MI-CCSI

Partnering to Better Care

Palliative Care Handout Packet

Serious Illness Conversation Guide

IINTRODUCE

If you provided the patient with the “What Matters to Me” workbook prior to the meeting/call, remind them of that. If not, just start with the introduction below.

“I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?”

ASSESS

“What is your understanding now of where you are with your illness?”

“How much information about what is likely to be ahead with your illness would you like from your healthcare team?”

SHARE (consistent with scope of practice)

“I want to share with you my understanding of where things are with your illness...”

Uncertain: “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”

OR Time: “I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year).”

OR Function: “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.”

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EXPLORE

“What are your most important goals if your health situation worsens?”

“What are your biggest fears and worries about the future with your health?”

“What gives you strength as you think about the future with your illness?”

“What abilities are so critical to your life that you can’t imagine living without them?”

If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

PLAN

“How much do your loved ones know about your priorities and wishes?”

How much does your doctor know about your priorities and wishes?

SUMMARIZE

“I’ve heard you say ________________. I will pass that information to the rest of the health care team.

Keeping that in mind, and what you know about your illness, I recommend that we ________________. That will help us make sure that your treatment plans reflect what’s important to you?

How does this plan seem to you? We will do everything we can to help you through this.

CLOSE

Thank you for speaking with me today. I know these conversations are hard and I appreciate you sharing this important information with me.

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What Matters to Me Workbook

What Matters to Me

A Workbook for People with Serious Illness

NAME	
DATE	

ARIADNE LABS

the **conversation** project

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This Workbook is designed to help people with a serious illness get ready to talk to their health care team (doctor, nurse, social worker, etc.) about what is most important to them.

This Workbook is NOT about making specific medical decisions. It's about thinking about what matters most to you — and sharing your goals and preferences with your health care team. Then together you can choose the kind of care that is right for you.

DO THIS

- **Do the Workbook by yourself or with someone else.** Choose the way that works best for you.
- **Take your time.** You don't need to complete the Workbook all in one sitting. It's okay to skip questions — or come back to them later.
- **Share it with your health care team.** Bring the filled-in Workbook to your next appointment so you can talk over your answers and questions.
- **Be prepared.** Even if you don't have an appointment soon, or you won't be seeing a family member soon, doing the Workbook will help YOU be clear about what matters to you.

TWO WAYS TO SHARE

1. If you are doing the Workbook on your computer, be sure to save it to your computer before typing in your answers. Otherwise, what you type will not be saved.
2. Many people find it easier to write their answers in the printed document, then make copies of the filled-in document to share with others.

FOR CAREGIVERS

If you are helping someone else complete this Workbook, here are some things to keep in mind:

- **Explain why this will help.** You might say, "I want to make sure we know what's most important to you, so we can have a more useful conversation with your health care team."
- **Take it in small pieces.** It's always okay to skip a question. You can even let the person pick the questions that appeal to them. If they get tired or overwhelmed, take a break and come back to it later.
- **If the person is prone to confusion, keep the number of helpers small.** Having many people present can increase pressure on the seriously ill person. Have one or two people assist in completing the Workbook, then share it with others.

My Health

What is your understanding of your current health situation?

How much information about what might be ahead with your illness would you like from your health care team?

About Me

MY GOOD DAYS • What does a good day look like for you?

Here are some things I like to do on a good day:

EXAMPLES

Get up and dressed • Play with my cat • Make a phone call • Watch TV • Have coffee with a friend

MY HARD DAYS • What does a hard day look like for you?

These are the toughest things for me to deal with on a hard day:

EXAMPLES

Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

MY GOALS • What are your most important goals if your health situation worsens?

These are some things I would like to be able to do in the future:

EXAMPLES

Take my dog for a walk • Attend my child's wedding • Feel well enough to go to church • Talk to my grandchildren when they come to visit

My Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.
Note: These scales represent a range of feelings; there are no right or wrong answers.

- **Answer where you are right now.** For each scale below, think about what you want now. Revisit your answers in the future, as they may change over time.
- **Use your answers as conversation starters.** Your answers can be a good starting point to talk with others about why you answered the way you did.

