# **Essentials of Pediatric Prosthetics**

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**Abstract:** Caring for the limb deficient child may be initially daunting but typically is quite rewarding for the orthopaedist and medical team. This article serves as a primer to those surgeons who are in training or infrequently treating this population. Insights are provided throughout to aid the orthopaedist in maneuvering the many facets of pediatric prosthetic care, including answers to questions commonly asked by surgeons or families. Involvement of the prosthetist early and then throughout the child's care is crucial in achieving optimal outcomes in prosthetic design, fit, function and utilization. Although a multidisciplinary team may not be available at all institutions, it is important to aim for this approach whenever possible. With the right balance of surgical, functional, prosthetic and therapeutic considerations, children with limb differences typically are able to keep up with their peers and participate in a variety of activities, such as school, sports, and music.

#### **Key Concepts:**

- The need to maintain functional limb length should be balanced with the ability to provide adequate clearance for prosthetic componentry in order to meet patient and family goals.
- A prosthetist should be involved early and throughout the treatment of the child with limb differences to aid in development and execution of the care plan.
- Whenever possible, a multidisciplinary team approach should be utilized for pediatric limb difference cases.
- Most children are able to successfully participate in a variety of recreational activities, including sports and music, while using their prostheses.

#### Introduction

The management of pediatric patients with limb differences is both challenging and rewarding. Pediatric orthopaedic surgeons can be faced sporadically—and sometimes suddenly—with patients who have prosthetic needs. Such cases might present as a newborn with a congenital limb difference or in the emergency department after a traumatic event. The care of these patients requires a firm understanding of anatomy, growth and development, biomechanics, and gait.

Additionally, the relationship with the patient and family may be long-term, and an appreciation of the social environment and support system is essential for each patient. These patients should ideally be managed by a multidisciplinary team, though this is not accessible at many institutions.

This review is the first of a two-part series for the pediatric orthopaedic surgeon or trainee who sees

patients with limb differences intermittently. Part one of this series is meant to serve as a resource to guide initial conversations about timing and future function, as a primer on prosthetic options and terminology, as well as a practical how-to guide for prosthetic prescription. The authors have identified—and answered—the most commonly asked questions by surgeons and families.

# Pediatric Limb Deficiency and Childhood Amputation

Congenital Limb Differences

The Centers for Disease Control and Prevention (CDC) estimates that limb differences annually occur in one out of 1,943 live births. These limb differences may vary from the failure of formation of a digit to a transverse auto-amputation of a limb. A thorough evaluation of the patient's affected limb(s) is important to determine the extent of involvement, formulate a treatment plan, and refer to additional specialists.

In 1989, the International Organization for Standardization (ISO) adopted standard language for describing congenital limb differences.<sup>2</sup> They categorized limb differences present prior to birth into two categories: transverse and longitudinal deficiencies. In cases where the distal segment(s) of the limb is missing, the limb difference is described as a transverse deficiency of the most proximal partial or missing segment. For example, a child with a very short radius and ulna, but nothing distal, would be classified as having a congenital *transverse partial absence* of the forearm. When bones along the longitudinal axis are shortened or missing, but distal segments are (partially or fully) present, the limb difference is described as a *longitudinal deficiency* naming the affected bones.

The incidence of an upper limb congenital difference is two to three times greater than that of the lower limb, with amniotic band syndrome being the most common etiology.<sup>3,4</sup> A congenital transverse partial absence of the upper third of the forearm is the most common upper

limb deficiency. Longitudinal deficiencies of the upper limb occur less often. Conversely, longitudinal deficiencies of the lower limb occur more frequently than transverse ones. Most common is the longitudinal partial reduction of toes, followed by longitudinal deficiencies of the femur, fibula and tibia.<sup>5</sup>

#### **Acquired Amputation**

Traumatic amputations in children tend to occur twice as often as amputations from tumor or infection.<sup>5</sup> In all age groups, finger amputations are the most common traumatic amputation, with a peak incidence in toddlers due to door injuries.<sup>6</sup> Adolescents are more likely to have injuries related to tools or lawnmowers, although the latter mechanism has a bimodal age distribution.<sup>7</sup> Traumatic amputations typically result in transverse or complete amputation of a limb, and may be complicated by severe soft tissue loss or trauma to other parts of the body. Of amputations associated with tumors, those secondary to osteogenic sarcoma or Ewing's sarcoma occur with the highest incidence and typically at 12-21 years.<sup>5</sup> Trauma or tumor-related cases are frequently more complex, both from a surgical standpoint as well as due to the emotional loss by patient and family.

#### **Prosthetic Nomenclature**

Regardless of the level of amputation, a prosthesis generally consists of a socket, interface, suspension, structure, and level-specific components. Additional components (e.g., feet, knees, terminal devices, elbows) are included based on the level of amputation and the purpose of the prosthesis (Figures 1 and 2). When deciding on the specific prosthesis design, the patient, family, and medical team should consider the amputation level, residual limb condition, the patient's development, and the patient and family goals. Understanding the contribution of each element of the prosthesis is critical to assure proper compatibility and function of the entire prosthesis.

