ENABLE II Intervention Outline

Session 1

- **Session Objective:**
  - Introduce Self and Intervention
  - Establish rapport with patient and caregiver

Session Protocol

- **Purpose of the study**:

Hello Mr./Mrs. _____. I am _____, the palliative nurse educator from Dartmouth Hitchcock Medical Center working on the research project called ENABLE II.

I am calling today to introduce myself and give you an overview of the program.

The format of the intervention is very simple. We have four parts to this program that we hope will assist you. **Please turn to page 5 in your manual**. You can see the four steps of the program here. I will walk through the steps and tell you a little about each one.

The first part of the program involves the coordination of your care by a nurse educator to help match resources to your needs. I am the nurse educator that will be involved in this process with you. The term coordination of care is referring to any non-medical part of your care or supportive services that you may need assistance with. Several examples of this would be if you are having difficulty with your financial situation, I could set you up to speak with someone, support groups, spiritual or psychiatric help.

The second part of the program is training in the problem solving technique. This is a process we will discuss later in this session, but it is a skill designated to reduce distress and help with decision making around a number of issues such as symptom management, life planning, and quality of life.

The third part of the intervention is the education about the many problems and concerns you may be coping with since your diagnosis of cancer. You can ask me any questions you may have, or voice any concerns to me and I will try to assist you in any way possible.

Lastly, is your participation in the Shared Medical Appointment that will address a broad array of physical and emotional symptoms. This is optional, but we do encourage you to try at least one SMA. This is a time when you and approximately 6-10 other participants will have the opportunity to talk with a Palliative Care physician and a nurse practitioner from the palliative care service. You will receive an invitation to the SMA in the mail.

The overall goal of this program is to evaluate if this intervention along with the services you are already receiving at DHMC will improve your care and quality of life.

Often times in health care, people fall through the cracks in terms of support and assistance. Part of this project is to provide a safety net for you so that you do not become one of the people who falls through the cracks. I am here to provide support and assistance to you and your care giver in any way possible.

At this point do you have any questions?

As part of the nurse educator intervention we will be speaking on the phone for at least four sessions; each session will last about 30 minutes. We will set the calls up together for a time that is convenient for you. This is the first session and I will call you once a week for three weeks after this call. After that, I will call you once a month to follow up with you and see if there are concerns/issues that I can assist you with.

Now, I would like to have an understanding of your cancer diagnosis and your treatment goals. Could you please briefly tell me about that??

Possible questions to ask to drive the conversation around patient's perception of diagnosis and goals of care.

Have you had conversations with your health care team about your treatment goals??

What do you expect of your current plan of care? What do you hope for?

Do you feel the care you are receiving now is consistent with your goals??

Do you feel you have different goals than your health care providers in terms of your care?? If yes, could you tell more about that?

- **Measuring distress:**

Since this program is designed to help you and improve your quality of life, I would like to know what things have been distressing to you. One of the tools that we will be using each time we talk is called the Distress Thermometer. You can find this in the front pocket of your book. You do not need to write on this. I will keep track of these each time we speak.

Go through the Holland Distress with the participant – Go through entire tool, reading exact instructions on form. This includes asking participant to respond yes or no to every source of distress.

(Initially, we had said: "but if participant scores less than 3 on the thermometer, in subsequent sessions, do not need to go through each section." As of 3/1/07 we decided on this rule to change see pg.5).

Okay, now that I have a better understanding of the things that have been causing you distress, I would like to tell you a little about the problem solving technique. **Please turn to page 9 of your manual.** When experiencing a serious illness one can be faced with difficult decisions about health care, as well as trying to solve new life problems that may have never been encountered before. It can be very useful to have an organized method to think through ones' options and to ultimately make more informed decisions. This problem-solving process can help move a person through the many difficult decisions that must be made toward the end of life. It has been shown to help people who are depressed and people who have chronic pain.

Please look at the diagram on the bottom of page 9. It is important to understand that the relationship between stressors and physical response is central to improving symptom management. When you are faced with a stress your body produces a physical response. This physical response may be an increased heart rate, increased blood pressure, or an increase in one of the physical symptoms you have been experiencing, such as pain or depression. If you do not address the problem, issue, or stress, it will increase those symptoms, and then you can get caught in a viscous cycle that is very difficult to break.

The goal of the problem solving technique is to keep your overall quality of life as high as possible by reducing the stressfulness of problems. The problem solving technique is one part of the intervention for this project that may be useful for you at some point.

The last thing I would like to do right now is to give you an overview of the steps involved in the problem solving process. We can walk through them together **if you turn to page 10 in your manual**. The first step is to identify a problem. Next, you choose a goal. Step three is when you list all the possible solutions you can think of in order to meet this goal. Next you will list the good and bad things about each solution that you have come up with. Step 5 is when you choose the best solution for you. And lastly, step 6 takes place in between our calls. This is when you will work on achieving your goal.

Do you have any questions?

I would just like to explain that this is a process where you come up with the problem, goals, solutions, and so forth. I will be here to help you and coach and assist you through the process.

Does this all make sense? Do you have any questions?

