

# Family-centered Audiology Care: Making Decisions and Setting Goals Together

Useful tools for getting the patient and their family members to address the hearing loss

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Family-centered Care (FCC) accepts that both the person with hearing loss and those around them should be the focus of audiologic rehabilitation. Strategies outlined here revolve around including family in discussions about taking action to resolve hearing difficulties and setting goals for successful hearing rehabilitation.

*As reported in the November 6, 2015 The Hearing Review online news, Phonak has convened a select group of hearing healthcare experts (see Acknowledgements section at the end of this article) to provide evidence-based recommendations to hearing care providers on how to better engage family members. Chaired by Dr Louise Hickson, the objective of this group is to facilitate family involvement throughout the hearing remediation process.*

**F**amily members have a key role to play in decisions made by adults with hearing loss. They provide an important perspective on the personal, interpersonal, social, and communicative contexts for our patients. As a consequence, they have the potential to influence all aspects of hearing help-seeking and rehabilitation, and we argue, therefore, that their input is extremely important and cannot be ignored by hearing care professionals (HCPs). In this article, we focus on a number of key decisions that adult patients make, and suggest ways that HCPs can involve family. First, we take as the premises for this article that:

- Hearing loss has its primary impact on everyday communication and individuals' perceptions and experiences of communication difficulty typically lead them to the clinic.
- Difficulties in everyday communication impact on both the individual with hearing loss and conversation partners, and everyone in the conversation shares in the responsibility for establishing and maintaining successful communication.
- Those close to the person with hearing loss, most commonly family members, frequently find themselves in the role of resolving communication difficulties as they arise.
- *Family-centered care* (FCC) is responsive to the impact of hearing loss on those around our adult patients and provides a model of care that emphasizes the role of significant others in addressing these everyday conversation difficulties.

Frequently, patients first begin to realize they have hearing loss through interactions with family and friends. The signs may be subtle, with requests for repetitions, difficulty hearing in noisy environments, or just the feeling that they are working harder to understand communication. This period of hearing loss awareness represents the first steps in the patient's hearing journey.<sup>1,2</sup>

The patient's journey towards seeking assistance from the HCP may begin with a suspicion that communication is not as easy or successful as it once was, and progresses to a clear recognition that communication difficulties are constantly arising as a result of the hearing loss. While this is a journey that most patients take with individuals who are part of their lives, it is common for patients to attend the hearing clinic alone. Thus, the key decisions that adult patients need to make are: 1) Should I do anything about my hearing and communication? and 2) What action will I take to address my hearing



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and communication difficulties? These two questions are often made without the support of people often affected by the hearing loss.

### 1) Should I do anything about my hearing and communication?

Every patient’s hearing journey is personal and deeply embedded in the context of his or her everyday personal and social life. Each individual must realize the presence of hearing loss at their own pace. The length of time it takes to become aware of these issues varies considerably and is affected by both internal and external factors.<sup>3-5</sup> Internal factors may include the variables that influence a person’s self-perception of hearing loss, such as stigma, and their ability to cope with communication difficulties.<sup>6</sup> External factors refer to the environmental, social, and personal influences on communication abilities. Given that each patient’s journey is a personal exploration with his/her own story, having an understanding of the motivating factors that brought him/her to the HCP is valuable when building an FCC approach to the management of hearing loss. We refer to obtaining this information from our patient as the “Patient Story” and it is a key component of FCC.

Yet, traditionally, HCPs take a medical/audiologic history either using a written intake form or asking closed set questions, such as “Do you have any ringing in your ears?” or “Have you ever worn a hearing aid?” This method of intake interview is limited as it neither explores the psychosocial, emotional components of hearing loss, nor does it take into account environmental influences on the patient’s communication. Eliciting the patient story using opened-ended queries, such as “Tell me about your hearing loss?” or “How does your hearing loss affect your daily life?” allows for a better understanding of the patient experience with hearing loss and opens the door to patients directing the conversation, rather than simply responding to the questions asked. Open-ended questions encourage disclosure and promote empathy and a greater understanding between patient and HCP than is offered via the traditional intake case history.

Perhaps though, the most important benefit of the open-ended question is the ability to invite the participation of *family members* into the dialogue allowing them to be part the assessment and treatment process. The patient story—augmented by the family

My Hearing Options				
What is it?	Hearing aids	Communication education	Assistive listening devices	No treatment
What is involved for you?	<ul style="list-style-type: none"> <li>Being fitted with hearing aids</li> <li>Wearing the hearing aids in my everyday life to help with my hearing problems</li> </ul>	<ul style="list-style-type: none"> <li>Participating in group sessions to learn strategies to manage my hearing problems</li> <li>Using the strategies to help in my everyday life</li> </ul>	<ul style="list-style-type: none"> <li>Buying some devices to help me hear in certain situations</li> <li>Wearing the devices in everyday life</li> </ul>	<ul style="list-style-type: none"> <li>Keep on going the way I am at the moment</li> </ul>
What is involved for your family?	<ul style="list-style-type: none"> <li>Attending when the hearing aids are fitted</li> <li>Helping you to wear the hearing aids</li> </ul>	<ul style="list-style-type: none"> <li>Participating in the group sessions to learn strategies to help you</li> <li>Using the strategies to help in everyday life</li> </ul>	<ul style="list-style-type: none"> <li>Learning about the devices</li> <li>Helping you wear the devices</li> </ul>	
Options I want to know more about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Options I will think about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 1a. Example of the first page in a Decision Aid for adults with hearing loss and their families (based on Laplante-Lévesque et al<sup>7</sup>). Each option has its own page, with the option of hearing aids shown below in Figure 1b.

