

Managing Uncertainty Day-To-Day

Outline of Telephone Calls for Nurse Trainers

Phone Calls: There are a total of four telephone calls, each one week apart.

Week 1 – Introduction and Breathing Relaxation

Week 2 – Pleasant Imagery

Week 3 – Calming Self-Talk

Week 4 – Distraction and Review

Monthly – Follow-up Calls

The basic structure of each phone call session is:

- I. Build rapport and provide basic information
- II. Review and reinforce practice over the past week
- III. Provide the rationale for the new skill
- IV. Teach or rehearse the new skill
- V. Discuss how the woman could apply it in her day to day life
- VI. Discuss reactions, outline the homework for the week

Note: during the first phone call and throughout, you will build and reinforce the overall rationale for the program

What you need

1. The outlines
2. The tape scripts for reference
3. Calendar to schedule appointments

Telephone Call Session 1

Start Time of call _____

I. Basic Information About Phone Call Sessions (2-3 minutes)

- ◆ *Explain that this is the first of four 20 to 30 -minute telephone call sessions, scheduled weekly over the next several weeks.*
- ◆ *Explain that sessions will be taped to be reviewed with the team.*
- ◆ *State that it is important to complete all of the telephone calls to get the most out of the program.*
- ◆ *Spend some time getting acquainted and building rapport.*

II. Introduction and Rationale

A. Review the Rationale For Managing Uncertainty Day-to-Day

Please note: When the data collectors/recruiters left the materials with the participant, the recruiter explained how to use the tape recorder and asked the participant to listen to the introductory tape in preparation for this telephone call. Thus, ask whether the woman had a chance to listen to the tape and had any questions. In any case, review the following...

Make the following points in a conversational way, asking the woman if this makes sense to her, if she has had similar experiences, etc.

- ◆ *Women who have survived breast cancer can be faced with many stressors including concerns about recurrence of breast cancer or the possibility of other cancers as well as concerns about the management of treatment side effects. These concerns are common and understandable. Yet, at times, these stressors can be difficult to deal with. The purpose of this program is to provide you with practical skills for dealing with uncertainty about recurrence, for managing treatment side effects, and to help you cope better overall.*
- ◆ *In this part of the program, we will provide you with practical skills that will help you deal with the times that you find yourself thinking about breast cancer; in other words, help you deal with your own personal triggers for uncertainty.*
- ◆ *Let me take a moment to describe to you what we mean by the word *triggers* and present some examples of triggers as experienced by women like yourself who are breast cancer survivors. Many women who have survived breast cancer find that there are things that happen in their current day-to-day lives that bring back memories, feelings, or concerns about breast cancer - *triggers*. Triggers can be things from your surroundings such as seeing something in the newspaper or on TV about breast cancer. Another trigger can be finding out about someone who has a recurrence or metastases. Certain things from the environment such as smells could trigger uncertainty. Or, a trigger can be things that you are doing such as going for annual check-up and mammography. Other triggers include*

bathing, dressing, shopping for new clothes, or seeing yourself in the mirror. Triggers can be physical symptoms or bodily sensations. Triggers can also be late-treatment side effects such as lymphedema (arm swelling), stiffness or numbness. Thus, different things can be triggers for different woman. Usually each woman has her own personal triggers for uncertainty.

- ◆ Now, let me also take another moment to tell you what I mean by *uncertainty*. Uncertainty refers to what we do not know or understand. For women surviving breast cancer, the greatest uncertainty is about breast cancer recurrence or spread. Each of these triggers usually cause women to become concerned about their future. Each woman has her own personal reaction to this uncertainty and each woman's reaction might be different at different times. There may be times when you are emotionally upset, worried, sad, or angry. There may be times when you just have many thoughts about your breast cancer experience running through your mind. There may be times when your body responds almost automatically to triggers and you feel jittery, tense, or nauseated. Or, there may be times when you just want to be alone or get overly busy to keep your mind off breast cancer. You may have all of these reactions to triggers or only a few. Sometimes you may know exactly what caused your upsetting thoughts or feelings, while other times you may not be sure why you are having that response. Finally, each woman has her own way of coping or dealing with these times of uncertainty.
- ◆ In this part of the program, called *Managing Uncertainty Day-to-Day*, we will help you build upon your own natural way of handling things as well as help you learn some new things to manage uncertainty. The skills that you will learn will be directed at helping you manage the different aspects of uncertainty. There are three tapes. This introduction is on Tape 1 side A. The other two tapes will present 4 different skills. On Tape 2, you will learn two basic relaxation skills to help you cope with physical tension and anxiety. The first skill is basic **breathing relaxation**, found on Tape 2, Side A, and the second skill is called **pleasant imagery**, found on Tape 2, Side B. On Tape 3, Side A, you will learn a skill called **calming self-talk**. Calming self-talk, something that you probably already do, is a skill that can be very useful for dealing with the emotions and thoughts that can occur during times of uncertainty. Finally, on Tape 3, Side B, you will learn several basic **distraction** skills. Distraction skills can help you cope with uncertainty about breast cancer by helping you get involved with enjoyable activities or by helping you get your mind on other (positive) things.
- ◆ For each skill, I will describe why it may be useful for you to use the skill, specifically what to do to practice the skill, and how to use it in your day-to-day life. I will talk to you about how to use your skills at times when you have come to expect that you may have feelings of uncertainty -- such as getting ready to go for a mammogram. I will also talk to you about how to use your skills when you are unexpectedly faced with feelings of uncertainty. In this way, you may be able to learn how to prevent certain times of uncertainty, as well as how to manage feelings of uncertainty once they occur. Please keep in mind that the goal of the program is to help you manage or deal with uncertainty and stress. You should not expect to be able to eliminate all stress and uncertainty. That is actually not possible.
- ◆ We will teach you a total of 4 skills – breathing relaxation, pleasant imagery, calming self-talk, and distraction. During each of the phone calls, we will talk about one of the strategies.

