

The *CARE* Project

Counseling, Aural Rehabilitation and Education

Developed by
Johnnie Sexton, Au.D./CCC-A
Executive Director, The CARE Project, Inc.

CARE is a Beacon of Hope for Families

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



Artwork: "Baldydelic" by Xris Kessler, acrylic on canvas, 2009.

The CARE Project, Inc.

- The CARE Project
 - Nonprofit agency
 - Devoted to helping families reach acceptance of hearing challenges
 - Teach families to advocate for the best life possible
 - Raise awareness of professionals on the importance of processing emotions associated with disability
 - Teach professionals to be better active listeners with families



What is it?

- Package
 - Workshop materials (teach/facilitate)
 - One- to two-day workshops
 - One hour classes/meetings over a number of weeks
 - Reading materials/activities
 - Books, coloring activities

CARE Project Components

- Workshop format
 - Slides
 - Documentary film
 - Grief analysis grid

CARE Project Components

- Literacy Pack
 - Original story book: “So You Want To Put A Bug in My Ear” written by Dail Daly Ballard, Speech Language Pathologist and illustrated by Xris Kessler
 - Family/classroom study guides



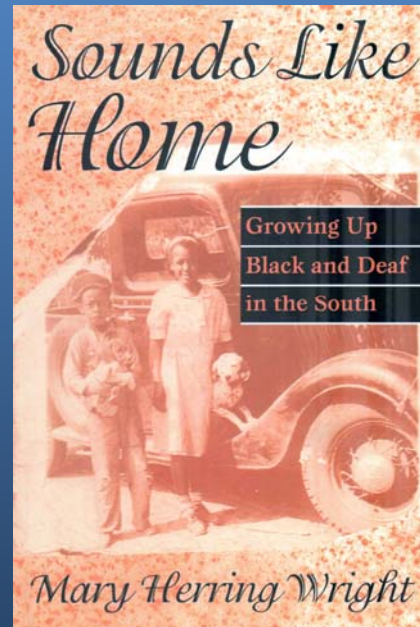
CARE Project Components

- Literacy Pack
 - Original coloring book for children
 - Drawn by a 7 year old: Bugs from a child's perspective



CARE Project Components

- Literacy Pack
 - 2 volume biography of Mary Herring Wright
 - Sounds Like Home
 - Far From Home



Who is this for?

- Parents/families
- Audiologists, speech language pathologists, teachers, counselors...all professionals who work with these families
- Students in pre-professional training programs who will work with families

CARE Staff

- Johnnie Sexton, AuD, Executive Director
- Xris Kessler, Media Director
- Cathy Meriam, Public Relations/Marketing
- Stewart Pittman, Operations Manager
- Program Services Coordinator (TBD)

Contact Information

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- 910-233-0994

Contributors

- Ken Frazier, M.Ed., NBCC Licensed Counselor
- Xris Kessler, Artist/Illustrator
- David Yoder, Ph.D., Director Emeritus and Senior Associate, Center for Literacy and Disability Studies, University of North Carolina School of Medicine
- Kris English, Ph.D., Audiologist
- Dail Ballard, M.S. Author/SLP
- Ethan Carpenter, Artist/Illustrator
- Video Interviews: Linda, Kyle, Jackie, Pam, Daisy, Joey, Aaron and the Hosley Family (Tanner, Mark, Robin, Wylene)
- Film Crew: Derek Tindall, Cathy Meriam

CARE Development Grant

- Awarded by East Carolina University to develop a counseling workshop model for children, their families and professionals
- CARE is a nonprofit organization

Supportive Agencies/Organizations

- Early Intervention
- Beginnings for Family Support
- Public Schools
- Parent groups
- Professional associations
 - Audiology
 - Speech pathology
 - Counseling
 - Others?

Created, developed and implemented by

JOHNIE SEXTON, AU.D.

Johnnie Sexton

- Aware of deafness since birth
- 33 years experience with individuals who are deaf and/or hard of hearing
- Experienced educational audiologist
- Non-dispensing audiology consulting practice: JESA, Inc.
- 17 on staff serving 35 school districts in NC



Johnnie Sexton

- Take on special projects...
 - Designed EI Audiology system for North Carolina
 - Consultant with assistive technologies manufacturers
 - Lectures and consultation worldwide
 - Consultant with:
 - Division of Vocational Rehabilitation
 - Division of Services for the Deaf and the Hard of Hearing



Johnnie Sexton

- Consumer protection...
 - Served over 20 years on state licensure boards for audiology and hearing aid dispensing
 - Concerned with making sure that all citizens are receiving the best of care
 - Prevent bad practice
 - Implement quality assurance measures and programs





**THE CARE PROJECT
DOCUMENTARY SHORT**



GRIEF

Grief

- A process
- A part of life
- Comes and goes
- Not just associated with loss and/or death
- Affects people in different ways
- Impacts families AND professionals involved

You give examples!

