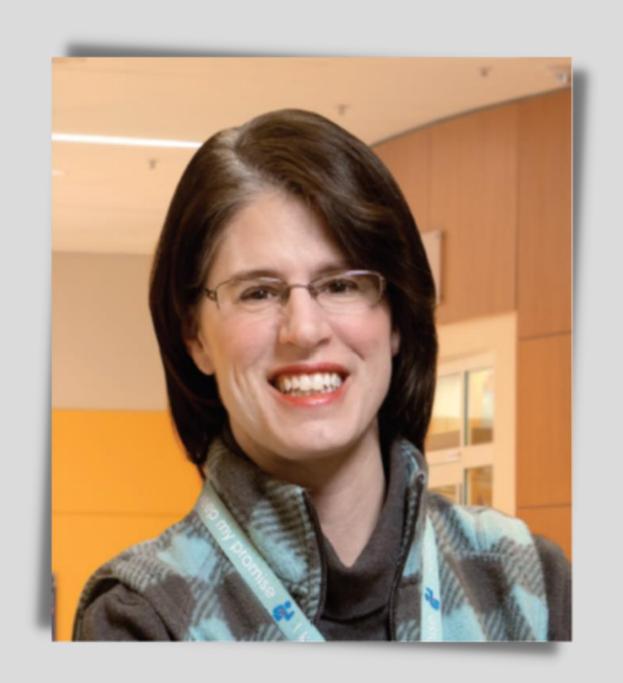
# Communicating in a Supportive Role





#### Facilitator





Lori Albers
CYSHCN Project Manager- Family Engagement

### Facilitator





De Anna Lynk
CYSHCN Project Manager- Parent to Parent Wisconsin



# Funding



#### Southeast Regional Center

Children and Youth with Special Health Care Needs



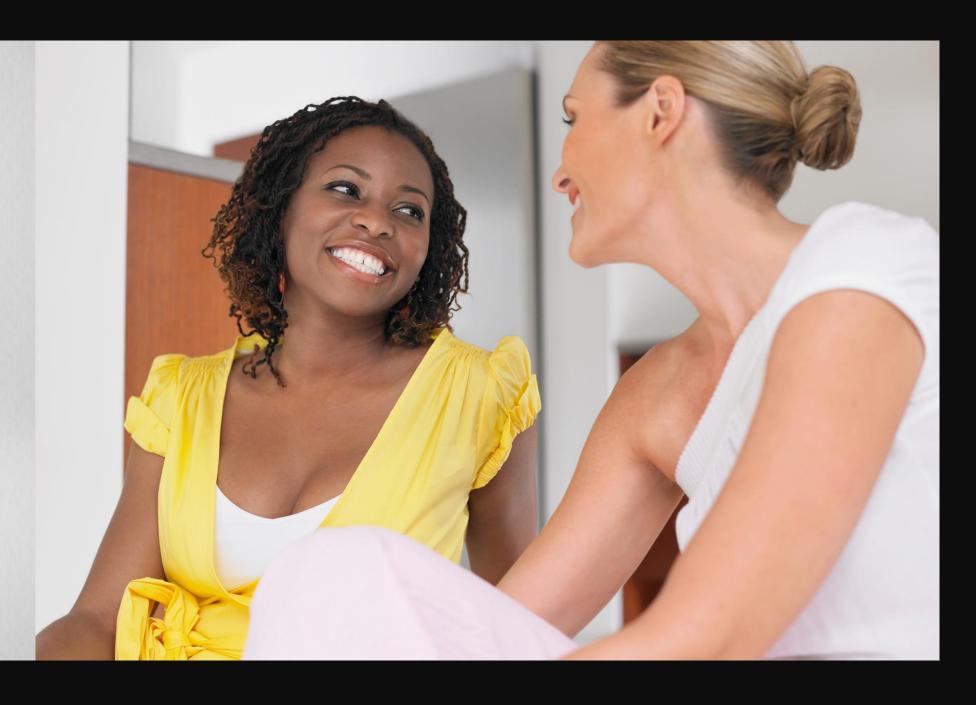


Kids deserve the best.