As a patient, I'd like to know…

○ ○ ○ ○ ○

Only the basics about my condition and my treatment — All the details about my condition and my treatment

When there is a medical decision to be made, I would like…

○ ○ ○ ○ ○

My health care team to make all the decisions — To have a say in decisions whenever possible

What are your concerns about medical treatments?

○ ○ ○ ○ ○

I worry that I won't get enough care — I worry that I'll get too much care

How much medical treatment are you willing to go through for the possibility of gaining more time?

○ ○ ○ ○ ○

Nothing: I don't want any more medical treatments — Everything: I want to try any medical treatments possible

If your health situation worsens, where do you want to be?

○ ○ ○ ○ ○

I strongly prefer to be in a health care facility — I strongly prefer to be at home, if possible

When it comes to sharing information about my illness with others…

○ ○ ○ ○ ○

I don't want those close to me to know all the details — I do want those close to me to know all the details

› MY FEARS AND WORRIES • What are your biggest fears and worries about the future with your health?

These are the main things I worry about:

EXAMPLES

I don't want to be in pain • I'm worried that I won't be able to get the care I want • I don't want to feel stuck someplace where no one will visit me • I worry about the cost of my care • What if I need more care than my caregivers can provide?

› MY STRENGTHS • As you think about the future with your illness, what gives you strength?

These are my main sources of strength in difficult times:

EXAMPLES

My friends • My family • My faith • My garden • Myself ("I just do it")

› MY ABILITIES • What abilities are so critical to your life that you can't imagine living without them?

I want to keep going as long as I can…

EXAMPLES

As long as I can at least sit up on the bed and occasionally talk to my grandchildren • As long as I can eat ice cream and watch the football game on TV • As long as I can recognize my loved ones • As long as my heart is beating, even though I'm not conscious

If you become sicker, which matters more to you: the possibility of a longer life, or the possibility of a better quality of life? Please explain.

MY WISHES AND PREFERENCES • What wishes and preferences do you have for your care?

If my health situation worsens, here's what I want to make sure DOES happen:

EXAMPLES

I want to stay as independent as possible • I want to get back home • I want my doctors to do absolutely everything they can to keep me alive • I want everybody to respect my wishes if I say I want to switch to comfort care only

And here's what I want to make sure DOES NOT happen:

EXAMPLES

I don't want to become a burden on my family • I don't want to be alone • I don't want to end up in the ICU on a lot of machines • I don't want to be in pain

Is there anything else you want to make sure your family, friends, and health care team know about you and your wishes and preferences for care if you get sicker?

MY QUESTIONS • What questions do you want to ask your health care team?

EXAMPLES

How will you work with me over the coming months? • What treatment options are available for me at this point — and what are the chances they'll work? • What can I expect if I decide I don't want more curative treatment? • If I get sicker, what can you do to help me stay comfortable? • What are the best-case and worst-case scenarios?

My People

Are there key people who will be involved in your care (family members, friends, faith leaders, others)? For each person you list, be sure to include their phone number and relationship to you.

How much do they know about your wishes and preferences? What role do you want them to have in decision making? When might you be able to talk to them about your wishes?

Which person would you want to make medical decisions on your behalf if you're not able to? This person is often called your health care proxy, agent, or surrogate. See the Guide to Choosing a Health Care Proxy for help.

Name, phone number, relationship to me

I have talked with this person about what matters most to me.	● Yes ○ No
I have filled out an official form naming this person as my health care proxy.	○ Yes ● No
I have checked to make sure my health care team has a copy of the official proxy form.	○ Yes ● No

My Health Care Team

Who are the key clinicians involved in your care?

My primary care provider	*Name*	*Phone number*
My social worker	*Name*	*Phone number*
My main specialist	*Name*	*Phone number*
Other	*Name*	*Phone number*

Next Steps

Now that you have completed the Workbook, what's next?

- **Talk it over with someone else.** If you filled out the Workbook on your own, make a time to share your answers and questions with a family member, a friend, or another person. You might want to give them a copy of the Workbook with your answers written in. See the Conversation Starter Guide for help.
- **Talk it over with your health care team.** Make an appointment to talk over the Workbook, sharing your answers and asking any questions. If your primary care doctor or main specialist works with a social worker, that person can be an excellent place to start. You might want to give your health care team a copy of the Workbook with your answers written in before your appointment. See the Guide for Talking with a Health Care Team for help.
- **Pick a proxy**. This is the person you choose to make medical decisions for you if you are not able to make them for yourself. See the Guide to Choosing a Health Care Proxy for help.
- **Keep talking**. People's preferences often change as their health changes or as time goes by. Revisit the Workbook over time to see if your answers have changed. And be sure to keep your health care team updated so they know what is most important to you.

