

Occupational Therapy Clinical Practice Guideline: Additional file 1

Occupational Therapy Evaluation for Epidermolysis Bullosa

Client Information

Name		Client ID	
Date of Birth		Evaluation Date	
Address		Phone Number	
Email			
Gender & Sex			

EB/Medical History

Type of EB		Primary Care Provider (PCP)	
Other Known Conditions or Diagnoses		PCP Address	
Medications		PCP Phone Number	
Dressing Materials			
Insurance/Payer			
Other Health Care Providers			

Social History

Family in Home		Primary Provider of Assistance in Home	
Relationship Status		Type of Home	
Sexual Orientation		Stairs In/At Home	
Caregiver Roles			
School			
Work			
Emotional Supports			

Leisure and other Activities

	1 = Dependent	2 = A lot of Help	3 = Help with Half	4 = A little Help	5 = No Help Needed
Leisure and other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

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Self-Care

	1 = Dependent	2 = A lot of Help	3 = Help with Half	4 = A little Help	5 = No Help Needed
Dressing: Lower Body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Dressing: Upper Body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Grooming (Hair, Teeth, Shaving, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Eating (Including feeding tube use)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Removing/Applying Dressings/Bandages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Equipment used in home					
Equipment used outside of home					
Caregivers/Carers					

Mobility

	1 = Dependent	2 = A lot of Help	3 = Help with Half	4 = A little Help	5 = No Help Needed
Getting Around in the House	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Negotiating Stairs (ascending/descending)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Getting Around School/Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Getting Around Outdoors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Transportation in the Community	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Flying and Distance Travel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Equipment used in home					

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Equipment used outside of home	
Caregivers/Carers	

Sleep

Equipment used in home	
Hours per night	
Difficulty falling asleep/staying asleep	

Household Management

	1 = Dependent	2 = A lot of Help	3 = Help with Half	4 = A little Help	5 = No Help Needed
Cleaning the Home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Cooking/Meal Preparation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Laundry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Opening Containers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Paying Bills/Managing Expenses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Environmental Controls/Appliances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Equipment used in home					
Caregivers/Carers					

Work/School

	1 = Dependent	2 = A lot of Help	3 = Help with Half	4 = A little Help	5 = No Help Needed
Writing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Typing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Working in Groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Comments</i>					
Social/Professional Relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

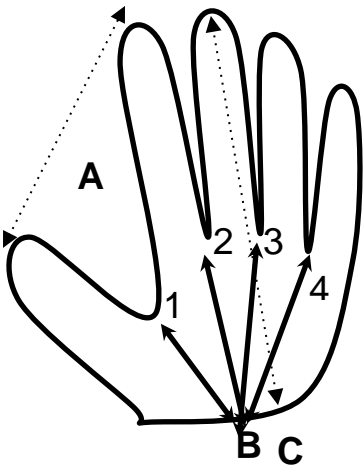
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Comments					
Participation in Physical Education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Adaptation/Modification Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments					
Equipment used in school/work					
Adaptations/Modifications					
Caregivers/Carers					

Hand/Skin Assessment

Hand Dominance		
Open or Blistered Areas		
Nature of Contractures	(Flexion vs. Cocooning vs Web Space)	
Gross Grasp	Percentage remaining: Left _____%, Right _____%	
Precision Pinches (If limited, indicate level of function)	<u>Left</u>	<u>Right</u>
	Lateral Pinch – Full Function <input type="checkbox"/> , Limited <input type="checkbox"/> _____% 2-Finger Pinch – Full Function <input type="checkbox"/> , Limited <input type="checkbox"/> _____% 3-Finger Pinch – Full Function <input type="checkbox"/> , Limited <input type="checkbox"/> _____%	Lateral Pinch – Full Function <input type="checkbox"/> , Limited <input type="checkbox"/> _____% 2-Finger Pinch – Full Function <input type="checkbox"/> , Limited <input type="checkbox"/> _____% 3-Finger Pinch – Full Function <input type="checkbox"/> , Limited <input type="checkbox"/> _____%
Functional Digital Use	Task	Pinch Utilized (Lateral, Pincer, 3-Jaw, Bimanual, Other)
	Turning Key	Level of Independence (Independent, Modified – Uses equipment or adaptation, Dependent – Requires assistance)
	Picking Up a Coin	
	Grasping a Pencil	
	Finger Feeding	
	Fork/Spoon Use	
	Knife Use	
	Holding a Cup	
	Using Scissors	
	Grasping Shoe String	
	Other (Indicate task):	

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- Draw an imaginary line connecting the ulnar styloid and radial head.
- B-Web spaces are measured from the imaginary line ~~between~~ at the wrist to the end of the web spaces.
- The length of the middle finger is measured. (C)
- Monitor web creep by comparing the change in long finger length with web length to account for normal growth.

Reference: Lipnick et al (1992) Physical rehabilitation of epidermolysis bullosa patients; Epidermolysis bullosa: Basic and clinical aspects. Weiss and Prinz (2013) also describe a method of web space measurement. In addition, various clinicians that work with persons with EB have developed, but not published, alternative methods.

	Left	Right																
A. First web opening																		
B. Wrist to web	<table border="1"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> </tr> </table>	1	2	3	4					<table border="1"> <tr> <td>1</td> <td>2</td> <td>3</td> <td>4</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> </tr> </table>	1	2	3	4				
1	2	3	4															
1	2	3	4															
C. Wrist to tip of middle finger																		

Evaluation Summary

ADDITIONAL COMMENTS

GOALS

(as agreed upon by client and team)

FOLLOW UP/PLAN OF CARE