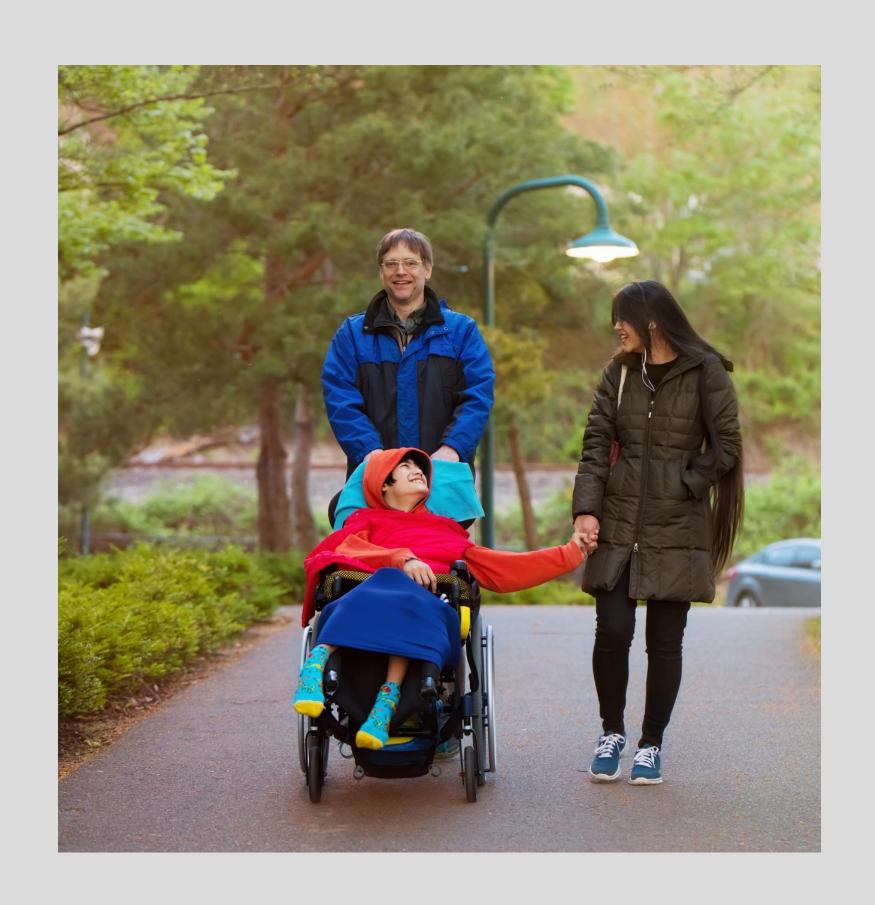
**Parent to Parent of Wisconsin** is funded by the Wisconsin **CYSHCN Program, Division of Public Health, Department of** Health Services through funds from the Maternal Child Health Title V Services Block **Grant, The Down Syndrome Association of Wisconsin and Children's Wisconsin** 

#### WHATIS PARENT TO PARENT?

is an intentional connection with a trained, volunteer support parent who has already learned the language and found the resources... someone who has "been there"

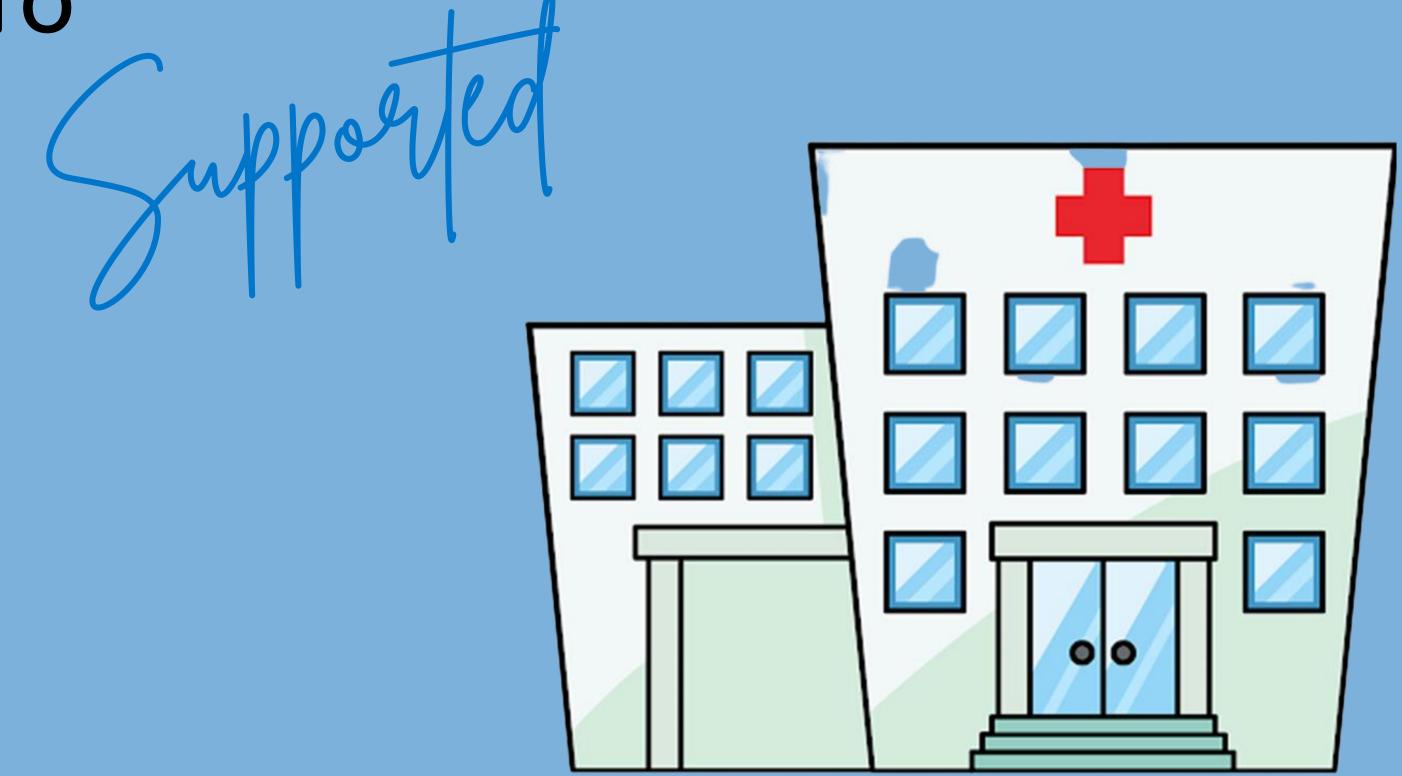


#### THE PARENT TO PARENT CONCEPT



Parents of children with special needs who have come to accept and understand their child's disability are one of the best sources of information and emotional support for other parents of children with special needs.

# FROM SCARED TO



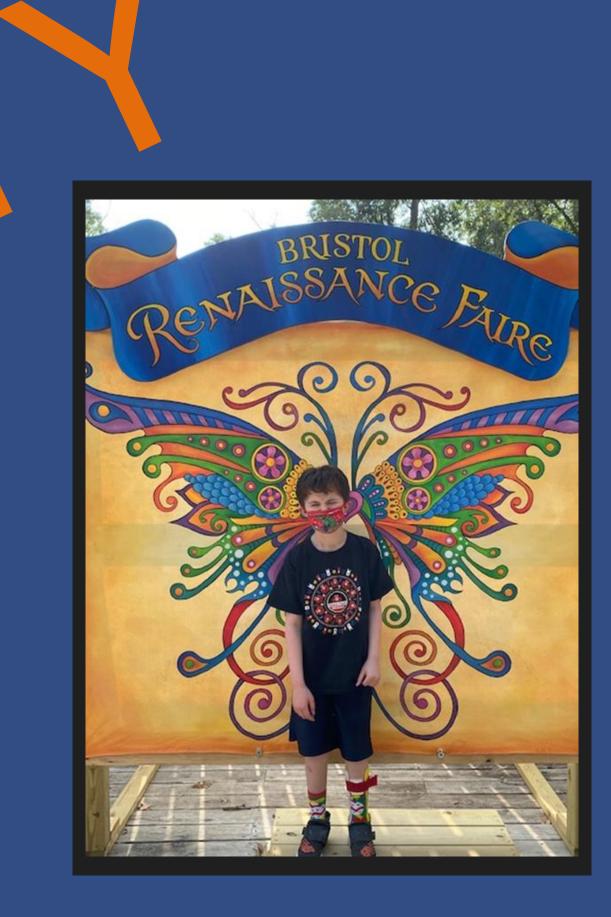


# MATTY











How many of you thought the story was challenging to listen to?