The socket is custom molded from the patient's residual limb and serves to connect the body to the prosthesis. The rigid nature of the socket transfers forces from the body to the prosthesis (and vice versa) to enhance control of the prosthesis. Generally, socket shapes are designed to load pressure tolerant (soft tissue) and unload pressure intolerant (boney prominences) areas of the limb. The socket works in conjunction with the interface to enhance comfort while maximizing prosthetic control.

The interface is material placed between the residual limb and socket. Interface options include gel or foam liners, prosthetic socks, and sheaths. Gel liners are typically prefabricated and well-suited for direct application to cylindrical limbs, while custom foam liners are often used for atypical limb shapes. Prosthetic socks, with various thicknesses, are used with most socket designs to accommodate for volumetric limb changes. Sheaths can be used to reduce friction against sensitive or fragile skin. An interface is almost always used, but there are some cases where direct contact between the skin and socket is appropriate.

Prosthetic suspension serves to keep the prosthesis on the patient's limb. Self-suspending prostheses take advantage of wider boney anatomy of the residual limb, such as on the malleoli for a Syme amputation. Sleeves are often used on cylindrical limbs, such as transtibial amputations, to attach the prosthetic socket to proximal limb segments. Alternatively, gel liners can be used in conjunction with a pin (or lanyard) at the distal end that secures into a lock mechanism in the socket. Other options include suction and vacuum suspension. Suction and vacuum require a consistent and intimate socket fit, so they are infrequently used in children whose limbs continuously grow and cause the socket fit to change.

Prosthetic components are connected to the socket by the structure of the prosthesis. Endoskeletal structure typically includes a lightweight, adjustable pylon connection, whereas an exoskeletal structure includes a

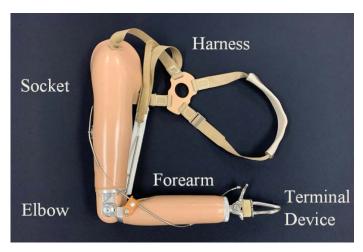


Figure 1. Transhumeral Prosthesis

Upper limb prostheses consist of a socket, suspension (harness), structure (forearm), and terminal device (hook or hand). Transhumeral prostheses additionally have an elbow. In this body-powered prosthesis, the harness is used for both suspension and to operate the elbow and terminal device.



Figure 2. Transfemoral
Prosthesis
Lower limb prostheses
consist of a socket,
suspension, structure
(pylon), and foot.
Transfemoral
prostheses additionally
have a knee. This
sample prosthesis would
likely be utilized with a
pelvic belt or liner for
suspension.

rigid, laminated prosthetic exterior. For patients or families that prefer anatomically shaped prostheses, exoskeletal designs are often used for younger children for durability, and endoskeletal designs with protective cosmetic foam covers are used for teenagers and adults.

Prostheses also include level-specific components (e.g., feet, hands) that help restore function and allow for

environmental interactions. For upper limb prostheses, these components are integrated into one of three control mechanisms: non-articulated, body-powered, and myoelectric. Non-articulated prostheses, commonly known as passive prostheses, use a terminal device that does not move and is recommended for early bimanual control, activity-specific goals, or cosmesis. A bodypowered prosthesis has a terminal device (hand or hook) that is operated by the patient through a harness with glenohumeral flexion and/or scapular abduction motions. Myoelectric prostheses use electric signals in residual muscles to operate the terminal device (hand or hook) through surface electrodes in the socket. Terminal devices are connected to the socket through a wrist unit that can rotate, lock, flex and/or allow for interchangeable terminal devices. More proximal amputations require the addition of elbow and/or shoulder joints. These joints can be mechanically or myoelectrically controlled and often have a locking feature.

For lower limb prostheses, feet are chosen based on a variety of patient characteristics, such as activity level, weight, shoe size, and clearance. Proximal amputations require additional prosthetic joints (knee and/or hip) to replicate missing joints and restore ambulatory mobility. Knee joints are also determined based on patient characteristics, and utilize locks, friction, hydraulics, microprocessors, or other features in combination with hip muscle activation to control knee flexion and extension.

