocial needs, such as self-esteem and body image. Instructions for each activity are provided in a step-by-step fashion. However, it is ultimately up to you how you would like to complete these activities and how often. This will largely depend on your child's needs.
- **Section III** contains instructions for accessing additional online resources through the Amputee Coalition on the topics of physical activities, psychosocial activities and caregiver health.



## Terminology

**Coping skills/mechanisms:** The way we deal with stressful situations. These can be effective or ineffective (The Free Dictionary, 2018).

**Intact limb:** The limb (either arm or leg) that was not amputated (The Free Dictionary, 2018).

**Mind-body connection:** Our thoughts, feelings and emotions can affect our body's physical functioning. The health of our mind can positively or negatively impact the health of our body (The Free Dictionary, 2018).

**Residual Limb:** The part of the amputated limb (either arm or leg) that remains after the amputation. This is also referred to as a stump (The Free Dictionary, 2018).

**Mindfulness:** Being in the present moment. Being aware of what is happening in the "now" and non-judgmentally accepting your thoughts, feelings and physical sensations (The Free Dictionary, 2018).

**Negative Self-Talk:** Your child thinking negatively about himself/herself or saying negative things about himself/herself (The Free Dictionary, 2018).

**Phantom Limb Pain:** Pain that feels like it is coming from a body part that is no longer there (The Free Dictionary, 2018).

**Trigger:** Something that leads to the onset of phantom limb pain (The Free Dictionary, 2018).

## **Ecological Model of Human Performance – EHP**

This resource guide is based on the Ecological Model of Human Performance (EHP). This model consists of four components;

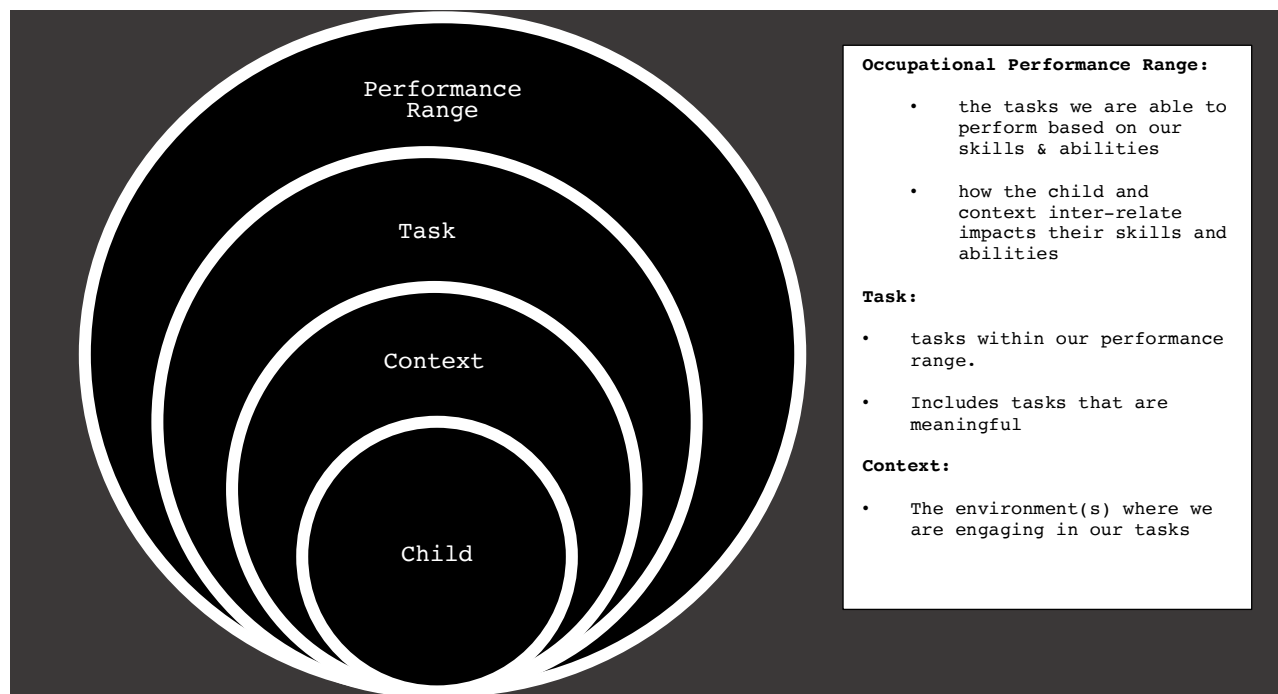
1. the person,
2. the task,
3. the context and
4. the performance.

(Dunn,2017)

Each of these components will be broken down following this paragraph. The goal of using this model is to increase your child's performance range. A performance range is the range of tasks available to the child at all times. This performance range is affected by the child's skills, abilities and contexts. Your child's performance range might be smaller due to the challenges associated with limb loss. Let's look at a quick example:

Rachel is an 8-year-old girl who recently received a lower arm amputation. Prior to this surgery, she enjoyed baking cookies with her mom at home. Now that she is home from the hospital, she is having difficulty engaging in this activity due to her phantom limb pain. While the context of her house is supportive of the task of baking cookies, her skills and abilities are limited due to difficulty attending to the task. Therefore, Rachel's performance range has decreased, because she cannot engage in the desired task of baking cookies with her mom.

Now, let's take a look at each of the four components of the EHP Model.



Each area is described in more detail:

1. **Child/Person.** The child is composed of the following Person factors:

**past experiences:** events that the child has been exposed to (e.g. playing on soccer team)

**personal values and interests:** (e.g. friends, story time with family, playing with siblings, eating ice cream). The focus is on the following areas:

- a. **sensorimotor skills:** your child's ability to use their senses to physically interact with their environment (e.g. swinging their leg to kick a ball)
- b. **cognitive skills:** your child's ability to think and make decisions (e.g. decided when it is safe to cross the street, counting, reading etc.)
- c. **psychosocial skills:** your child's psychological and emotional ability to interact with others (e.g. taking turns, waiting in line, expressing their feelings in an appropriate way)

2. **Context.** Contexts cannot be separated from the person. They can provide either supports or barriers to the child's performance. Context includes the circumstances in which an activity/event occurs. Contexts include:

- a. **Temporal:** age, developmental stage, health status and life cycle
- b. **Physical:** houses, land (e.g. classroom, park or home)
- c. **Social:** family, friends, school, church
- d. **Cultural:** religious or ethnic practices that influence a child's performance

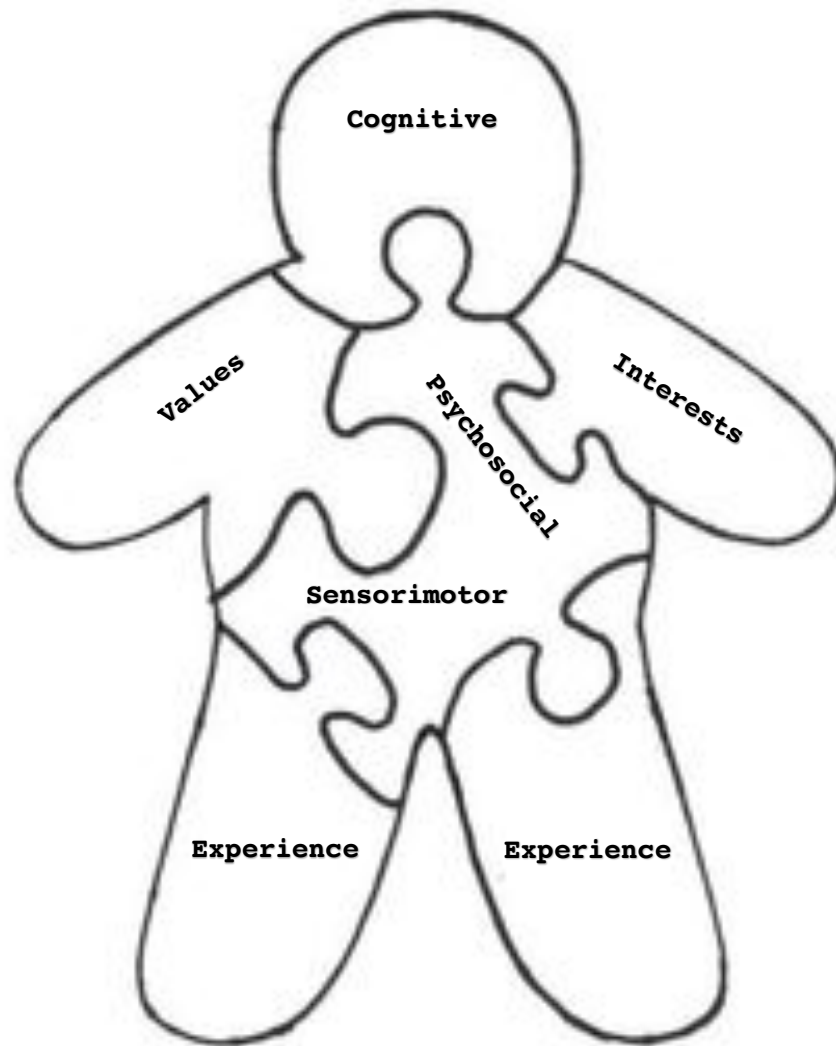
What contexts will help your child succeed?	What contexts are challenges for your child?
e.g. age, a home that she/he can easily move in, good friends and family	e.g. friends distance themselves from him/her, tired in the afternoon (age, developmental age), cost of equipment, church not accessible, decrease in social opportunities
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.

3. **Tasks.** Tasks are small or large things your child does to accomplish a goal. For example, he or she may gather painting supplies (small task) to accomplish the end goal of painting a picture (large task).