WITH THANKS TO

CAMBIA health foundation

CREATED BY

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V4

Empathic Responses

EMPATHIC RESPONSES

Naming	Understanding	Respecting	Supporting	Exploring	"I Wish"
This must be… • Frustrating • Overwhelming • Scary • Difficult • Challenging • Hard	What you just said really helps me understand the situation better.	I really admire your • Faith • Strength • Commitment to your family • Thoughtfulness • Love for your family	We will do our very best to make sure you have what you need.	Could you say more about what you mean when you say… • I don't want to give up • I'm hoping for a miracle	I wish we had a treatment that would cure you (make your illness go away).
I'm wondering if you are feeling … • Sad • Scared • Frustrated • Overwhelmed • Anxious • Angry	This really helps me better understand what you are thinking.	You (or your dad, mom, child, spouse) are/is such a strong person and have/has been through so much.	Our team is here to help you with this.	Help me understand more about…	I wish I had better news.
It sounds like you may be feeling …	I can see how dealing with this might be … • hard on you • frustrating • challenging • scary	I can really see how (strong, dedicated, loving, caring, etc.) you are.	We will work hard to get you the support that you need.	Tell me more…	I wish you weren't having to go through this.
In this situation, some people might feel …	I can see how important this is to you.	You are such a (strong, caring, dedicated) person.	We are committed to help you in any way we can.	Tell me more about what [a miracle, fighting, not giving up, etc.] might look like for you.	I wish that for you too. [In response to what a patient or family members wishes, such as a miracle]
I can't even imagine how (NAME EMOTION) this must be.	Dealing with this illness has been such a big part of your life and taken so much energy.	I'm really impressed by all that you've done to manage your illness (help your loved one deal with their illness).	We will go be here for you.	Can you say more about that?	I wish we weren't in this spot right now.

RESPONDING TO CHALLENGING QUESTIONS THAT SUGGEST STRONG EMOTION IS PRESENT

God's going to bring me a miracle. • I hope that for you, too. (**Remember: no buts!**) (**I WISH**) • I really admire and respect. your faith (**RESPECTING**) • Having faith is very important. (**RESPECTING**) • Can you share with me what a miracle might look like for you? (**EXPLORING**)	**How much time do I have left?** ***NOTE: This question may mean many things – they are scared, they want to know so they can plan, they are suffering, etc. Exploring what they want to know can be very helpful.*** • That is a great question. I am going to answer it the best that I can. Can you tell me what you are worried about? **(EXPLORING)** • That is a great question. I am going to answer it the best that I can. Can you tell me what information would be most helpful to you? **(EXPLORING)**	**Are you saying there is nothing more you can do?** • I can't even imagine how (**NAME EMOTION**) this must be. (**NAMING**) • It sounds like you might be feeling … (**NAMING**) ○ Alone ○ Scared ○ Frustrated ○ Etc. • I wish we had a treatment that would cure you. (**I WISH**) Our team is here to help you through this. (**SUPPORTING**)
Are you telling me my dad is dying? ***NOTE: These responses will affirm the question empathically – so do not use them if the patient is not dying.*** • This must be such a shock for you. (**NAMING**) • I can't even imagine how difficult this must be. (**UNDERSTANDING**) • I wish I had better news. (**I WISH**)	**Are you giving up on me?** • I wish we had more curative treatments to offer. **(I WISH**) Our team is committed to help you in every way we can. (**SUPPORTING**) • We will be here for you. (**SUPPORTING**) • It sounds like you might be feeling … **(NAMING/EXPLORING)** ○ Alone ○ Scared ○ Etc. • We will work hard to get you the support that you need. (**SUPPORTING**)	**My dad is a fighter!** • He is. He is such a strong person and he has been through so much. (**RESPECTING**) • I admire that so much about him. (**RESPECTING**) • I really admire how much you care about your dad. (**RESPECTING**) • It must be (**NAME EMOTION**) to see him so sick. (**NAMING**) • Tell me more about your dad and what matters most to him. (**EXPLORING**)

***Note: These phrases are examples of empathic continuers. Patients may not immediately respond to your first empathic statement. They will often need multiple successive empathic responses to their questions to work through an emotion. ***

Goals of Care Conversations training materials were developed and made available for public use through
U.S. Department of Veterans Affairs contracts with VitalTalk [Orders VA777-14-P-0400 and VA777-16-C-0015]. Updated June 2018.