#### Activity-Specific Prostheses

Children who require prostheses are generally highly active and interested in a wide array of activities. These activities often require the provision of a separate (secondary) prosthesis with activity-specific components that meet a child's needs when he or she cannot otherwise perform that activity (Figure 3). For children with upper limb differences, activity-specific terminal devices are available that can either be interchanged with



Figure 3. Sports Prostheses
Activity-specific or sports prostheses are typically
utilized by children starting in their early teens as they
advance in their skills or whenever their primary

prosthesis no longer suffices for their leisure activity.

a conventional terminal device or integrated into a secondary prosthesis. Examples include designs for gripping bicycle handlebars, weight lifting, and flexible terminal devices for sports. For children with a musical interest, there are terminal devices designed to hold a guitar pick, drum stick, or violin bow. Examples of activity-specific components for lower limb prosthetic patients include legs with carbon blades for running, feet that clip into ski boots, and knees designed for mountain biking. Leg prostheses are not generally used for swimming, but many children use a separate, waterresistant prosthesis at pools, water parks, showers, or beaches.

Patients and families are often well-informed about activity-specific prostheses through social media and marketing and may even request specific components for their child's sport or leisure activities. Note that if the child already has a primary prosthesis, insurance carriers tend not to cover the secondary prostheses as it is considered "not medically necessary." Children who have an active lifestyle are more likely to stay active as adults. Recreational and elite level amputee athletes challenge prosthetists, researchers and manufacturers to

develop specialized products to meet their needs. As a result, better techniques and components for the active child are continuously in development.<sup>8</sup>

# **Surgical Considerations**

It is important to balance surgical priorities with prosthetic goals to provide the best functional outcome for each patient. With respect to residual limb length, maintaining a long residual limb can result in better strength and function. In addition, joint disarticulations minimize bone overgrowth and the need for multiple revisions. However, some prosthetic components (e.g., feet, elbows) require a shorter residual limb length to create sufficient clearance for their use. Long residual limbs, including joint disarticulations, often do not allow adequate room for prosthetic components and may result in functional asymmetry, energetic costs, and poor cosmesis. Additionally, medial and lateral prominences in joint disarticulation amputations create a wide distal limb that may challenge prosthetic donning and doffing. For example, in the case of amputation through the ankle (Syme) the malleoli make the distal limb wider than the section of the limb just proximal. The resulting prosthetic socket will require an opening or other accommodation that may be bulky and less cosmetically appealing. However, in some cases this added boney width may advantageously be used for prosthetic suspension, thus eliminating the need for sleeves or belts. Such considerations must be weighed by the orthopaedist.

Generally speaking, the surgical level and limb length will be dictated by the affected limb's joint stability, bone integrity and viable tissues for closure. An epiphysiodesis in adolescence for those with joint disarticulations may provide added clearance for advanced prostheses as children grow enough to use adult componentry. In most cases, 5-10 centimeters of clearance between hip to knee length or 8-18 centimeters of clearance distal to the knee will provide enough room to fit an adult with advanced prosthetic components,

with the upper end of each range indicative of microprocessor-controlled devices.

In cases of young children with congenital deficiencies, the family may opt not to undergo surgery for removal of non-functional anatomy (e.g., partial foot, phalanges). This often can be initially accommodated in a prosthesis but may complicate and limit the design, function and cosmesis of future prostheses as the child grows. Such changes may dictate the ablation of that partial limb later in life. Therefore, these considerations should initially be discussed with the family.

# **Postoperative Care**

The goal of postoperative care is to protect the limb, maintain range of motion, and manage edema postoperatively to expedite the healing process. In situations where an amputation is planned, preparation is key. Whenever possible, a prosthetist should be involved in the discussions leading up to the amputation. Their insights may be valuable when deciding on amputation level, weighing surgical options such as resection of the malleoli or removal of the patella, and determining an immediate postoperative plan. Additionally, prosthetists can educate the patient and family on postoperative care, the process for receiving a prosthesis, and functional expectations thereafter. These discussions are often best done by the prosthetist who will be working directly with the patient. Whenever possible, the child/family should also be connected with other children with similar amputation levels and/or etiologies.

Postoperative management of pediatric patients varies depending on patient-specific considerations, such as age and amputation level. For example, infants and toddlers are often too small for specific postoperative prosthetic devices and may do best with a soft dressing or a cast. Adolescents and teenagers may use a cast, removable rigid dressing (RRD) with shrinkers (or compressogrip) or an immediate postoperative prosthesis (IPOP) for lower limbs and an RRD with compressogrip or soft dressing for upper limbs. With soft dressings, a

knee immobilizer may sometimes be used to maintain knee or elbow extension and to further protect the limb. Use of these devices will typically be discontinued once the patient is utilizing a prosthesis daily. Prosthetists often provide postoperative devices, and thus their involvement in post-operative decision-making should be considered.

# **Timing of a Prosthesis**

Accomplishment of developmental milestones should be considered with respect to the timing of prosthetic fitting and component sophistication. Key milestones that can help clinicians determine when to fit a prosthesis include the following:

#### Upper Limb Prosthetic Milestones

Sitting balance (around 5-7 months). Sitting balance has been the traditional determinant for early fitting of a child with their first upper limb prosthesis, typically a passive hand. Once the child starts to sit, they can explore their environment with both hands through bimanual activities and propping themselves up or crawling. In theory, the child will adapt to wearing their prosthesis so that by age two they are more amenable to learning how to operate a functional terminal device. By age five, most children will be coordinated enough to control a body-powered above elbow prosthesis but may lack the strength or range of motion to move the cableoperated arm through its full range. Thus, children with proximal absences are often fitted with "hybrid" prostheses that combine cable operated functions like flexing the elbow with switch or myoelectric control of the hand.