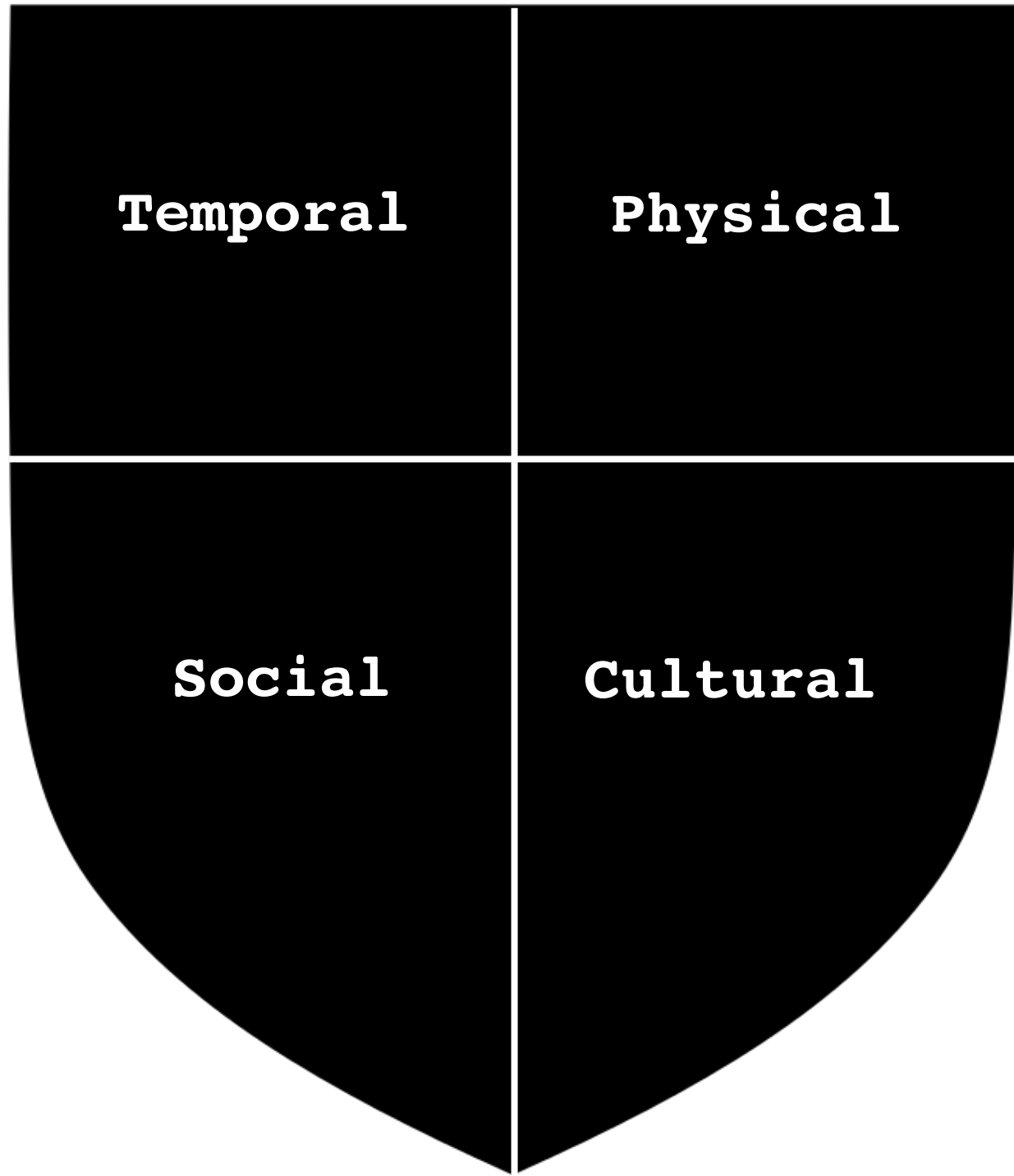
4. **Occupational Performance:** This happens when your child engages in tasks within a context. For example, baking cookies (task) at home in the kitchen (context).

What are some tasks your child enjoys?	Where does your child complete the tasks, and with whom?
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.
6.	6.
7.	7.

