

# Involving Families & Communication Partners in Rehabilitation

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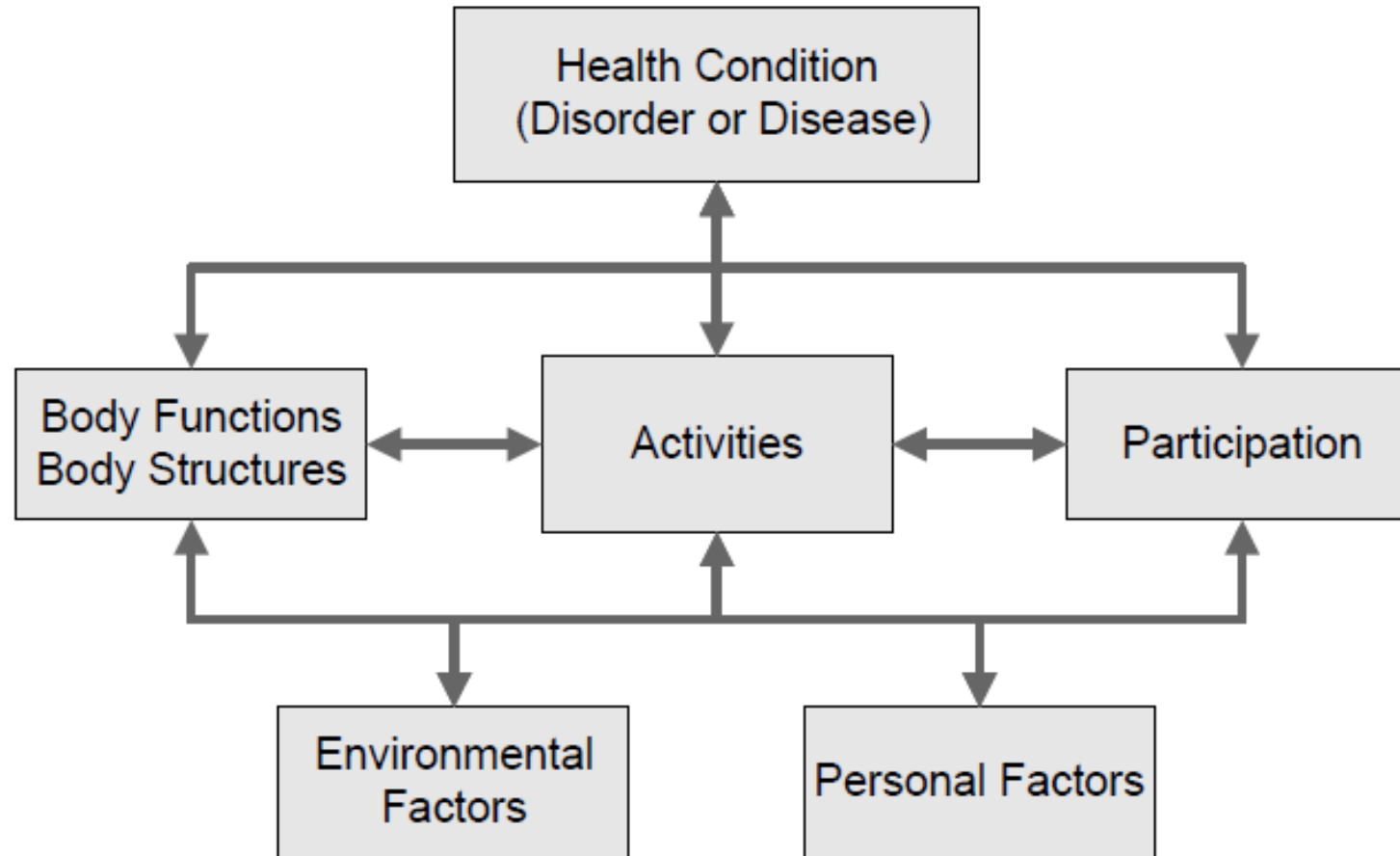


# Hearing Loss and Communication Loss

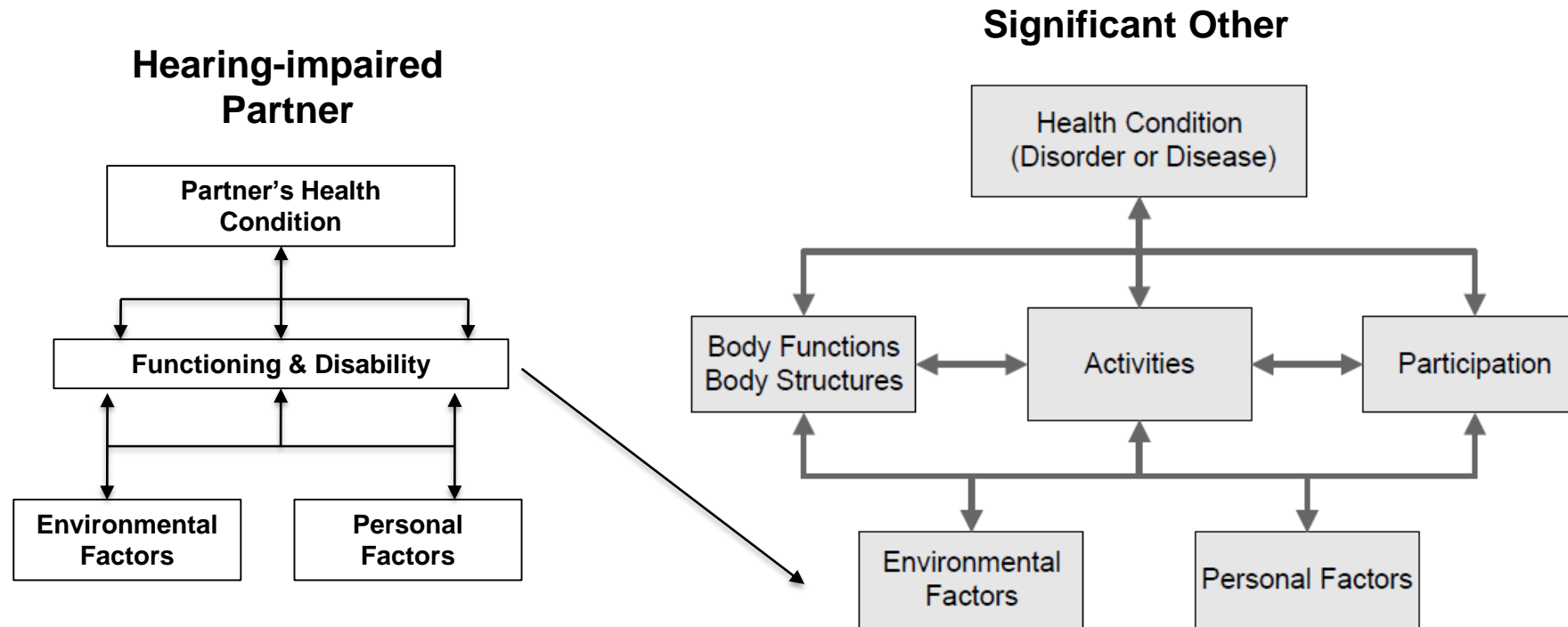
"Forgive me when you see me draw back when I would have gladly mingled with you. My misfortune is doubly painful to me because I am bound to be misunderstood; for me there can be no relaxation with my fellow men, no refined conversations, no mutual exchange of ideas. I must live almost alone, like one who has been banished; I can mix with society only as much as true necessity demands. If I approach near to people a hot terror seizes upon me, and I fear being exposed to the danger that my condition might be noticed."