Simulation Step-by-Step

Simulation Step – by – Step to Feedback

1. Have available for the call the documents titled, the "SI Guide Care Manager Conversation," and the "Empathic Response Guide."
2. Click on this link: https://www.surveymonkey.com/r/S32HZJF and have it ready. You will fill out the SurveyMonkey form after completing the Serious Illness conversation. Do Not fill out at this time.
3. Dial the phone number provided to you and call your assigned patient.
4. Using the SI Guide, complete the SI conversation.
5. After the SI conversation dialogue, complete the SurveyMonkey self-assessment (the form you previously opened). This will take approximately 5-8 minutes.
6. If you can't open the SurveyMonkey link, use the time to reflect on the following:
    - i. Did you use the guide and follow it?
    - ii. Identify the communication skills used to engaged with the patient.
        1. Reflections, open-ended questions, summaries, I wish or I hope statements
    - iii. Did the interaction feel like a conversation versus a survey?
    - iv. Did you refrain from wanting to talk about the medical management?
7. While you are completing the self-assessment, the Standard Patient (S/P), is completing the **S/P Feedback** form.
8. When you have completed your self-assessment, let the S/P know you are ready for the feedback session.
    - a. After the feedback, the call will end.
9. A copy of your self-assessment will be provided to you. This is for your own learning. It is not shared with others.

Purpose of this Simulation Activity

The overall purpose of this exercise is to reinforce the importance of adhering to the evidence-based Structured Serious Illness Conversation Guide, with a focus on the four areas outlined in the guideline. You will utilize key communication skills (i.e. open-ended questions, reflection, exploring, affirmations and I wish statements) in each of the areas to elicit more information and gain a fuller understanding of the patient's perspective.

To begin the conversation, the attendee provides an introduction of self and the purpose of the call today.

Introduction

Desired Attendee BEHAVIOR: Introduce, explain the purpose of and secure agreement from a patient to engage in a Serious Illness (SI) conversation.
PURPOSE: To provide a patient/family with context for the SI conversation. To obtain an individual's agreement to engage in the conversation.

4 Areas of the Serious Illness Conversation Guide

1. **Assessing Understanding**

Desired Attendee BEHAVIOR: Assess whether a patient has an adequate understanding of the seriousness of their condition/disease progression. Assess how much information the patient wants to know about what may be ahead with their illness.

PURPOSE: Determine if a patient/family has adequate understanding so that asking about their priorities if they were to get sicker is relevant to the patient.

2. **Elicit Values and Goals**

Desired Attendee BEHAVIOR: Elicit patient's values and goals of care (what's important if they get sicker, tradeoff's willing to make, concerns and worries).

PURPOSE: Patient's goals and values inform the current/future serious illness plan of care. Uses key words from the reference guide to elicit goals and values.

3. **Make a Plan**

Desired Attendee BEHAVIOR: Elicits how much the family and physician know about the patient's priorities and wishes.

PURPOSE; Ensure family and physician have a clear understanding of patient's goals and preferences so they can be incorporated into the plan of care and honored if patient is not decisional at some future point. Determine next steps based on the information elicited during this conversation.

4. **Summarize and Closure**

Desired Attendee BEHAVIOR: Summarize main points of the conversation. Confirm agreement on next steps.

PURPOSE: To validate patient/family goals and values have been understood by the care manager and identify next steps for the plan.