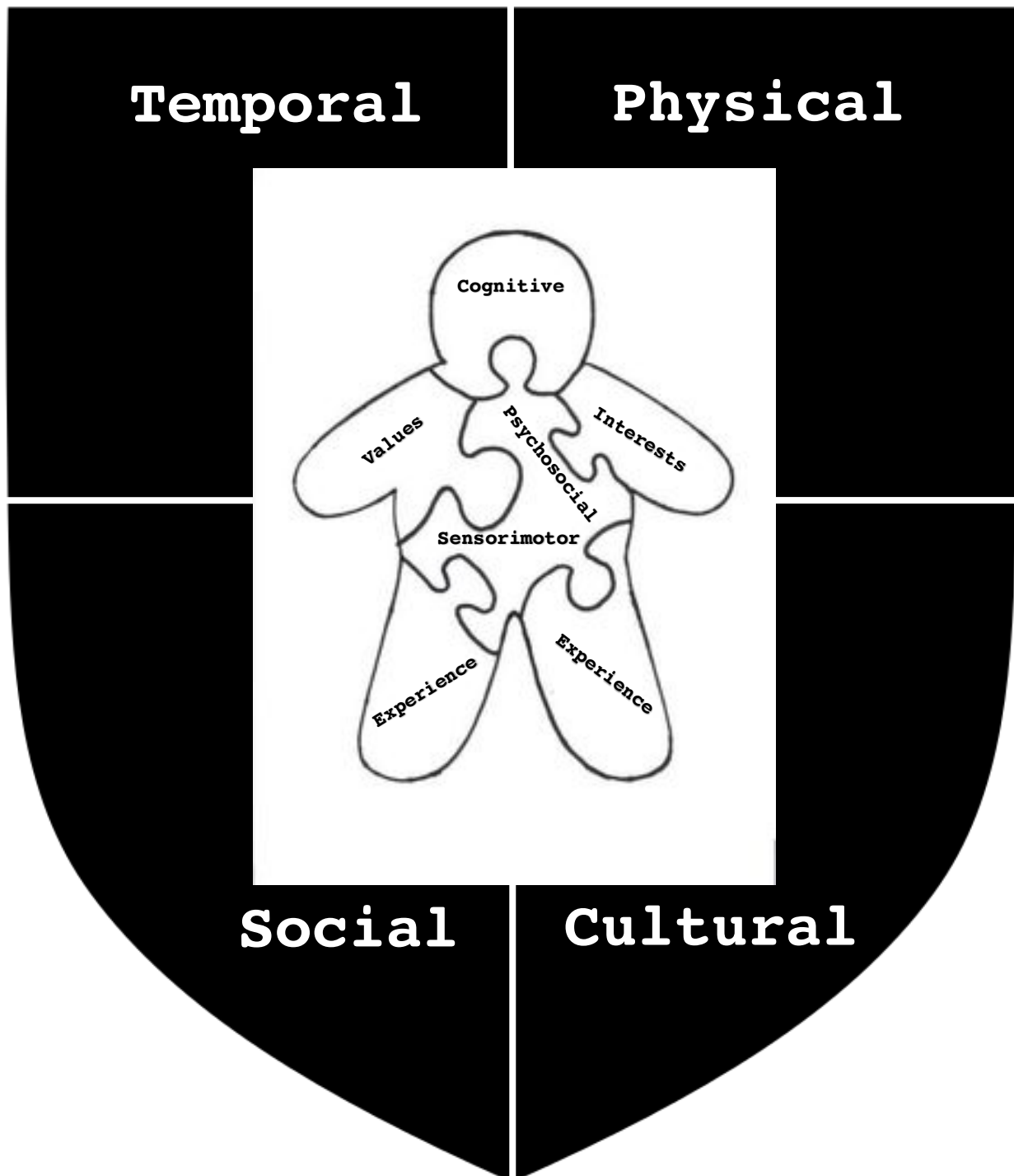
# The person



# The Context

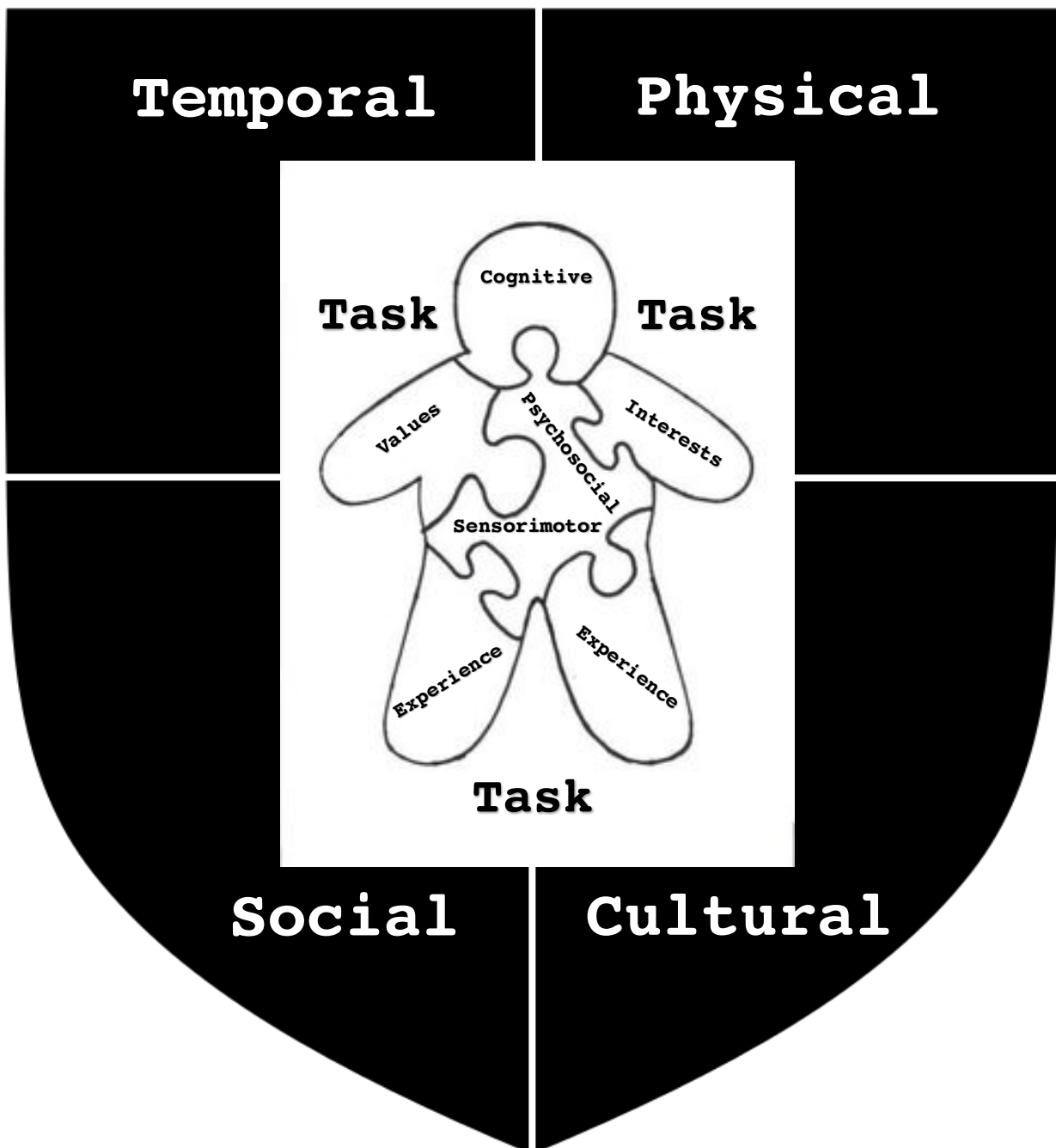


# The person and the context are inseparable



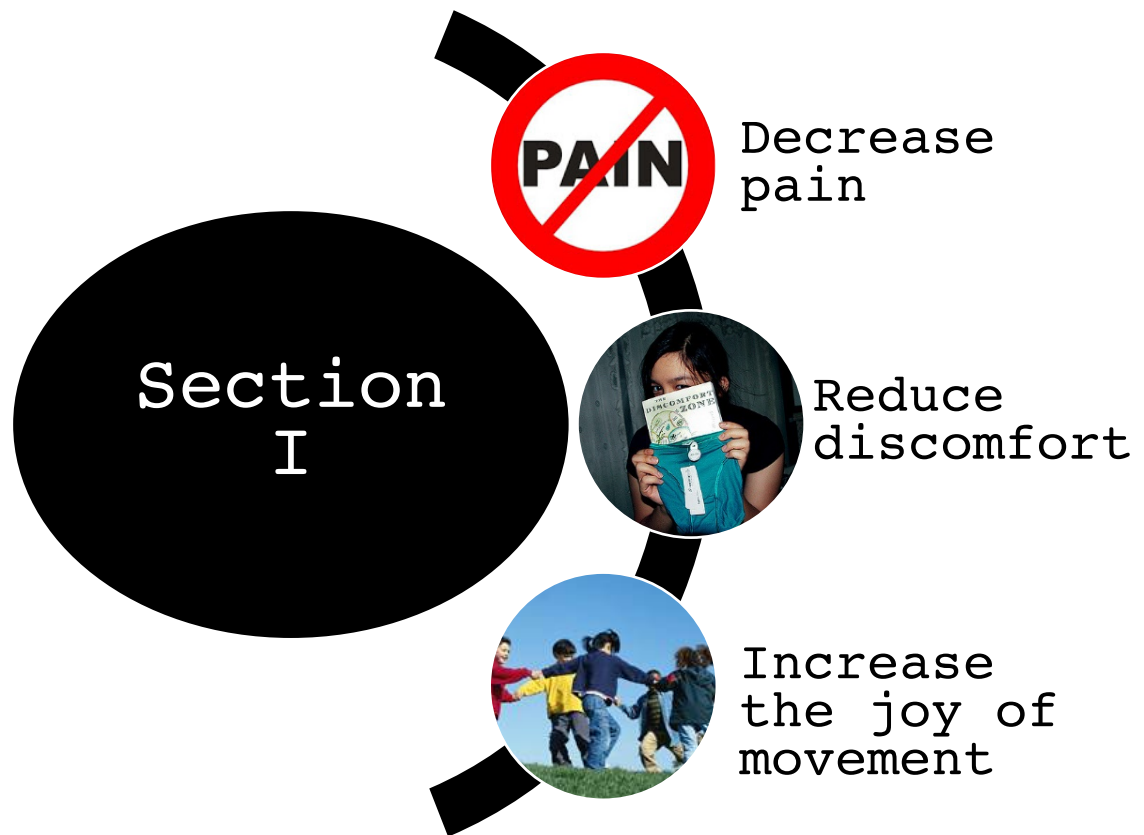


**Tasks surround the  
person and are performed  
within a context**



We have just covered the four components of the EHP Model. The last aspect of EHP we will discuss are the **five intervention strategies** that will be used to support your child's engagement in everyday life.

1. **establish/restore(targets skills):** developing a new skill your child doesn't have or improving a skill your child already has (e.g. establish-learning to fly a kite for the first time) (e.g. re-learning how to fly a kite after an amputation)
2. **adapt/modify(targets context):** changing how the activity is approached so s/he can participate in the task/occupation(e.g. using a one-handed technique to fly a kite). Assessing if adaptations or modifications can be done, for example: a bedroom, bathroom, a sport, a task, a routine.
3. **create (creating circumstances):** that support performance (e.g. constructing a mirror box to decrease phantom limb pain)
4. **prevent:** a decline in skills and abilities (e.g. teaching your child coping strategies)
5. **alter:** changing the context (e.g. changing the size of a kite to allow your child to fly it with ease)



**Activities to address your  
child's pain so she/he can do  
the things they want to do**

## **Mirror Therapy**

**What is mirror therapy?** The mirror box was first invented by Dr. Vilayanur S. Ramachandran to relieve phantom limb pain (Ramachandran, V.S. & Ramachandran, D.R., 1996). Dr. Ramachandran placed two mirrors on either side of a topless box. The patient placed their existing arm into the box and the mirror created the visual illusion that the missing limb still existed. According to Dr. Ramachandran, this illusion has a powerful effect on the brain, and it signals to the brain that the missing limb is now moving correctly. This provides the brain with feedback that it should stop sending signals to the missing limb, thus reducing the phantom limb pain!

**Purpose:** To relieve phantom limb pain

**Time to construct:** 10 minutes

**Time to Use:** 10-25 minutes per day

**Materials:**

**1. Upper extremity amputation:**

- a. scissors
- b. cardboard box (16x16 used in picture)
- c. lightweight mirror (16x16 used in picture)
- d. duct tape or other durable tape

**2. Lower extremity amputation:**

- a. light weight full body mirror or hanging closet mirror

Person  
Variable(s)

**Sensorimotor Skills:** Your child will learn how to move his/her arm or leg to reduce pain using the mirror box.

**Cognitive:** Your child will learn to make the decision about when to use the mirror box to manage their own pain.

**Psychosocial:** Your child will be able to engage with others without the distraction of pain.

Context

Home  
School

**Establish/Restore:**  
Establish a pain management routine using the mirror as needed.

**Create:** Construct a mirror box.

**Prevent:** Can use in the absence of pain to prevent future pain.

Approach

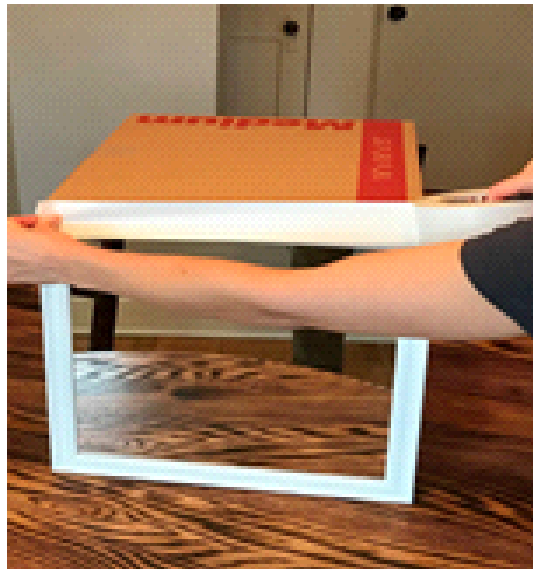
### Instructions for Constructing Mirror Box

1. Using scissors, cut the flaps on the top of the cardboard box
2. Place the mirror on any side of the cardboard box and secure all with duct tape
3. Position the box on a flat surface, preferably a table



### Instructions for Constructing Mirror Box

4. Using scissors, cut the flaps on the top of the cardboard box
5. Place the mirror on any side of the cardboard box and secure all with duct tape
6. Position the box on a flat surface, preferably a table



## Instructions for Using Mirror Box for Upper Extremity Amputations

Have your child sit at the table facing the opening of the box

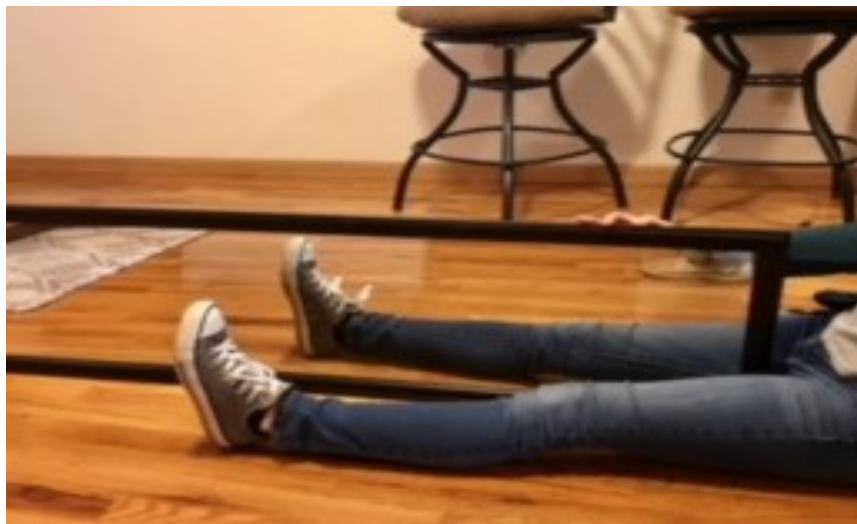
1. Position the box so that the mirror is facing their intact limb
2. Ask your child to place their residual limb inside the opening of the box
3. Ask your child to place the intact limb outside the box facing the mirror
4. Help your child position themselves so they see two limbs (the intact limb and the reflection of the intact limb).
5. Ask your child to move their intact limb in any way they wish
6. The goal is for your child to see two healthy functioning limbs
7. Encourage your child to move their intact limb in a variety of ways to prevent boredom
8. Continue for up to 25 minutes per day or as needed to reduce phantom limb pain





## **Instructions for Using Body Mirror for Lower Extremity Amputations**

1. Have your child sit on a flat surface with legs fully extended
2. Place a light-weight body length mirror in between his/her legs
3. Help your child position themselves, so they can see both their existing limb and the reflection of their existing limb
4. Repeat steps 6-9 as listed above in the Mirror Box instructions



### **Phantom Exercises**

Your child could decrease their phantom limb pain, simply by moving both the residual and intact limb. These movements are called "phantom exercises".

**Purpose:** To relieve phantom limb pain

**Time:** 15 minutes or until pain disappears

**Materials:** possibly a table, depending upon your child's needs

Person  
Variable(s)

**Sensorimotor Skills:** Your child will learn how to move his/her arm or leg to reduce pain.

**Cognitive:** Your child will learn to make the decision about when to use these exercises to manage his/her pain.

**Psychosocial:** Your child will be able to engage with others without the distraction of pain.

Context

Home, School, Park,  
Car

**Establish/Restore:**  
Establish an exercise routine to relieve phantom limb pain and restore the child's engagement in activities by relieving phantom limb pain.

Approach

### **Instructions for Performing Phantom Limb Exercises**

1. Ask your child what positions they are in when they feel the pain
2. Ask your child to place their Intact limb in the same position they feel their phantom limb in
3. Ask your child to move both Limbs (Intact and phantom) in opposite directions
4. Ask your child to bring their limbs back to the starting position they were in during step #2
5. Repeat as needed until phantom pain disappears

## **Desensitization Techniques**

Sometimes your child's residual limb can become sensitive to touch. De-sensitization is the process of gradually applying touch to the sensitive area until it is no longer painful. By gradually applying touch to the sensitive area, this area "gets used to it" and the pain goes away.

**Purpose:** To relieve phantom limb pain by Interrupting the body's response to the pain

**What are desensitization techniques:** Can Include applying massage, tapping or vibration to the painful area.

**Time:** 15 minutes or until pain disappears

**Materials:** none for the first two activities. The last desensitization activity requires a TENS unit, which is further explained on page 28.

Person  
Variable(s)

**Sensorimotor Skills:**

Your child will use  
his/her hand to apply  
the different  
techniques.

