

Session 7

Health and Healing



Meaning, Competency and Support

There are three main themes that come up in discussions with parents of children with health challenges and special needs. Those themes are: Meaning, Competency, and Support.

Most parents of children with health challenges or special needs say they are trying to make sense of their situation. Many ask the question, “Why me?” or “Why my child?”

Parents are also concerned with feeling capable. Parents of children with health challenges and special needs are often expected to go beyond the typical parenting role and participate in many aspects of care. (i.e., giving meds, participating in therapies, setting up appointments, creating educational plans, coordinating care etc.).

Parents need both formal and informal support people in place. Parenting a child with health challenges or special needs is a tough job. Asking for and receiving help will make a big difference in your quality of life, and in your child’s quality of life.

Recognizing that all families are unique, consider the three common themes, and how they relate to you.

Meaning

Making sense of your situation, recognizing some greater purpose, recognizing a higher power, using your faith, religion, or spirituality to provide comfort.

Competency

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

Support

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

Stages of Grief

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

Many parents explain grief, as a loss of "what might have been." This sense of loss may surface many times throughout the child's life. When typically developing peers, or siblings are experiencing societal or developmental milestones and your 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 you have for your child - and your acceptance of that child exactly as they are.

Eleanor Kubler Ross developed a framework for describing the stages of grief. The stages of grief are often **not linear** and people experience them in their own time and in their own way. Some people describe it more as a roller coaster than a progression of stages.

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.

Bargaining

Trying to "make a deal" may often 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 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.



Anticipatory Grief

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 a 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 have been 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.

Remember when we are navigating our journeys ...
We cannot direct the winds . . .
but WE CAN adjust the sails.



Home Practice Assignment: Adults Only

1. Consider the questions below and record your answers.

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 team (OT, PT, speech, medical 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 their 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?

2. Complete the **Family Log**

Home Family Time Assignment: Adults and Children

Pick an activity from the list your family generated in **Program Family Time** and engage in it together. Remember to laugh and have fun!

Session Seven COMPETENCIES: Adults and NP Facilitator

You and your group facilitator (parent educator) will review these competencies together. Please rate yourself according to your perception of your understanding of the key components of Session Seven.

Session Seven Competencies: Circle the one that best describes your current understanding. 1 is low, 3 is average, 5 is expert.

1. I understand and can relate my own personal experience to the themes of meaning, competency, and support.

1 3 5 (Parent)

1 3 5 (Facilitator)

2. I know the five stages of grief.

1 3 5 (Parent)

1 3 5 (Facilitator)

3. I can identify times in my life that I have experienced the difference stages of grief.

1 3 5 (Parent)

1 3 5 (Facilitator)

My examples are:

4. I recognize the stages of grief in my parenting partner.

1 3 5 (Parent)

1 3 5 (Facilitator)

My examples are:

5. I recognize the stages of grief in my children. My examples are:

1 3 5 (Parent)

1 3 5 (Facilitator)

NOTES: