

# Clinic Visit Tips

## ***Chronic GVHD Evaluation***

FHCRC/LTFU

# 10 GVHD Specific Questions to Ask a Patient

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1. Skin feels tight or hard, increased dryness, pruritus, or looks different (i.e., new rash, papules, discoloration)?
2. Inability to sweat or to keep body warm (sweat glands) ?
3. Loss of hair (scalp or body) or nail changes (ridges or brittle)?
4. Stiffness or pain in the wrists, fingers, or other joints?
5. Eye dryness, sensitivity to wind or air conditioning, pain?

# 10 GVHD Specific Questions (contd.)

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6. Oral dryness, taste alterations, sensitivities, ulcers/sores?
7. Foods or pills getting stuck upon swallowing (esophagus)?
8. Cough, dyspnea or wheezes on exertion or rest (lungs)?
9. Vaginal dryness, dyspareunia, itching (female); penile pain or dysuria (male) (genitalia)?
10. Unexplained weight loss or inability to gain weight (pancreatic insufficiency or hypercatabolism)

# Physical exam key elements

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- Weight
- Clinical performance score (KPS/LKS or ECOG)
- Range of motion (*wrists, shoulders, elbows, ankles*)
- Skin exam – entire body (*look, touch, pinch*)
- Oral exam (*Lacy/white patches? Mottled lips? Ulcers?*)
- Eye exam (*erythema conjunctiva/eyelids? premature gray eyelashes/brows? Blepharitis?*)

# Assessment of Range of Motion



# Skin Exam

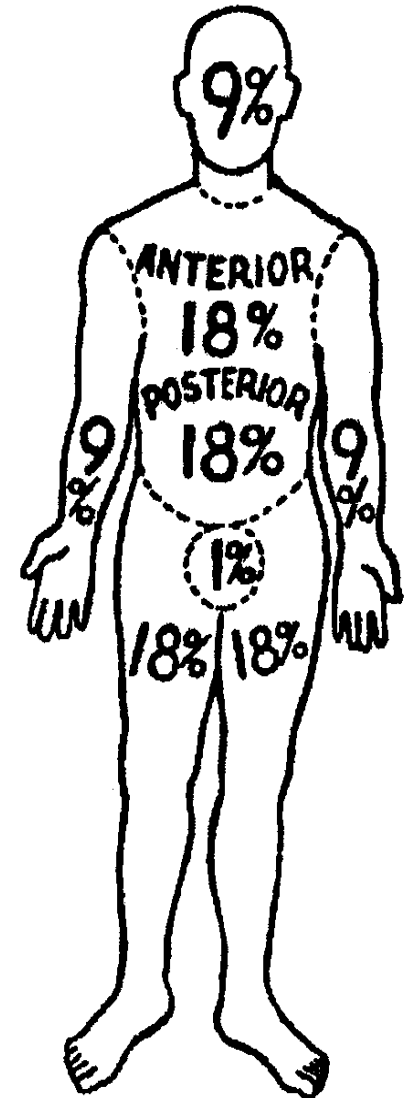
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Exam the entire body

Look for color and texture changes

Touch and pinch for change in texture and mobility:

- Thickened but moveable
- Thickened, moves poorly but can pinch
- Cannot pinch (hidebound)

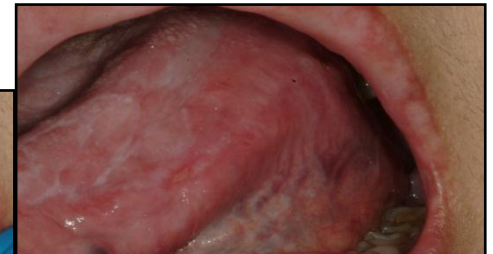
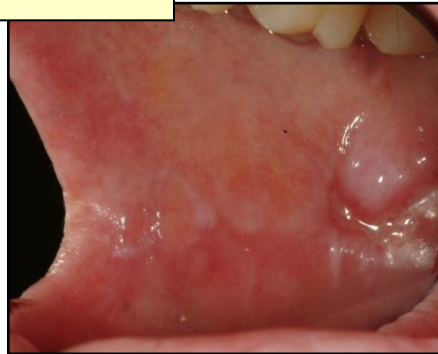


# Oral Exam

What & Where to look for chronic GVHD?