**Cognitive:** Your child  
will decide when to use  
these techniques to  
relieve his/her phantom  
limb pain.

Context

Any context

**Establish/Restore:**

Establish pain  
relieving techniques  
that your child can  
perform on their own  
in any setting

Approach

### **Instructions for Using Massage:**

1. Gently massage your child's amputation site using your hands
2. Periodically ask your child If the pain Is getting better, worse or the same
3. Continue for 15 minutes or until the pain has disappeared
4. Show your child how to massage their residual limb using their hands, so that they can do this on their own

### **Tips:**

- If you have tried this technique and It has not relieved your child's pain, try steps 1-4 on the Intact limb Instead of the residual limb.
- Try using different massage motions to see what works best for your child (circular motions, side to side, up and down using your thumbs, fingers and heel of your hand)



### **Instructions for Using Percussion Techniques:**

1. Using the tips of your fingers, gently tap your child's amputation site
2. Tap different areas of the amputation site
3. Check In with your child to see If this Is decreasing their pain
4. Show your child how to do this themselves
5. Use this percussion technique for 15 minutes or until pain subsides



Image retrieved from <https://www.amputee-coalition.org/resources/integration-of-massage-therapy/>



## **What is a TENS unit?**

A battery-powered portable device. The device has electrode pads that apply vibrations through the skin. TENS stands for transcutaneous electrical nerve stimulation. Transcutaneous means "through the skin".

### **How can a TENS unit help phantom limb pain?**

When the amputation site feels the vibration, it will send signals to the brain. This will tell the brain to stop sending the pain-causing signals to the amputated limb.

### **Is It safe?**

Yes, it only causes vibrations on the skin. Individuals do not need a prescription or training from a professional to use It.

### **Where can I purchase It?**

Walmart, Amazon, etc.

### **How much will It cost?**

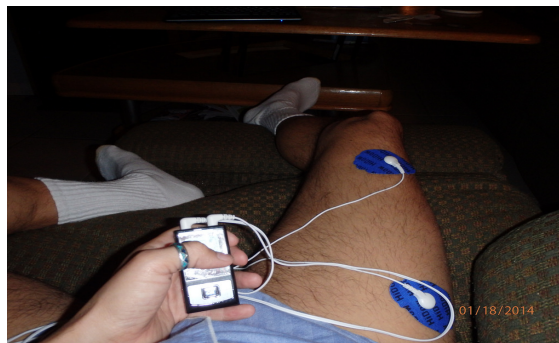
You can buy many TENS units for under \$30

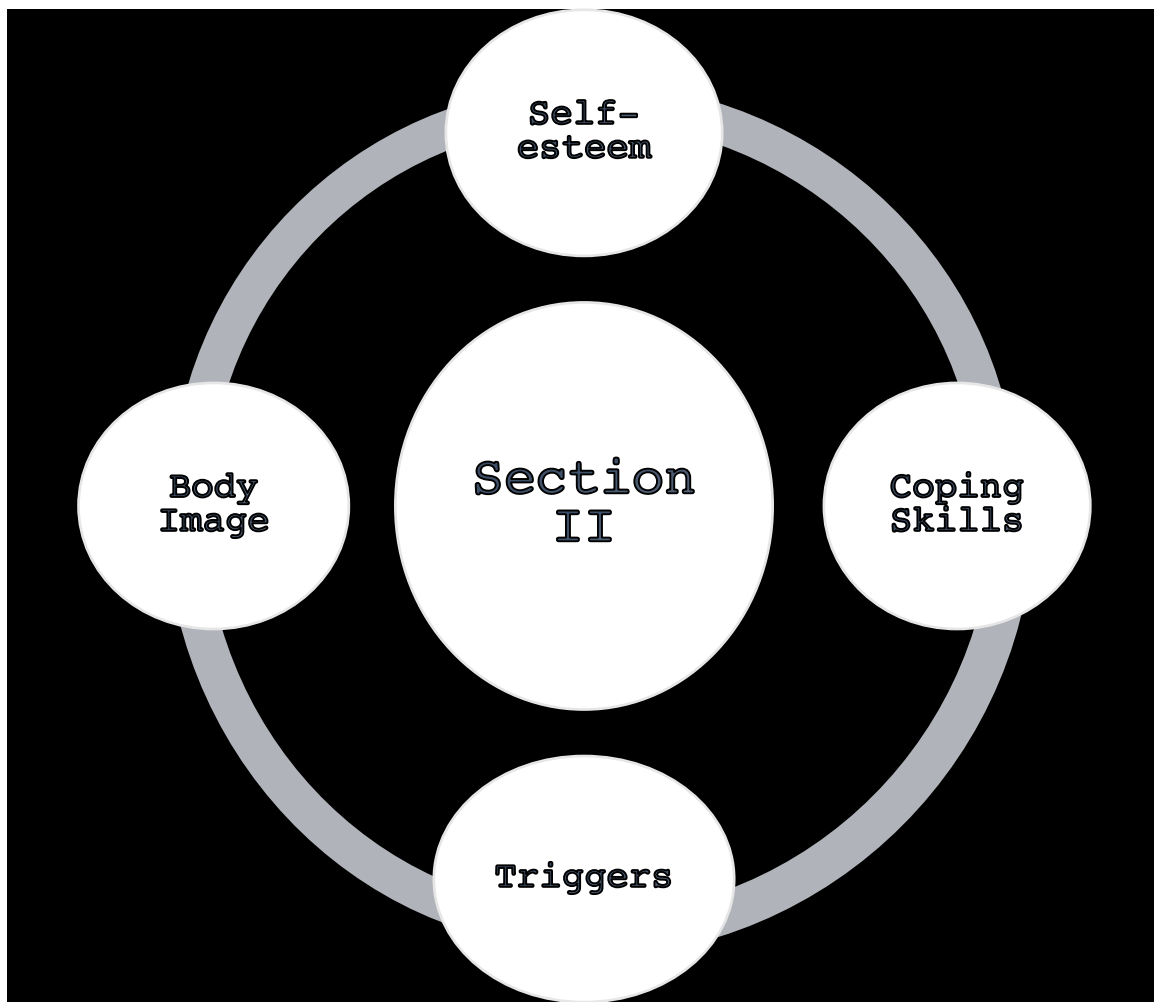
### **How do I use this on my child?**

You can follow the instructions provided in your TENS Unit box.

You can also watch this YouTube video to see how to use it by typing this link into the web browser of your computer:

<https://www.youtube.com/watch?v=Wo8iqgC6-oY>





**Psychosocial activities to  
help your child cope with  
phantom limb pain**

## Body Image

Your child might view his/her body differently after receiving an amputation. Phantom limb pain can also create this effect. Therefore, it is important to help your child develop a positive body image.

**Purpose:** To assist your child with identifying his/her unique features.

**Time:** 15 minutes

**Materials:** writing utensil

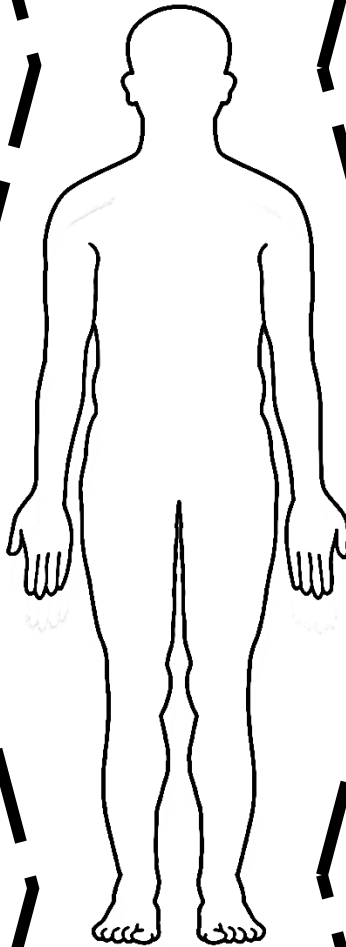
## Body Image Worksheet

My unique  
features:

- 1.
- 2.
- 3.
- 4.
- 5.

Things I  
love about  
my body:

- 1.
- 2.
- 3.
- 4.
- 5.

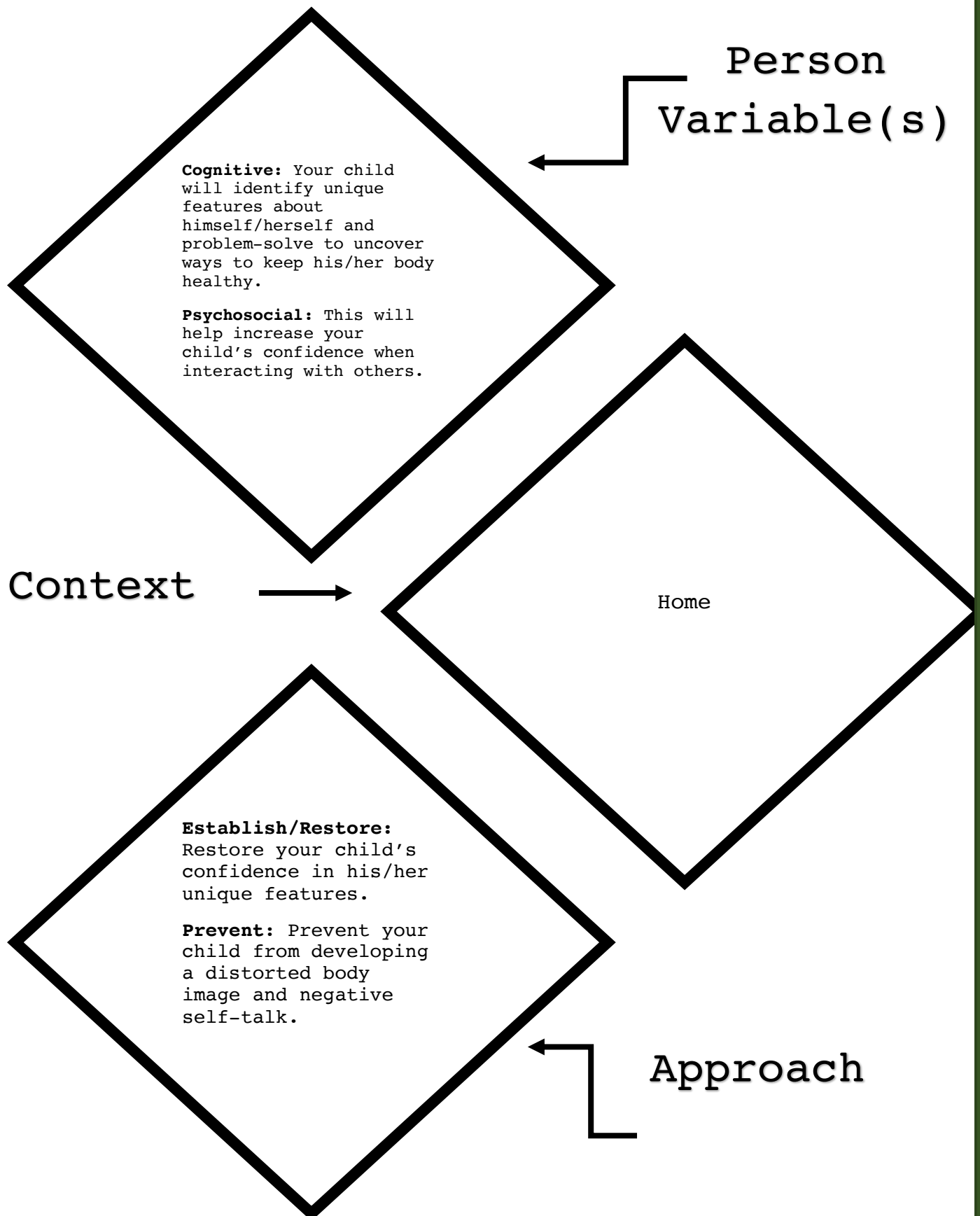


Actions I  
will do to  
keep my body  
healthy:

- 1.
- 2.
- 3.
- 4.
- 5.