I think that this is a lot of information for you today. I would like you to take your time and read through the first module of the manual for next week. The information will explain the PST in more detail and give some examples, feel free to use the PST during this week if any issues should arise. In addition please read the module on communication and social support and complete the activity on page 21 for next week. We will discuss the activity next time we talk.

So that you have an understanding of how the sessions will go, next week we will start with the Distress Thermometer and then we will discuss the communication and social support activity. After this, we will discuss any problems or issues that have come up during the past week.

Do you have any questions?

- Set date and time for next call…

Session 2

- **Session Objective**:
  - The focus of this session is to discuss any family-related or support-network problems/issues.
  - **If applicable** to review and encourage the use of the PST as a skill that could be used to facilitate any issues encompassing support and communication issues.

Session Protocol

- Establish patient's Holland Distress Thermometer level. Do not go through each section if distress thermometer less than 3. If 3 or greater, then ask patient to identify source of distress (cue them to look at list on thermometer). After patient identifies source(s), ask "so can I assume that the others you didn't mention on the list would be "no?"

- **If applicable**, discuss prior problem and solution selection, review barriers and success of prior week's goal (reinforce success, minimize failure and focus on what could be done differently). Modify the solution and/or tasks needed to resolve/manage this problem. (If this is applicable).

- **Introduce communication and social support**.

- Review activity and dialogue about any issues that may arise from the activity.

- Use PST if patient has identified a problem/issue.

In our emphasis on personal strength and independence, many of us forget that we are part of a network of support. We spend a good bit of time helping others, and we may need to remind ourselves that others are happy to help us out when we need it. In times of challenge and stress it may be our turn to accept that help and support.

Last week I requested that you do an activity that would help you identify your support network with family and friends. Shall we take a few minutes and just review how this activity worked for you? Who are your sources of support? Who else would you like to have support from? What surprised you as you played with shapes and colors, with people and relationships? Are there individuals or caregivers you forgot to put on your page? Do you need to help some people in your family or friends to see that you could use their support, or to see how they might be of help to you at this time? How easy is it for you to ask for, and receive support? Is there some problem with your support system that we can address using the problem solving approach?

If more than one of you did this exercise (e.g., spouse), were there differences between your perceptions of a support network?

Is there a specific problem or issue that you would like to work on now with me using PST? If yes – follow below…

Please take out a "problem-solving" worksheet and we will go through a problem/issue today that you have identified in relation to an issue surrounding a need of support or communication. Remember, you can always look back to the first module on problem solving for help.

Let's start by reviewing the stages of problem solving briefly and then identifying specific problem area or concern that you would like to address.

Work thru the problem using PST guidelines. If patient has no problem with support system then ask the patient to identify if there is any other problem today – or problem can be identified from the Holland Distress Thermometer. If problem is addressed, make sure the patient has a clear plan to carry out the chosen solution before closing the session.

- Assign the activity for the next module "symptom management" on page 29.

For the next week I would like you to read about the symptoms you've experienced or read about in Symptom Management Module starting on page 27. Then complete the activity included in the module. The activity is on page 29. Although you may not be experiencing any symptoms from your disease or treatment it is still an important activity to complete.

Our next schedule telephone call is _____ I look forward to talking to you then.

Session 3

Session Objective:

- ❖ The focus of this listen to any issues the patient identifies related to treatment-related symptoms and symptom management. If applicable to review and encourage the use of the PST as a skill that could be used to facilitate improved symptom management.

Session Protocol

1) Establish patient's Holland Distress Thermometer level. Do not go through each section if distress thermometer less than 3. If 3 or greater, then ask patient to identify source of distress (cue them to look at list on thermometer). After patient identifies source(s), ask "so can I assume that the others you didn't mention on the list would be "no?"

2) If applicable, discuss prior problem and solution selection (Did the patient reach their goal?) Review barriers and success of prior week's goal (reinforce success, minimize failure and focus on what could be done differently). Modify the solution and/or tasks needed to resolve/manage this problem. (If applicable)

3) Assist in identifying symptom management issues for patient and caregiver.

4) Assign activity for next module "advanced directives/unfinished business pg 72"

The symptoms of cancer and the treatment for this illness can be as confusing as they are overwhelming. We often feel lost in midst of the confusion and discomfort. Last week I requested that you do an activity that would help you identify any past or current symptoms and how you have managed them. I would like at this time to review that activity with you.

I see that you have identified _____ as an issue you have had in dealing with your symptom management. Is this something that you would like to talk about more and use PST to work through?

Work thru the problem using PST guidelines. If patient has no problem with symptom management then ask the patient if there is any other problem or issue that they would like to work on today. If PST completed, make sure the patient has a clear plan to carry out the chosen solution before closing the session.

For our call next week the last module I would like you to read and complete the activity is on Advance Care Planning and Unfinished business on page 72. If you have already completed your Advanced Care Directive or your DPOA-HC please review the Five Wishes document and other material in the module. If you have not completed any of your ACP please take the time to fill out the state (NH, VT) form I gave you with the educational material. The activity on unfinished business will also be helpful in our discussion during next week's call on_____.