## GVHD FEATURES:

- Lacy patch?
- Keratotic patch?
- Erythema?
- Ulcers?
- Mucoceles?



# Oral Exam Tips

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- Use of halogen light source is essential to an accurate evaluation (i.e., otoscopic instrument)
- Where to look?
  - lips, labial mucosa, buccal mucosa, tongue and soft palate
- What to look for?
  - erythema
  - lichenoid hyperkeratosis
  - pseudomembranous ulcers
  - Mucocelles (clear blister on the soft palate or inferior lips)
- Score the severity of each manifestation by the intensity (mild, moderate, severe) and the extent of oral involvement (i.e., number of mucocelles)



Patient: \_\_\_\_\_ / UW# \_\_\_\_\_ Date Evaluation: \_\_\_\_\_

	SCORE 0	SCORE 1	SCORE 2	SCORE 3
<b>PERFORMANCE SCORE:</b> <input type="text"/>	<input type="checkbox"/> Asymptomatic and fully active (ECOG 0; KPS or LPS 100%)	<input type="checkbox"/> Symptomatic, fully ambulatory, restricted only in physically strenuous activity (ECOG 1, KPS or LPS 80-90%)	<input type="checkbox"/> Symptomatic, ambulatory, capable of self-care, >50% of waking hours out of bed (ECOG 2, KPS or LPS 60-70%)	<input type="checkbox"/> Symptomatic, limited self-care, >50% of waking hours in bed (ECOG 3-4, KPS or LPS <60%)
<b>KPS ECOG LPS</b>				

**SKIN†**

**SCORE % BSA**

<input type="checkbox"/> No BSA involved	<input type="checkbox"/> 1-18% BSA	<input type="checkbox"/> 19-50% BSA	<input type="checkbox"/> >50% BSA
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GVHD features to be scored by BSA:

**Check all that apply:**

Maculopapular rash/erythema

Lichen planus-like features

Sclerotic features

Papulosquamous lesions or ichthyosis

Keratosis pilaris-like GVHD

<b>SKIN FEATURES SCORE:</b>	<input type="checkbox"/> No sclerotic features	<input type="checkbox"/> Superficial sclerotic features “not hidebound” (able to pinch)	<b>Check all that apply:</b>
			<input type="checkbox"/> Deep sclerotic features
			<input type="checkbox"/> “Hidebound” (unable to pinch)
			<input type="checkbox"/> Impaired mobility
			<input type="checkbox"/> Ulceration

Other skin GVHD features (NOT scored by BSA)

**Check all that apply:**

Hyperpigmentation

Hypopigmentation

Poikiloderma

Severe or generalized pruritus

Hair involvement

Nail involvement



Abnormality present but explained entirely by non-GVHD documented cause (specify): \_\_\_\_\_

Abnormality thought to represent GVHD PLUS other causes (specify): \_\_\_\_\_

<b>MOUTH</b>	<input type="checkbox"/> No symptoms	<input type="checkbox"/> Mild symptoms <b>with</b> disease signs but not limiting oral intake significantly	<input type="checkbox"/> Moderate symptoms <b>with</b> disease signs with partial limitation of oral intake	<input type="checkbox"/> Severe symptoms with disease signs on examination <b>with</b> major limitation of oral intake
<i>Lichen planus-like features present:</i>				
<input type="checkbox"/> Yes				
<input type="checkbox"/> No				
<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____				
<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____				

† Skin scoring should use both percentage of BSA involved by disease signs and the cutaneous features scales. When a discrepancy exists between the percentage of total body surface (BSA) score and the skin feature score, OR if superficial sclerotic features are present (Score 2), but there is impaired mobility or ulceration (Score 3), the higher level should be used for the final skin scoring.

