



Rehabilitation Considerations for the Pediatric Upper Extremity Amputee

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Overview



- Shriners Hospitals
- Limb Deficiency Clinic
- Assessment
- Prosthetic training and parent education
- Therapist's role and adaptive equipment

Shriners Hospitals for Children® - Twin Cities



At a glance

Facts and figures:

- **91-year-old** organization, founded in 1922
- Network of **22 healthcare facilities** that provide compassionate, high-quality, family-centered pediatric medical and surgical care



Orthopaedic

Canada

Chicago

Erie

Greenville

Honolulu

Houston

Lexington

Los Angeles

Mexico

N. California

Philadelphia

Portland

Salt Lake City

Shreveport

Spokane

Springfield

St. Louis

Tampa

Twin Cities

Burns

Boston

Cincinnati

Galveston

N. California

Spinal Cord Injuries

Chicago

N. California

Philadelphia

Cleft Lip/Palate

Boston

Chicago

Cincinnati

Houston

Los Angeles

N. California

Portland

Springfield

Shreveport

Twin Cities



- Serve children birth - 21
- Acceptance is based solely on a child's medical need, not their ability to pay
- We serve a large geographical area: ND, SD, IA, WI, NE, MI UP, and parts of Canada
- Inpatient care unit
- Outpatient specialty clinics

Limb Deficiency Clinic

- Children we treat are wide ranging and diverse in their diagnoses
- Focus of this presentation will be upper limb differences
- No assembly line approach
- We evaluate the unique needs of each child



Upper Limb Formation



- Begins at 4 weeks gestation
- Hand is fully formed by 8 weeks
- Sometimes the arm difference is identified on ultrasound

Limb Formation Facts

- 60% of limb formation differences have no known cause or are genetic in origin
- Some congenital abnormalities may be due to poor blood supply, constricting amniotic bands
- Only 4% are due to maternal drug exposure such as thalidomide

Unilateral Congenital Below Elbow Deficiency

- Isolated congenital malformation
- 1:30,000 live births



Loss of a Hand is Devastating

- Intimately intertwined with psychosocial roles
 - Gestures
 - Caressing
 - Communication
 - Sensation
- Physical/functional loss
 - Grasp
 - Symmetry in reach

Impact of Limb Deficiency on Families

- Parents often have guilt and sorrow
- Educate them on reasons for the difference
- Acquired amputations more difficult on families
- Our social workers offer counseling and can refer them on to a psychologist



Social Worker's Role

- See every patient/family at their initial visit
- Also see on an as-needed basis
- Services tailored to patient's needs, including grief, loss, and adjustment to the diagnosis
- May provide online resources for community support

Online Resources for Parents

- www.helpinghandsgroup.org
- www.limbdifferences.org
- www.acpoc.org
- <http://singlehandedsolutions.blogspot.com>
- www.superhands.us
- <http://www.littlefins.org>.

“How well a parent accepts a limb deficiency and how well they cope with it has a great deal to do with how well the child does either with or without a prosthesis.”

Yoshio Setoguchi MD

O&P Edge 2005

Rehab of the Upper Limb Amputee Requires a Multi-Disciplinary Approach

- Orthopedic Surgeon
- Pediatrician
- Physician Assistant
- Nurse
- Social Worker
- Occupational and Physical Therapist
- Orthotist and Prosthetist
- Radiologist



Initial Visit

- Internet- Parents may do self-directed research
- Some parents arrive with unrealistic expectations
- Understand their goals and concerns
- Educate them about their options

Infant and Toddler Gross Motor Assessment



Assess Ability to Use Arms Together

- We use toys to understand how they use their arms together
- What compensations do they use?
- Can they support toys at midline?



How Do They Stabilize Objects?



How Does the Length of Their Forearm Impact Function and Fitting?



Long Forearm and Partial Hand



- Partial hand difficult to fit with a prosthesis
- High degree of rejection



What Activities Do They Have Difficulties With?

