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## Session Seven: Health and Healing

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### Session Seven Supply List

**Basic Supplies:**

Flip chart and markers or optional for virtual sessions- whiteboard, and PowerPoint slides  
Parent Handbooks  
Facilitator Manual  
Tissues (e.g., Kleenex)

**Equipment:** None

**Other:** Snacks for children and adults, the **Nurturing Game®**, paper and markers or pen

| Activity  | Time       |
|---|------------|
| 7.1 Icebreaker: Well-being Check-In                                     | 5 Minutes  |
| 7.2 Check-In: Family Rules and Parent Sheet                             | 15 Minutes |
| 7.3 Health and Healing  | 25 Minutes |
| 7.4 Cultural Considerations   | 20 Minutes |
| 7.5 Stages of Grief   | 20 Minutes |
| 7.6 Home Practice Assignment: Worksheet: Meaning Competency and Support | 5 Minutes  |
| 7.7 Program Family Time: Traditions                                     | 30 Minutes |
| Home Family Time Assignment: Develop A Tradition                        |            |

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**Activity 7:1**      **Icebreaker: Well-being**  
**Population:**    **Adults**  
**Time:**            **5 Minutes**  
**Construct:**      **Self-Awareness, Empathy**  
**Materials:**      **None**

**Goal:** To recognize and validate the level of well-being that each parent identifies going in to the session and provide empathic support.

### Objectives:

1. To increase parent awareness of their well-being.
2. To validate the level of well-being and vitality each individual has identified.
3. To provide opportunity for empathic responses from group members toward parents who have identified the need for support.

### Before the Session Begins

Before the participants arrive, write the Icebreaker on the Flip chart to serve as a visual reference point.

**On a scale of 1 to 5, I give myself a \_\_\_\_\_ this week in the area of well-being.**

### Procedures:

1. Ask participants to sit in a circle (prior to group members arriving chairs should be placed in a large circle with no obstacles in the center.) Welcome parents to the group and review the agenda for the session. Explain that each of the next sessions will begin with an identical Icebreaker. Explain that the parents are to identify their level of well-being and vitality. **Well-being means how you are personally handling and coping with the challenges of family life.** They are to rate themselves on a scale of one (1) to five (5). One (1) being low and five (5) being high.
2. Ask the parents to respond to the following statement:  
**On a scale of 1 to 5, I give myself a \_\_\_\_\_ this week in the area of well-being.**
3. Ask parents to note which group members are feeling a bit depleted in the area of well-being (rate themselves a 1 or 2) and which parents rated themselves on the higher end (4 or 5). As a group we can share and balance our vitality by supporting others when they are depleted and we have energy to spare.
4. Ask in general for those who are feeling depleted: *“Is there anything that the group could do to be helpful?”*
5. Remind the group that the *Nurturing Parenting® Program* is designed to help them process challenges and learn coping skills that can help them when times get tough.

### Notes and Suggestions:

See Notes and Suggestions for Session Two.

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**Activity 7:2**      **Home Practice Check-in**  
**Population:**    **Adults**  
**Time:**            **15 Minutes**  
**Construct:**      **Self-Awareness, Empathy**  
**Materials:**      **Parent Handbooks, Facilitator Manual, Flip chart and markers or optional for virtual sessions- whiteboard, and PowerPoint slides**

**Goal:** To provide parents with the opportunity to discuss the Home Practice Assignment from the previous session and to enhance understanding of concepts and skills.

**Objectives:**

1. To “check-in” on progress and provide encouragement for the development of Family Rules.
2. To review the procedures for establishing Family Rules.

**Procedures:**

1. Review with parents the philosophy of the **Home Practice Assignment:** *Practice skills, try your best, and share your experiences with the group.*
2. Ask parents to turn to the Home Practice Assignment in their Parent Handbook and to take out the first draft of Family Rules. Focus the next 15 minutes discussing the Home Practice and the Home Family Time assignments.