TEAM			
NAME		[ M ]	
PT NO	PLACE EPIC LABEL HERE	[ F ]	
DOB			

\*SLTF003\*

Patient: \_\_\_\_\_

	SCORE 0	SCORE 1	SCORE 2	SCORE 3
<b>EYES</b>	<input type="checkbox"/> No symptoms	<input type="checkbox"/> Mild dry eye symptoms not affecting ADL (requirement of lubricant eye drops ≤ 3 x per day))	<input type="checkbox"/> Moderate dry eye symptoms partially affecting ADL (requiring lubricant eye drops > 3 x per day or punctal plugs), <b>WITHOUT</b> new vision impairment due to KCS	<input type="checkbox"/> Severe dry eye symptoms significantly affecting ADL (special eyewear to relieve pain) <b>OR</b> unable to work because of ocular symptoms <b>OR</b> loss of vision due to KCS
<i>Keratoconjunctivitis sicca (KCS) confirmed by ophthalmologist:</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not examined			
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____			
	<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____			

**GI Tract**

*Check all that apply:*

<input type="checkbox"/> Esophageal web/proximal stricture or ring	<input type="checkbox"/> No symptoms	<input type="checkbox"/> Symptoms without significant weight loss* (<5%)	<input type="checkbox"/> Symptoms associated with mild to moderate weight loss* (5-15%) <b>OR</b> moderate diarrhea without significant interference with daily living	<input type="checkbox"/> Symptoms associated with significant weight loss* >15%, requires nutritional supplement for most calorie needs <b>OR</b> esophageal dilation <b>OR</b> severe diarrhea with significant interference with daily living
<input type="checkbox"/> Dysphagia				
<input type="checkbox"/> Anorexia				
<input type="checkbox"/> Nausea				
<input type="checkbox"/> Vomiting				
<input type="checkbox"/> Diarrhea				
<input type="checkbox"/> Weight loss ≥5%*				
<input type="checkbox"/> Failure to thrive				
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____			
	<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____			

<b>LIVER</b>	<input type="checkbox"/> Normal total bilirubin and ALT or AP < 3 x ULN	<input type="checkbox"/> Normal total bilirubin with ALT ≥3 to 5 x ULN or AP ≥ 3 x ULN	<input type="checkbox"/> Elevated total bilirubin but ≤3 mg/dL or ALT > 5 ULN	<input type="checkbox"/> Elevated total bilirubin > 3 mg/dL
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____			
	<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____			

**LUNGS\*\***

<b>Symptom score:</b>	<input type="checkbox"/> No symptoms	<input type="checkbox"/> Mild symptoms (shortness of breath after climbing one flight of steps)	<input type="checkbox"/> Moderate symptoms (shortness of breath after walking on flat ground)	<input type="checkbox"/> Severe symptoms (shortness of breath at rest; requiring O <sub>2</sub> )
<b>Lung score:</b>	<input type="checkbox"/> FEV1 ≥80%	<input type="checkbox"/> FEV1 60-79%	<input type="checkbox"/> FEV1 40-59%	<input type="checkbox"/> FEV1 ≤39%
% FEV1 <input type="text"/>				
<i>Pulmonary function tests</i>	<input type="checkbox"/> Not performed			
	<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____			
	<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____			

\* Weight loss within 3 months. \*\*Lung scoring should be performed using both the symptoms and FEV1 scores whenever possible. \*\*FEV1 should be used in the final lung scoring where there is discrepancy between symptoms and FEV1 scores.

TEAM \_\_\_\_\_  
 NAME \_\_\_\_\_ [ M ]  
 PT NO \_\_\_\_\_ [ F ]  
 DOB \_\_\_\_\_

PLACE EPIC LABEL HERE



Patient: \_\_\_\_\_

	SCORE 0	SCORE 1	SCORE 2	SCORE 3
<b>JOINTS AND FASCIA</b>	<input type="checkbox"/> No symptoms	<input type="checkbox"/> Mild tightness of arms or legs, normal or mild decreased range of motion (ROM) <b>AND</b> not affecting ADL	<input type="checkbox"/> Tightness of arms or legs <b>OR</b> joint contractures, erythema thought due to fasciitis, moderate decrease ROM <b>AND</b> mild to moderate limitation of ADL	<input type="checkbox"/> Contractures <b>WITH</b> significant decrease of ROM <b>AND</b> significant limitation of ADL (unable to tie shoes, button shirts, dress self etc.)
<u>P-ROM score</u> (see below)				
Shoulder (1-7) _____				
Elbow (1-7) _____				
Wrist/finger (1-7) _____				
Ankle (1-4) _____				
<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____				
<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____				

