

Coach Manual for the Coping Kit for Parents

***Note: this is a longer version of the instructions provided in case coaches have time to go through more than one activity. In our initial study, we only practiced the breathing exercise and briefly described the rest of the activities.*

Parents of children with a serious illness experience high levels of stress. This stress can adversely impact the health and wellbeing of the parents and the family as a whole, as well as the parents' ability to address the needs of their children and to make major medical decisions.

The "**Coping Kit for Parents**" is designed to be a flexible and brief stress management intervention that is accessible to all parents of children with serious illness who are hospitalized at CHOP, that is feasible to implement in the midst of high caregiving demands and other stressors, that can be readily implemented with existing hospital staff infrastructure, and that is a cost-effective way to provide support to all parents of children with serious illness who are inpatients at CHOP. The ultimate goals of the intervention are to improve caregiving and adaption of these parents so they can support their children and other family members.

The intervention consists of three levels of activities, with evidence-based activities in each phase for a total of ten possible activities. The activities progress across the levels from easier to harder:

- Level 1:
 - breathing exercise
 - progressive muscle relaxation,
 - guided imagery
- Level 2:
 - identifying connections to others (social support)
 - becoming aware of personal strengths
 - recognizing emotions
- Level 3:
 - positive experiences (benefit finding)
 - identifying hopes
 - envisioning the future
 - journey (narrative expression)

You will meet with each parent in person at least once to introduce the intervention and go over the activities.

You will give each parent a set of cards that describes each of the ten activities, a handout with instructions for the activities, and contact information for parents to request additional support if they start to feel upset or overwhelmed while doing the activities. The goal of the intervention is not to have every parent do all ten activities on a regular basis, but rather to give them a menu of coping skills that they can choose from based on which activities are most interesting or helpful to them.

In the initial meeting, it's important to remember that some parents may initially not be very interested in this kind of program because they are focused on their sick child, and possibly their other children. These may see focusing on taking care of themselves as irrelevant or indulgent. It's important to make it clear that parents who are able to use these skills to manage their stress and take care of themselves may be better able to take care of their sick child (and their other children). In other words, sometimes the best way for parents to take care of their child is to take care of themselves.

The intervention consists of three levels. We suggest that parents start with the activities in Level 1 and work their way up to the activities in Level 3, but it will be up to the parent which activities they do and in what order.

Level 1 is basic relaxation skills to help parents deal with stress in the short term (breathing, progressive muscle relaxation, guided imagery). Parents who learn these skills may be better able to calm down in a specific stressful situation, and then be able to conserve and build up their reserves for future crises. They can also use these skills if they start to feel upset or stressed out while working on higher level activities.

Level 2 is the intermediate coping skills (identifying social support (Connections), identifying personal strengths, and recognizing feelings). These skills require more effort from the parents and require that they think about themselves and others. These activities can help parents be both more aware of when they are experiencing stress and more aware of the resources they can use to manage stress. In the short term, these activities may be upsetting for some parents as they may have to think about and confront unpleasant emotions and situations. In the long term, learning these skills will help parents adapt to what may be a long lasting stressful situation (e.g. a child with a chronic condition). Parents will be encouraged to use the skills they learned in level 1 to deal with any new stress caused by the activities in level 2. Parents will also be told they can stop at any time if the activities are too upsetting. Parents will be given contact information if they need additional support.

Level 3 is advanced coping skills (Benefit finding (Positive Experiences), Hopes, Envisioning a positive future, and writing about their experiences (Journey)). Parents will be encouraged to think about the big picture. What positive experiences have they had in spite of or even because of their child's illness? What are they hoping for in the future with their child? Can they envision a positive future? How have their positive and negative experiences changed them? These activities may help parents experience a sense of personal growth and meaning even when they are going through very difficult experiences. Parents may draw on some of what they learned about themselves and others in level 2 activities to work on the level 3 activities. Again, these activities may be stressful and upsetting in and of themselves requiring the use of level 1 skills, but may lead to better adaptation and outcomes in the long term.

The first session will take place in the hospital while the child is an inpatient. Ideally the coach will meet with the parent in a small conference room near the child's room, but the activities can also be done at the child's bedside if necessary.