**Parent Only Section** discussion questions:

- a. Is it ever ok to break the rules?
  - b. Should the child with health challenges or special needs have leniency?
  - c. What does it mean to treat family members “fairly”?
  - d. Can children learn to manipulate the circumstances?
  - e. What would our home be like if we treated every member as if they were valuable?
3. In concluding the discussion ensure that parents understand, if rules are based on values ALL family members including the child with health challenges or special needs will be responsible for upholding them. It may be appropriate to refer back to the key components of discipline from Session Five.
  4. Review their first draft of **Family Rules** with each family:
    - a. Did families sit together as a group and work on the rules?
    - b. Do the rules reflect values for the family?
    - c. Are the rules for all family members?
    - d. Are the consequences appropriate and will they leave “dignity” intact?

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5. Ask parents how Home Family Time went. Encourage families to enjoy each other's company by doing a fun activity after a family meeting discussing rules. When children feel a positive connection, they are more likely to cooperate with expectations.
6. Collect the **Family Logs** and return the Family Logs from Session 6.

### **Notes and Suggestions:**

**Remind parents each week to complete the competency questions in their Parent Handbook and make arrangements to review them with the appropriate team member. The Team member assigned will complete the Competency Assessment Form. (CODE: HCCA-V2)**

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**Activity 7:3**      **Health and Healing**  
**Population:**    **Adults**  
**Time:**            **25 Minutes**  
**Construct:**      **Self- awareness, Empathy, Developmental Expectations**  
**Materials:**      **Parent Handbooks, Flip chart and markers or optional for virtual sessions- whiteboard, and PowerPoint slides**

**Goal:** To consider a framework for exploring how families respond to health challenges and to provide opportunities for parents to explore their own thoughts and feelings regarding their early healthcare experiences and the health and well-being of their children.

### Objectives:

1. To share early experiences/perceptions of healthcare.
2. To provide an overview of a framework - three elements that impact the response of families to health challenges.
3. To provide an opportunity for parents to share their own perceptions about healthcare experiences and begin to consider hopes and fears related to the treatment of their child with challenges.

### Procedures:

1. Explain that our first exposure to healthcare is often a visit to the doctor's office, clinic or hospital as a child. It is in these early experiences that we begin to formulate ideas, thoughts and feelings about healthcare. Our perceptions may change as we become older and more experienced or knowledgeable, but often we still have clear memories (good or bad) of those first experiences that continue to influence us. Ask parents to take turns responding to the following statements:

**My first experience with healthcare was \_\_\_\_\_ (name the event).**

**I was \_\_\_\_ years old.**

**What I remember most is \_\_\_\_\_.**

2. Mention to parents that often the first cognitive memory of a healthcare experience is around age five. Younger children and many children with cognitive disabilities may have healthcare experiences that they do not cognitively remember. However, these memories may be stored in the body as cellular memory, in the brain as emotional memory, or in the psyche as an unconscious memory.
3. Explain that we all grew up in a family (of some form), a community and a society. Within the context of those systems, we developed cultural values, attitudes, and beliefs. Most of us grew up in a society where western medicine is practiced. Western medicine is based on a medical model that most often has the goal of treating a physical disease or illness, or its symptoms. Often families dealing with the health challenge of a child struggle to make decisions regarding what medical interventions are necessary, appropriate and beneficial to their child.

The healthcare system is based on a "medical model" that considers the scientific validity of any particular intervention. The family sees the child as a whole person and may struggle to make decisions about what the next steps may be in the care of their child. Each family has its own unique culture and history that impacts the way they perceive the world and experience healthcare. This session will provide parents with an opportunity

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to think about and discuss where they and their family stand on particular issues and how their unique experiences in the world have shaped their perceptions.