- ADLs, e.g. shoe tying, starting zippers and buttons, toileting, etc.
- Sports or special interests? Different sports may need different prostheses.
- School skills: keyboarding, scissors
- Older kids: homemaking, job demands, driving

Standardized Assessments

- Unilateral Below Elbow Test (UBET)
- PedsQL- Quality of Life
- Pediatric Outcomes Data Collection Instrument (PODCI)- musculoskeletal health
- Prosthetic Satisfaction Index (PSI)

Unilateral Below Elbow Test (UBET): Button a Vest: 5-7 year old task



UBET Function Test

Button a Shirt: 8-10 year old task



The Pediatric Quality of Life Inventory

PedsQL™

- Quality of life measurement for healthy children and adolescents with acute and chronic health conditions

4 Core domains:

- Physical
- Emotional
- Social
- School Functioning

Use of PedsQL™

23 questions

- How much of a problem is _____ during last month?
- Child self-report: ages 5-7, ages 8-12, ages 13-18
- Parent report: ages 2-4, 5-7, 8-12, 13-18

Useful for monitoring Health related QOL
to help identify concerns they may have.

Pediatric Orthopaedic Data Collection Instrument (PODCI)

- Musculoskeletal health
- Self-report ages 11-18; parent version ages 2-18
- Evaluates changes following pediatric orthopedic interventions for a broad range of diagnoses

108 questions: 7 dimensions

1. upper extremity function
2. transfers and mobility
3. physical function and sports
4. comfort (lack of pain)
5. happiness
6. satisfaction
7. expectations

Use of PODCI

Useful for monitoring for progression of a disease process and as means to evaluate benefits of surgical and non-surgical intervention (prosthesis)

- Most important sections are sports and UE; how they compare to normal children

Prosthetic Satisfaction Index (PSI)

- Standardized measure of prosthesis satisfaction
- Parent and child versions
- 14 questions to assess degree of satisfaction with the prosthesis (fit, looks, works, follow up care)
- Provides feedback to determine satisfaction with the prosthesis and areas for improvement

Following Your Assessment: Educate the Parents about Prosthesis Options Available for their Child

- Discuss benefits and drawbacks of each prosthesis styles
- Share your clinical experience and recommendations
- Discuss past research about prosthetic outcomes

Initial Visit Recommendations

- Fitting of a prosthesis is an individual family and team decision
- If a prosthesis is not indicated by the team, i.e. long residual limb, educate family on reasons why
- The family may prefer no prosthesis
- Identify any ADL concerns that can be addressed with adaptive equipment or techniques

Not Wearing is a Choice



Infant and Toddlers: When to Fit

- Prosthetic care has been an area of controversy
- Should they be fit? If so, when and with what
- You never know who will be a good wearer and user if you don't fit
- Prosthesis helps with balance, body image, encourages midline play



Rejection of a prosthesis is less likely if a child is fit before age 2

- Kuyper and Breedijk, “Prosthetic management of children in the Netherlands with upper extremity deficiency” *Prosthetics orthotics International* 2001
- Postema and VanDerDonk “Prosthesis rejection in children with unilateral congenital arm defect” *Clinical Rehabilitation* 1999
- Scotland and Galway, “A long term review of children with congenital and acquired deficiencies” *J Bone and Joint Surgery* 1983
- Brooks and Shaperman, “Infant prosthetic fitting: A study of the results” *American J Occupational Therapy* 1965

Benefits of First Passive Hand Prosthesis (Infant)

- Child becomes accustomed to wearing a prosthesis
- Incorporate prosthesis into body image
- Explore arm movements at arm's length
- Gross motor
 - maintain sitting balance
 - crawl in a typical pattern
- Opportunity to develop bimanual skills
- Useful prehensile tool

Prosthetic Options: Passive Hand: Age 6 – 18 Months



- Passive Fisted Hand
- Passive Open Hand
- E-Z Feed Hand



Prosthetic Training: Parent Education Infant



- Components and how to don
- Wear schedule
- Encourage active reach with the prosthesis
- Stabilize objects passively
- Position activities at midline and at hand level
- Place objects in the terminal device
- Incorporate prosthesis for gross motor skills

Activities for Two-Handed Play

Age 12-18 Months

- Toys with music and lights
- Use the prosthesis to stabilize pages of a book
- Throw and catch a large ball
- Handle of a bucket over prosthesis at the wrist
- Both arms to push a toy cart
- Put biter biscuits in the E-Z Feed hand

Switch to a Body Powered Voluntary Opening Prosthesis (18 Months)



B scapular abduction and humeral flexion to open the TD



Prosthetic Training

First Active Prosthesis



Success with Opening the Terminal Device

- Start by placing objects into the hand for them
- Use the prosthesis as a passive stabilizer
- Teach parents how the control cable works
- Guide child's arms into bilateral scapular abduction and shoulder flexion for opening
- May take awhile to grasp this concept
- Pay attention to their sound arm