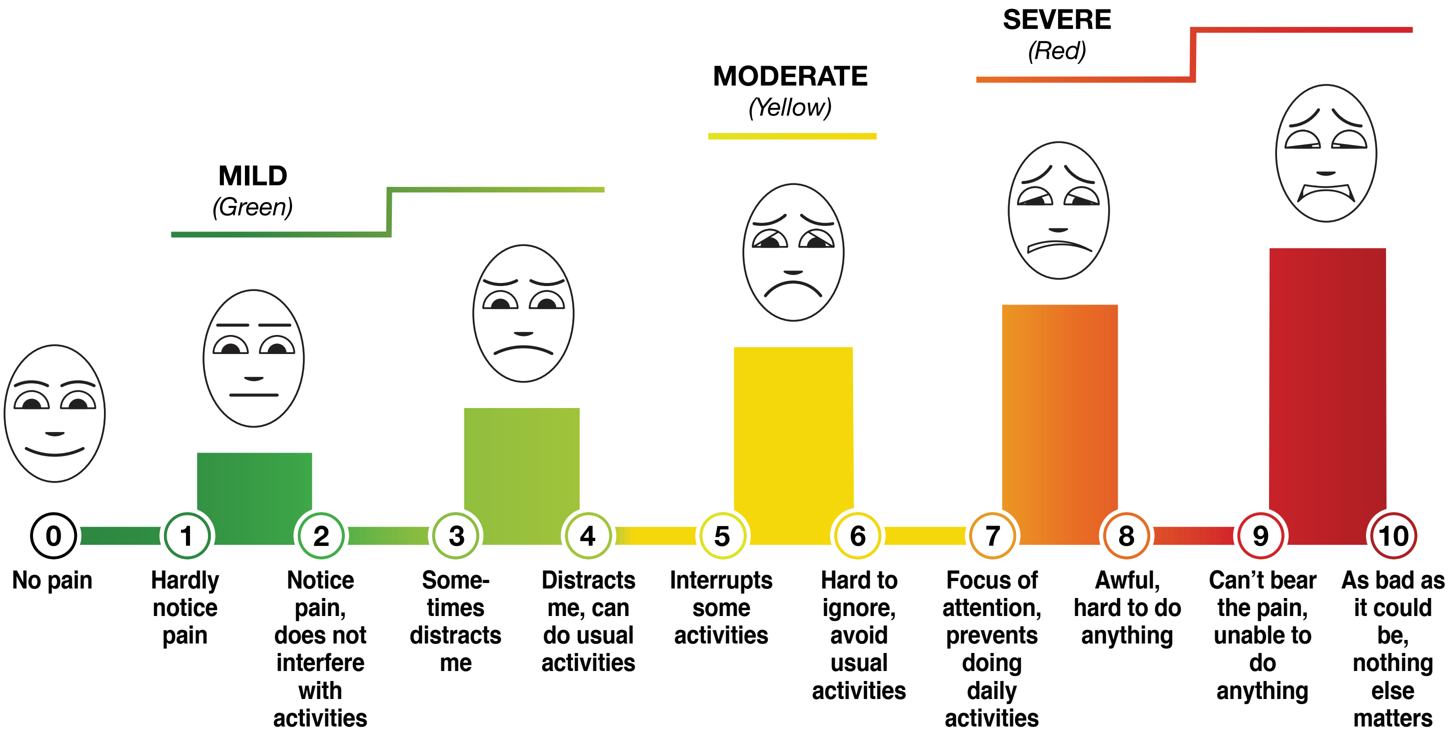
The Role of the Standard Patient

For this training and breakout, the goal of the simulation is:

- Keeping the Attendee Focused on and using the Serious Illness Guideline
- Evaluating and sharing with the attendee the experience of the conversation from a patient's perspective
- Providing feedback to offer encouragement to the attendee by listing 1-2 strengths.
- Providing feedback to encourage continued skill development by identifying 1-2 specific examples of opportunities for improvement.
- Most importantly, to provide feedback that will assist patients, families/significant others, and health care professionals in having crucial conversations when a serious illness is present.