Engage the woman in a dialogue about how they cope with uncertainty about recurrence. Ask the woman questions: What have you done to manage your uncertainty in the past? Have you ever tried to distract yourself from uncertainty?

◆ The following are points to be made regarding the rationale during the next few sessions:

1. *These strategies are not a substitute for your regular medical care*
2. *The strategies may help you lessen, but not eliminate, uncertainty.*
3. *Research has shown that these strategies are effective in helping people with other problems deal more effectively. We expect that they will help you too. Let us know what you think.*
4. *It is important to practice these strategies at times when you are not feeling uncertainty. Learning something new, like a sport or music, takes time and practice. Do you have a favorite musical instrument? Well, as you know, to play the ?? well, you need to practice. It is difficult to learn new things when you are feeling uncertain. Just like it is difficult to learn a new skill during a music recital. So just like a music teacher might have you practice scales over and over and increase the difficulty as you go, I am going to have you practice.*
5. *Some of these strategies may be things you've tried before on your own. We are trying to work with things you already do to help you refine your skills and apply them to uncertainty.*

Ask the woman if there are any questions??

This rationale is repeated on Tape 1, Side A. Listen to it again sometime this week.

III. Practice with Coping Strategy - Breathing relaxation - TAPE 2, SIDE A

A. Describe and demonstrate strategy

Today you will start by learning breathing relaxation. Relaxation is one of the techniques which can help you cope with your uncertainty and feel better all around. Now I'd like you to try the breathing relaxation tape with your audiotapes from your Managing Uncertainty Day-to-Day kit while I hold on the phone.

- ◆ *Explain how to use the tape player*
- ◆ *Ask the woman to push the stop button on the tape after she is asked to open her eyes*

B. Review reactions

- ◆ *How was it? Have you ever done anything like this before?*
- ◆ *Any problems, questions?*

- ◆ How well were you able to concentrate?
- ◆ Reassure woman that problems usually go away with practice
- ◆ Explain that with practice the woman will get better at the technique.

IV. Application – on the tape.

- ◆ Do you see this as something you could use?
- ◆ How/when?

V. Homework and End of Call Instructions

- A. Discuss woman's reaction to phone call session and overall program.
- B. Ask the woman to listen to the relaxation tape often. At least once each day is best, but at least twice over the course of the week. Discuss with her when and where she plans to practice.
- C. In preparation for the next phone call session, ask the woman to familiarize herself with the next skill – pleasant imagery – by listening to it at least once to Tape 2, Side B before the next phone call.
- D. Tell the woman that you will call next week and arrange a time and schedule the next phone call in about 1 week.

End Time of Session _____

Telephone Call Session 2

Start Time of call _____

I. Review the Basic Information About Phone Call Sessions (2-3 minutes)

- ◆ Review that this is the second of four 20 to 30 -minute telephone call sessions, scheduled weekly over the next several weeks
- ◆ Remind the woman that the sessions will be taped to reviewed with the team

II. Review use of Introduction and Breathing Relaxation Tapes

- ◆ Did you listen to the breathing relaxation tape? When? Where?
- ◆ Did it help? Did you have any problems or questions?
- ◆ Did you listen to the pleasant imagery tape at least once?

III. Review of Practice with Pleasant Imagery

A. Describe and demonstrate strategy

Pleasant imagery is a strategy where you imagine a pleasant relaxing place or memory. It is somewhat like daydreaming and it can serve to help you relax and get distracted from uncertainty.

B. Review reactions – what did you think of the tape?

- ◆ How was it? Have you ever done anything like this before?
- ◆ Any problems, questions?
- ◆ How well were you able to concentrate?
- ◆ Reassure woman that problems usually go away with practice
- ◆ Explain that with practice the woman will get better at the technique.