4. Explain to parents that this may or may not be true of them. However, researchers have found in their discussions with parents that there are three main elements that seem to provide “peace” to parents throughout the process of dealing with life altering changes.
5. Write the words **MEANING**, **COMPETENCY**, and **SUPPORT** on the flipchart or optional PowerPoint slide and review the following with parents:

### **MEANING**

Can you make sense of this? Is there some greater purpose? Is there some lesson to be learned? What do your religious and cultural beliefs teach you about - suffering, pain, grief, loss, death? Simply put ...

- What are you learning about yourself, your child, and your family?

### **COMPETENCY**

Do you have all the information you need to make informed decisions and feel competent in caring for your child’s physical and emotional needs? Consider. . .

- Are you able to make informed medical and educational decisions? Do you have the information you need?
- Are your decisions congruent to your belief system? Do the choices you are making feel right to you?
- Do professionals associated with your child’s care respect your decisions?
- Are you confident with your child’s team (OT, OT, speech, medical team, educators?)
- What do your cultural beliefs tell you about hierarchy? (Is it okay to question a teacher or doctor?)
- Are you a full partner in your child’s education or healthcare? (Do you want that role?)

### **SUPPORT**

Having informal or formal support people in place who validate you and your family emotionally and provide tangible support when necessary. For example. . .

- Are there people in your life supporting your decisions? Who are they?
- Do you have a sounding board? (Someone who will just listen!)
- Is there someone in your corner who can be objective and non-judgmental? Who is that person?
- Is there someone you can call any time you need help and know it will be given? When is the last time you asked that person for help?

Ask parents their perceptions and thoughts regarding the framework. Does this framework fit for their circumstances? They will be exploring these questions further in their Home Practice this week.

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6. Explain that parents will work in pairs and take 2 to 3 minutes each responding to these statements. The person listening should not give advice to the person answering the questions. It is important to listen without judgement. Couples attending the program together should not be paired together for this activity.

**One HOPE I have for my child is \_\_\_\_\_.**

**One FEAR I have for my child is \_\_\_\_\_.**

**One thing that I feel confident about is \_\_\_\_\_.**

**One thing that I feel unsure about is \_\_\_\_\_.**

7. Thank parents for their willingness to share and be involved in this exercise. Acknowledge them for the work they are doing to create a caring environment for all of their children.

### **Notes and Suggestions:**

1. This framework was developed by Javier Kane, MD. In conjunction with the pediatric palliative care movement.
2. If you are providing the program in a virtual format, allow time for parents to share with the large group, and/or strategically place pairs in breakout rooms.
3. The final statements may be very difficult for some parents to express. It is important that participants express their thoughts and feelings and that one other person be a witness to that expression. Recognize that some parents may need additional supports, especially if dealing with end-of-life issues. Speak with parents about referrals to agencies that have expertise in pediatric end-of-life issues if a need is identified.

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**Activity: 7:4**      **Cultural Considerations**  
**Population:**    **Adult**  
**Time:**            **20 Minutes**  
**Construct:**      **Self-Awareness, Empathy**  
**Materials:**      **Flip chart and markers, or optional for virtual sessions - whiteboard, and PowerPoint slides**

**Goal:** To provide an opportunity for parents to discuss the impact of culture on healthcare experiences.

**Objectives:**

1. To review lived experience in healthcare or education systems and facilitate discussion.
2. To consider the culture of the healthcare (or education) system and how to retain family culture within that structure.

**Procedures:**

1. Ask parents to consider that a culture is a set of beliefs, values, expectations, traditions and values held by a group of people in a society, organization, ethnic group, family or profession. In the last activity we began to talk about your personal experience. Much of our belief system is based on our experiences in our own families or communities. Different cultures may have different perceptions of disabilities, sickness, health, healing, pain, death and dying.

As you are well aware, each person brings a unique background and belief system to the equation. Ask parents to begin thinking about their own culture, religious beliefs and values. Also, consider that healthcare has a culture of its own.

