

The GRIEF EXPERIENCE and EMOTIONAL BACKLASH OF HEARING LOSS

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BASIC HUMAN NEEDS

- A sense of community, culture and belonging
- An effective way to communicate thoughts and feelings and interact
- A positive sense of self and esteem and power
- Personal validation and respect from others
- A sense of purpose, meaning and contribution
- An ability to feel independent and able to effectively care for oneself
- A sense of safety and security
- A sense of connectedness to a Higher Power and frame of reference

- When one experiences Sensorineural hearing loss (especially sudden, unexpected or the result of injury) it can be a

profound and acute grief experience

at times utterly overwhelming and terrifying – for both the Person with Hearing Loss (PHL) and the Communication Partners (CPs)

- It is a *major CRISIS* in one's life – "The Crisis of Hearing Loss"
- Crisis is when questions arise that can't be answered.
- And those BASIC HUMAN NEEDS become threatened.

SOME GENERAL THOUGHTS/BELIEFS ABOUT GRIEF AND GRIEVING:

- It is a natural and normal and healthy reaction to loss (of any kind)
- It affects the whole person - physically, cognitively, psychologically
- One must go through and allow the process of grief in order to heal and ultimately experience emotional growth and peace. It is actually evidence of strength.
- "You must not walk around the perimeter of loss. Instead, you must go through the center, the grief's very core, in order to continue your life in a meaningful way" (M. Harvey)
- The process of grief involves significant changes in one's life and the lives of those around them – adding more layers to the grief.

GENERAL THOUGHTS (continued)

- Many kinds of losses – throughout our lives. Job loss, death, loss of health, loss of relationships, loss of pets, loss of security, and the list goes on – All are valid
- Focus today is mostly on the "griefs" related to the loss of hearing
- Kubler-Ross's Five Stages: Denial, anger, bargaining, depression, acceptance -all have relevance to hearing loss
- David Kessler adds a "Sixth Stage" of grief: Finding Meaning
- People going through grief and loss experience painful emotions which vacillate and are triggered by various life events....shock, anger, resentment, fear, guilt, sadness, hopelessness, depression, anxiety, panic.....sound familiar?
- ALL of these feelings are normal.

Many factors influence one's experience and process of grief:

- Our personalities
- Our upbringing and family messages
- Our relationships and support people
- Our level of understanding about what is happening
- The circumstances around the loss
- The level of one's resources
- One's health and age
- One's inner strength and capacity for resilience
- One's culture or faith
- ...to name a few

Some Unhelpful Beliefs or Comments- that exacerbate the Grief Experience:

These tend to slow down or interfere with the PHL's process or journey through grief to acceptance and may involve **unfair stigmas** and ignorance.

- If I just ignore or deny it, it won't be so bad
- If I admit it others will think less of me or will avoid me
- I am a burden to others and make things more difficult
- It shouldn't be such a big deal – "It's not as bad as _____"
- I need to just deal with it and not feel upset

- "You've lost most of your hearing anyway- why is it a big deal that you have lost a little more?" or "Why are you worried about protecting your hearing now? What difference does it make?"
- Being accused of "selective hearing" – "You just heard me sneeze, why can't you hear me talking?"
- "My life is over – I can no longer participate like I used to - I have nothing to offer now."

****What is TRUE is that life won't ever be exactly the same for you (or your family members) as it has been. Changes are inevitable and necessary.****

People may label their experience with hearing loss in different ways but the description of it being a "TRAUMA" is fitting in many cases.

This is not necessarily "demeaning" or "pathologizing" but is actually a

VALIDATION

of the depth and complexity of this experience.

In general, people without hearing loss, (and even some of us with hearing loss), aren't aware of or able to articulate all the nuances and layers of the hearing loss experience that contributes to the grief and frustration one may feel at different times.

Monique Hammond aptly outlined a number of steps that people with hearing loss often have to go through:

Pick up the sound, interpret relevance, filter out ambient noise, fill-in-the-blanks based on context, observe and process subtle changes in the non-verbal communication, understand actual message, decide how or what to say, then respond...but the conversation has moved on.

Monique Hammond clarified the fact that:

PHL tend need more time to process sound and thus become more hypervigilant in order to consciously focus on each of the following steps:

1. pick up the sound – This may mean they are *straining* to hear
2. interpret the sound – determine if it is relevant, important or whether it is benign conversation or small talk
3. filter out background, ambient noises which may seem louder (tinnitus) than the message
4. Begin to "fill in the blanks" of missing information or sounds by guessing based on context, recent subject or the person to whom they are talking
5. Observe and process subtle changes in the non-verbal communication, tone, and dynamics of the situation
6. Try and understand the actual message or information
7. Make a decision about how or what to respond – by this time there may be significant emotional triggers and feelings
8. *Then* respond – but by this point significant time may have lapsed, the subject may have changed, the conversation has moved on and one has missed the opportunity to fully participate!