How many of you felt uncomfortable from hearing the story?

Could you identify a time in the story that you could have supported Lori in her journey?

What questions came to mind?

### CHRONIC STRESS

"Chronic stress is the response to emotional pressure suffered for a prolonged period of time in which an individual perceives they have little or no control."

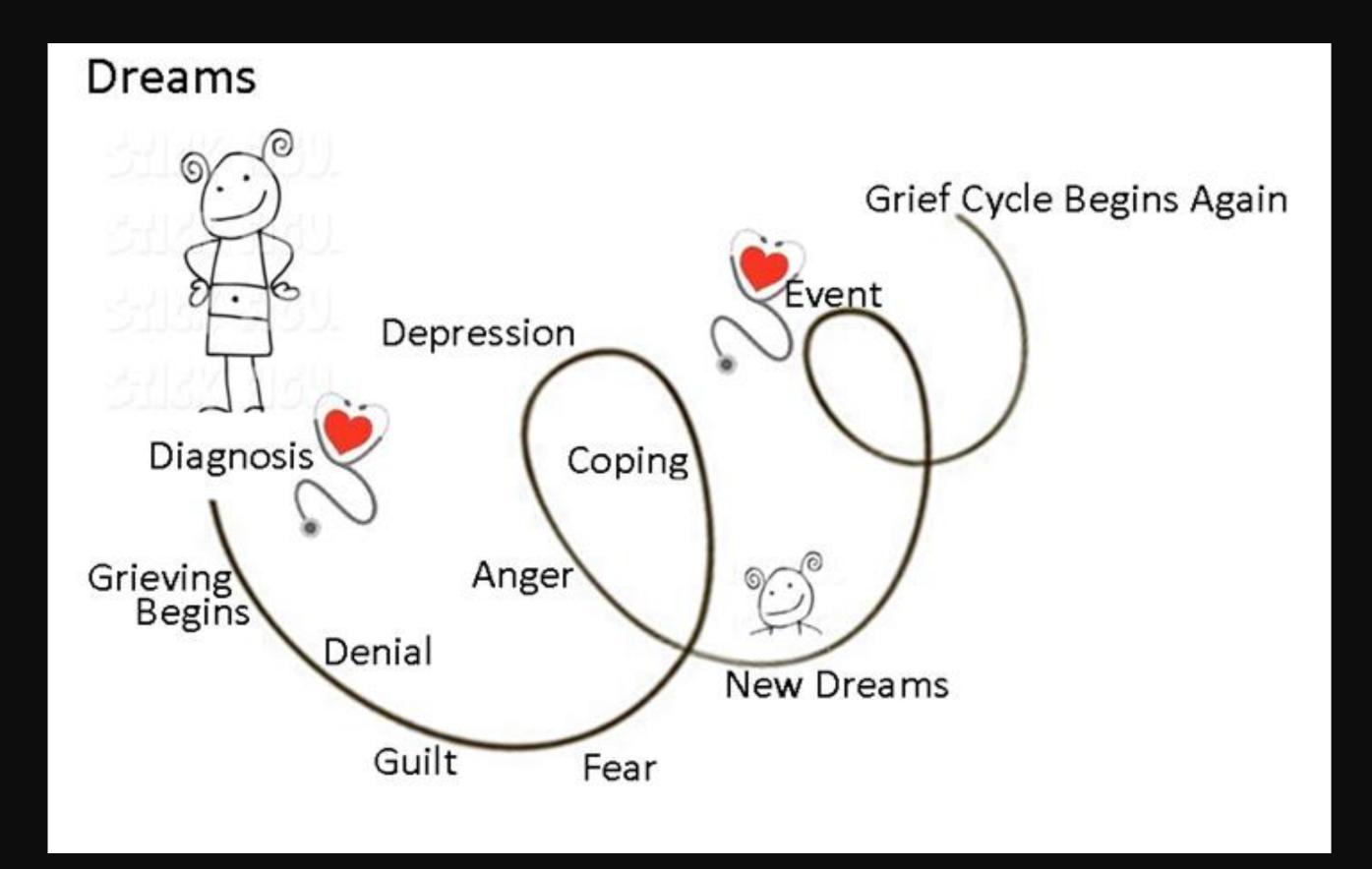
- Endocrine system response
- Can cause changes in the brain
- Effects memory function