- a. What is the culture of the healthcare system? Does it allow you to incorporate your own values?
  - b. Which of your beliefs help you navigate the healthcare system with competency?
  - c. Who are your "partners" in the healthcare system? (e.g., child life, social work, nurse, particular physician, chaplain)
2. Ask parents to respond to the following statements:

**One thing that a healthcare provider did for my child (myself) that showed a sense of caring and concern was \_\_\_\_.**

**One thing that a healthcare provider did that I felt was insensitive to my child (myself) was \_\_\_\_.**

**One thing I would like healthcare providers to know about my child (my family) is \_\_\_\_\_.**

3. Another area where culture is important is the educational system. If it seems more appropriate for your particular group you can use education-related scenarios.
  - a. What is the culture of the educational system? Does it allow you to incorporate your own values?
  - b. Which of your beliefs help you navigate the educational system with competency?

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- c. Who are your “partners” in the educational system? (e.g., counselor, advocate, teacher, a particular administrator.)
4. Answer the following questions:
- One thing that an educator did for my child (myself) that showed a sense of caring and concern was \_\_\_\_\_.**
- One thing that an educator did that I felt was insensitive to my child (myself) was \_\_\_\_\_.**
- One thing I would like educators to know about my child (my family) is \_\_\_\_\_.**

### Notes and Suggestions:

1. It may be helpful to consider some standard views on what particular ethnic groups commonly believe. It is equally important to recognize the difference between and among family members and to base your perceptions on what they tell you. The **Multicultural Parenting Guide**<sup>®</sup> (available from Family Development Resources, Inc. at [www.nurturingparenting.com](http://www.nurturingparenting.com)) will provide facilitators with some useful information but is not an absolute of how families should or will respond.
2. For additional resources see **Appendix B**, *Institute for Patient and Family Centered Care*.

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**Activity 7:5**      **Stages of Grief**  
**Population:**    **Adult**  
**Time:**            **20 Minutes**  
**Construct:**      **Self Awareness, Empathy, Developmental Expectations**  
**Materials:**      **Parent Handbooks, Flip chart and markers or optional for virtual sessions- whiteboard, and PowerPoint slides**

**Goal:**    To understand the stages of grief

**Objectives:**

1. To describe the stages of grief and loss.
2. To reference the stages of grief as appropriate for parents of children with special needs or health challenges.
3. To explore the impact of past experiences with loss on current responses to family situations.

**Procedures:**

1. Write the **STAGES OF GRIEF** on the Flip chart or create a PowerPoint slide. Write the statement “We Can Not Direct the Winds – but We Can Adjust the Sails” on the Flip chart or slide.
2. Have parents turn to the information on grief in their **Parent Handbooks** (Session 7).
3. Review the following information:

Grief is a normal reaction to loss. We often associate grief with the death or permanent loss of a loved one. However, grieving is an on-going process and many parents, family members and children experience grief when a child is diagnosed with a special need, a life-altering illness, or a health challenge. Stages of grief can be experienced over the course of a child’s illness, or at different stages in a child’s life.

Many parents explain grief, as a loss of “what might have been.” This sense of loss may surface many times throughout their child’s life. When typically developing peers, or siblings are experiencing societal or developmental milestones and their child is not, it can bring about a sense of loss.

It is important to recognize that a sense of grief or loss is a normal reaction. It in no way diminishes the love a parent has for their child. Parents can accept children as they are and still experience grief.

Eleanor Kubler Ross developed a framework for describing the stages of grief after working with patients at the end-of-life. The stages of grief are often not linear and people experience them in their own time and in their own way. Some people describe grief as a roller coaster not a progression of stages.

### STAGES OF GRIEF

**Shock/Denial/Disbelief**

Often acts as a buffer after receiving shocking or unwelcome news.

**Anger**

Often a response to fear, anger shows up as wanting to blame someone or something.

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### **Bargaining**

Trying to “make a deal.” Bargaining may be associated with quiet guilt or be an attempt to postpone accepting reality. Some people feel regret or remorse.