Some centers and experienced parents argue that the child born with an absent limb is different than the older child with an acquired amputation. Children born with an upper limb difference or very early amputation will generally adapt and display remarkable dexterity with their affected limb(s). The prosthetic socket blocks limb sensory feedback and may limit development of

strategies to be as functional as possible without a prosthesis. This is especially evident for children born with bilateral hand or arm absences. For most patients with congenital upper limb absence, it is recommended that several options are offered to the parents including early fitting versus waiting until the child is old enough to express specific challenges for which a prosthesis may help. It is also important to consider that wearing no prosthesis is a perfectly viable and acceptable option for children with upper limb deficiencies who are generally able to adapt and function independently. 9 Older children with acquired amputation from trauma or disease will often adapt well to prosthesis use since they have lost function, sensation, and dexterity in their affected limb(s). In the long term, patients and families should be included in the decision-making process to select what works best for them.

#### Lower Limb Prosthetic Milestones

Pulling to stand (between 10-14 months). The ideal time to start fitting a child with a lower limb prosthesis is when they begin to pull to a stand. If the child has a knee disarticulation or more proximal deficiency, it is often possible to include the prosthetic knee joint initially to facilitate crawling, pulling to stand, cruising and walking. This generally works best when the family has access to ongoing physical therapy and regular followup with their prosthetist. Including an articulated knee for children under age three is sometimes complicated by the lack of appropriately sized knees and that the child may become frustrated by frequent falls. As a result, some centers prefer to use manually locked knees (or a monolithic non-articulated prosthesis) until the child begins to walk. The articulated knee can be added later, but typically by age three most children can control a prosthetic knee joint.

For younger children with bilateral knee disarticulations or transfemoral levels, a pair of short prostheses ("stubbies") with crepe soles or specialized feet may be fitted first until the child learns to tolerate the sockets

and achieve controlled household ambulation. This approach also often works well for older children with acquired amputations to help them adapt first to tolerating their sockets and gaining balance. As the child adapts, the short prostheses can be gradually lengthened, feet added, and then knee joints added. Generally, it is preferable to help the child adapt to using functional knees as soon as they are able, and it is technically feasible to do so.

Development of normal walking patterns. By age two, most children walk with heel strike, reciprocal arm swing and a knee flexion wave. Mature gait, including running, generally appears by age four. For children who are managing their prostheses well and demonstrate the ability to jog or run, it is possible to start fitting them with dynamic response feet including various running "blades" at a very early age. Most centers probably start including a prosthetic foot with energy storing or dynamic response when the child starts running and when there is a prosthetic foot matched to their size, body weight, and activity level.

#### Growth and Prosthetic Replacement

Children will require a new prosthesis about every 12 to 24 months until they are skeletally mature. For adults, prostheses are generally replaced every three to five years. For prosthetists fitting a growing child, the greatest challenge is designing a system that the child will not outgrow too quickly. Prosthetists should be consulted for modifications to the prosthesis that will extend the device's usable life as the child grows. Physical or occupational therapy is a key component of the child's training and adaptation whenever a new prosthesis or major control strategy is introduced, or a new major developmental stage is entered.

# Physician Evaluation, Prescription, and Documentation

Regardless of a patient's age, the process of justifying and prescribing a prosthesis is largely dictated by requirements established by the Centers for Medicare and Medicaid Services (CMS) and followed by most insurers. CMS policies specify the process and documentation required by physician and prosthetist to justify a prosthesis, whether it is the child's first or a replacement.

The process starts with the physician's evaluation and recommendation for the prosthesis, followed by an initial prescription to "evaluate and treat" the patient. This initial prescription should include the patient's name, diagnosis, start date, a basic description of the type of prosthesis (e.g., transfemoral, transtibial), and the physician's name, credentials, and signature. The level of detail of the initial prescription may vary based on the physician's familiarity with prosthetic design options. Once the prosthetist receives the initial order, they will request a copy of the physician's notes and evaluate the patient and state of the current prosthesis (if applicable). The prosthetist must justify the medical necessity of the new prosthesis and each major component. A detailed written order including descriptions, billing codes and quantities for the prosthesis, its major components and any supplies will be requested. This must be corroborated in the physician's notes, signed, and returned to the prosthetist.