Prosthetic Training

Age 18 – 24 months

- Key is training the parents
- Review moving components
- Establish a wear schedule
- Home program suggestions
- Birth to Three program

Switch to a Voluntary Closing Terminal Device at Age 2



ADEPT Terminal Device



Lite Touch Terminal Device

Voluntary Closing TD Training

Age 2-3

- These kids begin to grasp and master the concept of how the TD works
- Start with simple form board
- Age-appropriate play with easy to hold objects that fit in TD



Ages 3 - 4

What to Expect with a Prosthesis

- Remove and put on the prosthesis
- Most can open and close the terminal device
- Can do most ADLs
- Some training and support still needed



Team Decision for Myoelectric Prosthesis



Myoelectric Prosthesis Training



Teach Parents How to Put the Prosthesis On



Prosthetic Training May Include



One Prosthesis with Several Terminal Devices



Above Elbow Amputees

- Length of humerus impacts function
- Turntable – position hand in towards body
- Elbow joint – friction
- May consider a friction wrist



Body Powered Above Elbow

Scapular Protraction & Shoulder Extension



Evaluate Strength of Arm with Prosthesis



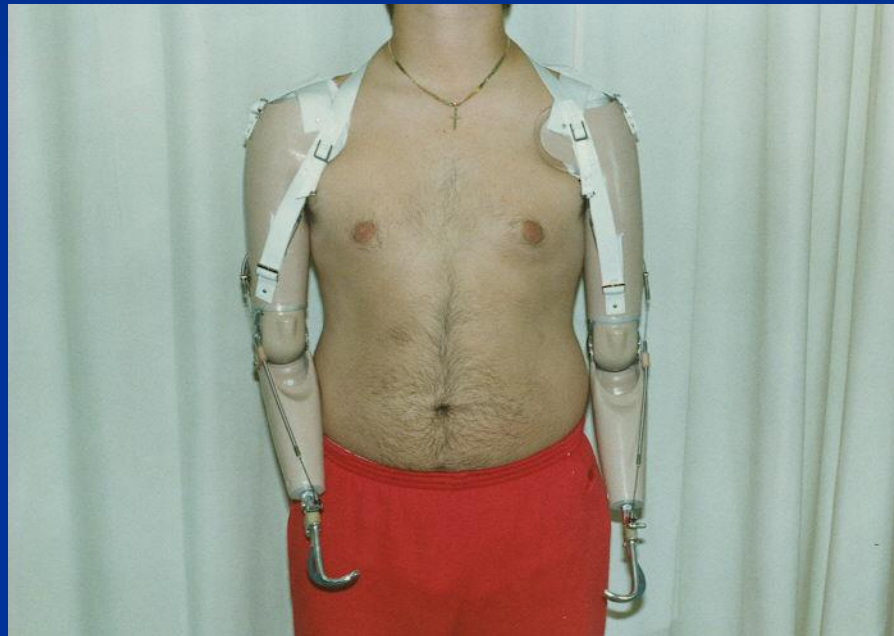
Strengthening Home Programs



Considerations for Missing Both Forearms



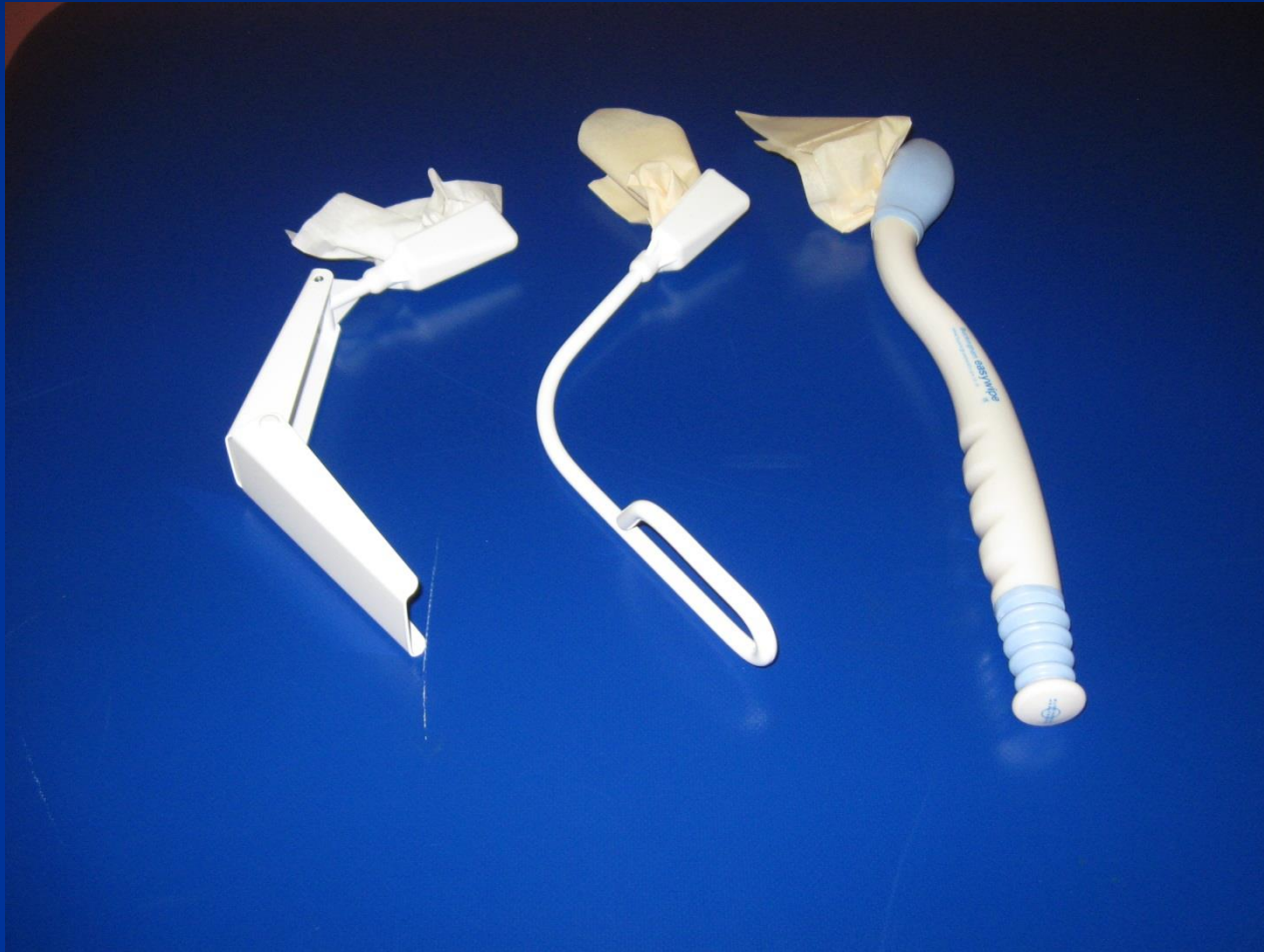
Bilateral Arm Amputee



Dressing Tree



Bottom Wipers



Bidet





Follow-Up

Return to Clinic very 6 months

- Routine f/u
important to ensure a
properly fitting
prosthesis
- Determine wear and
use and need for
change; tools
- Parents critical in a
child's success