How my body  
keeps me  
healthy:

- 1.
- 2.
- 3.
- 4.
- 5.



### **Instructions for Body Image**

1. Ask the child to define body image
2. Explain body image to the child. "Body image is what you think about yourself and how you look". What do you think of your body?
3. Read each category and ask the child to answer the statements.
  - Additional assistance may be required from the caregiver to record the child's answers.
4. Review the completed worksheet with your child.
5. Ask the child to choose one word that describes himself/herself and have the child write the word inside the body outline. This outline is found in the center of the page.
6. Refer to the completed activity when the child begins to express negative self-talk about his/her body.

## Self-Esteem








The child can become distracted by the phantom limb pain, making it difficult to have positive self-esteem.

**Purpose:** To increase your child's self-esteem each day for a week

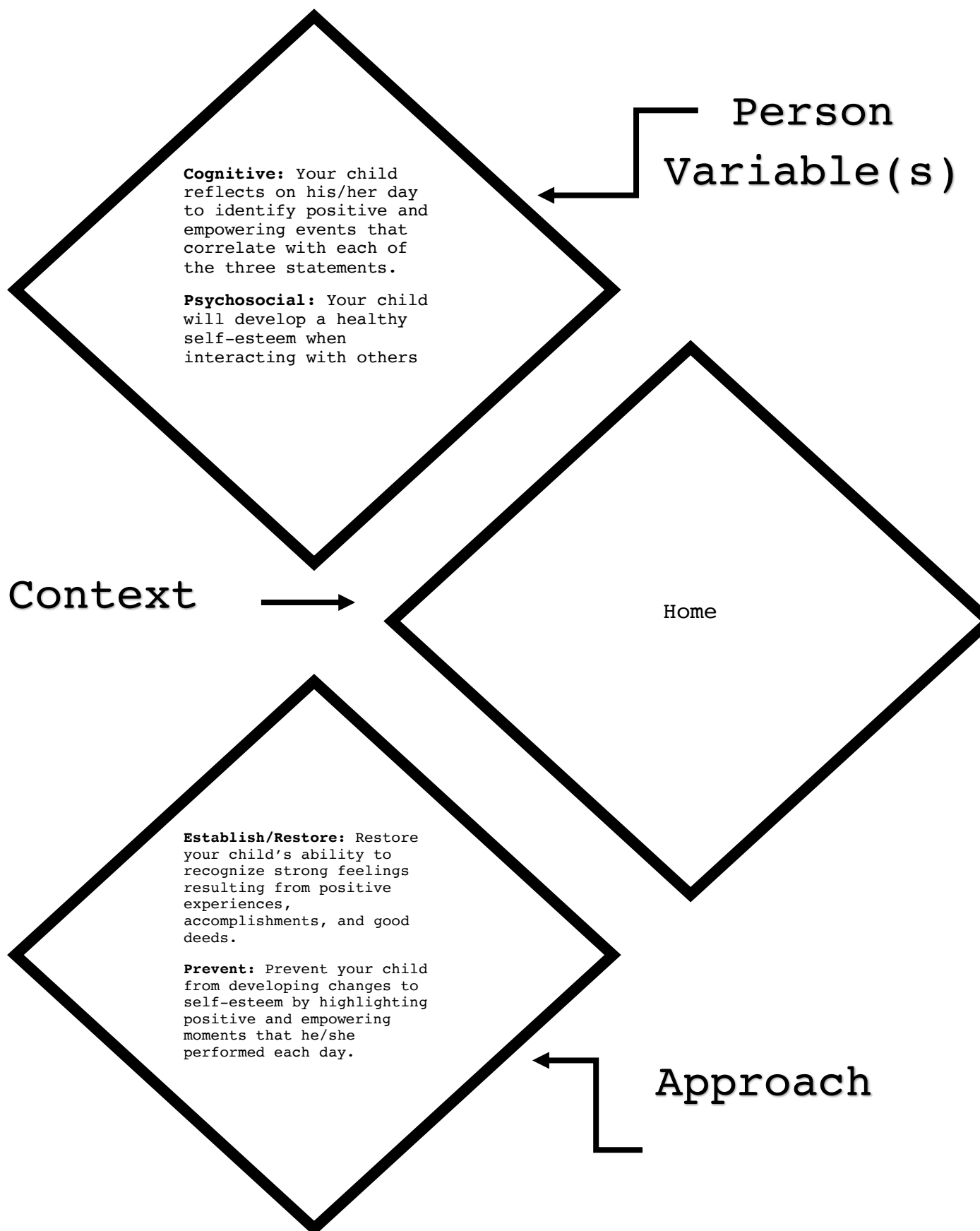
**Time:** 5 minutes

**Materials:** Writing utensil

## Self-Esteem Worksheet

<b>Monday</b> 	Something that made me feel good about myself today:	
	How I responded to this feeling:	
	Other things I can do to get the same feeling:	
<b>Tuesday</b> 	Something I accomplished today:	
	How I felt about my accomplishment:	
	What I learned from my accomplishment:	
<b>Wednesday</b> 	Something positive I observed today:	
	How this act of positivity made me feel:	
	A positive act I can do for someone else:	
<b>Thursday</b> 	I felt proud of myself today when:	
	How I responded to this sense of content:	
	Other things I can do to feel proud of myself:	
<b>Friday</b> 	A skill I worked on today:	
	How this skill can help my body:	
	Other skills I want to work on:	
<b>Saturday</b> 	Someone I'm thankful for:	
	How I feel when someone tells me they're thankful for me:	
	Things about myself I'm thankful for:	
<b>Sunday</b> 	A mistake I made today:	
	How this mistake made me feel:	
	What I learned from this mistake that helped me grow:	





### **Instructions for Self-Esteem**

1. Ask the child to define self-esteem.
2. Explain self-esteem to the child. "Self-esteem describes confidence and how a person feel about his/her abilities." How would you rate your self-esteem?
3. Read the three statements in the box that correspond with the day of the week.
4. Ask your child to write a response for each statement.
  - \* Additional assistance may be required from the caregiver to record the child's answers.
5. Review the responses with your child
6. Repeat steps 3-5 each day until all seven days have been completed
7. Refer to the handout when your child begins to express changes in self-esteem.

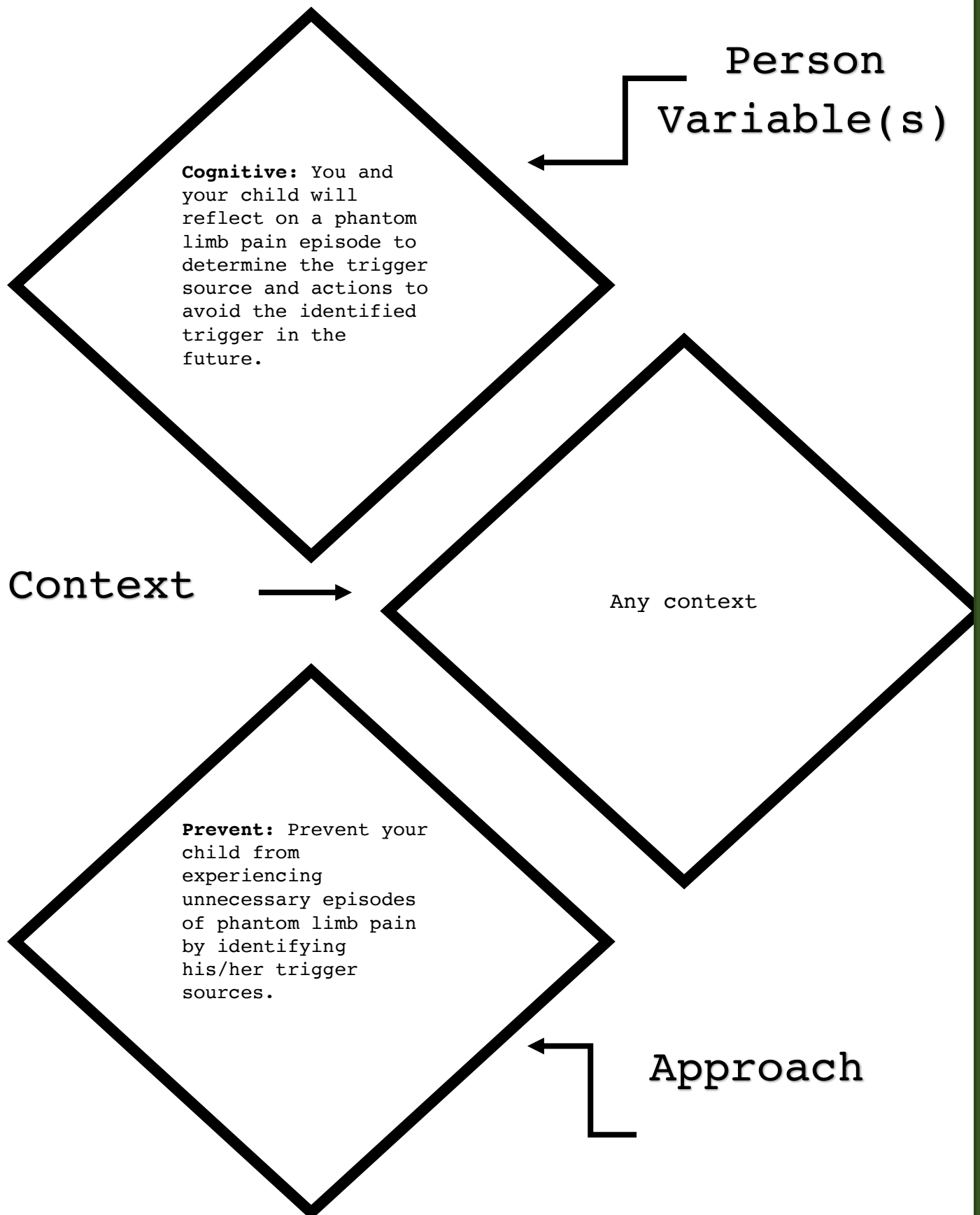
## **Finding Triggers**

Phantom limb pain is often triggered by physical and psychosocial triggers. According to research, boys experience more physical triggers whereas girls experience more psychosocial triggers (Wilkins, McGrath, Finley & Katz, 2004). Children of both genders have difficulty identifying what is triggering their pain (Wilkins, McGrath, Finley & Katz, 2004). This journal will help you and your child identify and document his/her phantom limb pain triggers.

**Purpose:** To become aware your child's phantom limb pain triggers

**Time:** 3 minutes

**Materials:** writing utensil



### **Instructions for Finding Triggers**

1. Assist the child with filling in one journal entry on the finding triggers page when the child begins to experience phantom limb pain
2. Brainstorm with the child to determine how the trigger can be avoided in the future
3. Repeat as needed or until the phantom limb pain has ended.