(Ludwig van Beethoven)

# WHO International Classification of Functioning: To live with Chronic Illness or Handicap



# Third Party Disability (Hickson and Scarinci, 2007)



Hickson and Scarinci, 2007

# Communication Partners

## Significant others

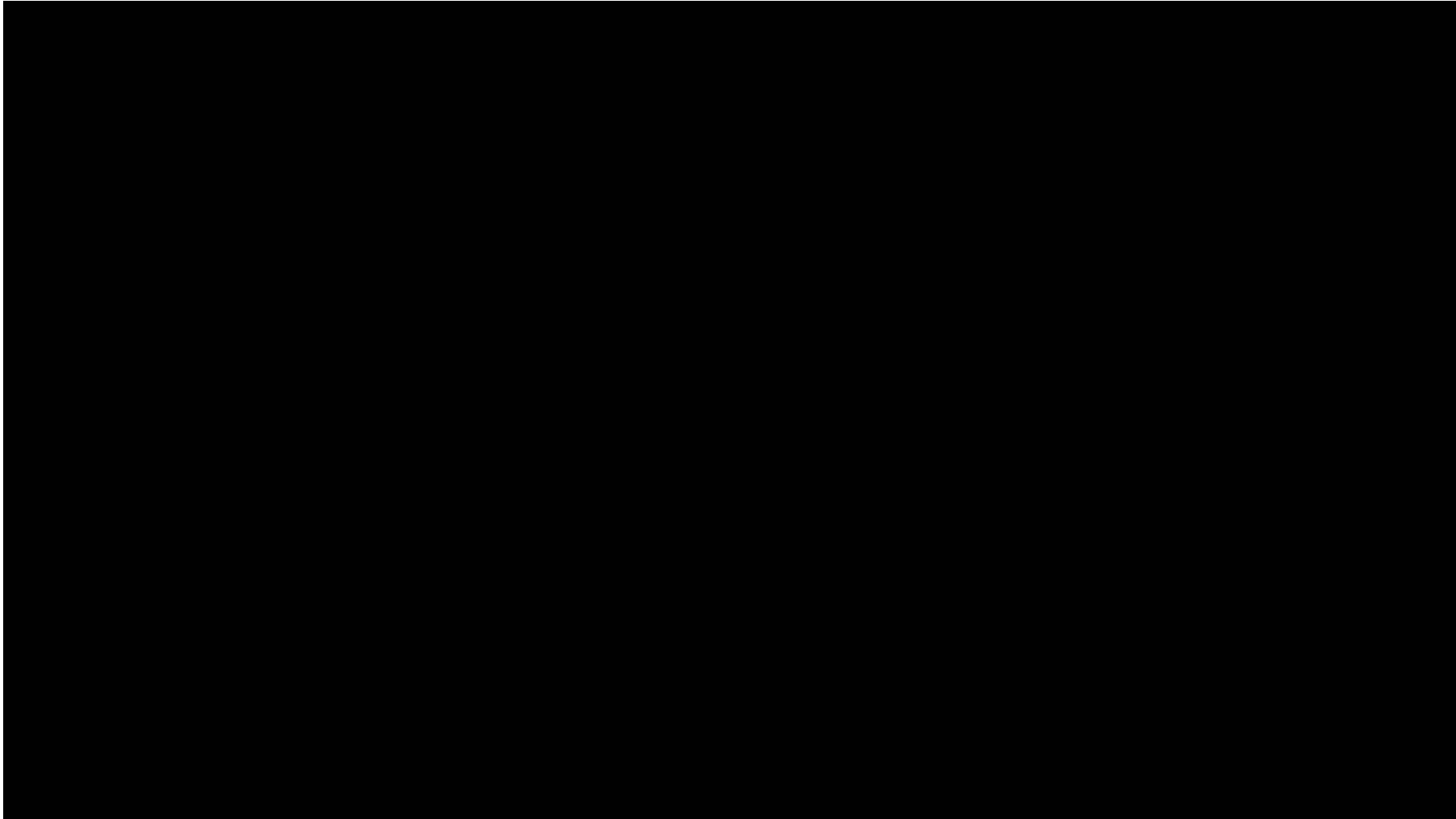
A person who has a major influence on the behavior and self-esteem of another (e.g., spouse, partner, family member, friend)

## Communication partners

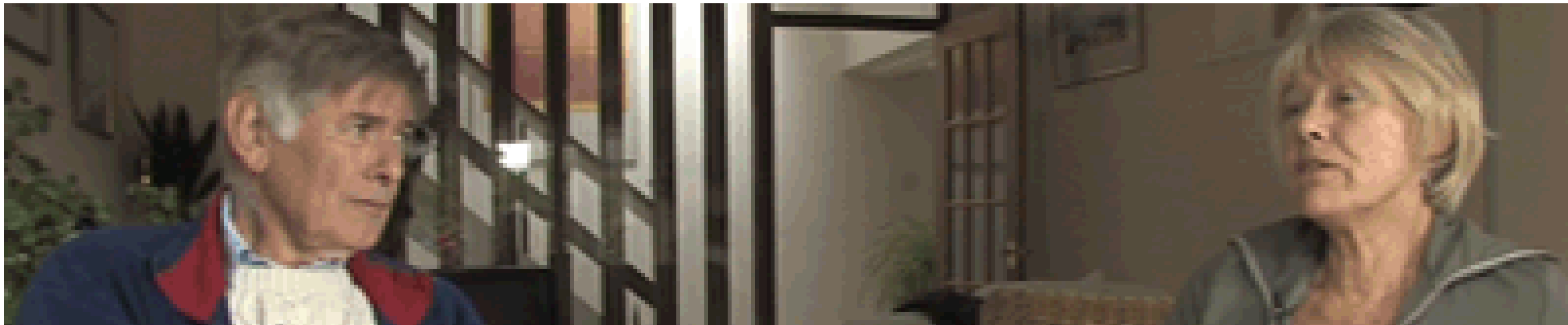
Each event in a person's life involves a communication partnership in a communication environment

Include the cooperative relationships necessary for successful communication

# Gill and John: A Real-Life Example



## Video Reflection



How has Gill's hearing loss affected the relationship between Gill and John?

How has Gill's hearing loss transformed the roles John and Gill play at social gatherings?

# The Communication Partner Experience

Common themes evident across studies:

1. Fear of loss of relationship
2. Pragmatic adjustments to deal with hearing loss
3. Managing the adjustments leads to negative consequences for relationship



Preminger, 2009



# Theme 1 - Fear of Loss of the Relationship



“The whole quality of our interactions was being stripped away and I was fearful that I couldn’t communicate with him.”

(Hallam, Ashton, Sherbourne & Gailey, 2008)

## Theme 2 - Pragmatic Adjustments Have to be Made



“We stopped going out and I get quite worked up about the idea, if they invite us I don’t want to go...it is no pleasure.”

(Hallam, Ashton, Sherbourne & Gailey, 2008)

## Theme 3 - Adjusting Leads to Negative Consequences

“We don’t talk a lot”

“Trivial remarks aren’t worth the effort”

“Constant repetition is tiring and annoying”

“It kills the moment”

“It is very stressful, I cannot, a part of our relationship in a way has died”



(Scarinci, Worrall & Hickson, 2008)

# Why Involve Communication Partners in Rehabilitation?

Family members are also affected by the hearing loss = **third-party disability**

Older adults with hearing loss are more likely to **seek help** for hearing difficulties if they perceive their family members are **supportive** of hearing rehabilitation

Older adults with hearing loss who had more **positive support** from family members were more likely to be **successful hearing aid users**