Hearing aids	
What is involved?	<ul style="list-style-type: none"> <li>Being fitted with hearing aids</li> <li>Wearing the hearing aids in my everyday life to help with my hearing problems</li> </ul>
What is expected from you and your family?	<ul style="list-style-type: none"> <li>Attending 3 or 4 appointments at a hearing clinic</li> <li>Returning to the clinic if you have problems with the hearing aids</li> </ul>
What are the positives?	<ul style="list-style-type: none"> <li>You will be able to hear soft sounds better</li> <li>You will hear better in one-to-one conversations, in small groups and when listening to TV or radio</li> </ul>
What are the negatives?	<ul style="list-style-type: none"> <li>Hearing aids will not sound natural in noise or in large groups.</li> <li>You will need to persevere to get used to hearing aids</li> <li>Most hearing aids can be seen by others</li> </ul>

Figure 1b. Example page from a Decision Aid on the option of hearing aids.

member’s input—can provide the HCP with relevant information about the individual and family’s journey toward understanding hearing loss. It will help to understand whether or not they are ready to do anything about hearing and communication.

### 2) What action will I take to address my hearing and communication difficulties?

Once patients have decided to do something about their hearing and communication difficulties, the next major decision they have to make is *what* they will do to address those difficulties. Commonly, options include amplification devices of various kinds, assistive listening devices, communication education and/or auditory training.

Laplante-Lévesque, Hickson and Worrall<sup>7</sup> interviewed older adults about their experiences with such decisions, and they

identified family members as playing a vital role in decision making. This applied whether or not the family member was present when the HCP explained the options to the patient. Likewise, Poost-Foroosh et al<sup>8</sup> identified family member involvement in appointments as a facilitator of hearing aid adoption by adults, and Hickson et al<sup>9</sup> found that older adults with more positive support from their significant others were more likely to be successful hearing aid users than those with less positive support.

However, the question remains: How can HCPs involve family members in this important decision making process? We present three clinical tools that may assist the HCP in this process.

## 1) The Decision Aid

One tool that has been evaluated in

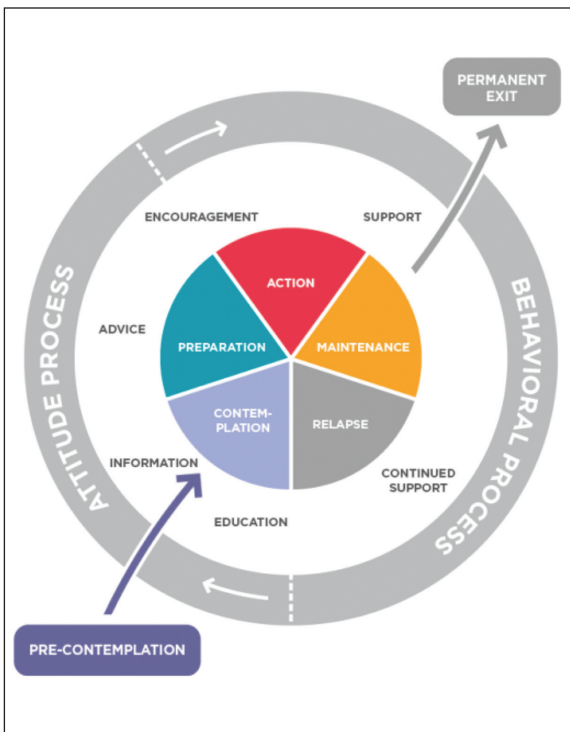


Figure 2. Stages of Change model and HCP actions at different stages, as described by Prochaska and DiClemente.<sup>11</sup> Illustration adapted from Jorgensen et al<sup>16</sup> and used with permission from the Ida Institute, Nærum, Denmark (<http://idainstitute.com>).