C. Develop ideas for personal imagery

- ◆ Ask the woman what sort of pleasant scenes help her relax and get distracted.

IV. Application – on the tape.

- ◆ Do you see this as something you could use?
- ◆ How/when?

V. Homework and End of Call Instructions

- A. Discuss woman's reaction to phone call session and overall program.
- B. Ask the woman to listen to the pleasant imagery tape at least once daily or as often as she can this week. She can also continue to use the breathing relaxation tape

- C. In preparation for the next session, ask the woman to familiarize herself with the next skill – calming self-talk – by listening to Tape 3 Side, A at least once before the next call.
- D. Tell the woman that you will call in one week and schedule the phone call for next week.

End Time of Session _____

Telephone Call Session 3

I. Review the Basic Information About Phone Call Sessions (2-3 minutes)

- ◆ Review that this is the third of four 20 to 30 -minute telephone call sessions, scheduled weekly over the next several weeks.
- ◆ Remind the woman that the sessions will be taped to reviewed with the team.

II. Review use of Breathing Relaxation and Pleasant Imagery Tapes

- ◆ Did you listen to your breathing relaxation or pleasant imagery tapes? When? Where?
- ◆ Did they help? Did you have any problems or questions?
- ◆ Did you listen at least once to the calming self-talk tape?

III. Rationale for Calming Self-Talk –

Make the following points in a conversational way.

- ◆ Most of the time, people have thoughts that run through their minds. The process of thinking or “talking to yourself” is normal and natural. However, there are times when you might have troublesome thoughts or questions that run through your mind. Some of these thoughts may come from uncertainty about breast cancer. Although these thoughts are understandable, these troublesome thoughts can lead to increased anxiety and tension. They may also lead to other negative changes in how you feel or act day-to-day.
- ◆ The next skill that we will cover in this program is specifically designed to help you deal with troublesome thoughts. The skill is called calming self-talk. Calming self-talk is a skill that can help you control and decrease uncertainty by learning to talk to yourself using calming, comforting words or sentences. You need to be positive with yourself – and also realistic. You might think of what you would say to a close friend if you were trying to comfort her in a time of uncertainty.
- ◆ There are two ways you can use this skill. The first way is to help you get prepared to deal with triggers before the troublesome thoughts even start. The second way you can use this skill is to help you deal with unexpected troublesome thoughts after they happen.

IV. Practice with Calming Self-Talk –

- ◆ In order to learn to get prepared for triggers, you need to know what situations trigger your troublesome thoughts, and then you need to try to use calming self-talk before, during, and after you are in the situation. What are your common triggers? Help the woman develop a list of at least three situations that lead to troublesome thoughts. If she cannot come up with her own list, ask her... What do you think when you get a headache? Go to the doctor's office? Here that a friend or relative has cancer?

- ◆ Develop a list of troublesome thoughts that the woman has during these three situations. If she cannot think of her own thoughts, give her some examples from the tape scripts.
- ◆ Now, help the woman develop some calming self-talk that she can use in each of these situations. (See the tape scripts for ideas)
- ◆ Spend about 10 minutes on this topic. If the woman cannot think of her own thoughts, give her some examples of what other woman have thought (*I am afraid my breast cancer will come back, I cannot deal with this, etc.*). Ask her how she could help these other woman see things differently or cope better in the situation.

V. Application

- ◆ Do you see this as something you could use? How/when?
- ◆ This week, see if you can catch yourself when you are having troublesome thoughts. Then, try to use calming self-talk to help deal with these thoughts.
- ◆ Mention that you will be asking if she caught herself having any troublesome thoughts in your next phone call.

VI. Homework and End of Call Instructions

- A. Discuss woman's reaction to phone call session and overall program.
- B. Ask the woman to listen to the calming self-talk tape at least twice this week. She can also continue to use the other tapes – pleasant imagery and breathing relaxation.
- C. In preparation for the next phone call session, ask the woman to familiarize herself with the next skill – distraction – by listening to Tape 3, Side B at least once before the next phone call.
- D. Schedule the next phone call for next week.

End Time of Session _____

Telephone Call Session 4

I. Review the Basic Information About Phone Call Sessions (2-3 minutes)

- ◆ Review that this is the fourth and final of four 20 to 30 -minute telephone call session. After today, there will be more phone calls to track your progress, see how things are going, etc.
- ◆ Remind the woman that the sessions will be taped to reviewed with the team

II. Review use of Breathing Relaxation, Pleasant Imagery, and Calming Self-Talk Tapes

- ◆ Did you listen to your calming self-talk and other tapes? When? Where?
- ◆ Did they help? Did you have any problems or questions?
- ◆ Did you listen at least once to the distraction tape?