<b>GENITAL TRACT</b> (See Supplemental figure <sup>‡</sup> )	<input type="checkbox"/> No signs	<input type="checkbox"/> Mild signs <sup>‡</sup> and females with or without discomfort on exam	<input type="checkbox"/> Moderate signs <sup>‡</sup> and may have symptoms with discomfort on exam	<input type="checkbox"/> Severe signs <sup>‡</sup> with or without symptoms
<input type="checkbox"/> Not examined				
Currently sexually active				
<input type="checkbox"/> Yes				
<input type="checkbox"/> No				
<input type="checkbox"/> Abnormality present but explained entirely by non-GVHD documented cause (specify): _____				
<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes (specify): _____				

**Other indicators, clinical features or complications related to chronic GVHD (check all that apply and assign a score to severity (0-3) based on functional impact where applicable none – 0, mild -1, moderate -2, severe – 3)**

<input type="checkbox"/> Ascites (serositis) _____	<input type="checkbox"/> Myasthenia Gravis _____	<input type="checkbox"/> Eosinophilia > 500/μl _____
<input type="checkbox"/> Pericardial Effusion _____	<input type="checkbox"/> Peripheral Neuropathy _____	<input type="checkbox"/> Platelets < 100,000/μl _____
<input type="checkbox"/> Pleural Effusion(s) _____	<input type="checkbox"/> Polymyositis _____	<input type="checkbox"/> Others (specify): _____
<input type="checkbox"/> Nephrotic syndrome _____	<input type="checkbox"/> Weight loss >5%* without GI symptoms	

Biopsy obtained:  Yes  No      Organ biopsied: \_\_\_\_\_      GVHD confirmed by histology:  Yes  No

Overall GVHD Severity (Opinion of the evaluator)       No GVHD       Mild       Moderate       Severe

Change from prior evaluations:  No prior or current GVHD       Improved       Stable       Worse       N/A (baseline)

**Photographic Range of Motion (P-ROM):**

	1 (Worst)	2	3	4	5	6	7 (Normal)
Shoulder							
	1 (Worst)	2	3	4	5	6	7 (Normal)
Elbow							
	1 (Worst)	2	3	4	5	6	7 (Normal)
Wrist/finger							
	1 (Worst)	2	3	4 (Normal)			
Ankle							

Completed by: \_\_\_\_\_ Date form completed: \_\_\_\_\_

TEAM \_\_\_\_\_

NAME \_\_\_\_\_ [ M ]

PT NO \_\_\_\_\_ [ F ]

DOB \_\_\_\_\_

PLACE EPIC LABEL HERE




\*SLTF003\*

Range of motion assessment form

Patient \_\_\_\_\_ DOB \_\_\_\_\_ Assessment Date \_\_\_\_\_

Circle the number that best represent the degree of maximum flexibility of each of the 4 joints below



Minimum Flexibility Maximum

**Shoulder**

1 2 3 4 5 6 7

**Elbow**

1 2 3 4 5 6 7

**Wrist and fingers**

1 2 3 4 5 6 7

**Foot Dorsiflexion**

1 2 3 4

## Supplement Figure – Genital Tract Chronic Graft-versus-Host Assessment and Scoring Form

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_ Assessment date: \_\_\_\_\_