GRIEF COMES IN DIFFERENT FORMS

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



**PARENT/FAMILY
PERSPECTIVE**

Attachment

- 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

The process begins

- Parents learn their child isn't "perfect"
- Professionals "dump" lots of information on the parents
- Parents are not usually allowed time for the process to occur
- Professionals feel uncomfortable/untrained

Stages of Grief

- Shock: stunned to hear the news
- Denial: this can't be happening to us, not my child, it can't be true, they must be mistaken
- Pain: realizing the truth in a state of anguish
- Anger: mad, blaming, lashing out

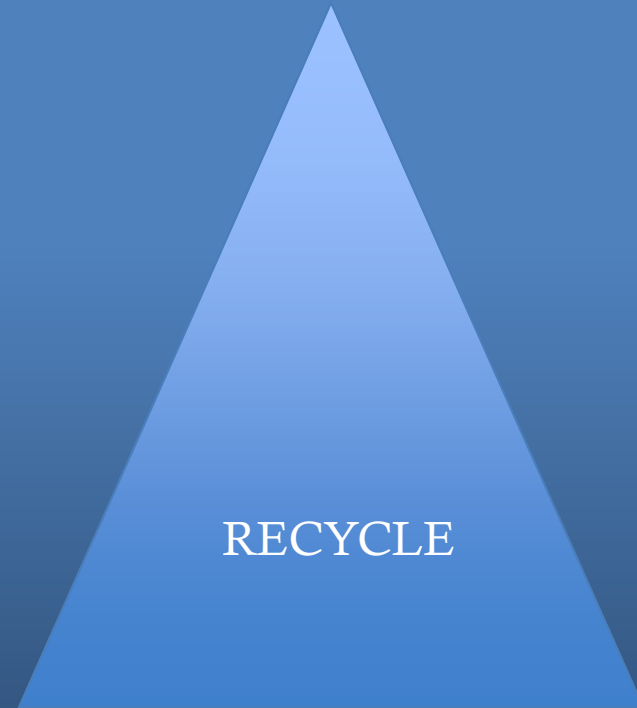
Stages of Grief

- Depression: it sinks in, it is true and you feel really, really bad
- Acceptance: come to accept what is and to know that this is real, embrace the situation
- Advocate: move beyond acceptance to ensure the child has every opportunity to be successful and happy