Successful Prosthetic Wear

- Early fitting
- Full time wear
- Properly fitting and up-to-date equipment
- Therapeutic training
- Early childhood OT services
 - Incorporate the prosthesis into bimanual act.
 - Develop consistent grasp and self-help abilities
 - Use vision in place of sensory feedback
 - Develop problem solving skills

Follow-Up Assessment of Prosthesis Proficiency



Develop Positive Self Esteem

- Explain their hand difference
- Show and tell
- Child amputee books:
 - *The Making of My Special Hand: Madison's Story*
 - *Harry and Willy and Carrothead*

Follow-Up Prosthetic Training

- Difficulty opening/closing the terminal device
- Fit with a new style of prosthesis
- Practice donning/doffing
- ADL concerns



Teach Adaptive Strategies or Provide Assistive Devices



Fingernail Clipping



Starting Zippers



Shoe Tying



Considerations for the Older Child

Very few activities they are unable to do
with/without a prosthesis

- Keyboarding
- Driving
- Musical Instruments
- Sports
- Special Interests: photography, knitting

Musical Instruments



Silicone Passive Hand



Sports Prostheses

- Passive sports prosthesis
- Basketball
- Hockey
- Gymnastics
- Fixed hook – monkey bars
- Baseball
- Weight lifting



Camp Achieve



Summary

- Nurturing and educating patients and parents is key to adjustment and a child's success
- We believe early fitting and consistent wear when young contribute to prosthetic use later
- Understand a child's special interests and activities; there may be a tool to assist them
- Research helps guide current practice

Thank You



Cliff Welch, Icon