The CARE Project

Counseling, Aural Rehabilitation and Education

Developed by

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www.thecareproject.me
WHAT IS GRIEF?

Sorrow
Mourning
Distress
Deep emotional outpouring
HOW DO PROFESSIONALS HANDLE GRIEF WITH FAMILIES?

Information “dumping”
Avoidance
Dismiss it
Nervously talk

Tell them how to feel
Tell them what you would do
“It could be worse”
“Everything will be fine”
HOW DO PARENTS/FAMILIES HANDLE GRIEF?
PARENT/FAMILY PERSPECTIVE
Attachment (Bowlby, 1986)

• Bond is established before birth between parent and child
• Expectation that the baby will be
  – Perfect
  – Normal
  – Wonderful
  – Disability free
  – Disease free
BREAKING BAD NEWS

Kris English, Ph.D.
The process begins

- Parents learn their child isn’t “perfect”
- Professionals “dump” lots of information on the parents
- Parents are not usually allowed time to process emotional reactions
- Professionals feel uncomfortable/untrained and may not have the time to deal with emotions
Grief

PARENTS WANT EMOTIONAL SUPPORT
What Parents Want vs Receive

Information Wanted vs. Received by Parents at Hearing Loss Confirmation

- Degree of loss
- Auditory system
- Amplification
- Educational options
- Speech/Lang dev
- Etiology
- Home activities
- Written Information
- Financial Support
- Emotional Support
- Parent Contacts
- Referral Sources

Martin, George, O’Neal, & Daly (1987); *Sweetow & Barrager (1980)

Slide provided by David Luterman via Karen Anderson.
PARENTS AND PROFESSIONALS MUST BECOME PARTNERS
GRIEF
GRIEF COMES IN DIFFERENT FORMS
Grief

• A process
• A part of life
• Common to all people
• Comes and goes
• Affects people in different ways
• Impacts families AND professionals involved
Examples of Grief

- Critical illness diagnosis
- Loss of a pet
- Inability to have children
- Body image issues
- Divorce
- Failure at school/Failure at work
- Loss of job
- Hearing your child has a disability
Sexton, 2010; English, 2002; Kubler-Ross, 1970

STAGES OF GRIEF
Stunned to hear the news!

SHOCK
This can’t be happening to us
Not my child
It can’t be true
They must be mistaken

DENIAL
Realizing the truth
A state of anguish

PAIN
Anger

Mad
Blaming
Lashing out
It sinks in
It is true
You feel really, really bad

DEPRESSION
Embrace the truth
Begin to find peace within
Begin to find peace with others

ACCEPTANCE
Move beyond acceptance
Ensure the child has every opportunity
Strive to have a successful and happy life

ADVOCACY
Grief may return over the lifespan
May not go through all stages
No one “exits” the process, never to return

RECYCLE
Emotional Stages of Grief
Sexton, 2010

- Shock
- Denial
- Pain
- Anger
- Depression
- Acceptance
- Advocate
Focus on Active Listening and Shared Experiences

The CARE Project
“I have learned a great deal from listening carefully. Most people NEVER LISTEN.”

ERNEST HEMINGWAY
CARE focuses on Active Listening

• Don’t respond with information

• Be the “other adult”

• Acknowledge/validate what is said by parents/family

• Guide towards discussion

• Don’t lecture

• Don’t tell what you would do if it were you

• Be active in listening

• Don’t create co-dependencies
CARE...shared experiences

- Each person has a story to tell/share
  - Individually/one on one
  - Organize groups/pair up strangers
- Ask them to share the story with each other
- Report back to the group
- Use those key points to facilitate group discussion
- Creates a sense of community/connectedness/comfort in others
CARE Documentary Film: Different Perspectives

- Culturally Deaf Adult
- 7 year old identified through NHS
  - his parents
  - his grandmother
- Hard of Hearing Adult with Hearing Aids
- Deaf Adult with Cochlear Implant
- Hearing Daughter of deaf adult
- Hearing Son of deaf parents
- Teacher/counselor
- Mother of deaf/blind child
CARE is a Beacon of Hope for Families and Professionals

Sheds light on emotional issues of hearing loss and its impact on families, caregivers and professionals

The CARE Project Status

• Phase One completed and launched
  – March, 2010

• Initiate pilot project (schools, universities, hospital/clinics, EI programs, etc.)
  – Winter, 2010

• Establish Living Journal
  – Winter, 2010

• Documentary film premiere events
  – East Coast (Fall, 2011)
  – West Coast: San Francisco (Spring, 2011)
To date, over 100 people have contributed to The CARE Project process and the work continues in the United States. In 2011, CARE will be established in other countries.

IT TAKES A VILLAGE
Thank You!

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