	SCORE 0	SCORE 1	SCORE 2	SCORE 3
<b>GENITAL TRACT</b>	<input type="checkbox"/> No signs	<input type="checkbox"/> Mild signs and females may have symptoms* WITH discomfort on exam	<input type="checkbox"/> Moderate signs and may have symptoms* with discomfort on exam	<input type="checkbox"/> Severe signs with or without symptoms *
<b>Check:</b> <input type="checkbox"/> Male <input type="checkbox"/> Female				
<b>Currently sexually active:</b> <input type="checkbox"/> Yes <input type="checkbox"/> No				
<b>Check all signs that apply:</b>				
<input type="checkbox"/> Lichen planus-like features		<input type="checkbox"/> Erosions		
<input type="checkbox"/> Lichen sclerosis-like features		<input type="checkbox"/> Fissures		
<input type="checkbox"/> Vaginal scarring (female)		<input type="checkbox"/> Ulcers		
<input type="checkbox"/> Clitoral/labial agglutination (female)		<input type="checkbox"/> Phimosis (male)		
<input type="checkbox"/> Labial resorption (female)		<input type="checkbox"/> Urethral meatus scarring/ stenosis (male)		
<input type="checkbox"/> Abnormality present but <u>NOT</u> thought to represent GVHD (specify cause): _____				
<input type="checkbox"/> Abnormality thought to represent GVHD <u>PLUS</u> other causes(specify cause): _____				

\*Genital symptoms are not specific to cGVHD and can represent premature gonadal failure or genital tract infection.

- If a gynecologist is unavailable**, external examination may be performed to determine “discomfort on exam” as follows:
- Spread the labia majora to inspect the vulva for the above signs. Touch the vestibular gland openings (Skene’s and Bartholin’s), labia minora and majora gently with a qtip. Vulvar pain elicited by the gentle touch of a qtip is classified as discomfort on examination. Palpate the vaginal walls with a single digit to detect bands, shortening, narrowing or other signs of vaginal scarring.
  - If the woman is sexually active, determine whether qtip palpation or gentle palpation of scarred ridges elicits pain similar to that which the woman experiences during intercourse.

**Female genitalia:** Severity of signs:

- Mild (any of the following); erythema on vulvar mucosal surfaces, vulvar lichen-planus or vulvar lichen-sclerosis.
- Moderate (any of the following); erosive inflammatory changes of the vulvar mucosa, fissures in vulvar folds
- Severe (any of the following); labial fusion, clitoral hood agglutination, fibrinous vaginal adhesions, circumferential fibrous vaginal banding, vaginal shortening, synechia, dense sclerotic changes, and complete vaginal stenosis.

**Male genitalia:** Diagnostic features include lichen planus-like or lichen sclerosis-like features and phimosis or urethral scarring or stenosis. Severity of signs:

- Mild: lichen planus-like feature;
- Moderate: lichen sclerosis-like feature or moderate erythema;
- Severe: phimosis or urethral/meatal scarring.

Biopsy obtained: <input type="checkbox"/> Yes <input type="checkbox"/> No	Site biopsied: _____	GVHD confirmed by histology: <input type="checkbox"/> Yes <input type="checkbox"/> No
Change from previous evaluation: <input type="checkbox"/> No prior or current GVHD <input type="checkbox"/> Improved <input type="checkbox"/> Stable <input type="checkbox"/> Worse <input type="checkbox"/> N/A (baseline)		

Completed by (print name): \_\_\_\_\_ Date form completed: \_\_\_\_\_

ASSESSMENT OF SKIN THICKNESS  
Modified Rodnan Score\*

**Patient Name:** \_\_\_\_\_ **Date of Birth:** \_\_\_\_\_

Calculate skin score by summing the scores from all evaluated anatomic areas.

A. Evaluate skin thickness by clinical palpation:

- 0 = normal skin thickness
- 1 = mildly increased skin thickness
- 2 = moderately increased skin thickness
- 3 = severely increased skin thickness (inability to pinch skin into a fold)

B. Surface of anatomic areas evaluated (N = 17)

Area of Body		Dates:	Score	Score	Score	Score	Score
		Range					
Face		0-3					
Anterior chest		0-3					
Abdomen		0-3					
Fingers	R	0-3					
	L	0-3					
Dorsum of hands	R	0-3					
	L	0-3					
Forearms	R	0-3					
	L	0-3					
Upper arms	R	0-3					
	L	0-3					
Thighs	R	0-3					
	L	0-3					
Lower legs	R	0-3					
	L	0-3					
Dorsum of feet	R	0-3					
	L	0-3					
TOTAL		0-51					

“Skin Thickness Score in Systemic Sclerosis: An Assessment of Inter-observer Variability in 3 Independent Studies,” Clements et al, *The Journal of Rheumatology* 1993, 20:11, 1892-1896