## Finding Triggers Journal

Date:

Time:

Where was I  
when the pain  
began?

What was I  
doing when the  
pain began?

How long did  
the pain last?

How did I  
respond to the  
pain

How can I prevent this from happening in the future?

## Positive Affirmations

It is believed that a mind-body connection exists with phantom limb pain. This means that your body reacts to your thoughts, feelings, and actions. A positive affirmation is a statement that an individual reads or writes and recites out loud to produce positive change in an area of his/her life. When you repeat a positive affirmation, you're strengthening your thoughts and feelings which can influence your actions.

**Purpose:** To provide a list of positive affirmations for your child to recite when experiencing phantom limb pain.

**Time:** 3-5 minutes.

- It is recommended that this be performed multiple times per day

**Materials:** None

Person  
Variable(s)

**Cognitive:** The child interprets the words and processes them through his/her brain to produce an unconscious belief about the effectiveness of the affirmation.

**Sensorimotor:** The child uses deep breathing to calm the body systems (heart rate, blood pressure, stress level). The child also uses his/her senses to internalize the meaning and purpose of the spoken words.

**Psychosocial:** Your child will be able to cope with pain during social interactions.

Context

Any context

**Prevent:** Prevent your child from creating ineffective coping skills. Ineffective coping skills could cause increase frustration and feelings of hopelessness.

**Establish/Restore:** Restore your child's coping skills for maintaining a sense of control over his/her body when phantom limb pain begins.

Approach



### **Instructions for Positive Affirmations**

1. Have the child find a quiet spot for the activity.
2. Have the child rest in a comfortable position.  
This could be sitting, lying down, or lying on the side. A quiet spot is recommended for this activity. Placing a blanket, stuffed animal, pillows and other comforting items around the child is optional.
3. Ask the child to close his/her eyes and take three deep breaths. The child should breathe in through his/her nose and out through his/her mouth. The deep breaths are taken to begin calming the child's body and mind.
4. Ask the child to pick an affirmation from the list and read it out loud.
5. Have the child take another deep breath and repeat the affirmation.
6. Repeat the alternation between reading and a deep breath as needed or until the phantom limb pain has disappeared.

### **Alternate Considerations:**

- This activity can also be performed throughout the day in the absence of phantom limb pain
- Your child can recite more than one affirmation at a time or combine affirmations
- Your child can create his/her own affirmations

### **Affirmations**

"I am in control of my phantom limb pain"

" I am able to control my phantom limb pain more and more each day"

" My body is healthy and free of phantom limb pain"

" I love my body and all of its features, even when I have phantom limb pain"

" I am in my happy place. I feel no phantom limb pain when I'm in my happy place"

" My phantom limb pain is no longer triggered by \_\_\_\_\_"  
(refer to the finding triggers activity and choose 1 trigger)

" I allow the phantom limb pain to enter and leave like a wave on a beach"

" Phantom limb pain doesn't bother me when I play with my family and friends"

" My body is powerful and pain free"

My Own Affirmation:

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---

My Favorite Affirmation:

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## **Progressive Muscle Relaxation**

Phantom limb pain can make your child feel as though his/her muscle are tight. Progressive muscle relaxation is a technique that's used to release tension by calming the muscles in your body. This is performed in steps that target each part of your body. The order often starts in your feet and moves up to your head.

**Purpose:** To assist your child with relaxing the muscles in his/her body during an episode of phantom limb pain.

**Time:** 15 minutes

**Materials:** None

Person  
Variable(s)

**Sensorimotor:** your child scans his/her body to identify areas of pain and tightness. Once the areas have been identified, a technique is performed to reduce the muscle tightness in that area.

**Cognitive:** your child listens to the spoken progressive muscle relaxation guide and independently follows each set of directions.

Context

Any context

**Establish/restore:**  
Establish a new coping mechanism for phantom limb pain. Restore your child's ability to control

**Prevent:** Prevent your child from developing unhealthy coping mechanisms for phantom limb pain

Approach

### **Instructions for Progressive Muscle Relaxation**

1. Have your child choose a quiet spot and sit or lay down
2. Ask your child to close his/her eyes.
3. Read the script to the child. Speak slowly, calmly and in a soft tone as you read through the script.
  - The script can be found on the next page.

## **Progressive Muscle Relaxation Script**

Okay, \_\_\_\_\_ (insert child's name), we're going to begin now.

Close your eyes and take a deep breath. Breathe in through your nose and out through your mouth. When you breathe in, I want you to pretend that you are filling a balloon inside your tummy. When you breathe out, I want you to pretend that all the air in this balloon is slowly flowing out. Make sure you do this slowly. You don't want the balloon to fly away. Remember, the balloon should inflate when you breathe in and deflate when you breathe out. Practice this for five deep breaths. See how big you can fill this balloon each time you take a deep breath. (Observe your child take five slow and controlled breaths).

Keep breathing as we move to another part of your body. Now I want you to slowly wiggle your toes. Now that you've moved them around a little bit, I want you to press them firmly into the ground and then lift them back up off the ground. This time, press those toes into the ground for three seconds before slowly lifting them up toward the sky. Pretend there's a bubble on the ground that you're trying to pop. Press as hard as you can to pop this bubble. Once you've popped it, then you can slowly bring your toes back up toward the sky. Don't forget to keep taking deep balloon breaths like we just practiced. Repeat this bubble popping process for a total of five bubbles. Remember, this is a tough bubble, so you must press as hard as you can to get it to pop. Don't forget to bring those toes back up toward the sky once its popped so that another bubble can take its place. (Observe your child press his/her toes into the ground five times)

Now that your toes are loose, we're going to move to your legs. Wiggle those legs around until all the jitters are out of them. I want you to hold them really still for this part. Don't forget to keep breathing those big balloon breaths. Start to squeeze your legs as tight as you can. Hold them tight, tight, tight. Okay, now let go of that squeeze and slowly relax your legs. I want you to try that again. This time, hold that squeeze for one deep breath. Ready, squeeze, squeeze, squeeze. Now hold, hold, hold, hold. Make sure you're filling that balloon in your belly. Good, now slowly release your leg muscles. I want to see those leg muscles being squeezed as hard as you can. Show me this for five slow squeezes. Squeeze. Squeeze. Squeeze. Breathe, breathe, breathe. Now release, release, release. (Remain silent as your child completes this five times). Your legs should now feel nice and relaxed.

Before we move to your arms, I want you to focus on your body and feel how relaxed your legs and toes are now. There should be no pain in this area of your body. It should feel like you have Jell-O for legs and toes. Let's see if we can get your arms to feel the same way now. Like we did with all the other movements, I want you to do this as slowly as possible. Begin by making a fist. Now squeeze that fist and make it as tight as you can. Tight, tight, tight. Feel the tightness shooting from your wrist all the way up to your shoulder. As you're squeezing your fist, I want you to fill up that balloon. Deep breath in. Feel that balloon fill up in your tummy. Don't forget to keep squeezing your fist too. Now hold that squeeze and slowly start to let the air out of your balloon. As your balloon begins to shrink, I want you to loosen your fist and bring those fingers out away from your palm. Straighten those fingers like you're going to give someone a high-five. Remember to make slow and controlled movements. This time I want you to pretend that you're squeezing a squishy ball filled with goo. Start to slowly tighten your grip around this ball as you make a fist. Watch how the slime inside begins to squish out the sides as you tighten your grip. Once you get all the gooey slime squished out of your ball, I want you to straighten your fingers and slowly release the ball from your hand. Watch the slime drip from your fingers as you straighten them out. Let's continue this five more times. Get those fingers ready to squeeze all that slime out of the ball. Once you've found that slime ball, begin to squeeze. (Observe your child squeeze his/her hand five times). Good job. We're almost done.

Now I want to calm that silly brain of yours. We're going to use those balloon breaths to do this. Try to get all of your thoughts out of your head before we begin. I want you to lay as still as possible this time. No wiggling. I know it's hard. I want to see you be as still as a statue. Take one deep breath in and search your body for any tight areas that need to be relaxed. If you find any, begin to slowly squeeze that area. Squeeze it as tight as you can. Tight, tight, tight. Now slowly release that tightness. As you're doing this, I want you to push your thoughts away with that tightness. Push it as far away from your body as possible. There should be no tightness and no pain. Now that you've tried this once, I want you to analyze your body again. Notice how different it feels now that you have released all that tightness in your toes, legs, and arms. Take five more slow breaths and push as much of the tightness and pain that's left in your body away as you breathe out. Show me that you can control your body by pushing away all those bad feelings and pain. You can do this. Practice this for five times. (observe your child take five deep breaths). (Remain silent until the child has released all of the built-up pain and tension in his/her body. This may take a few minutes).

Great job. You should feel that jiggly Jell-O all throughout your body now. I want you to open your eyes and slowly begin to move. Notice the changes you feel in your body after getting rid of all that pain and tightness. Next time you begin to feel phantom limb pain, you can try out these techniques to calm the muscle tightness in your body.



## Deep Breathing Techniques

Deep breathing techniques can be used when you feel stressed, anxious or upset. This technique helps to control your breathing pattern, slow your heart rate and decrease your blood pressure.

**Purpose:** To help your child maintain remain calm when experiencing phantom limb pain

**Time:** 5 minutes

**Materials:** None

Person  
Variable(s)

**Sensorimotor:** Your child will use the deep breathing techniques to help him/her respond to phantom limb pain in a calm manner

**Cognitive:** Your child will process the instructions for the breathing technique and follow its counting pattern for inhaling and exhaling.

Context

Any context

**Establish/Restore:** Establish a new coping mechanism for your child to use after the onset of phantom limb pain. Restore your child's ability to respond effectively to painful phantom limb pain sensations.

**Prevent:** Prevent your child from developing increased levels of anxiety associated with the presence of phantom limb pain.

**Adapt/Modify:** Modify the bumble bee breathing technique by having your child place an earplug in the ear on the same side as his/her residual limb.

Approach

### **Instructions for Deep Breathing Techniques**

1. Have your child find a quiet environment
2. Ask your child to choose a breathing technique
3. Read the instructions for the chosen breathing technique and have your child imitate the actions. Remember to read each instruction slowly and in a calm voice.

