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

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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- www.thecareproject.me
- 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
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
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

![Diagram of the emotional response to grief over time, showing stages such as shock, denial, anger, pain, depression, acceptance, and advocacy.](image-url)
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)
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:  

1. Documentary Segments Checklist

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All Rights Reserved
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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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