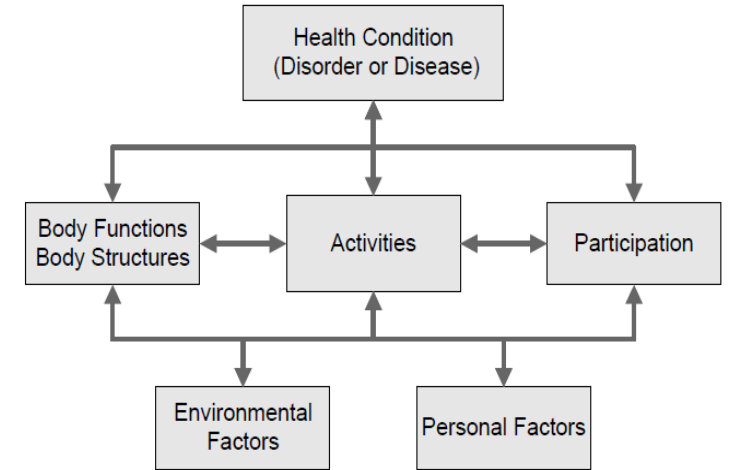
(Scarinci et al., 2009a, 2009b, 2012)

(Meyer et al., 2014; van den Brink et al., 1996; Wallhagen, 2010)

(Hickson et al., 2014)

# Involving family and friends in the management process

- WHO & third party disability
- Influence help-seeking & success of rehab programme
- Understanding is required for support
- Various roles of the family member (Ekberg et al, 2015)
- Positive experiences (Manchaiah et al 2012)



# What do patients, family members & clinicians want?

- Everyone value the involvement of the family
- Aud's have an opportunity to facilitate family centred practices within hearing rehab
- Patients acknowledge significant role of family members in
  - help seeking
  - decisions about rehab
- Valuable to discuss family concerns with Aud

Ekberg (2015)



# How are family members currently involved in hearing rehabilitation? (Ekberg 2015)

- Family members not typically invited to speak
- Family Members are strongly interested to participate and share their experiences
- Family members self-select to answer questions from the Aud that were directed to the patient
- They self-initiate to expand on patient's speaking turns
- Self-initiate questions to the Aud

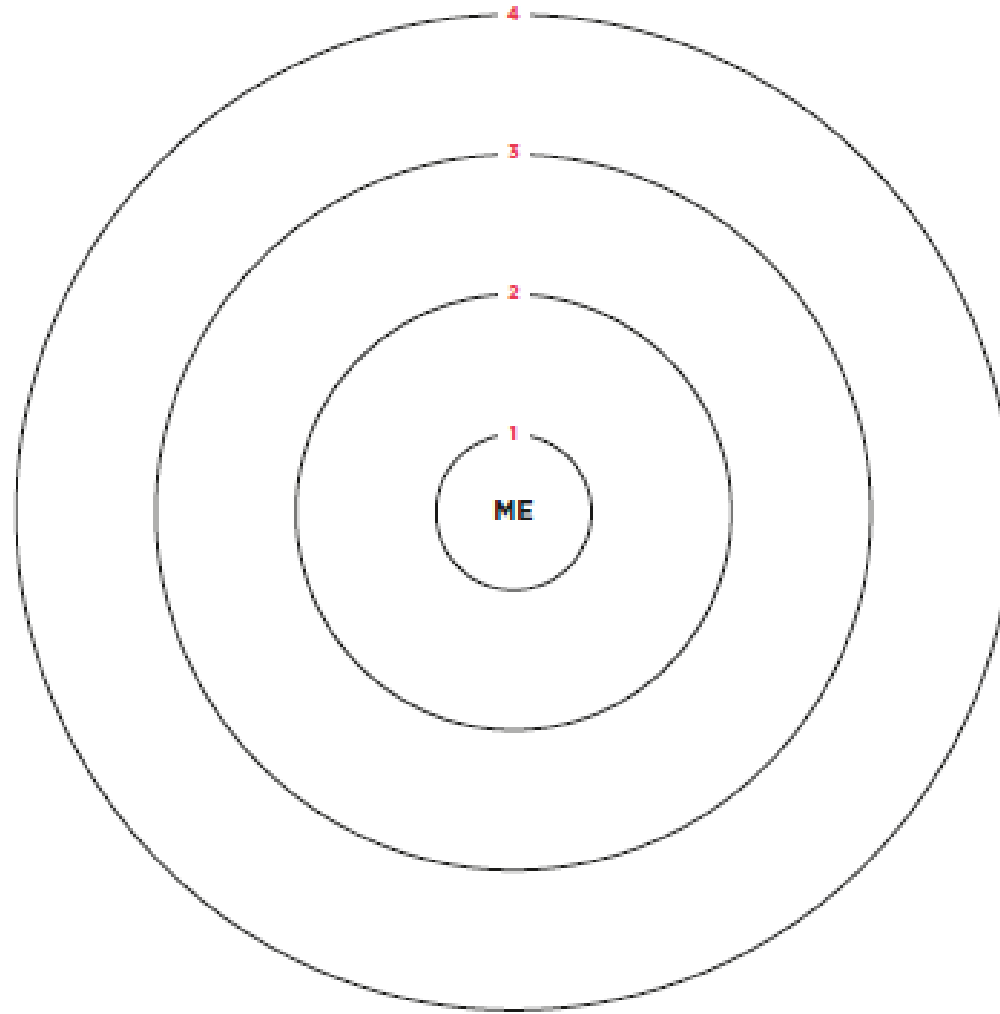
- Auds typically responds by shifting conversation back to patient
- Family member contribution brief & “shut out” of conversation between patient & Aud

# Communication Partner Tools





# Communication Rings



# Communication Rings



**Ring No. 1.** The center or core represents the person completing the rings.



**Ring No. 2.** The inner circle represents the most important people in the individual's social network – those the individual shares a lot of time with or feels particularly close to.

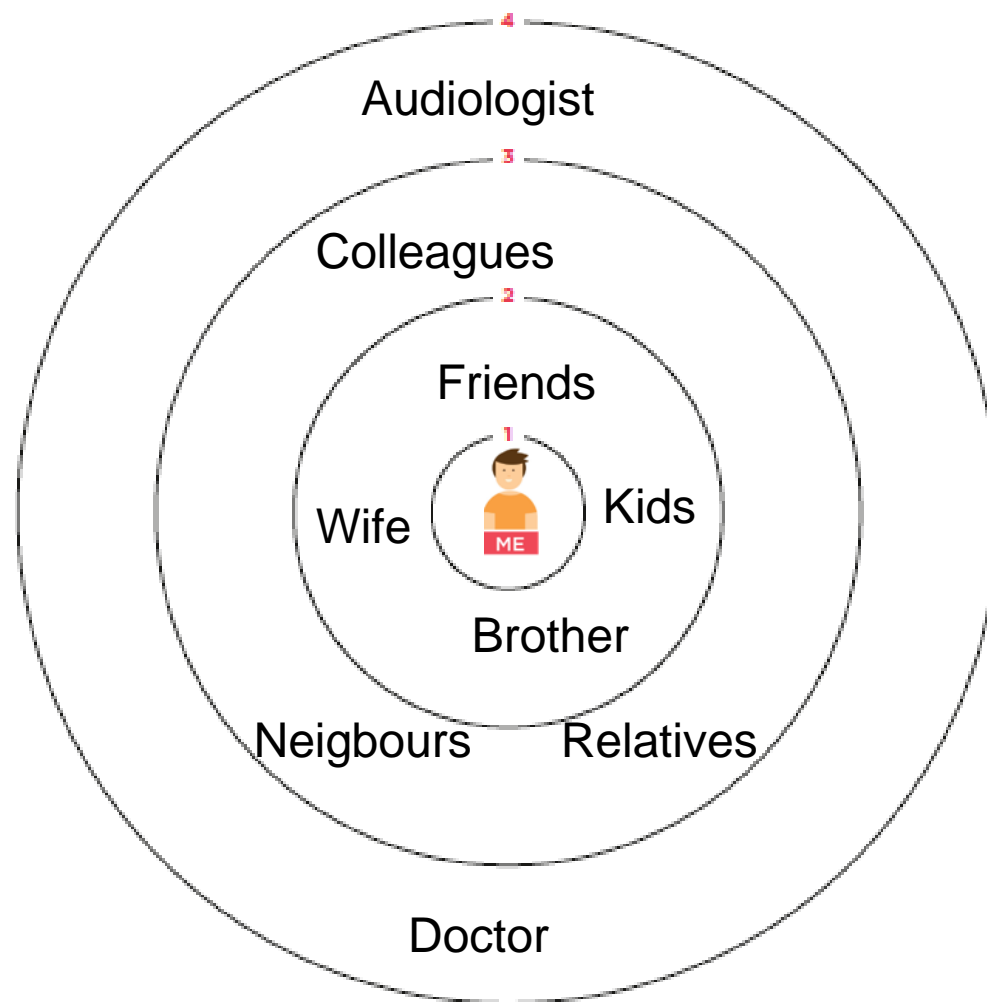


**Ring No. 3.** The middle circle represents people who are still very important but not as close or important as the people in the inner circle.



**Ring No. 4.** The outer circle is reserved for those individuals who are less important but are present on a regular basis.

# Communication Rings



# The GPS-Goal Sharing for Partners Strategy



# Developing Shared Goals

## DEVELOPING SHARED GOALS (EXAMPLE)

**1** CP: WHERE DO YOU FIND COMMUNICATION MOST EASY?

*At night, in the living room, after we turn the TV off*

PHL: WHERE DO YOU FIND COMMUNICATION MOST EASY?

*At the dinner table, when it is just the two of us*

**2** CP: HOW DOES THE HEARING LOSS AFFECT YOU?

*I can't keep straight all the conversations going on when all the grandchildren come and visit*

PHL: HOW DOES THE HEARING LOSS AFFECT YOU?

*I feel bad when she misses the silly riddles the grandkids like to tell*

**3** CP: HOW DOES THE HEARING LOSS AFFECT YOUR PARTNER?

*He helps me a lot, but I can see it gets old sometimes*

PHL: HOW DOES THE HEARING LOSS AFFECT YOUR PARTNER?

*She doesn't want to go to parties like she used to*

**4** WHAT PROBLEMS DO YOU BOTH EXPERIENCE?

*We miss eating out with the family and sharing the good times*