#### CHRONIC SORROW

- recurring intense feelings of grief in the lives of parents or caregivers with children who have chronic health conditions
- A normal grief response that is associated with an ongoing living loss
- An emotional gap between "what is" versus the parents' view of "what should have been." www.chronicsorrow.org

# The Cyclical Nature of Grieving



### Grief and Grieving States

### Ken Moses –

Parent, Psychotherapist and psychological consultant



Adapted from: The Impact of Childhood Disability: The Parent's Struggle"

- Denial
- Anxiety
- Fears
- Guilt
- Depression
- Anger

### Grief How can we help someone who is grieving?



### Benefits of Peer Support

#### **Desired Benefits**

Peer Support



#### **Informational Support**

- Sharing experiences and information
- Modeling effective skills

#### **Emotional Support**

- Encouragement
- Reinforcement
- Decreased sense of isolation

#### **Mutual Support**

- Shared problem solving
- Both receiving and giving help

- · Increased confidence
- Increased perceived social support
- Increased understanding of self-care
- · Increased mood

Improved health-related quality of life

 Improved health behaviors (e.g., weight monitoring, diet, talking meds)

 Improved chronic disease control

 Decreased hospitalizations and mortality



### Healing at the Cellular Level

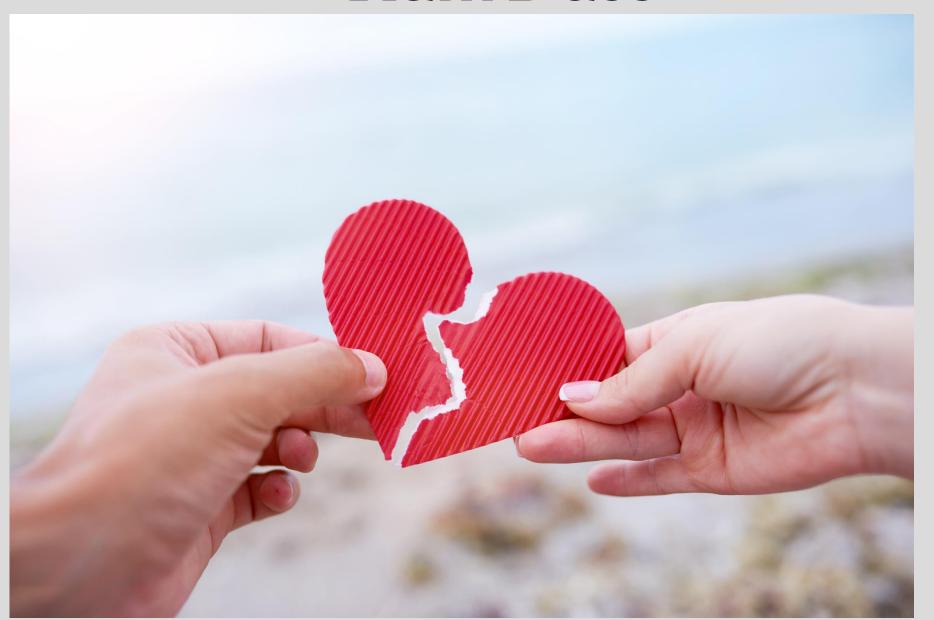
Research has shown that parents who receive and benefit from parent to parent/emotional support not only stop the rapid shortening of their telomeres, there is evidence that the telomeres actually become longer, reversing some of the effects of stress.