GRIEFS AND LOSSES related to Hearing Loss- a partial list

- 1. SOCIETAL REACTIONS
- 2. EMOTIONS/SELF-ESTEEM/IDENTITY
- 3. COMMUNICATION AND RELATIONSHIPS
- 4. PHYSICAL and COGNITIVE
- 5. VOCATIONAL
- 6. LEISURE/COMMUNITY

SOCIETAL REACTIONS

- Often *minimization or discounting* of its impact as it is compared to other losses – more unique to HL than other losses –loss is loss; it's not a contest.
- Not only thought as "not a big deal" but it is *made fun of*. Humor is fine *IF* coming from the PHL. (Greeting cards)
- *Invisible nature* of this loss – what one can't see can't be that bad and is easy to ignore
- *Expectations* that since you look the same you should be able to act or perform the same
- Leads to *feeling marginal or peripheral, irrelevant, useless and invalidated*

EMOTIONS, SELF-ESTEEM AND IDENTITY

- *Grieving one's "old self*, former identity, status; having to *redefine oneself* - "hijacking" of former self
- *Personality changes* – may find self more withdrawn
- *Being viewed as inferior* or that one's hearing loss is a reflection on their entire being
- *Loss of confidence* – more self-doubt; Unwillingness to try new things and avoidance of unpredictable new situations
- *Loss of assertiveness* – feel like a burden and feel guilty that one is making things more difficult or complicated
- *Decreased independence*- having to ask for more assistance

EMOTIONS, SELF-ESTEEM AND IDENTITY - continued

- *Loss of a sense of security and safety* – not wanting to be alone at night; loss of feeling 'carefree'.
- *Knowing you are missing something* and misunderstanding– leads to emotional distress, embarrassment, anxiety and diminished confidence.
- *Friends and family concerned or sad* and find it difficult to see PHL suffer or miss out
- Being faced with *inequities or "unfairness of life"*
- Loss of control or *feeling powerless or helpless*; Not wanting to "let go" and lose the ability to decide how YOU want to live your life;
- May feel *one step closer* or further along in the aging or dying process.

COMMUNICATION AND RELATIONSHIPS

- *Loss of spontaneity*, playfulness, intimacy, pillow talk
- *Loss of the 'off the wall', side comments*, small talk, jokes or light-hearted banter
- *Loss of same level of interaction/initiation* of conversation – don't introduce new topics
- *Loss of a richness of content* - feeling that communication is "dumbed down", abbreviated, censored
- *Loss of information* - being left out and the *dreaded*: "oh nothing – never mind – it wasn't important".
- Loss related to the *disruption and change of established life patterns and routine* – things do take more work
- Loss of *not hearing one's children or grandchildren* or being able to communicate more readily in person.

PHYSICAL and COGNITIVE

- Loss of energy or stamina - **FATIGUE!**
- *Extreme concentration* all the time – high stress and can cause eye strain- headaches
- Sometimes *difficulty concentrating and inattentiveness* or 'tuning in' due to TMI.
- Processing *slower and difficulty following* conversations
- *Unable to get a good night's sleep* especially with tinnitus
- Being *unable to trust one's body* if have additional issues such as imbalance, vertigo or nausea.
- *Hyperacusis and Tinnitus* – loss of silence - interferes with language processing and attentiveness

VOCATIONAL

- *Career 'crisis'* - Unable to do one's job at the same level (ex: musicians, sales, teaching, management, serving, phone work)
- Feeling of *incompetence* – loss of status
- Need for *retraining or job changes* one doesn't want or choose
- *Lack of awareness* of job-related information - uninformed
- *Lack of camaraderie*-feeling "marginal"
- *Financial losses* and changes

LEISURE AND COMMUNITY

- World feels like it has shrunk
- **Isolation and lack of community** - loss of friends or former social connections
- **Loss of involvement** in worship or volunteer experiences
- Change or **discontinuing of leisure activities** – travel may become more difficult, theatre or concerts not experienced in the same way - if at all
- **Family involvement may change** – Holidays a lot more challenging and may lose some of their joy or pleasure
- **Environmental stress** - EVERYTHING being too loud, too much commotion, visual overload

SPECIFIC CONSIDERATIONS FOR NOISE-INDUCED HEARING LOSS:

Grief may have added dimensions or factors due to possibly being related to trauma or injury:

- Feeling **guilt or regret** or stupidity about not protecting one's hearing or of putting oneself in situations that were potentially damaging
- Feeling **anger or resentment** with one's place of work or other environment for not having appropriate regulations in place or enforced – it may not be the "victims" fault.
- Frustration with the **lack of awareness, education or sensitivity** about the hearing loss – one may still be at risk even if not directly working with noisy equipment.