**5** SHARED GOALS

- 1. Reduce difficulty at family dinners*
- 2. Hearing the grandchildren better*

**6** STEPS TOWARD GOAL

### 1. FAMILY DINNERS

- a. Sit at the end of the table so I can see everyone well*
- b. All the lights on*
- c. Wear the hearing aids*
- d. Get a good night's sleep the night before*
- e. Put the little ones nearest me because their voices are small*

### 2. HEAR THE GRANDKIDS BETTER

- a. Let them know they have to look at me when we have a conversation*
- b. Invite them over one at a time so we can keep the background activity to a minimum*
- c. Wear the hearing aids*
- d. Don't fake it*

# Goal Sharing for Partners



## DEVELOPING SHARED GOALS

<b>1</b> PHL: WHERE DO YOU FIND COMMUNICATION MOST EASY?   	<b>CP:</b> WHERE DO YOU FIND COMMUNICATION MOST EASY?   
<b>2</b> PHL: HOW DOES THE HEARING LOSS AFFECT YOU?   	<b>CP:</b> HOW DOES THE HEARING LOSS AFFECT YOU?   
<b>3</b> PHL: HOW DOES THE HEARING LOSS AFFECT YOUR PARTNER?   	<b>CP:</b> HOW DOES THE HEARING LOSS AFFECT YOUR PARTNER?   
<b>4</b> WHAT PROBLEMS DO YOU BOTH EXPERIENCE?   	
<b>5</b> SHARED GOALS   	
<b>6</b> STEPS TOWARD GOAL   	

The GPS offers a way to:

Open a dialogue with the person with hearing loss and the communication partner in the appointment

Help them acknowledge limitations caused by hearing loss

Enable them to accept responsibility to work together to improve communication

Allow them to set common goals

# Prepare for Appointments



## Living Well Online

When is it easy or hard to communicate and what can you do to make it better?