Defense & Veterans Pain Rating Skills

Defense and Veterans Pain Rating Scale



v2.1

DVPRS SUPPLEMENTAL QUESTIONS

For clinicians to evaluate the biopsychosocial impact of pain

1. Circle the one number that describes how, during the past 24 hours, pain has interfered with your usual <u>ACTIVITY</u>:

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

Does not interfere ***Completely interferes***

2. Circle the one number that describes how, during the past 24 hours, pain has interfered with your <u>SLEEP</u>:

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

Does not interfere ***Completely interferes***

3. Circle the one number that describes how, during the past 24 hours, pain has affected your <u>MOOD</u>:

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

Does not affect ***Completely affects***

4. Circle the one number that describes how, during the past 24 hours, pain has contributed to your <u>STRESS</u>:

0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

Does not contribute ***Contributes a great deal***

**Reference for pain interference: Cleeland CS, Ryan KM. Pain assessment: global use of the Brief Pain Inventory. Ann Acad Med Singapore 23(2): 129-138, 1994.* v 2.1

Edmonton Symptom Assessment System

Edmonton Symptom Assessment System

(ESAS-r)

Numerical Scale

Page 1 of 1

Patient name: ______________________________
Address: ______________________________
Date of birth: ______________________________
Phone #: ______________________________
PHN: ______________________________
PATIENT LABEL

Please circle the number that best describes how you feel now:

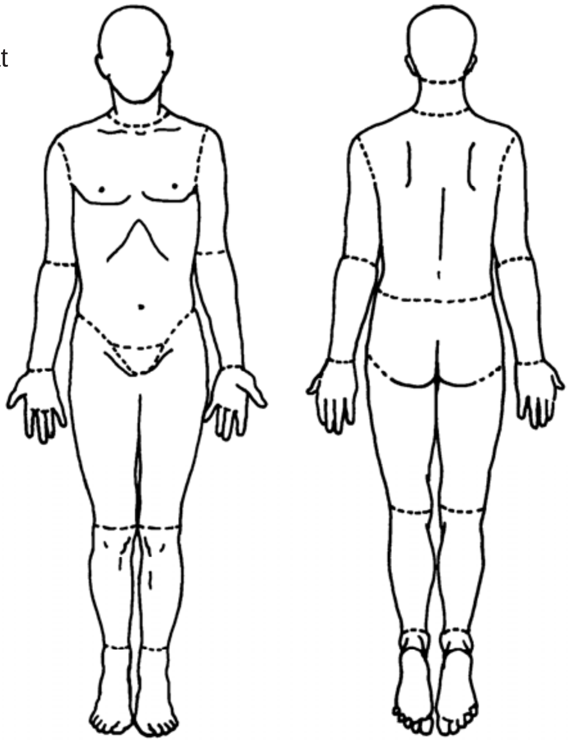
No pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible pain
No tiredness *(tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible tiredness
No drowsiness *(drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible drowsiness
No nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible nausea
No lack of appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible lack of appetite
No shortness of breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible shortness of breath
No depression *(depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible depression
No anxiety *(anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible anxiety
Best wellbeing *(wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible wellbeing
No __________ other problem *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst possible ______________________

Completed by: (check one)

- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

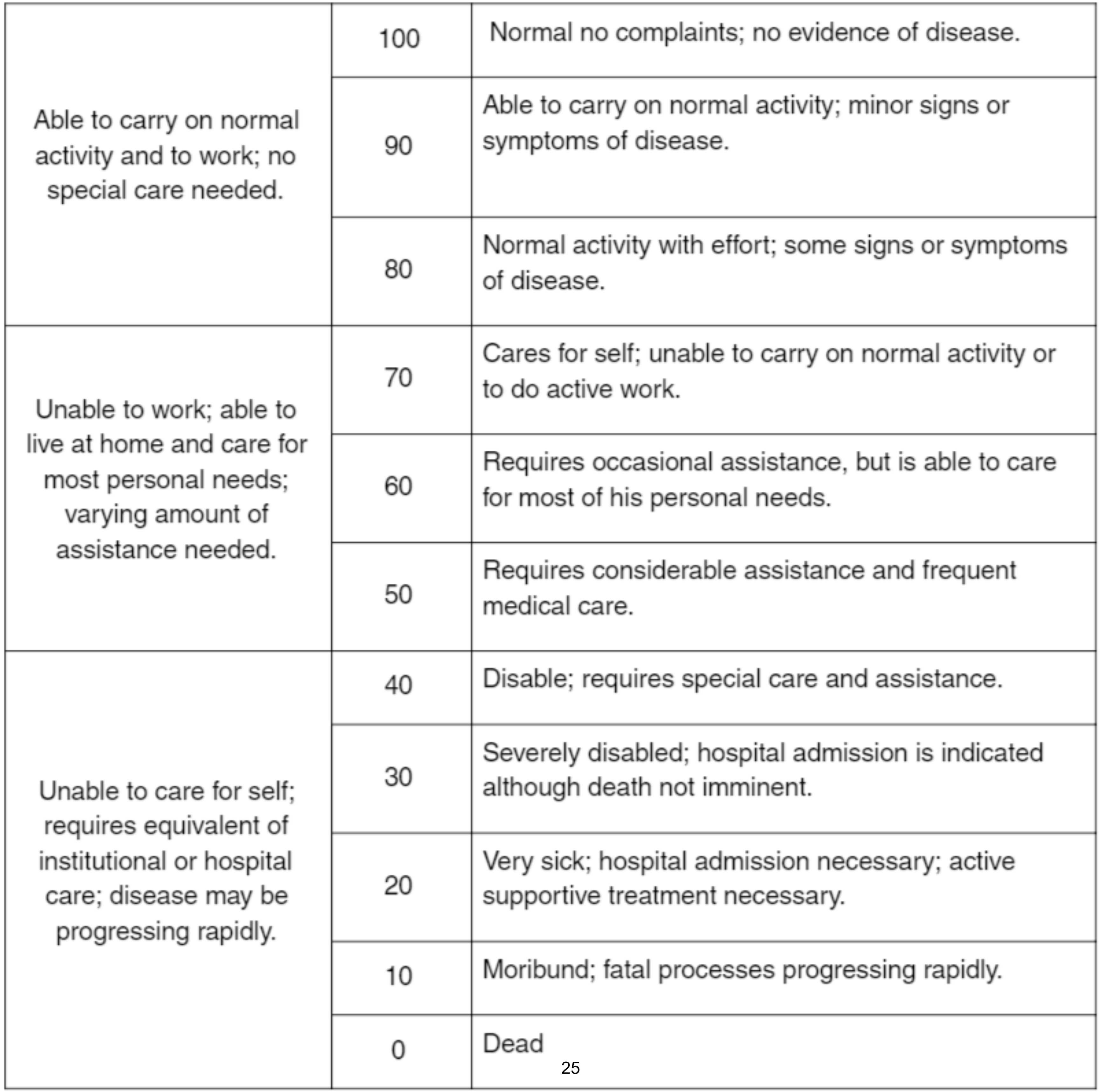
Date and time: ___________________________

Please mark on these pictures where it is that you hurt:



Karnofsky Performance Status Scale

KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA



Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disable; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

NYHA Functional Classification

Doctors usually classify patients' heart failure according to the severity of their symptoms. The table below describes the most commonly used classification system, the **New York Heart Association (NYHA) Functional Classification**[1]. It places patients in one of four categories based on how much they are limited during physical activity.

Class	**Patient Symptoms**
I	No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
II	Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
III	Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
IV	Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.
Class	**Objective Assessment**
A	No objective evidence of cardiovascular disease. No symptoms and no limitation in ordinary physical activity.
B	Objective evidence of minimal cardiovascular disease. Mild symptoms and slight limitation during ordinary activity. Comfortable at rest.
C	Objective evidence of moderately severe cardiovascular disease. Marked limitation in activity due to symptoms, even during less-than-ordinary activity. Comfortable only at rest.
D	Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.

For Example:

- A patient with minimal or no symptoms but a large pressure gradient across the aortic valve or severe obstruction of the left main coronary artery is classified:
  - **Function Capacity I, Objective Assessment D**
- A patient with severe anginal syndrome but angiographically normal coronary arteries is classified:
  - **Functional Capacity IV, Objective Assessment A**

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[1] *Adapted from Dolgin M, Association NYH, Fox AC, Gorlin R, Levin RI, New York Heart Association. Criteria Committee. Nomenclature and criteria for diagnosis of diseases of the heart and great vessels. 9th ed. Boston, MA: Lippincott Williams and Wilkins; March 1, 1994.*

Original source: Criteria Committee, New York Heart Association, Inc. Diseases of the Heart and Blood Vessels. Nomenclature and Criteria for diagnosis, 6th edition Boston, Little, Brown and Co. 1964, p 114.

