Chronic Graft Versus Host Disease
Symptoms & Organ Site Assessment

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# cGVHD Disease Symptoms & Organ Site Assessment

<table>
<thead>
<tr>
<th>PERFORMANCE</th>
<th>SCORE 0</th>
<th>SCORE 1</th>
<th>SCORE 2</th>
<th>SCORE 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCORE:</td>
<td>Asymptomatic and fully active (ECOG 0; KPS or LPS 100%)</td>
<td>Symptomatic, fully ambulatory, restricted only in physically strenuous activity (ECOG 1, KPS or LPS 80-90%)</td>
<td>Symptomatic, ambulatory, capable of self-care, &gt;50% of waking hours out of bed (ECOG 2, KPS or LPS 60-70%)</td>
<td>Symptomatic, limited self-care, &gt;50% of waking hours in bed (ECOG 3-4, KPS or LPS &lt;60%)</td>
</tr>
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<table>
<thead>
<tr>
<th>KPS ECOG LPS</th>
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<tbody>
<tr>
<td>100%</td>
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</tbody>
</table>

## SKIN

**Score % BSA**

- **GVHD features to be scored by BSA**
  - No BSA involved
  - 1-18% BSA involved
  - 19-50% BSA involved
  - >50% BSA involved

- **Check all that apply:**
  - Maculopapular rash/erythema
  - Lichen planus-like features
  - Sclerotic features
  - Papulosquamous lesions or ichthyosis
  - Keratosis pilaris-like GVHD

## SKIN FEATURES

**Score:**

- No sclerotic features
- Superficial sclerotic features "not hidebound" (able to pinch)
- Deep sclerotic features "hidebound" (unable to pinch)
- Impaired mobility
- Ulceration

## Other skin GVHD features (NOT scored by BSA)

- Hyperpigmentation
- Hypermucosal
- Poliklisterma
- Severe or generalized pruritus
- Hair involvement
- Nail involvement

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

### MOUTH

- **Lichen planus-like features present:**
  - No symptoms
  - Mild symptoms with disease signs but not limiting oral intake significantly
  - Moderate symptoms with disease signs with partial limitation of oral intake
  - Severe symptoms with disease signs on examination with major limitation of oral intake

- **No**

**Abnormality present but explained entirely by non-GVHD documented cause (specify):**
cGVHD Disease Symptoms & Organ Site Assessment

<table>
<thead>
<tr>
<th></th>
<th>SCORE 0</th>
<th>SCORE 1</th>
<th>SCORE 2</th>
<th>SCORE 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>EYES</td>
<td>No symptoms</td>
<td>Mild dry eye symptoms not affecting ADL</td>
<td>Moderate dry eye symptoms partially affecting ADL (requiring lubricant eye drops ≤ 3 x per day or parenteral plags), WITHOUT new vision impairment due to KCS</td>
<td>Severe dry eye symptoms significantly affecting ADL (special eyewear to relieve pain) OR unable to work because of ocular symptoms OR loss of vision due to KCS</td>
</tr>
</tbody>
</table>

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

|        | No symptoms | Symptoms without significant weight loss* (<5%) | Symptoms associated with mild to moderate weight loss* (≤15%) OR moderate diarrhea without significant interference with daily living | Symptoms associated with significant weight loss* >15%, requires nutritional supplement for most caloric needs OR esophageal dilation OR severe diarrhea with significant interference with daily living |

**GI Tract**

**Check all that apply:**
- Esophageal web/ proximal stricture or ring
- Dysphagia
- Anorexia
- Nausea
- Vomiting
- Diarrhea

**Weight loss ≥5%* Failure to thrive**

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

<table>
<thead>
<tr>
<th></th>
<th>Normal total bilirubin and ALT or AP ≥ 5 x ULN or AP ≥ 3 x ULN</th>
<th>Elevated total bilirubin but ≤3 mg/dL or ALT &gt; 3 ULN</th>
</tr>
</thead>
<tbody>
<tr>
<td>LIVER</td>
<td></td>
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</table>