The Economist April, 2011 http://www.economist.com/node/18526881?story\_id=18526881

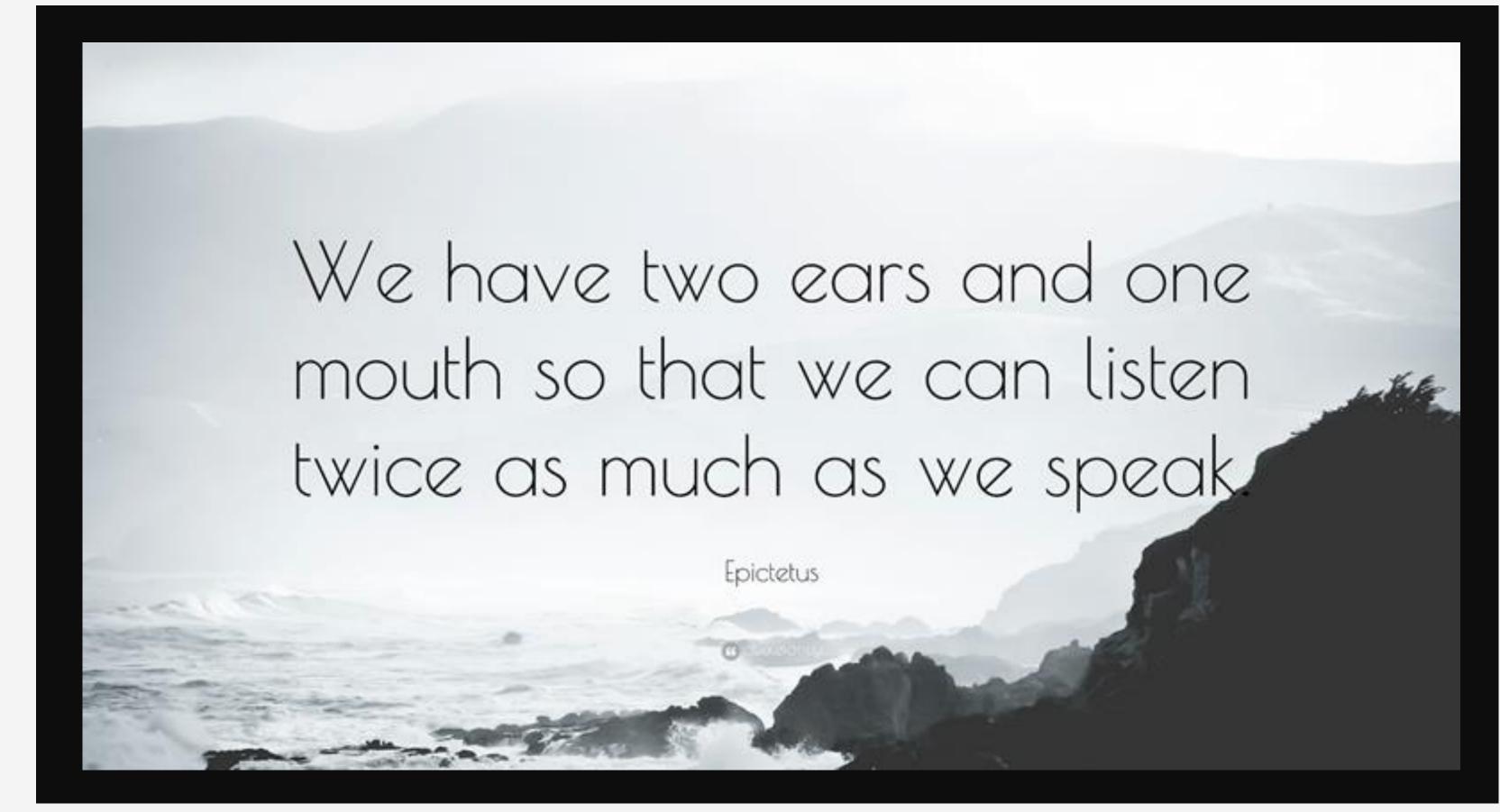
National Geographic: The Science of Stress; YouTube, https://www.youtube.com/watch?v=ZyBsy5SQxqU

## BEHERE NOW

"You begin to hear the secret, that being fully in the moment is the greatest gift you can give to each situation" -Ram Dass



# Listening



# Level of Listening



- To understand
- Application
- Judgment
- Telling my story
- Non-listening



"When a person feels that he is truly accepted by another, as he is, then he is freed to move from there and to begin to think about how he wants to change, how he wants to grow, how he can become different, how he might become more of what he is capable of being."