Parents will be told that the stress management skills they are learning are progressive and will be encouraged to try each of the ten activities at least once, and to do at least one activity each day for 5 minutes.

You will be meeting with each parent (or caregiver) for about 30 minutes or less (the meeting will be longer if you practice more activities with the parent). During this meeting, you will give the parent The Coping Kit for Parents (the set of cards) and a handout with instructions similar to what you will be telling them in the meeting.

Note that the suggested script is given in italics, but you do not have to follow this word for word as long as you cover the key points. You should also be ready to modify the script and the activities depending on the parent you are meeting with and how much time you have.

Giving the Coping Kit to the Parent

Thank you for taking the time to meet with me. Today I have a gift for you. Taking care of a sick child can be overwhelming and exhausting. We are trying to develop ways to help parents and other caregivers cope with the stress and pressures of this situation.

[Give cards to parent]

This set of cards contains ten coping activities that I'd like to go through with you. These are all activities that help people manage stress and negative situations. We know that many parents are completely focused on helping their child get better and doing whatever they can for their child. Sometimes that means they don't get much sleep, they don't get to eat, and in general they don't have much time to take care of themselves because their child comes first. Many parents can do this for a while, but sometimes the stress can become overwhelming after a while. If parents are not able to take the time to care for themselves, it may even start to interfere with how much they can help their child, no matter how hard they are trying.

The goal of the Coping Kit for Parents is to help parents learn the skills to take care of themselves so that they can continue to take care of their children. Many parents of sick children don't have the time or money to go a stress management or coping skills class. So what we want to do is bring the class to parents in these cards. We want to teach parents basic coping skills that they can practice on their own even if they are at their child's bedside in the hospital or caring for their child at home.

The Coping Kit is not intended to replace or substitute for professional counseling. But our hope is that parents who learn some of these coping skills may have less need for counseling in the future.

The idea of the Coping Kit is that each day you can take 5 minutes for yourself and pick one activity from the Kit. It's up to you which activity you want to do and you can do more than one each day if you want to. You can do each activity as many times as you want. You might find it helpful to go through them in order, or you might find that you prefer to go in your own order. Some activities may appeal to you more than others. Our hope is that you will find at least a few activities that you can do on a regular basis.

While these activities are all based on research showing what kinds of activities help people cope with stressful situations, this is the first time this specific group of activities has been offered to parents in your situation. The purpose of this current project is to find out what parents like you think of the coping kit. The next stage of the project will be to make sure that the Coping Kit is actually helping parents. Therefore, we greatly appreciate any suggestions you have on how we can make these activities better.

Note that the activities are divided into three levels. Level 1 activities will help you calm down if you are feeling stressed out or upset. We suggest starting with these activities as a first line of defense against stress.

Level 2 activities require you to think more about yourself, how you are feeling, and who is supporting you. These activities can help you be both more aware of when you are experiencing stress and more aware of the resources you can use to manage stress. These activities require more effort, and while can be very beneficial in the long term, they may also lead to some negative thoughts and emotions as you do them. Therefore we suggest being ready to do a level 1 activity such as breathing or relaxation if a level 2 activity causes you to feel upset or stressed.

Level 3 activities are the most advanced activities. They require you to think about your current situation and your child's future. These activities may help you experience a sense of personal growth and meaning even when you are going through difficult experiences. They may also require that you draw on some of what you learned about yourself and others from the level 2 activities, and you may need to use level 1 activities to cope with negative thoughts and emotions that these advanced activities may trigger. Like level 2 activities, these activities may be difficult in the short term, but should increase your ability to cope with stress in the long term.

You should feel free to stop any activity at any time if you start to feel too upset or overwhelmed. You should also feel free to contact me if you feel like you need additional support or you have any concerns.

While today I will be doing the activities with you asking you some of the questions directly, you do not have to show me anything you write down and you do not have to turn in or show us any of the activities you complete on your own. We may ask if some parents are willing to share examples of activities they completed so that we can use those examples to help other parents in the future, but it will be up to you whether you want to share any completed activities.