A physician's notes must properly justify the prosthesis and should include: a thorough physical examination, description of the child's current activities and functional abilities (including K-level with justification for lower limb users), goals and motivation for using the new or replacement prosthesis, and the rationale for inclusion (or replacement) of all major parts of the device (e.g., socket, suspension, elbow, foot). It is generally not sufficient to simply state that the child has outgrown the device and needs a new one. The following information is helpful when justifying replacement prostheses: changes due to growth (e.g., height, weight), developmental milestones, new goals, radiographical changes, and evaluation prosthesis fit and function. A note template can be used to ensure inclusion of

necessary documentation (Addendum: Physician Documentation Template for Prescribing Prostheses, pages 14-15).

CMS and most insurers classify lower limb prosthesis users by functional levels (K-levels, Table 1). K-level designation often determines insurance coverage for certain components (e.g., knees, feet). Determination of K-level evaluation is the responsibility of the physician, with input from the care team. Standardized outcome measures can be used to justify K-Level determination, but these measures are generally not validated for use with children. Therefore, pediatric functional levels are largely based on clinical judgement, exam, and observation of the child's ability to vary their walking speed or run with their existing prosthesis. It is important to remember that a K-level refers both to the child's current functional abilities as well as *potential* improvement.

# **Process for Receiving a Prosthesis**

Following a physician's referral, the prosthetist will evaluate the patient to obtain medical history, patient/family goals, physical and functional examination, sensation, and the condition of the residual limb. The prosthetist then captures the shape of the residual limb by making a plaster or fiberglass mold or 3D scan. Based on the measurements taken and the design of the prosthesis, the prosthetist modifies the mold or scan to fabricate a clear thermoplastic test socket. This test socket is easily modifiable to fine tune the fit, alignment, and function before fabricating the final prosthesis. Two test sockets are often necessary to achieve satisfactory fit. The patient is then provided a definitive prosthesis for long-term use. Frequent followup appointments are scheduled to ensure proper fit and function; all adjustments within the first 90 days are included in the cost of the prosthesis.

# **Therapeutic Intervention**

Therapy for children with prostheses primarily centers on optimization of functional daily activities and/or

| Table 1. Descriptions of Functional Levels |   |  |
|--|---|--|
| K0   | No ability or potential to ambulate or transfer safely. <i>A prosthesis is not warranted</i> .  |  |
| K1   | Ability or potential to use a prosthesis for transfers or ambulation on level surfaces at a fixed cadence only within their home. <i>This is rare for children</i> .  |  |
| K2   | Ability or potential to traverse low-level environmental barriers such as curbs, stairs or uneven surfaces at a steady fixed cadence within or outside of their home. <i>This is common for first time users or toddlers</i> .  |  |
| К3   | Ability or potential to traverse all environmental barriers such as curbs, stairs or uneven surfaces, with variable cadence within or outside of their home. They may participate in play, school, therapeutic or exercise activities that demand prosthetic use beyond simple locomotion. This is a determinant for providing components with advanced designs (e.g., hydraulic knees, energy-storing feet). |  |
| K4   | Ability or potential for ambulation that exceeds basic skills, exhibiting high impact, stress, or energy levels. <i>This is typical of the prosthetic demands of the child, active adult, or athlete.</i>   |  |

mobility in their home, educational, and community environments. <sup>14,15</sup> Further evolution of goals depends upon the individual and their presentation (e.g., etiology, limb involvement). It is important to remember that therapy episodes of care are individualized for each child, taking into consideration multiple factors to meet the needs of the child and their family.

In the event of a traumatic amputation, therapy should be involved in the acute stage to address independent function.<sup>15</sup> For lower limb amputations this includes bed mobility, transfers, and accessing their environment as

independently as possible. Progressive weight-bearing should begin when cleared by the surgeon and fitted with an appropriate postoperative prosthesis. 15,16 Early treatment or prevention of contractures ensures optimal lower limb position in standing and gait as the child progresses through rehabilitation.<sup>15</sup> For upper limb amputations, functional mobility with the added component of fine motor control and coordination in essential activities of daily living (ADLs), such as dressing and grooming, should be addressed. In all cases, the child should be trained early in the rehabilitation process to avoid potential overuse of the uninvolved limb or the use of excessive compensatory strategies. As the child heals and progresses beyond the acute hospital stay, both physical and occupational therapy are important considerations based on the child's needs. Therapy can occur both on an inpatient rehabilitation unit and in an outpatient clinic.

The treatment of children with congenital limb deficiencies similarly has goals of optimizing function and preventing or managing contractures. Achievement of these goals promotes age appropriate gross motor milestone attainment. Frequently, the child can receive services through both an outpatient clinic setting and school-based services. The supplementation of school-based therapeutic services ensures that the child is able to optimally access and engage in educational activities with their same-age peers.