Thomas Gordon, Model of Active Listening

### Listening in a Supportive Role

- Listening may be the most helpful thing that you can do. When you really listen to someone you use more than just your ears...you use your heart as well.
  - It takes courage on the speaker's part and patience on the listener's part.
- When you listen, a person is able to feel and communicate genuine acceptance of another, and possess a capacity for being a powerful helping agent for another.
- How the person is feeling should be the focus of the conversation.

# Ways to Indicate Listening



# How to do it?

- Concentrate on what is being said
- Answer or acknowledge when asked
- Allow emotions including crying
- Take notes
- Ask for input on different topics

### Common Mistakes

Dismissing the Problem

Ignoring Feelings

Playing the Expert

Giving False Hope/Raising Expectations



### Remember to THINK before you speak

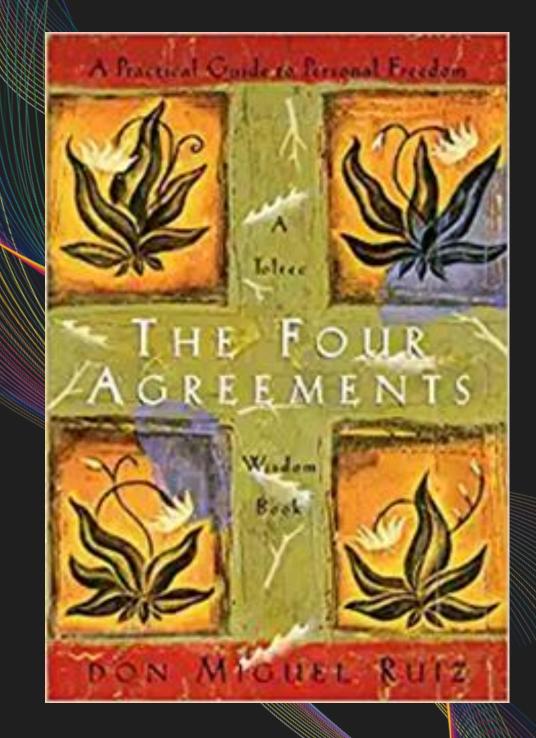
```
Is it TRUE?
Is it HELPFUL?
Is it INSPIRING?
Is it NECESSARY?
Is it KIND?
```

## Parent's Response

- Don't take response personally
- Be comfortable with boundaries
- Give them space to share
- You may not agree with their perspective
- Listen, suspend judgement

#### The Four Agreements are:

- Be Impeccable With Your Word.
- Don't Take Anything Personally.
  - Don't Make Assumptions.
    - Always Do Your Best.



Don Miguel Ruiz

#### Be Impeccable With Your Word

Speak with integrity. Say only what you mean. Avoid using the word to speak against yourself or to gossip about others. Use the power of your word in the direction of truth and love.

#### Don't Take Anything Personally

Nothing others do is because of you. What others do is a projection of their own reality, their own dream. When you are immune to the opinions and actions of others, you won't be the victim of needless suffering.

#### Don't Make Assumptions

Find the courage to ask questions and express what you really want. Communicate with others as clearly as you can to avoid misunderstandings, sadness and drama. With just one agreement, you can change your life.

#### Always Do Your Best

Your best is going to change from moment to moment. It will be different when you are healthy as opposed to sick. Under any circumstance, simply do your best, and you will avoid self-judgment, self-abuse and regret.



Children live happier, healthier, safer and more productive lives when their parents are strengthened, educated and supported.

# Connecting to Support

#### A parent match can be based upon:

- Diagnosis
- Upcoming surgery or treatment
- Upcoming transition or change



#### Process for receiving a one-to-one match:

- Submit the online form at p2p.org to receive a match.
- A Parent to Parent staff member will reach out to gather further information. This information allows for the best, personalized match.
- Once a match is made, you will receive a call from a support parent within a few days.

# Referring for Support

To make a Parent to Parent Referral:

Visit: <a href="https://www.p2pwi.org">www.p2pwi.org</a>
Get Connected tab





#### Lori Albers

CYSHCN Project Manager 414-266-3198 lalbers@chw.org

### De Anna Lynk

CYSHCN Project Manager 414-336-0636 dlynk@chw.org

https://p2pwi.org/

https://www.facebook.com/parent2parent.wi/