I'm going to go through all ten of the activities with you today so you will be familiar with them. You can see that the cards are divided into ten sections with different colored cards for each section.

Some cards have space for you to write things down. You should feel free to write on the any of cards.

You should also feel free to take cards out of the ring to take them with you in your pocket or purse if you want to do a particular activity away from home and you don't want to take the whole set with you.

I am also giving you a handout to remind you of some of the things we will talk about today. But once you are familiar with the activities you shouldn't need the handout, and for some activities you don't even need the cards once you are familiar with the activity.

Do you have any questions before we go through the activities together?

Go through each activity with the parent. Try to do the complete activity if possible.

Level 1

Breathing

First try to make sure you are comfortable. There are 6 cards numbered 1-6. Close your eyes and take deep breaths. Try to breathe in slowly through your nose, fill your lungs completely, and then slowly let the air out through your mouth. As you let your breath out, put card number 1 down.

Breathe in. Breathe out. (repeat 5 times)

[For this activity simply do the activity with the parent.]

How do you feel now? It may seem a little silly, but sometimes just stopping to breathe can make a big difference in how we feel and can really help give us the energy and focus to keep doing what we need to do.

Relax

This is a progressive muscle relaxation task. Today we are going to do it together.

[For each activity, ask them to tense the area, count to 5, and then tell them to relax and count to 5]

1. Take a deep breath and let it out. Try to continue to breathe deeply as you do this exercise.
2. Feet: curl your toes downward. Relax.
3. Lower legs and feet: tighten your calf muscles by pulling toes toward you. Relax.
4. Entire leg: Squeeze thigh muscles while tightening calf muscles and pulling toes toward you. Relax.
5. Hands: Clench your fists. Relax.
6. Entire arm: tighten biceps by drawing your forearms up toward your shoulders and “making a muscle” while clenching your fists. Relax.
7. Buttocks: tighten by pulling your buttocks together. Relax.
8. Stomach: suck your stomach in. Relax.
9. Chest: tighten by taking a deep breath. Relax.
10. Neck and Shoulders: raise your shoulders up toward your ears. Relax.
11. Mouth: open your mouth wide. Relax.
12. Eyes: clench your eyelids tightly shut. Relax.
13. Forehead: raise your eyebrows as far as you can. Relax.

How do you feel now? This is a very popular way to help people relax. You can do this at home on your own with the cards to remind you of the steps. Or you can follow the more detailed steps described in the handout. Once you're used to doing the exercise, you can close your eyes

and do it without any cards or instructions. You should feel free to change the body parts or cards if you want to. There are lots of different ways to do this kind of activity, so feel free to do what helps you relax and feel better.

Guided Imagery

Now we are going to do a guided imagery activity. Which would you find more relaxing: imaging yourself at the beach or imagining yourself walking in a forest?

Beach

Close your eyes and breathe deeply. Continue to take deep breaths as you imagine you are walking along the beach on a beautiful day. Feel the warm sunlight on your face. Feel the warm sand under your feet. Hear the sounds of the waves against the shore. Feel a light breeze on your face as you walk along the beach. Listen to the cries of the sea gulls and watch them glide through the sky and swoop down to the water. Pick up a shell from the sand. Picture the shape and color of the shell. Sit down on the sand to watch the waves come in and out as the sun slowly sets. Relax and let yourself drift as the sun sets. When you are ready to leave this peaceful place, slowly begin to reawaken your body. Know that you can return to this beach visualization in your imagination whenever you like.. When you are ready, open your eyes and return to full wakefulness, feeling alert and refreshed.

Forest

Imagine yourself walking on a path through a forest. The path is soft beneath your shoes, a mixture of soil, fallen leaves, pine needles, and moss. As you walk, your body relaxes and your mind clears, more and more with each step you take. Breathe in the fresh mountain air, filling your lungs completely. Now exhale. Breathe out all the air. Feeling refreshed. The air is cool, but comfortable. Sun filters through the trees, making a moving dappled pattern on the ground before you. Listen to the sounds of the forest.... Birds singing. A gentle breeze blowing. The leaves on the trees shift and sway in the soft wind. When you are ready to leave this peaceful place, slowly begin to reawaken your body. Know that you can return to this forest visualization in your imagination whenever you like.. When you are ready, open your eyes and return to full wakefulness, feeling alert and refreshed.