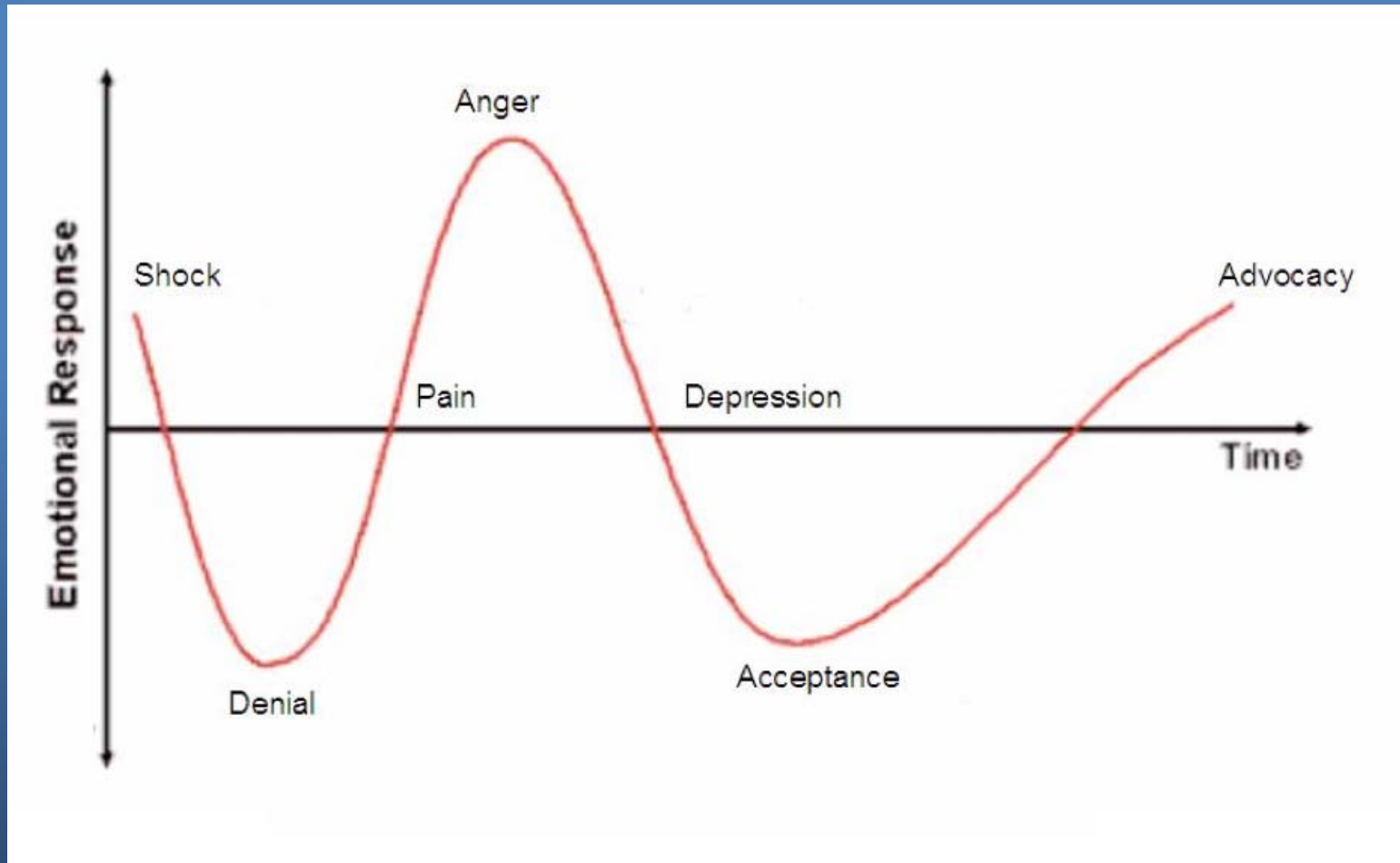
Emotional Stages of Grief

Sexton, 2010

- Shock
- Denial
- Pain
- Anger
- Depression
- Acceptance
- Advocate

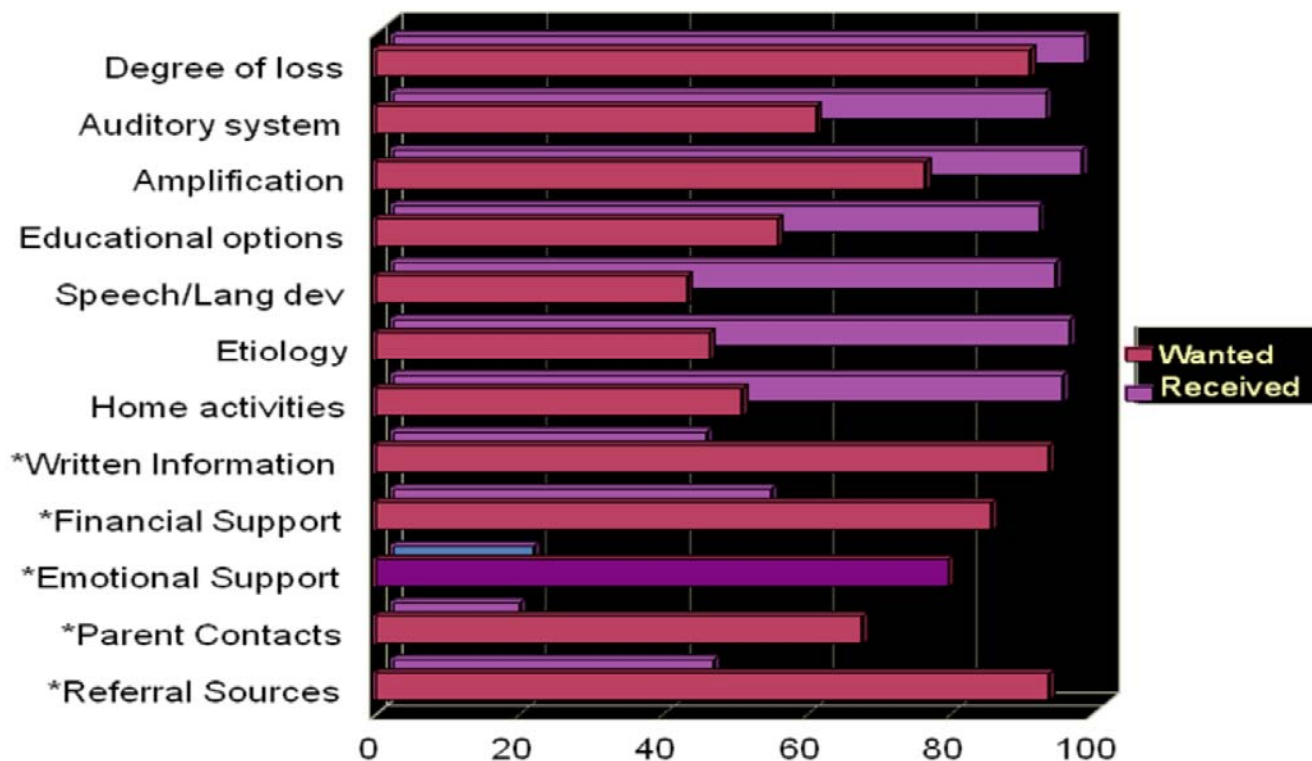


Grief



What Parents Want vs Receive

Information Wanted vs. Received by Parents at Hearing Loss Confirmation



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

Counseling

- Problem solving
- Nonprofessional
- Informational
- Effective listening
- Emotional stages
- Outcomes

Problem Solving

- Allow brainstorming
- Come up with a list of possibilities
- Have discussion on each
- Make choices
- Develop strategies

Nonprofessional

- Not a substitute for professional counseling
- As long as it is within the professional practice area (hearing loss) of the facilitator, it is acceptable
- Get people to open up and talk
- Get issues and problems on the table
- Create a sense of community
- Develop strategies to cope

Informational

- Understand basic information about child's hearing loss
- Understand basic information about hearing technology
- Establish network of professionals who can provide support

Effective Listening

- Don't respond with information
- Acknowledge/validate whatever is said
- Guide towards discussion
- Don't lecture
- Don't tell what you would do if it were you
- Be active in listening
- Don't create codependencies

Opening Up the Group

- Each person tells his/her story to the group
- Pair up participants who do not know each other
- Ask them to share the story with each other
- Report back to the group
- Chart key points that surface
- Use those key points to facilitate group discussion

Hearing Loss Information

- Do you know your child's hearing loss?