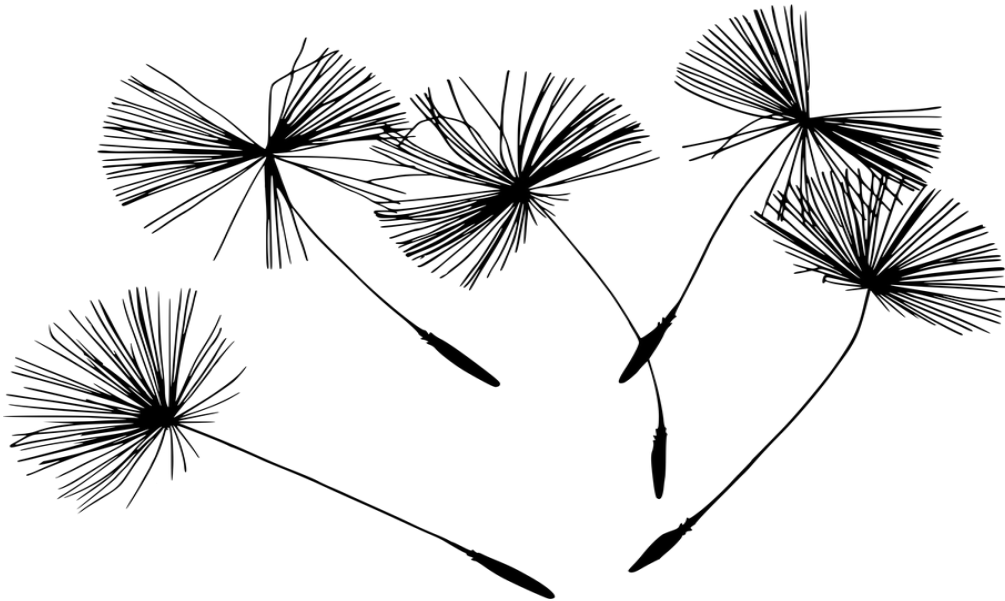
### **Tummy Breathing with a Stuffy**

1. Have your child pick a stuffed animal
2. Ask your child to lay on his/her back with eyes closed.
3. Ask your child to place the stuffed animal on his/her back and hold it there
4. Read the script to the child: "We're going to practice tummy breathing. I want you to hold your stuffed animal on your tummy when you practice this breathing technique. Take one deep breath in through your nose. Feel your stuffed animal rise toward the sky when you inhale. Now hold your breath for three seconds. One, two, three. Now breathe out slowly through your mouth. Feel your stuffed animal being pressed back into your tummy. I want you to continue this for 10 more breaths. (Observe your child complete 10 breaths or continue until the phantom limb pain subsides.)
5. Ask the child to open his/her eyes and slowly stand up.



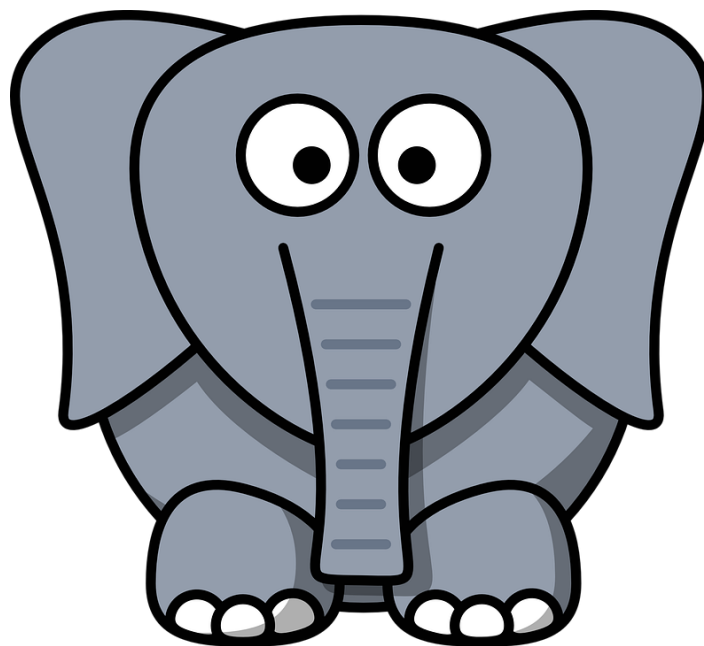
## Flower Breathing

1. Ask your child to sit or lay on his/her back with eyes closed
2. Read the script to your child: "We're going to practice flower breathing. I want you to pretend that you're holding a dandelion. You're going to practice blowing the white seeds off the dandelion. Don't blow them off yet though. Hold your dandelion and take one deep breath in through your nose. Now hold that breath for one slow second. O-n-e. Then blow out as hard as you can through your mouth to blow all those seeds off the stem of the dandelion. Now I want you to practice this ten more times. Remember to pick a new dandelion each time. (Observe your child complete 10 breaths or continue until the phantom limb pain subsides.)"
3. Ask the child to open his/her eyes and slowly stand up.



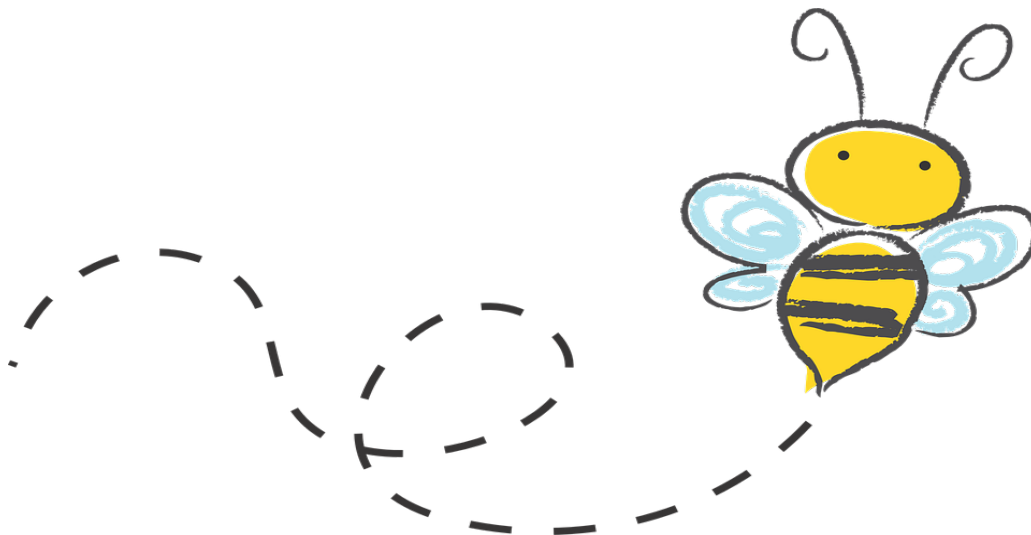
### Elephant Breathing

1. Ask your child to stand up and raise his/her arms up toward the sky then back down to the ground. Make sure there's no hazards near the child.
2. Read the script to your child: "We're going to practice elephant breathing. I want you to pretend that you're an elephant and your arms are the elephant's trunk. When you breathe in through your nose, I want you to raise your arms up to the sky. When you exhale through your mouth, I want you to slowly swing your arms down toward the ground. Let's practice this. Slowly raise your arms up as you breathe in for five seconds. One, two, three, four five. Then slowly lower your arms as you exhale for five seconds. One, two, three, four, five. I want you to repeat this 10 more times. (Observe your child complete 10 breaths or continue until the phantom limb pain subsides.)"
3. Ask the child to open his/her eyes



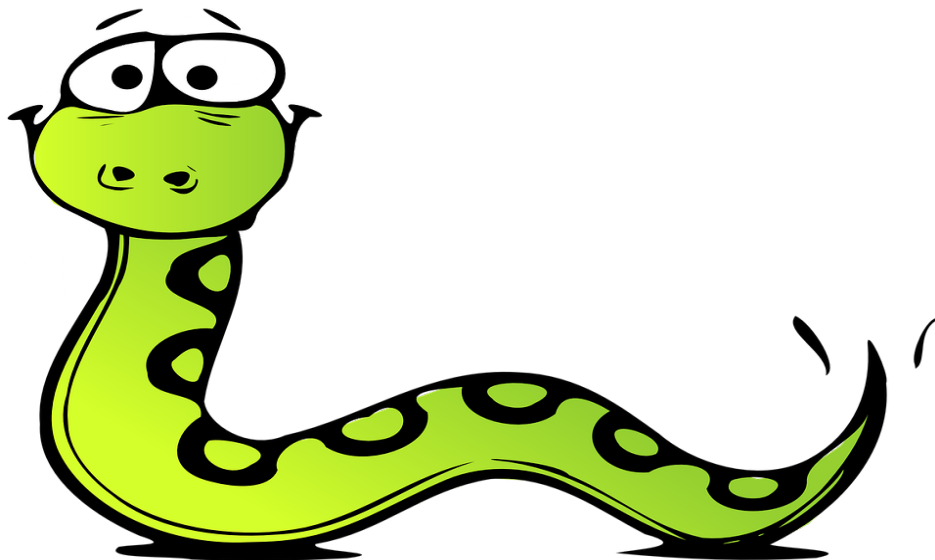
### Bumble Bee Breathing

1. Ask your child to sit on the ground with his/her legs crossed and eyes closed
2. To adapt this activity, you can place an earplug in your child's ear to simulate the same effect as having a finger placed in the ear.
3. Read the script to the child: "We're going to practice bumble bee breathing. I want you to pretend that you're a bumble bee flying through a field of flowers. Begin by taking a deep breath in through your nose. Then place your pointer fingers in your ear and hum as you exhale. Listen to the sound this makes. Think about how the vibration from the sound feels as you slowly hum. Try to see how far your bumble bee can buzz through the field of flowers when you exhale. You can also practice changing how loud your bumble bee is by humming quieter or louder. I want you to repeat this bumble bee breathing 10 more times. (Observe your child complete 10 breaths or continue until the phantom limb pain subsides.)"
4. Ask the child to open his/her eyes and slowly stand up.



### **Snake breathing**

1. Ask your child to sit with his/her eyes closed
2. Read the script to the child: " We're going to practice snake breathing. I want you to pretend that you're a snake. First decide what kind of snake you are. Then choose how big you are and what color you are. Next, show me your best hissing sound. Good. Now that you've changed yourself into a snake, I want you to take one deep breath in through your nose for four counts. One, two, three, four. Now exhale through your mouth while making that hissing sound you just practiced. Think about how your breath feels on your tongue as you exhale and make the hissing sound. I want you to practice this snake breathing 10 more times. Each time, you can change the sound of your hiss to be quieter or louder than the last breath. (Observe your child complete 10 breaths or continue until the phantom limb pain subsides.)
3. Ask the child to open his/her eyes and slowly stand up.





## Guided imagery

Guided imagery is a relaxation technique that's used to calm an individual's mind and body. This often consists of one person reading a prewritten script out loud while the other person listens quietly. As the story progresses, the listener creates images in his/her mind that matches what's being described in the script. The listener also interprets the events described in the script through all five body senses: sight, sound, smell, touch and taste. As a result, the listener's mind and body focuses on to the story instead of the phantom limb pain.

**Purpose:** To shift your child's attention from the painful feeling in their residual limb to the image that's being created.

**Time:** 5 Minutes

**Materials:** None

Person  
Variable(s)

**Sensorimotor:** Your child listens to the story and uses his or her senses to imagine the associated taste, touch, sound, sight and smell of the described activity.

**Cognitive:** Your child processes the sensory action described in the story and makes the connection to his/her own body.

Context

Any context

**Establish/Restore:** Restore your child's ability to shift his/her attention away from the phantom limb pain and toward a visualized activity.

**Prevent:** Prevent your child from becoming distracted by the phantom limb pain. Also, prevent your child from becoming preoccupied with the painful sensation radiating through his/her residual limb region.