# **Multidisciplinary Team Approach**

The pediatric prosthetic patient benefits from management by a multidisciplinary team. This team ideally would include a prosthetist, orthopaedic surgeon, physiatrist, physical and/or occupational therapist, psychologist and social worker. The prosthetist generally provides insights into the potential design and timing of the prosthesis, as well as potential function with it. The orthopaedist tends to focus on the overall skeletal development of the child and potential need and timing of future surgical interventions. The physiatrist provides the perspective of the child's

overall development from a functional standpoint and often recommends additional interventions, such as therapy, that may be needed. The physical and/or occupational therapist evaluates the child's function and goals, which then provide insights to the rest of the team for the potential use of a prosthesis. They also provide ongoing care of the patient prior to and once fitted with a prosthesis. The inclusion of a psychologist as part of the team is often missed but important. This specialist provides counseling to the family and patient, as well as insights to the rest of the medical team for optimization of care from an emotional and psychosocial aspect. In cases of trauma, the psychologist frequently provides ongoing patient care. A social worker can connect the family with crucial community resources as they maneuver through various aspects of living with limb loss or deficiency.

The prosthetist is frequently involved in the patient's care across the aforementioned disciplines as the knowledge received from each specialist often has implications for the prosthesis design and the care provided. The prosthetist tends to meet with the patient and their family frequently early on in the treatment and thereafter on an ongoing basis for the rest of their life, often serving as a screener for other medical services. Although prosthetists cannot refer patients, they may request that the orthopaedist consider making such referral to another medical specialty.

Establishing a multidisciplinary prosthetics clinic provides a consistent team of clinicians working together for children with prosthetic needs. By working collaboratively, the specialists are able to see trends that may otherwise be missed and to pull from the collective knowledge to inform treatment decisions. As a whole, the team not only works to optimize development and function but also supports the child and family as they interact with their world. The authors feel this approach is critical in achieving excellent prosthetic use and long-term outcomes, yet acknowledge that it is not always possible in all centers.

| Table 2. Common Questions that Physicians Ask  |   |  |  |  |
|--|---|--|--|--|
| What is the recommended timeline for postoperative care?   | Immediate postoperative limb shaping and protective devices are often used. Patients are usually ready for initial prosthetic casting at approximately 3-4 weeks postop, as their limb is healed well enough to tolerate a prosthesis and weight-bearing.   |  |  |  |
| What is the ideal limb length? (now versus adulthood)  | In skeletally immature children, a joint disarticulation will frequently be chosen to avoid bone overgrowth. An epiphysiodesis may be necessary to create a limb difference of 8-18 cm below knee or 5-10 cm above knee at adulthood to give patients a wide variety of options for lower limb prostheses.  |  |  |  |
| When should the first prosthesis be fit? (age/milestones, healing)   | Children are typically fitted with their first prosthesis based on the timing of developmental milestones: sitting for upper limb and pulling to a stand for lower limb. For acquired amputations, the child is fitted once the sutures are removed and the limb heals enough to tolerate prosthesis fitting.   |  |  |  |
| At what age do you fit with a prosthetic knee?   | New research has demonstrated that early fitting of a prosthetic knee, as the child pulls to a stand, can provide significant advantages in childhood development by allowing the patient to tall kneel and reciprocally crawl. <sup>17</sup>   |  |  |  |
| When do you fit a non-articulated, body-powered, versus myoelectric upper limb prosthesis?                             | A non-articulated (passive) prosthesis is typically fitted as the child begins to sit. Around two years, the child is able to utilize a prehensor on a body-powered or myoelectric prosthesis. For adolescent or teenage-acquired amputations, a myoelectric prosthesis may be desired for finer motor skills and cosmesis or a high-definition non-articulated (passive) prosthesis for cosmesis only. |  |  |  |
| When can we fit advanced technology, such as a microprocessor-controlled knee (or ankle) or a multi-articulating hand? | Due to the weight and size of technologically advanced components, most children will not have the clearance, body size, or weight tolerance to use them until they reach their midteens.   |  |  |  |
| When should we fit a sports- or activity-specific prosthesis?  | Many children are able to begin playing sports using their primary prosthesis without any adaptations When they find that they are unable fully to participate in the activity, they may need an activity-specific prosthesis.  |  |  |  |
| What do I need to include on the prescription?   | Initial prescription: A clear description of the patient's amputation level, K-level (lower limb only), start date, and general description of prosthesis prescribed.  Direct written order: Detailed description and billing codes for all prosthetic components, amputation level, and K-level (lower limb only).   |  |  |  |
| When should I refer to physical versus occupational therapy?   | Generally, referrals should be made to physical therapy (PT) for gross motor function and occupational therapy (OT) for fine motor control.   |  |  |  |