Palliative Performance Scale

Palliative Performance Scale (PPSv2)

PPS Level	Ambulation	Activity Level & Evidence of Disease	Self -care	Intake	Conscious level
PPS 100%	Full	Normal activity & work **No evidence** of disease	Full	Normal	Full
PPS 90%	Full	Normal activity & work **Some evidence** of disease	Full	Normal	Full
PPS 80%	Full	Normal activity & work *with* effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable normal activity & work **Significant** disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance	Normal or reduced	Full or confusion
PPS 50%	Mainly sit/lie	Unable to do any work **Extensive** disease	Considerable assistance	Normal or reduced	Full or drowsy or confusion
PPS 40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
PPS 30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Reduced	Full or drowsy +/- confusion
PPS 20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal sips	Full or drowsy +/- confusion
PPS 10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma
PPS 0%	Dead	-	-	-	-

Instructions: PPS level is determined by reading left to right to find a 'best horizontal fit.' Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, 'leftward' columns take precedence over 'rightward' columns. Also, see 'definitions of terms' below.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. **Ambulation (**Use item **Self-Care** to help decide the level)
   - **Full** — no restrictions or assistance
   - **Reduced ambulation —** degree to which the patient can walk and transfer with occasional assistance
   - **Mainly sit/lie vs Mainly in bed —** the amount of time that the patient is *able to* sit up or *needs* to lie down
   - **Totally bed bound —** unable to get out of bed or do self-care

2. **Activity & Evidence of Disease (**Use **Ambulation** to help decide the level.)
   - **Activity** — Refers to normal activities linked to daily routines (ADL), house work and hobbies/leisure.
   - **Job/work** — Refers to normal activities linked to both paid and unpaid work, including homemaking and volunteer activities.
   - Both include cases in which a patient continues the activity but may reduce either the time or effort involved.

   Evidence of Disease
   - **No evidence of disease** — Individual is normal and healthy with no physical or investigative evidence of disease.
   - **'Some,' 'significant,'** and **'extensive' disease** — Refers to physical or investigative evidence which shows disease progression, sometimes despite active treatments.

   - Example 1: Breast cancer:
     some = a local recurrence
     significant = one or two metastases in the lung or bone
     extensive = multiple metastases (lung, bone, liver or brain), hypercalcemia or other complication

   Example 2: CHF:
   some = regular use of diuretic &/or ACE inhibitors to control
   significant = exacerbations of CHF, effusion or edema necessitating increases or changes in drug management
   extensive = 1 or more hospital admissions in past 12 months for acute CHF & general decline with effusions, edema, SOB

3. **Self-Care**
   - **Full** — Able to do all normal activities such as transfer out of bed, walk, wash, toilet and eat without assistance.
   - **Occasional assistance** — Requires *minor* assistance from several times a week to once every day, for the activities noted above.
   - **Considerable assistance** — Requires *moderate* assistance every day, for *some* of the activities noted above (getting to the bathroom, cutting up food, etc.)
   - **Mainly assistance** — Requires *major* assistance every day, for *most* of the activities noted above (getting up, washing face and shaving, etc.). Can usually eat with minimal or no help. This may fluctuate with level of fatigue.
   - **Total care** — Always requires assistance for all care. May or may not be able to chew and swallow food.

4. **Intake**
   - **Normal** — eats normal amounts of food for the individual as when healthy
   - **Normal or reduced** — highly variable for the individual; 'reduced' means intake is less than normal amounts when healthy
   - **Minimal to sips** — very small amounts, usually pureed or liquid, and well below normal intake.
   - **Mouth care only** — no oral intake

5. **Conscious Level**
   - **Full** — fully alert and orientated, with normal (for the patient) cognitive abilities (thinking, memory, etc.)
   - **Full or confusion** — level of consciousness is full or may be reduced. If reduced, confusion denotes delirium or dementia which may be mild, moderate or severe, with multiple possible etiologies.
   - **Full or drowsy +/-** confusion — level of consciousness is full or may be markedly reduced; sometimes included in the term stupor. Implies fatigue, drug side effects, delirium or closeness to death.
   - **Drowsy or coma +/- confusion** — no response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period. Usually indicates imminent death