### **Depression**

Feelings of deep sadness, in children and adults, depression may show up as sleeping and eating problems, withdrawal, irritability, etc.

### **Acceptance**

Feelings of anger and/or depression have decreased, ready to move forward with a sense of being at peace with the outcome.

#### 4. **Anticipatory Grief**

Ask parents to think of the words anticipate and grief. To anticipate is to expect a particular thing to happen. Grief is a feeling. Mourning is the act of expressing grief. **Anticipatory grief can be defined as the act of mourning what might or might not be in the future.**

**It is human nature to spend time in the present thinking about the past and anticipating the future.**

Most people have experienced losses in their past. When current grief shows up, it is likely that past issues of loss will compound (add to) the current loss. People will feel sad about the current situation and it will remind them of other losses in their lives. When families have a child with a challenge, they often experience compound grief because of the many things they have perceived as losses in the past.

It is also human nature to project into the future what might happen. It is important for our well-being to maintain hope and anticipate positive things to come. However, when people have experienced loss in the past, are currently feeling sadness associated with loss and are projecting “what might be into the future” it is typical that they will “anticipate” more loss and sadness.

It is important to know that anticipatory grief is normal. It is also important to find ways to be present to the positive things that the world has to offer right now in the present and to use each day to its fullest potential. Many parents regret that they have used what could be precious time with their child(ren) in the present, worrying about what might happen in the future or hanging on to past disappointments or hurts.

- Loss of past – what might have been
- Loss of present – sadness for how things are right now
- Loss of future – what might or might not be

#### 5. One of the important components of helping children and ourselves resolve grief and work through all of the stages successfully is to enjoy the moment.

- Spend time doing meaningful things with your children.
- Develop meaningful routines and traditions that provide on going comfort to the family. (Regardless of the outcome, or the challenge).

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6. Explain that examples of “meaningful traditions” can be: taking pictures at holiday time, baking or cooking a particular food, bed-time routines that include prayers or stories, saying “*Good-bye*” and “*I love you*” each time you part company, making scrap books of memorable times together, playing a particular game, or having a vacation at a special place each year.
7. Ask parents about their own experiences with grief.
  - a. What stage are they in right now in relation to their child’s special needs or health challenges? Has grief been a part of their experience?
  - b. How comfortable are they with the expression of grief (sometimes called mourning).
  - c. What messages did they receive about expressing grief while growing up?
  - d. What messages do they give their children?
  - e. How difficult is it for parents, in general, to accept the intense emotions involved in grief when they are being exhibited by children?
  - f. Do children try to protect their parents from feeling grief?
  - g. Do parents try to protect their children from feeling grief?
8. Explain that it is very common for parents and children to try and protect each other from painful experiences. Studies as far back as the 1970’s have described a phenomenon called “mutual pretense.” Both parents and children avoid discussions with each other and underestimate the understanding of one another when communicating about the seriousness or poor prognosis of an illness.
9. Tell parents in the next few weeks we will be learning communication techniques that could be helpful in discussions about grief and loss in general and in opening up discussion about end-of-life issues if it became necessary.
10. Remind parents that in Session Three we learned the thinking, feeling, growing and doing method of helping children to grieve.

### Notes and Suggestions:

1. Respect where the parents are in the grief process. If parents deny feelings of grief or loss, respect their assessment of their own feelings. Do not assume that they are in denial. They may have moved through the stages and be in a state of acceptance viewing the experience as a gift. There is no right or wrong way to navigate the stages of grief. Many couples will be in different stages of grief and this can create problems in connection and communication. Stress and communication will be addressed in later sessions of the program.
2. If providing the program in person leave the box of tissues in a place that is accessible to all participants and allow parents to take a tissue if they want to. If a parent becomes tearful during the session, resist the urge to hand them a tissue. Although handing someone a tissue is a sign of compassion, it may send the message that it is time to stop crying instead of supporting their need to express grief. If providing a virtual session, tell parents they may want to have a tissue near-by as the activities in this session can sometimes support the expression of grief. Remind parents to practice self-compassion, as this session can be emotional.