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

<table>
<thead>
<tr>
<th></th>
<th>No symptoms</th>
<th>Mild symptoms (shortness of breath after climbing one flight of steps)</th>
<th>Moderate symptoms (shortness of breath after walking on flat ground)</th>
<th>Severe symptoms (shortness of breath at rest; requiring O2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>LUNGS**</td>
<td></td>
<td></td>
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</tbody>
</table>

**Symptom score:**

<table>
<thead>
<tr>
<th>Lang score:</th>
<th>FEV1 ≥80%</th>
<th>FEV1 60-79%</th>
<th>FEV1 40-59%</th>
<th>FEV1 ≤39%</th>
</tr>
</thead>
</table>

**Pulmonary function tests Not performed**

**Abnormality present but explained entirely by non-GVHD documented cause (specify):**
**cGVHD Disease Symptoms & Organ Site Assessment**

<table>
<thead>
<tr>
<th>Joints and Fascia</th>
<th>Score 0</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>P-ROM score</td>
<td>No Symptom</td>
<td>Mild tightness of arms or legs, normal or mild decreased range of motion (ROM) AND not affecting ADL</td>
<td>Tightness of arms or legs OR joint contractures, erythema thought due to fischiitis, moderate decrease ROM AND mild to moderate limitation of ADL</td>
<td>Contractures WITH significant decrease of ROM AND significant limitation of ADL (unable to tie shoes, button shirts, dress self etc.)</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Genital Tract</th>
<th>Score 0</th>
<th>Score 1</th>
<th>Score 2</th>
<th>Score 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>See Supplemental figure(s)</td>
<td>No Signs</td>
<td>Mild signs(^1) and females with or without discomfort on exam</td>
<td>Moderate signs(^2) and may have symptoms with discomfort on exam</td>
<td>Severe signs(^3) with or without symptoms</td>
</tr>
</tbody>
</table>

Abnormality present but explained entirely by non-GVHD documented cause (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 \(-1\), mild \(-1\), moderate \(-2\), severe \(-3\)):

- Ascites (serositis)
- Myasthenia Gravis
- Pericardial Effusion
- Peripheral Neuropathy
- Pleural Effusion(s)
- Polymyositis
- Nephrotic Syndrome
- Weight loss>5% without GI symptoms

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

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

† 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.

*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.

**Abbreviations**: ECOG (Eastern Cooperative Oncology Group), KPS (Karnofsky Performance Status), LPS (Lansky Performance Status), BSA (body surface area); ADL (activities of daily living); LFTs (liver function tests); AP (alkaline phosphatase); ALT (alanine aminotransferase); ULN (normal upper limit).

‡ To be completed by specialist or trained medical provider (see Supplemental Figure).
Patient Journal

- Start a journal to document your clinical manifestations and symptoms.
- Document your response to treatment (Is this treatment therapy managing my symptoms?)
- Take pictures of your skin (Note skin rash, coloring and texture, sores, range of motion, tightness, jaundice, and dryness).
- Review your lab values (Make note of your liver function test, CBC, etc)
- Long-term follow-up care. Make note of when you should f/u with your specialists (Ocular, dental, dermatologist), complete diagnostic testing (PFT's, bone density, labs) and get vaccinated.
References


• The National Marrow Donor Program® (NMDP)/Be The Match® in consultation with Sandra A. Mitchell, CRNP, MScN, AOCN; National Institutes of Health Clinical Center; and Steven Z. Pavletic, M.D.; National Cancer Institute, National Institutes of Health, Bethesda, Md.

• Photos/ Keratosis Pilaris; Lichen Planus-like; Hypopigmentation; Sclerosis; Erosion; Maculopapular: Maria L. Turner, M.D.; Edward W. Cowen, M.D.; Dermatology Branch, National Cancer Institute, NIH, Bethesda, Md.