Approach

### **Instructions for Guided Imagery**

1. Ask your child to find a quiet spot
2. Have the child sit or lay down with his/her eyes closed
3. Read the guided image activity to the child slowly using a calm and soft-spoken voice.

### **Guided Imagery Activity**

Okay, \_\_\_\_\_ (insert your child's name), I want you to sit or lay quietly with your eyes closed while I read you a script about baking cookies. Try to clear your mind and imagine what I'm reading to you as if it were happening right now. You've just returned home from school and see a big bowl of chocolate chip cookie dough on the counter. You rush over to the bowl and take one big sniff. Smell the sweet scent of chocolate as it flows from the bowl into your nose.

Then grab a spoon from the drawer and use it to scoop up a small chunk of cookie dough. Place the dough into your hand and begin rolling it into the shape of a ball. Feel the sticky dough attaching itself to the inside of your hand as the chocolate chips lightly press into your palm. Once you've formed a ball, place it onto the cookie sheet next to the mixing bowl. Now repeat this process until the entire sheet has been filled with cookies. (Pause for five slow seconds to allow the child to imagine the cookie tray filling with balls of rolled cookie dough)

Then pick up the cookie sheet and bring it over to the oven. Open the oven door and feel the heat flow onto your face and arms as you slide the cookie sheet onto the tray. While you're waiting for the cookies to bake, take three deep breaths. Inhale through your nose and exhale through your mouth. Begin. (Observe your child complete three deep breaths)

Beep, beep, beep! Sounds like the cookies are done. Walk over to the drawer and place your hand inside a hot pad. Then walk to the oven and open the door. Take a few seconds to smell the baked cookie scent as it fills the room. Take a peek at the cookies to make sure they're done before you pull the tray out. The cookies should have melted into a flat circle and have a golden tint around the edges. If they look fully cooked, reach inside and carefully pull the tray out. Feel the heat touch your arm as you do this. Once the tray is out, set it on the stovetop to cool. While the cookies are cooling, I want you to take three more deep breaths. This time hold your breath for three seconds before releasing your breath. Begin. (Observe your child take 3 deep breaths).

The cookies are ready! Hurry over to the tray and pick one out to try. Gently bring the cookie to your mouth and take one big bite. Feel the warmth of the cookie inside your mouth as you bite down and begin chewing. Taste the chocolate chips as they melt on your tongue. Listen to the crunching of the dough each time you bite down. Crunch, crunch, crunch. Take one slow deep breath to smell the cookie scent as it circles in the air around you like a tornado. Now exhale slowly as you begin to open your eyes.

Great Job! Hopefully you aren't too hungry for chocolate chip cookies now.

## Heartbeat Exercises

(These exercises are designed for children wearing a prosthetic device.)

A child's heartbeat can increase when he/she is upset. Phantom limb pain can be unpredictable and upsetting which can increase your child's heartrate.

**Purpose:** To assist your child with decreasing his/her heartrate when they experience an upsetting episode of phantom limb pain

**Time:** 5-10 minutes depending on the child's heartrate after exercise

**Materials:** None

Person  
Variable(s)

**Sensorimotor:** A set of exercises are performed to increase your child's heartrate. Your child detects his/her heartrate after performing a set of exercises and focuses on each heartbeat until the heart relaxes to a normal, steady pace.

**Cognitive:** Your child uses counting skills while performing each exercise. When monitoring heartrate, your child processes the speed of each heartbeat instead of focusing on the pain.

Context

Any context

**Establish/Restore:** Restore your child's ability to control his/her heartrate through concentration and deep breathing.

**Prevent:** Prevent your child from developing an unhealthy coping mechanism in response to an increased heartrate.

Approach

### **Instructions for Heartbeat Exercises**

1. Ask your child to pick an open space in a quiet area to perform exercises. Make sure there's enough room to prevent avoidable injury from contact with a hazardous item.
2. Have the child stand up
3. Instruct the child to listen to the directions before attempting each exercise
4. Read the name of each exercise, one at a time, to the child and observe the child complete each exercise, one at a time.
  - Remind your child to not feel discouraged if he or she cannot perform every exercise. A list of alternate exercises for upper extremity and lower extremity amputations is provided on page 74.
5. After all exercises have been completed, ask the child to sit quietly with his/her eyes closed and place both hands on the chest over the heart.
6. Ask the child to focus on the pounding heartrate until it returns to a normal pace while taking deep breaths slowly



## Heartbeat Exercises

(These exercises are designed for children wearing a prosthetic device.)

### 1. **Jumping Jacks x10**

**Instructions:** stand with your feet together and arms at your side. Jump your feet out to the side and lift your arms out to the side and up toward your head. Then bring your feet together and arms back down to your side. Do this as quickly as possible 10 times.



## **2. High Knees x20**

Instructions: Stand with your feet slightly apart. Bring one knee up toward the sky as you swing your opposite arm in the same upward direction with your elbow bent. Lower your arm and leg as you alternate this action to the other side. Do this as quickly as possible 20 times.



### 3. Butt Kicks x20

Instructions: Stand with your feet slightly apart. Swing one foot back toward your bottom as you swing the opposite arm up toward the sky with the elbow bent. Lower your arm and leg as you alternate this action to the other side. Do this as quickly as possible 20 times.





#### 4. Mountain Climbers x20

**Instructions:** Get onto your hands and knees with your elbows straight and hands flat on the ground. Keeping your hands in that position, lengthen your legs all the way and hold yourself up on your toes. Your back should be flat and your knees should be off the ground. While in this position, lift one foot off the ground and bring your leg toward your nose with the knee bent. Then straighten your leg back to the starting position and alternate this action to the other side. Keep your head in line with your body the entire time by focusing on the ground. Do this as quickly as possible 20 times.



### 5. Burpees x5

**Instructions:** Stand with your legs slightly apart and hands at your side. Lower both hands to touch the ground in front of you as you bend your knees. Once your hands are flat on the ground, keep them there and kick your legs back. You should be on your toes with straight arms like in the mountain climber position. Your back should be flat and your knees should be off the ground. Hold yourself up in this position and jump your legs back to the position they were in before with your hands flat on the ground. Then jump up and shoot your arms up above your head toward the sky. Once you land, repeat the process again. Do this as quickly as possible 5 times.



## **Heartbeat Exercises**

(These exercises are designed for children without a prosthetic device)

You and your child can decide what activities you will use to get his/her heartrate up. Here is a list of simple ideas:

### **Exercises for Upper Extremity Amputations:**

1. Rolling on the ground
2. Hopping, skipping, running, galloping
3. Swimming
4. Dancing
5. Seesaw

### **Exercises for Lower Extremity Amputations:**

1. Rolling on the ground
2. Monkey Bars
3. Swimming
4. Swinging on a swing
5. Climbing



# Section III



**Resources for Caregivers.  
Additional information on  
phantom limb pain that  
address the wellbeing of your  
family unit**

## **Supplemental Resources for Physical Activities**

The **Amputee Coalition website** lists a variety of sports/exercises that can be adapted for individuals with limb loss. Many of these activities can be performed by children, including bike riding, swimming and soccer.

1. To locate this page, visit the Amputee Coalition website at:  
<https://www.amputee-coalition.org/>
2. Locate the search Icon In the top right-hand corner
3. Click on the Icon and type In "physical activity"
4. Then, click on the first search Item on the list
5. Scroll through the various resources and click on one that Interests you and your child



## **Supplemental Resources for Psychosocial Activities**

Phantom Limb Pain can be difficult to understand. Helping your child understand limb loss itself, could help them positively respond to their phantom limb pain.

The **Amputee Coalition website** provides a list of story books and coloring books designed to teach your child about limb loss in a positive and reassuring way. To view these books, follow the steps below.

1. Go to [www.amputee-coalition.org](http://www.amputee-coalition.org)
2. Click on the search icon on the top right side of the screen
3. Type in "Resources to Help Children Understand Limb Loss" and click enter
4. Click on the first item that says "Resources to Help Children Understand Limb Loss"
5. Look over the options with your child and help them choose a book or coloring book that they are interested in
6. Once you have found a book, order it and help your child use it once it arrives

## **Supplemental Resources for Caregiver Health**

Being a caregiver to a child with an amputation is an important and rewarding role. To provide the best care for your child, it is equally important that you are taking care of yourself both mentally and physically.

The **Amputee Coalition website** offers tips on how you can:

organize your life, eat healthy, get enough rest, monitor your physical and emotional health, exercise regularly, accept help from others and set aside time for yourself.

It also offers a list of other online resources for caregivers like you.

Follow steps 1-6 below to discover how you can

1. Go to [www.amputee-coalition.org](http://www.amputee-coalition.org)
2. Click on the search icon on the top right side of your screen
3. Type in "Survival Guide for Caregivers"
4. Click on the first search item that says "Survival Guide for Caregivers: De-stressing to Stay Healthy"
5. Scroll through this page to explore the resources
6. Use these resources as needed to help you along your journey or caring for your child

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## **CHAPTER V**

### **Summary**

The P.L.P is a resource guide for caregivers of children with phantom limb pain. It contains physical and psychosocial activities that caregivers can do with their child to help them decrease their pain level. These activities can be performed in a variety of natural contexts, including school, home, the park and even in the car. Each activity can be performed in the absence of a skilled therapist and does not require any specific training. Activities can take anywhere from 15-20 minutes and can be completed as often as necessary. The activities include step by step instructions with visual aids, making it simple for caregivers to follow. A terminology page is provided to explain medical and occupational therapy jargon. The resource guide is divided into three sections. Section I includes physical activities to reduce phantom limb pain. Psychosocial activities are addressed in Section II and online resources for caregiver health is included in Section III.

### **Possible Implementation**

The P.L.P implementation process begins with the occupational therapist reviewing the P.L.P with the caregiver prior to discharge from a hospital, outpatient or rehabilitation setting. The occupational therapist then assists the caregiver with identifying their child's needs prior to discharge from Occupational Therapy services. The OT then goes through the P.L.P, discuss the instructions on how to navigate and use the resource guide effectively.

## **Conclusions**

In conclusion, there is little to no research involving a pain-management guide for caregivers to use with their children whom are experiencing phantom limb pain. This scholarly project is proposing a resource guide to address both the physical and psychosocial implications of phantom limb pain, appropriate for children and their families based on proven current treatment approaches used for adults but adapted to meet the needs of a child. It is the OT students hope that children, caregivers and OT's find it beneficial.

## **Limitations**

One limitation of the P.L.P is that it is recommended to be used only with children aged 6-12. Individuals of all ages are susceptible to phantom limb pain, therefore, children outside of this age range would likely benefit from more age-appropriate activities. A second limitation to the P.L.P is that not every activity will be effective for each child. The caregiver will have to use a trial and error method to determine what activities are effective for their child. Another limitation to this product is the general focus on upper and lower extremity amputation, but the guide does not specify level of amputation (i.e. hand, elbow, above or below knee).

## **Recommendations**

1. Resource guide assessment to determine efficacy of the product.
2. Publication of results of resource guide assessment/research to contribute to a currently limited research pool.

3. Send any results or information to the authors so they can conduct research as well on the efficacy of the resource guide.

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