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**Activity 7:6**      **Home Practice Assignment**  
**Population:**    **Adults**  
**Time:**            **5 Minutes**  
**Construct:**      **Self-Awareness, Empathy**  
**Materials:**      **Parent Handbooks**

**Goal:** To provide parents the opportunity to explore their feelings and thoughts regarding the health and well-being of their child and family.

### Objectives:

1. To complete the questions in the Parent Handbook
2. To use the responses as a tool for discussion in Session Eight.
3. To gain insight into self and family perceptions of the impact of challenges on well-being.

### Procedures:

1. Ask parents to turn to the **Home Practice Assignment** for **Session Seven** in their **Parent Handbook**. They will be responding to the questions:

#### Meaning

- a. Have you been able to identify some greater purpose related to your child's challenge?
- b. What are you learning about yourself, your child, your family?
- c. What do your religious and cultural beliefs teach you about – suffering, pain, grief, loss, death?

#### Competency

- a. Are you able to make informed medical or educational decisions?
- b. Are your decisions congruent to your belief system?
- c. Do professionals associated with your child's care respect your decisions?
- d. Are you confident with your child's healthcare team or educators?
- e. Are you able to advocate for your child in the educational or healthcare system?
- f. What do your cultural beliefs tell you about hierarchy? (Is it ok to question a teacher or a doctor?)
- g. Are you a full partner in your child's education or healthcare? (Do you want that role?)

#### Support

- a. Are there people in your life supporting your decisions? Who are they?
- b. Do you have a sounding board?
- c. Is there someone in your corner who can be objective and non-judgmental? Who is that person?
- d. Is there someone you can call any time that you need help and know it will be given? When is the last time you asked that person for help?

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2. Assign the **Family Log** and **Week Seven Competencies**.
3. Have each parent fill out an **Evaluation Form**.
4. End the parent session with a **Praise Circle**.

### **Notes and Suggestions:**

Adjust the Praise Circle accordingly for virtual sessions. Suggestion: have each person participating type one or two words in the chatbox regarding their experience and read them out loud or provide the participants a link to create a Word-cloud (e.g., [Wordclouds.com](http://Wordclouds.com)).

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**Activity 7:7**      **Program Family Time: Traditions**  
**Population:**    **Adults and Children**  
**Time:**            **30 minutes**  
**Construct:**      **Self-Awareness**  
**Materials:**      **Food, drink, paper products, paper and markers, Family Murals, *Nurturing Game*<sup>®</sup>**

**Goal:** To build positive parent/child relationships and to help families establish nurturing routines and memories.

**Objectives:**

1. To provide families with an opportunity to make a list of traditions that creates meaning in their lives.
2. To provide families with an opportunity to learn a new game and review the concepts learned in the program by playing the *Nurturing Game*<sup>®</sup>.

**Procedures:**

Facilitators will serve parents and children snacks and beverages and collect trash when they are finished.

1. **Program Family Time**
  - a. Ask families to sit together and create a list of current or potential family “traditions.”
  - b. Play the *Nurturing Game*<sup>®</sup> and encourage families to begin a new tradition.
2. **Home Family Activity:** Pick an activity from the list your family generated in **Program Family Time** and engage in it together. Remember to laugh and have fun!
3. End the Session with the **Good-bye Song**.

**Notes and Suggestions:**

1. When the program is done virtually, encourage families to enjoy a snack at home after each session.
2. Virtual adaptation. Use the Program Family Time to create a list of potential family traditions and encourage them to play a game or practice a tradition during Home Family Time this week.
3. You do not have to use the Good-bye Song that was suggested in session one. However, you should use the same song every session, so children begin to recognize the song as a transition to the session end.