| Table 3. Common Questions that Families Ask                             |  |  |  |  |  |
|---|--|--|--|--|--|
| Is my child going to walk (or function without an arm)?                 | Assuming normal cognitive function, your child will walk, attend school, participate in recreation and keep up with his/her peers. Your child will learn to use their intact arm as their dominant hand, while the affected arm supports. They will learn new ways to complete various tasks, with and without a prosthesis.   |  |  |  |  |
| How will other kids treat my child?                                     | Children will be curious about your child's limb deficiency and prosthesis. They may ask questions of your child as to how they lost their limb, why they use a prosthesis, or how it works. Helping your child be comfortable with their body image will help empower them to be comfortable answering those questions. A psychologist or child life specialist can provide invaluable guidance.  |  |  |  |  |
| Will my child be able to participate in extracurricular activities?     | Certainly. Your child will be able to do anything they want; they may just have to find their own way to participate. In the U.S., the participation of children with amputations or limb differences in sports has become progressively more mainstream due to the 2013 U.S. Department of Education's Office for Civil Rights mandate that school districts receiving federal dollars are legally obligated to provide access to sports for students with disabilities. <sup>18</sup> Children may participate in organized competitions through schools, the Paralympics, The Challenged Athletes Foundation (CAF), and the Endeavor Games. |  |  |  |  |
| How long after surgery before my child will get his/her leg or arm?     | Within 1-2 months after surgery, your child's limb will likely be healed enough for prosthetic fitting.  |  |  |  |  |
| How long does it take to make a prosthesis? What is the process?        | A prosthesis takes about 2-6 weeks to complete, depending on how quickly insurance authorization can be obtained.  |  |  |  |  |
| Does insurance pay for a prosthesis? Is there a charge for every visit? | Prostheses used for daily function by children are typically covered by insurance, but activity-specific uses are not. Adjustments to a delivered prosthesis are generally covered within the first 90 days.   |  |  |  |  |
| How often will I need to come back for follow-ups as my child grows?    | Initially your child may follow-up on a weekly or monthly basis, but thereafter, it is typically on a quarterly basis, depending on the frequency of growth or damage from typical use to the prosthesis.  |  |  |  |  |
| How often will we need to get a new prosthesis?                         | Most children grow enough annually to necessitate a new prosthesis. As your child reaches their mid-teens, they can usually wear the prosthesis for 18-24 months before a new one is required.   |  |  |  |  |
| Can we just 3D print a prosthesis for our child?                        | Current materials used in 3D printing do not have the necessary strength and durability for use by a growing child.  |  |  |  |  |
| My child does not want to wear his/her arm anymore. What should I do?   | Oftentimes children with upper limb prostheses find that they are able to accomplish most daily tasks without anything, so they stop using their device. In their teens or adulthood, they may want to resume wearing a prosthesis for specific tasks or cosmesis.   |  |  |  |  |

#### Resources

Patients and families frequently ask their surgeon for community resources, such as support groups, specialized camps, and transition resources. Due to their wide array of needs and resources available, the prosthetist, therapist and social worker may be the best at connecting the child locally with resources. Although many excellent resources exist nationally, we name the two most comprehensive ones:

The Association of Children's Prosthetic-Orthotic Clinics' (ACPOC) website provides a resource page for parents. This has a broad array of resources related to support groups, adaptive sports, camps, fitness and recreation, transitioning from childhood to adulthood, technology and limb difference resource newsletters or magazines. More information: <a href="https://acpoc.org/parents/">https://acpoc.org/parents/</a>.

The Amputee Coalition (AC) sponsors the National Limb Loss Resource Center. It should be noted that this site is not focused solely on the pediatric patient, so greater effort may be needed to find the applicable resources on this website. However, their website does allow sorting to identify resources specific to children and parents. More information: <a href="https://www.amputee-coalition.org/limb-loss-resource-center/">https://www.amputee-coalition.org/limb-loss-resource-center/</a>.

#### Conclusion

Caring for pediatric patients with limb loss or absence is rewarding work. Most children are able to use their prostheses to participate in a variety of activities, including sports and recreation. To optimize outcomes, it is key for the orthopaedist to work closely with a multidisciplinary team of rehabilitation professionals. In particular, a prosthetist should be consulted early in treatment and throughout the course of care as they may provide the orthopaedist with insights crucial for prosthesis design and function. Each member of the clinical team plays a unique role in restoring mobility and quality of life in pediatric patients with limb loss or absence.

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#### ADDENDUM: PHYSICIAN WORKSHEET

Medical History:

|    | a.       | Date of Amputation or limb loss:   |  |
|----|----------|--|--|
|    | b.       | Affected side(s)/level(s):   |  |
|    | c.       | Cause of amputation or limb difference:                                      |  |
|    | d.       | Comorbidities:   |  |
|    | e.       | Clinical course, therapeutic interventions to date and results:              |  |
|    |          |  |  |
| 2. | Physica  | al Examination (comment on any impact that might impact prosthetic usage):   |  |
|    | a.       | Height, weight, any recent gain/loss:  |  |
|    | b.       | Cognitive ability / family support to use and care for their prosthesis:     |  |
|    |          |  |  |
|    | c.       | Cardiopulmonary status:  |  |
|    | d.       | Musculoskeletal status:  |  |
|    |          |  |  |
|    | e.       | Neurological status and sensation:   |  |
|    | f.       | Strength deficits:   |  |
|    | g.       | ROM limits:  |  |
|    | h.       | Residual limb condition:   |  |
|    | i.       | Other intact limb condition(s):  |  |
| 3. | Function | onal limitations due to their limb difference (ADLs, sports, hobbies, etc.): |  |
|    |          |  |  |
| 4. | Desire   | and motivation to use a prosthesis:  |  |
| 5. |          | Lower Limb only:   |  |
|    | a.       | Gait deviations:   |  |
|    | b.       | Balance / coordination:  |  |
|    |          | Assistive device use:  |  |
|    |          | K – Level Classification (circle one and complete iv):                       |  |

- - i. **K-0** (Does not have the ability or potential to ambulate or transfer safely with or without assistance and a prosthesis does not enhance their quality of life or mobility.)
  - ii. **K-1** (Has ability or potential to use a prosthesis for transfers or ambulation on level surfaces at a fixed cadence. Typical of a household ambulator or a someone who only walks around in their own home.)
  - iii. **K-2** (Has the ability or potential to ambulate and to traverse low level environmental barriers such as curbs, stairs or uneven surfaces. Typical of the limited community ambulator.
  - iv. **K-3** (Has the ability or potential to ambulate with variable cadence. Typically, a community ambulator who also can traverse most environmental barriers and may participate in play, school, therapeutic or exercise activity that demand prosthetic use beyond simple locomotion.
  - v. **K-4** (Has the ability or potential for prosthetic ambulation that exceeds basic ambulation skills, exhibiting high impact, stress or energy levels. Typical of the prosthetic demands of the child, active adult or athlete.
  - vi. Examples of activities that justify the selected K-level:\_\_\_\_\_

| 1.          | rostnetic recommendation:   |
|-------------|---|
|             | a. Type (circle one): new prosthesis, replacement prosthesis, replace components,                   |
|             | activity/sport-specific prosthesis  |
|             | b. All prostheses (circle in each section):   |
|             | i. Socket and interface: hard socket / flexible inner socket / gel liner / custom foam              |
|             | liner / single-ply socks / multi-ply socks / sheaths / other:                                       |
|             | ii. Suspension: pin or lanyard locking / self-suspending / sleeve / suction /                       |
|             | other:  |
|             | iii. Structure: endoskeletal / exoskeletal  |
|             | c. Lower limb only (circle in each section):  |
|             | i. Knee: NA / manual lock / single axis / weight-activated stance control /                         |
|             | pneumatic / hydraulic swing and stance control / microprocessor-controlled /                        |
|             | other:  |
|             | ii. Foot: SACH / single-axis / flexible keel / dynamic / energy-storing /                           |
|             | microprocessor-controlled / other:  |
|             | d. Upper limb only (circle in each section):  |
|             | i. Elbow: NA / passive locking / friction / positive locking / externally powered                   |
|             | ii. Wrist: friction / constant friction / quick disconnect / flexion / externally powered           |
|             | iii. Terminal Device(s): passive mitt / hook / hand / multi-articulating hand /                     |
|             | other:  |
|             | iv. Control strategy: Passive / body-powered / myoelectric / external power / hybrid                |
|             | v. Other:   |
| 2 1         | rognosis with this prosthesis (goals and estimated timeline to reach them):                         |
| <b>2.</b> 1 | a. Goals to be achieved:  |
|             | b. Estimated time until accomplishment:   |
| 3. 7        | Yew prosthesis only:  |
| 3. 1        | a. Rationale for first time prosthesis (circle any that apply):                                     |
|             | i. Recent amputation  |
|             | ii. Developmental milestones accomplished that indicate readiness for a prosthesis:                 |
|             | ii. Developmental inflestones accompnished that indicate readiness for a prostness.                 |
|             | iii. New goals expressed by patient and family for which a prosthesis would                         |
|             | reasonably help them achieve, especially with regard to ADL's or functional                         |
|             | goals   |
|             |   |
| 1           | iv. Other:eplacement prosthesis/components only:  |
| 4. /        | a. Reason current prosthesis needs to be replaced:  |
|             | b. Condition of current prosthesis:   |
|             |   |
|             | i. Socket (fit, needs not met):   |
|             | ii. Component condition (knee, foot, hook, hand, elbow):  |
|             | iii. Structure condition (pylon, exoskeletal, height):  |
|             | c. Reason(s) for replacement:   |
| Prior pro   | thesis or component (circle any that apply): no longer functions as needed / was damaged            |
| _           | epair / was lost or stolen / no longer fits as documented above due to growth or other changes /    |
| -           |   |
|             | condition or goals changed / unable to safely repair to achieve necessary fit or function / cost of |
| repairs e   | ceeds 70% of a new device / other:  |