Session 4

Session Objective:

- ❖ The focus of this session is to listen and address issues of advance care planning, advanced directives and unfinished business. If applicable to review and encourage the use of the PST as a skill that could be used to facilitate completion of Advanced Directives/Unfinished business.

Key Points:

- Differentiate between the Five Wishes and the New Hampshire and Vermont AD documents.

- Stress the appointed DPOA-HC is not the "decision-maker" per se, but rather a person who can be sure that PATIENT'S DECISIONS are honored.

Session Protocol

1) Establish patient's Holland Distress Thermometer level. Do not go through each section if distress thermometer less than 3. If 3 or greater, then ask patient to identify source of distress (cue them to look at list on thermometer). After patient identifies source(s), ask "so can I assume that the others you didn't mention on the list would be "no?"

2) If applicable, discuss prior problem and solution selection. Review barriers and success of prior week's goal (reinforce success, minimize failure and focus on what could be done differently). Modify the solution and/or tasks needed to resolve/manage this problem. *(If applicable*)

3) Introduce "unfinished business" and advance care planning.

Most of us have a lot of things that we want to do and have not yet done. We get some of those things done each day and feel some sense of accomplishment.

There are other things that we just seem to "put off" for another day. Those things stay on our list—a real list or a list in our heads—and seem to hang over our heads. Some of those are just routine things, like cleaning out closets or labeling photographs. Others are important things that are difficult to approach, like resolving troubled relationships or writing our wills. Still others are simply things we want to do, like travel to a particular spot or visit with old friends and family.

A health care challenge may remind us of our personal "unfinished business" those things that we want to do and have not done. We may become anxious to take care of some of these things. Or we may just want to do some of the things we have put off**. In completing the activity on unfinished business what issues arose for you?**

Is there a specific issue that came up for you that we could use PST to work on?

Work thru the problem using PST guidelines. If patient has no problem with unfinished business then ask the patient if they can identify any new problem or issue today. If PST is used, make sure the patient has a clear plan to carry out the chosen solution before closing the session.

You had an opportunity this week to review the educational material on ACP do you have any questions about that information. Did you read the 5 Wishes material? If so, did that generate any new insights… distress… was it helpful…etc. Is there anyway I can assist you if you have not completed your ACP?

(Nurse Educator: Make sure the patient has a specific plan to officially complete the ACP and get it into the medical record)

This is the completion of the initial intervention. Our hope is that you will continue to use the PST as issues arise. I will continue to follow-up with you on a monthly basis by phone. During these follow-up calls I will be asking you to update me on healthcare issues using the Holland Distress Thermometer and hearing any other concerns you may have. I encourage you to attend one of the SMA's if you have not already just to see how this intervention might benefit you.

If you should have any non emergent questions or concerns please feel free to call me at _____ during the hours of 8-5PM Monday –Friday.

Follow-Up Phone Call Protocol

(These calls are made at least once per month but can be more frequent, if needed.)

Hello, Mr/Mrs_____ this is _____ from DHMC calling to hear how you are doing. What has this month been like for you? I would like you to complete the Holland Distress Thermometer so I can gain a better understanding of some of the issues you might be dealing with. Establish patient's Holland Distress Thermometer level (0-10). Do not go through each section if distress thermometer less than 3. If 3 or greater, then ask patient to identify source of distress (cue them to look at list on thermometer). After patient identifies source(s), ask "so can I assume that the others you didn't mention on the list would be "no?"

(I see you are dealing with _____.) Have you been able to use the PST to help you work on this issue? Have you been able to use the PST in other issues you may have had this past month? Can you tell me if you have any difficulties in using this technique to solve some of your problems? What about any successes?

Let's just briefly review the Problem-Solving Steps… Do you remember what the first step is? That's right, identifying the problem…and then…? If the patient is having a current problem, and they want to work on it with you, have the patient work through the problem using the PST guidelines while you are on the phone with them.

Have you had any opportunity to be part of a SMA?

Are there any other issues that you would like to discuss today? I will call you again next month to talk with you again. If there is anyway I can help during this time please don't hesitate to call.

I will call you next month during the week of_____.

******Possible questions to explore with patient around treatment clarification and quality of life issues. These questions could be asked in a module specific format**.

What fears or worries do you have about your illness or medical care?

- For example, do you feel that there are needs or services that you need to discuss?
- Does the patient find meaning in the symptom they are experiencing? In other words, what does this symptom mean to them?
- What was the last hospitalization related to your illness like for you?

Are they being followed by palliative care???

Who or what sustains you when you face serious challenges in life? Do you have any religious or spiritual beliefs that help you deal with difficult times?

What present or future experiences are most important for you to live well at this time in your life?

In what way do you feel you could make this time especially meaningful to you?

What experiences have you had in dealing with family/friends who have died or been seriously ill? What did you learn from those experiences? Did they help you form any ideas about your choices for future medical care?

What have you discussed with your family about what you might choose for your future medical care, including care at the end-of-life? Do you think you have had enough discussion and has it been specific enough? Are they having these conversations (about their goals and fears, and meaning in the illness) with their health care providers?