III. Rationale for Distraction

- ◆ Planning pleasant activities into your day-to-day life can serve as a powerful distraction from uncertainty about breast cancer. Moreover, women who are involved in many enjoyable or pleasant activities on a regular basis tend to feel better and cope better overall. By staying active, you are able to keep yourself busy with enjoyable things and keep your attention or thoughts away from triggers of uncertainty. When you are distracted your anxiety may be less severe and you will feel better overall.
- ◆ Sometimes we get so busy with the things we “have” to do that we forget to do things that we *like* to do, things that make us feel good. It is important to do enjoyable activities each day. On busy days, this may mean finding 10 minutes here or there to do something for yourself; on days where you have more time, you can take the time to really pamper yourself. You can actively plan to do one, two, or three enjoyable activities each day. This will help you to feel in control of your life.

IV. Practice with Distraction

- ◆ There are three steps to building pleasant activities into your daily life. **First**, you need to make a list of things that are truly pleasant for you. What do you enjoy? Have any of your old interests become neglected? Are there some new things that you always wanted to do, but you have just not gotten started?
- ◆ Now, write down some pleasant activities on your list. (Here are some prompts)
 - Listening to music
 - Praying or meditating
 - Reading
 - Church activities or volunteer work
 - Looking at photographs
 - Going through magazines

- Watching a movie or a favorite TV show
- Cooking or baking
- Taking a walk or exercising
- Getting your hair done
- Taking a warm bath
- Playing games
- Visiting with family or friends on the phone or in person
- Sewing
- Painting or drawing
- Writing a letter to a friend
- Write in some others _____

- ◆ Make the point that it is important to have a variety of things on your list. Use what the woman tells you to say “I like how you have included some social activities with other people, some things that you can do at home alone, and some things that you do outside of the home. You can also include some things that are physically active and other things that you can do while resting.
- ◆ Now that we have some ideas, the **second** thing to do to build distraction into your day-to-day life is to, set a goal to do something enjoyable for yourself every day. Help the woman set her own goals. Use the following prompts if you need to... You might start by just setting a simple goal to do one thing from your list each day. It is important to set a reasonable goal that you can realistically accomplish. Then, you might gradually increase the things you plan to do each day to two and then three things. You may already do one or two things on a regular basis – that’s great! If so, your goal may be to add some new activities, things that you used to enjoy but have not done lately, or things that you have always wanted to try. The more you do that is enjoyable, the better. Set a specific time each day to do your pleasant activity. For example, you might make a promise to yourself to listen to 10 minutes of relaxing music every day in the evening after dinner. Or, you might plan to take a short walk every morning after breakfast.
- ◆ **Third**, make sure that you actually do the activities. There are several strategies you can use to be sure you stick to your goals. How can you be sure you’ll do it? Use the following prompts if you need to... In the morning each day, you could write down on a calendar what your goal is for that day. Then at night before bed, check it off the goals that you accomplished that day. Or, you might tell a friend or family member what it is that you plan to do that day. Then, actually tell the person when you accomplished your goal and how you feel.
- ◆ Up until this point, we have focused on how to get yourself regularly involved in pleasant activities on a day-to-day basis. You can also use distraction to deal directly with triggers or other difficult situation as they occur. Removing yourself temporarily from a troublesome situation can help you to manage feelings of uncertainty. Then, when you are feeling more in control, you can come back and deal more effectively with the situation if that’s necessary.

- ◆ Thus, if you find yourself faced with a trigger, you might see if you can stop what you are doing temporarily and switch to doing something enjoyable. The key is to find the things that work for you – things that you can really get involved in that will take your mind off the situation and make you feel better.

Here are some examples of using distraction to deal with triggers of uncertainty.

1. What might you do while at the doctor's office, waiting for your mammogram or check-up?? Use what the woman says and reinforce the good ideas. If she needs more try these ideas... If you plan ahead, you can bring a good book that you are reading or a crossword puzzle to do. Or bring an upbeat, chatty friend. If you didn't bring anything or anyone with you, pick up a newspaper or magazine in the waiting room and find something that grabs your attention – an article, a picture, the comics.
2. How about if you are shopping for new clothes and you are getting discouraged and depressed because you can't find anything that fits right. How could you use distraction under these circumstances?? (Here are some ideas... Arrange to meet a friend for lunch or a cup of coffee. Take a stroll in a nearby park. Or shop for something other than clothes – such as a card or present for someone with an upcoming birthday, or some new makeup).

V. Application

- ◆ Do you see this as something you could use? How/when?
- ◆ This week, see if you can do just one extra thing that is enjoyable

VI. Program Review and Final Comments

- A. You now have 4 new skills to use on your own or with the tapes. I encourage you to keep practicing on your own.
- B. Well, as I said, this is our last training phone call. I will still be in touch on a monthly basis to see how you are doing.

End Time of Session _____