GPS: Developing Shared Goals		
Easy Communication		
Step 1	_____	
Step 2	PHL: Problems I Experience	PHL: Problems My CP Experiences
	CP: Problems I Experience	CP: Problems My CP Experiences
Step 3	What Problems Do You Both Experience?	
Steps 4 & 5	Order of importance	Shared Goals & Strategies to Achieve Goals
	<input type="checkbox"/>	_____
	<input type="checkbox"/>	_____
	<input type="checkbox"/>	_____
Notes: CP = Communication Partner; PHL = Person with Hearing Loss		

Figure 3. The Goal-sharing for Partners Strategy worksheet (from Preminger and Lind<sup>13</sup>).

research and is now being used clinically is the Decision Aid (Figure 1a). A Decision Aid is a simple written document that presents brief facts about each option in a process: what it is, what is involved in it, and what are the advantages and disadvantages. Examples of Decision Aids (also called Option Grids) for hearing can be found in Laplante-Lévesque, Hickson and Worrall<sup>10</sup> and at <http://optiongrid.org>.

The first page shows all the possible options and patients are asked to indicate by ticking the boxes which ones they would like to know more about. From there, the HCP tells the patient more about those options that interest them. In the final part of the process, the patient indicates on the first page which options they will now think more about based on the information they have received.

A Decision Aid is a supplement to verbal discussion with the patient and the family members. If family members are not able to attend the appointment, then the patient can take the Decision Aid home and discuss it with family members before making a decision. We encourage HCPs to develop a Decision Aid, such as the example

in Figures 1a-b to include in their clinical practice. These figures represent an extension of published research in this area and includes an important addition: responses to the questions “What is involved for your family?” and “What is expected of you and your family?”

## 2) The Transtheoretical Model of Change

Another possible way to help the patient and family through the hearing journey is to consider the application of the Transtheoretical Model of Change.<sup>11</sup> This model not only highlights the stages of attitude change and later behavior change that patients may go through in their hearing journey, but it makes reference to the types of support that the HCP might provide to support the journey. If applied in an FCC approach to clinical interaction, this model allows for both patient and family member to be supported by the HCP with respect to their attitudes and beliefs towards intervention.

Figure 2 outlines the stages patients (and by extension, their family members) typically go through and importantly the different types of responses HCPs may provide at each stage.

For example, the HCP might recognize times when education and informational counseling might be the more appropriate responses to a patient’s expressed attitudes and needs, by contrast with encouragement and support for the actions the patient may have taken.

## 3) The Goal-sharing for Partners Strategy (GPS)

As patients and their families discuss what they hope to achieve by taking action, they will likely consider situations where they have communication success and communication failures. The HCP can use this discussion to assist the patient and family members in formalizing their goals and strategies. The Goal-sharing for Partners Strategy (GPS) is a tool that may be used in order to guide this process (Figure 3).<sup>12</sup> The GPS is a goal setting tool, much like the COSI,<sup>13</sup> in which an individual with hearing loss and a family member are asked together to consider:

- 1) Situations which result in successful communication;
- 2) Problems that each experience in specific situations due to the hearing loss;

- 3) Problems they experience together in specific situations due to the hearing loss;
- 4) Specific goals that they would like to achieve, and
- 5) The steps they can take to achieve these goals.

During informal discussions with HCP colleagues, several voiced concerns about the implementation of the GPS. It was believed that the GPS would take too long to complete or that it was unnecessary because “I already take an extensive case history.”

To address these concerns, authors BB, RH, and JP are evaluating the GPS in a busy audiology/ENT practice, with it being administered after the case history and before a diagnostic or hearing aid evaluation. Preliminary results suggest that, unlike the COSI, the GPS is not an outcome measure. Rather, it is a tool to start a conversation and to learn the patient’s story using an FCC approach. After using the GPS with three adult patients each attending with a family member, author BB has noted that the GPS is a helpful tool because “it pulls the family member into the conversation in a way that other questionnaires or counseling methods do not,” and it is helpful to get the perspective of a family member especially when meeting a patient for the first time. Another HCP reported that, when using the GPS, it “separated me as a HCP who is concerned about my patient’s total communication, not just the amplification device”—a particularly timely attribute as many hearing care practices face increased competition from larger dispensing chains and/or Big Box retail, and are also unbundling hearing aid costs from professional fees.

When asked if it was useful to have the GPS conversation that included both the patient and a family member, one patient reported “Until somebody pointed it out, we just didn’t think about it.” The adult daughter of a patient noted that prior to the interview she was unaware of some of the problems her father was experiencing and that the GPS experience was useful to clarify their options.

Earlier, the key decisions that adult patients need to make were noted. Use of the GPS appears to help patients and family members realize that these decisions are truly *family decisions* rather than those made alone

by the patient with hearing loss. Thus the key decisions may be revised to:

- 1) Should *we* do anything about the hearing loss and our communication?
- 2) What action will *we* take to address the hearing loss and our communication difficulties?

## Summary

Family-centered Care (FCC) accepts that both the person with hearing loss and those around them should be the focus of audiological rehabilitation. This paper is the third in a series<sup>14,15</sup> that is aimed at helping HCPs to operationalize FCC, to involve families in a meaningful way, and to optimize opportunities to improve the quality of life of people with hearing loss and their families. Strategies outlined here revolve around including family in discussions about taking action to resolve hearing difficulties and setting goals for successful hearing rehabilitation.

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