## My Turn to Talk for Adults

What questions do you want to ask in the appointment and who you need to communicate with?



## Why Improve My Hearing?

How would improving your hearing and communication effect your daily life?

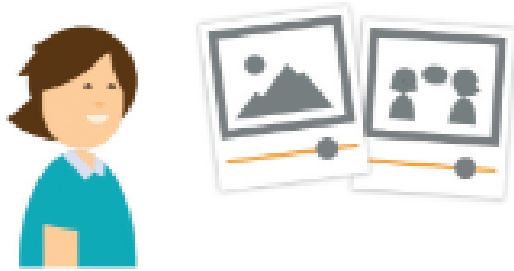


## Tinnitus Thermometer

How are you experiencing tinnitus right now?

[www.idainstitute.com/telecare](http://www.idainstitute.com/telecare)

# Why Improve My Hearing?



## Why Improve My Hearing?

How would improving your hearing and communication effect your daily life?

## Situation 1

### ✓ Identify a situation

Choose a photo that shows a situation where you've had difficulty hearing.

Shopping



Describe your situation

Mark the number that best describes how important it is for you to improve your hearing.



### ✓ Why did you place the marker where you did?

Because I struggle to hear in many situations but I do manage to get by.

### ✓ What will happen if you continue as you are today?

I will struggle when I speak to people I do not know - like the cashier in the supermarket

### ✓ What would happen if you get a hearing aid and improve your hearing right now?

I will be less dependent on others to help repeat the things I miss

Add a situation or go to the summary

Add another +



# Dilemma Game

1 TV Testing

3 From the Next Room

5 Nutty Professor

7 The Technology Isn't Working

9 Should I Tell My Colleagues?

11 On the Phone

2 Out to Dinner

4 The Audiogram

6 Burger Joint

8 Teaching Your Friends and Family

10 Hearing Loss is Natural

# Dilemma: TV Testing

## Dilemma 1

Exploring



### TV Testing

Your family often complain that when you watch TV it's too loud. They tell you that they can hear it from other rooms, that they can't have a conversation with you if the TV is on, or that they don't want to watch TV with you because it's too loud. They may have even told you that you're losing your hearing.

You don't think the television is too loud. If you think about it, though, you have noticed that when you turn on the TV after someone else has been watching it, you always have to put the volume up.

How would you deal with the situation?



FLIP CARD

## Dilemma 1

Exploring



### Suggestions

**A.** Self-test – See if you can watch TV on the volume that everyone else does.

**B.** Compromise – Turn the TV down lower than you would like, even if that is still higher than your family would like.

**C.** Make a note to ask your doctor about your hearing at your next regular check-up.

**D.** Or...



FLIP CARD

# The Purpose of the Communication Partner Tools

- ✓ Acknowledge the hearing loss as a communication loss
- ✓ Acknowledge activity limitations and participation restrictions that each partner faces as a result of the communication loss
- ✓ Develop an understanding of their shared responsibility in dealing with the communication loss
- ✓ Establish realistic communication goals
- ✓ Identify the necessary steps to achieve these goals



# Practical Suggestions

- Invite family members to attend appointments (remember the “how”)
- Prepare your patient and their family (Telecare tools)
- Seeking & actively listening to family members' contributions
- Responding openly & empathically to their contributions
- Use tools to engage family members (e.g. GPS, Communication Rings, Dilemma Game)

Ekberg et al 2015

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THANK YOU

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