How did that feel? For this activity you should find a quiet place where you can close your eyes for 5 minutes and try to picture a calm, relaxing place. It can be a beach or forest like we did today, or some other location like a lake, park or mountain. It can be a place that you've actually gone to or a place that you've always wanted to go to as long as you can picture it clearly in your head.

Level 2

Connections

Part 1

Who are the relatives, friends, and other people in your community who are helping you, your child, and your family in some way? This can include neighbors, co-workers, people from a religious organization you belong to, or people from your child's school.

On the first card write down the names of some these people and how they are supporting you. You don't have to write down everyone today. You can add more people later. Or if you can't think of anyone right now, you can come back to it later.

Name	How are they helping	How you would contact them
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Example:

Name	How are they are helping?	Contact
Jane	Gives the other kids rides to practice	cell phone #
Ladies from church	Bring dinner over twice a week	email for organizer

Part 2

Now think about whether there are other relatives, friends, or people in your community who you could ask for additional help from if you need it. It can be something you need right now, or it can be something you might need in the future. If you can think of someone write down their name, what you would ask them for, and how you would get in touch with them. For example if you wanted to ask your child's teacher to send a card from the class, you could write down her name, a card, and that you can e-mail her.

Name	How could they help	How to Contact
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Example:

Name	How could they help?	Contact
Teacher	Have the class send cards	e-mail

Strengths

When you are in a stressful situation, and someone you care about is sick, it's easy to focus on the negative and feel like you haven't done enough. People (especially parents of sick children) are often unaware of their own strengths and take for granted the amazing things they do every day. Sometimes it helps to take a moment to think about everything you have accomplished and the unique strengths you bring to this stressful situation or that you have developed over time.

Each card lists a character strength. Which character strength have you shown recently? How did you apply this strength to taking care of your child? Feel free to add new strengths to the cards.

Creativity
Curiosity
Open Mindedness
Love Of Learning
Perspective
Bravery
Persistence
Kindness
Love
Fairness

Leadership
Teamwork
Forgiveness
Modesty
Caution
Self-Control
Gratitude
Hope
Humor
Faith

Feel

Sometimes when people are in a stressful situation and they are focused on taking care of someone else, they get used to ignoring their own feelings. They can get into the habit of repressing or ignoring their emotions, both positive and negative, which can actually make it harder to deal with stress in the future. Recognizing and labeling what you are feeling can sometimes make it easier to manage these feelings without getting overwhelmed by them. And sometimes it's important to give yourself permission to feel a certain way even if you wish you didn't feel that way. You might feel angry, scared, or jealous and judge yourself for feeling that way. Recognizing the emotion without judging yourself for having it can sometimes make it more manageable.

Look at the emotion on each card. Have you felt this way recently? What made you feel this way? Were there specific events, thoughts, or memories that led to this feeling? Write down new emotions if what you are experiencing is not on the cards.

Interested
Excited
Strong
Proud
Inspired
Determined
Attentive
Thankful
Grateful
Alert

Guilty
Scared
Angry
Ashamed
Nervous
Afraid
Bitter
Overwhelmed
Sad
Irritable

Level 3

Positive Experiences

When you are going through something very difficult, sometimes it helps to deliberately think of positive things (no matter how small) that have happened as a result of your stressful situation. The goal of this activity is not to ignore the negative things or pretend they are not happening. The goal is to be aware of both the positive and the negative. Try to think of positive things that have happened to you, your child, or your family as a result of everything your child has gone through. They can be good things that have happened, things other people have done, or things you have learned about yourself or others. Try to write down one or more positive experiences on the cards provided.

Hopes

What I would like you to do now is think about hopes or goals you have for your child. It can be very helpful to have clear hopes in mind that you are working toward. Sometimes those hopes change as your child's situation changes, but many parents find it helpful to have clear hopes in mind even if their child's situation is very difficult.

Now write down one or more of these hopes on the cards. Write each hope on a separate card.