- Do you understand your child's technology?
- Do you have good resources for support?
- Can you talk about your child and needs with others (i.e., teachers, neighbors, etc.)?

Take the Lid Off the Box!



Write a Letter

- During the day, each participant is asked to write a letter
- Read each letter aloud for the group at the end of the day
- Describe feelings and list needs

Workshop Activities

- Introductions
- Series of video interviews
- Grief Analysis Grid
- Discussion after each segment

The CARE Project: 7 Stages of Grief
Analysis Grid Worksheet

Name:

Date:

I. Documentary Segments Checklist

	Shock	Denial	Pain	Anger	Depression	Acceptance	Advocate
Pam							
Kyle							
Daisy							
Aaron							
Jackie							
Linda							
Joey							
Tanner							
Mark							
Robin							
Wylene							

The CARE Project: 7 Stages of Grief
Analysis Grid Worksheet

Name:

Date:

II. Documentary Segments Comments

	Comments/observations
Pam	
Kyle	
Daisy	
Aaron	
Jackie	
Linda	
Joey	
Tanner	
Mark	
Robin	
Wylene	

Group Activity Guidelines

- PLEASE participate
- Be mindful of the time for others to speak
- Be considerate of individual's experiences, emotions and point of view
- PLEASE turn off all cell phones
- Breaks will occur periodically... but if you have to go, you have to go!

No Bias

- The *CARE* Project does not prescribe to any one philosophy or mindset
- All perspectives on deafness, hard of hearing, technology and methodologies are acceptable
- *CARE* is meant to raise awareness and facilitate the processing of emotions
- *CARE* is NOT a substitute for long-term counseling

Wrap up

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