- Getting caught in the **'negative feedback loop'** of "shoulda, coulda, woulda" and wasting emotional energy.
- With service-related hearing loss events there is also the presence of **PTSD** and the numerous psychological issues
- Frequent co-occurrence of **TINNITUS** or **HYPERACUSIS** and the frequent pain one endures – all of this *invisible!*
- Loss of the **"sounds of silence"**

SO...WHAT NOW? HOW DOES ONE COPE AND MOVE FORWARD?

- **Be willing to talk openly** about one's feelings – the sadness, frustration, fatigue, disappointments
- Be willing to **accept that some days will be bad** and hard
- Acknowledge that limitations don't mean defectiveness, inferiority or stupidity – *grieve not being perfect*
- **Cry – if that feels right** – for what has been lost and what has changed. Let yourself feel whatever it is you feel without judgment.
- **Ask (assertively)** for what you need - no one appreciates a martyr; no one is a mind-reader
- **Educate yourself AND others** – this is a responsibility of anyone with hearing loss whether we like it or not
- **Practice MINDFULNESS** and focus on the present moment

- **Practice good self-care** – find balance and relaxation.

S.T.R.O.N.G

S- SLEEP ENOUGH

T- TAKE MEDICATIONS / TREAT ILLNESS

R- REFUSE/REDUCE CHEMICALS

D- ONCE A DAY-DO SOMETHING YOU ARE GOOD AT or FIND PLEASURABLE

N- NUTRITION

G- GET EXERCISE/GET MOVING

- **Reassess your expectations** – both of self AND others – be realistic- this is a continual process
- **Recognize you are the same person** with the same gifts that need to find new ways to be expressed. Figure out what you CAN do and let go of what you can't – let go of what was.
- **Practice "Radical Acceptance":**
 - Let go of fighting reality- shift attitude to: "It is what it is".
 - Freedom of suffering requires ACCEPTANCE from deep within of what is true and acknowledging it.
 - To ACCEPT something is NOT the same as judging it as good.
 - Acceptance is an act of CHOICE – keep turning your mind toward acceptance – over and over.
 - Acceptance is a verb not a noun; a journey not a destination and is rarely 100%
 - Remember the words of the SERENITY PRAYER

- **Finding meaning: The Sixth Stage** (David Kessler)
 - Only you can **find your own meaning** – it is relative and personal - Cherish what is really important to you
 - **Takes time** – can be months or years
 - It is **not the same as understanding why** this happened or judging it as good
 - Finding meaning **doesn't negate the loss** or the changes in one's life.
 - It is tied to having or **regaining hope** – hope is really a temporary loss even if the hearing loss is permanent

Crises have a way of not only crushing but also strengthening the human spirit. Chinese word for "Crisis" is composed of two characters: **Danger and Opportunity.** (MH)

CLOSING THOUGHTS....

- Despite these realities and despite developing new attitudes, **emotional pain and grief can and probably will still resurface** at various times in our life.
- **Avoid berating oneself** for not having positive thoughts or attitudes, or feeling frustrated and sad or overwhelmed at times.
- This leads to "shoulding on" ourselves and feeling guilty or inadequate, as if we are not trying hard enough.
- Know that we can **simultaneously "embrace and lament"** the hearing loss and find our own wisdom in accepting that paradox.
- Hearing loss is **"life-altering"** – it doesn't have to be "life shattering".
- **Gracefully accept yourself** and your own process and meanings.

And from author Vicki Harrison:

"Grief is like the ocean; it comes in waves, ebbing and flowing. Sometimes the water is calm and sometimes it is overwhelming. All we can do is learn to swim." (and I would add: "and ride the waves".)

THANK YOU!!

COMMENTS, QUESTIONS??

RESOURCES

- Listen With the Heart: Relationships and Hearing Loss by Michael A. Harvey, Ph.D.
- Odyssey of Hearing Loss by Michael A. Harvey
- Shouting Won't Help by Katherine Bouton
- Living with Hearing Loss: Workbook by Sam Trychin, Ph.D
- Change Your Mind About Tinnitus by Dr. Paul Arezzo
- A Grace Disguised by Jerry Sittser
- Lessons of Loss: A Guide to Coping by Robert A Neimeyer
- Finding Meaning: The Sixth Stage of Grief by David Kessler
- And numerous Hearing Health and Hearing Loss magazine articles, lecture notes and conversations.