Next, for each hope you wrote down, ask yourself, is this hope something I have any control over? Sometimes the biggest and most important hopes are just outside of our control.

Are any of the hopes you wrote down something you have some control over? If not, can you think of another hope or goal that you do have some control over, even if it's a smaller more specific hope? It's okay if you can't think of one right now. You can work on this again on your own.

Now for the hopes you have some control over, I want you to write down anything that you can think of that you can do to make progress toward this goal, no matter how small. It's okay if you can't think of anything right now.

If you decide to work on this activity again on your own, you can do part 2 of this activity. First review all of the hopes you have written down today and ask yourself if you have made any progress toward that hope either because of a change in the situation or because of your own efforts.

Then see if you can think of additional hopes to write down. The situation may have changed since you first wrote down your hopes, so you may have new hopes relevant to your current situation. Ask yourself the same questions we asked today: Do I have any control of this hope? Is there anything else I can do to work toward this hope?

Writing down the uncontrollable hopes can be helpful too. Sometimes it helps to know what we are hoping for while also accepting that it's not up to us whether it happens or not. But it

also helps to have other hopes that we can do something about, and keep thinking about what we can do to work toward that hope. If that doesn't work out, we can try to think of a new strategy or a whole new hope that we can work toward.

[If they think of something, ask them to write it down on the first Hope card. Don't worry about challenging the hope even if it doesn't seem appropriate. If the parent can't think of anything, tell them it's okay. Come back to this activity at the end of the session. If they still can't think of anything, encourage them to continue to think about it and talk to their child's doctors and nurses, other family members, or other parents to get some ideas.]

Do you feel like you are making progress toward this hope?

Is there anything you are doing or can do to make progress toward this hope?

[Encourage them to write down any ideas they come up with on the card.]

For this activity, what you can do at home are two things. You can work on thinking of two more hopes you have. You can work on adding things you are or can do to work toward one of your hopes. Or you can add new hopes as your situation changes over time.

Envision

When you are in the middle of a stressful situation, it is natural to focus on everything negative that is going on right now. Sometimes it can help to take a step back and picture something positive but realistic (no matter how small) that could happen in the future. Ideally it would be something that could happen in the next 1 to 3 months, but it can be farther off than that if you want.

Every family's situation is different, and it's not always easy for parents to picture something positive in the future. As with the hopes, I want you to try to picture something that you think your child's doctors and nurses would agree is a realistic possibility.

[It's fine if they use something similar to one of their hopes. If they can't think of anything, you can refer back to the hopes if they had any. If they still can't think of anything, encourage them continue thinking about it and to discuss it with their child's doctor or nurse and others if appropriate. An example would be that the child would be at home in the back yard with her siblings on a summer afternoon while her siblings splash around in a small wading pool. The child may still be on oxygen or other supportive technology, but she would be home enjoying the day with her siblings.]

Now I want you to close your eyes and picture as vividly as possible that event happening. What details can you see?

Now I'd like you to write down a brief description of this vision. Over time you may think of other positive visions of the future that you would like to write down. For this activity you would take 5 minutes to close your eyes and envision this positive future in as much detail as possible.

Journey

For this activity we ask you to write down or record your thoughts about a question below or some other experience you have had recently. You can write your thoughts on a card, in a notebook or journal, on a computer, or somewhere else. You can even make an audio or video recording if you want to.

(one question on each card)

What is a positive or negative experience you have gone through while taking care of your child?

How did you feel during this experience?

How did this experience change you?

What did you learn from this experience?

Wrap up

[If time allows, go back to any unfinished activities like hopes or envision]

Those are the ten activities in the Kit. Do you feel any different now than you did at the beginning of our meeting? I know it was a lot to do all ten of the activities, but you can normally do just 1 or 2 of them at a time.

Do you have any questions about the Coping Kit for Parents or any of the activities? Do you feel like you could do these activities on your own for 5 minutes a day?

What do you think is the best time and place for you to do these activities? Feel free to take the cards out of the ring to take them with you in your purse or pocket if that's more convenient.

I will be in touch with you in one week to see how things are going and ask you some questions about how you used the Coping Kit.

Thank you for meeting with me today and I hope this has been helpful for you.