Findings from consumer survey

Summary report: Power Users

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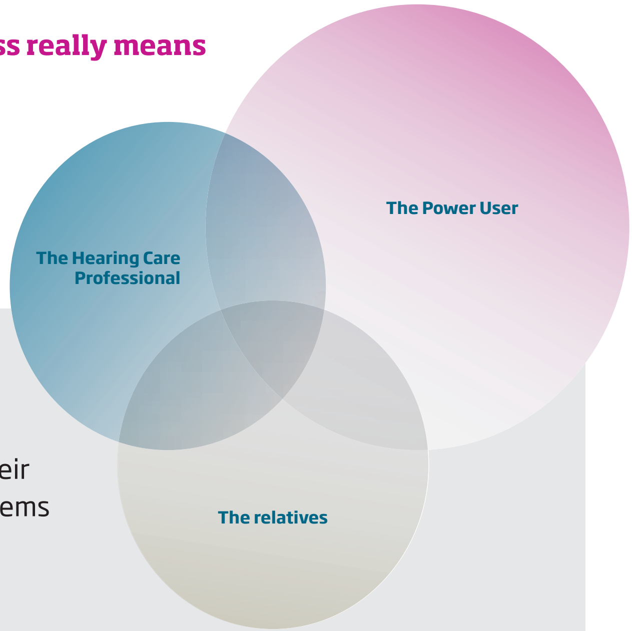
PEOPLE FIRST

The Power user study
was carried out in the time span from **November 2009 to February 2010**
in co-operation with the strategic design consultancy **Design-It**

The **purpose** of
the **Power User*** **study** was to understand
what living with a severe and profound hearing loss really means



Project scope:

To uncover insights about Power Users and their relatives, their everyday life and the direct and indirect challenges and problems that stem from severe and profound hearing impairment.

* Whenever the term "Power User" is mentioned in this booklet, it is a reference to the specific segment of severe and profoundly hearing impaired hearing instrument users.

Main Insight
The Constant Battle

LIFE WITH A SEVERE OR PROFOUND HEARING LOSS IS A CONSTANT BATTLE

Life as a Power User is a constant battle

The constant battle is caused by a sum of many challenges:

- Concentrating hard to understand **everything** that is being communicated
- Depending completely on the functionality of their hearing aid
- Experiencing individual, specific problems concerning work
- Depending on lip reading and the possibility to read body language
- Sensitivity to noise, background noise, and cross-talking
- Depending on behaviour modification from their surroundings
- Depending on their relatives

- **Most of the individual challenges are well known. The real insight is the sum of challenges and the fact that these constantly affect the Power Users in all aspects of their life situations.**
- **The battle is not only present for the users. Especially close relatives to the severely or profoundly hearing impaired are also implicated in that battle - however not to the same degree.**

The constant battle is particularly evident in the following four insights:

1 **Missing out**
Insight into the social, personal and practical consequences a person with a severe or profound hearing loss experiences every day and in the course of life.

2 **The Miracle Machine**
Describes the love/hate relationship that grows out of living with a hearing instrument, and the challenges of getting new hearing instruments when one is highly dependent on them.

3 **The Human Hearing Aid**
About the important, but not always easy role of the Power User's communication partner* and other close relatives.

4 **My Expert**
Describes the special nature of the relationship and the interaction between the Power User and their Hearing Care Professional (hereafter called HCP).

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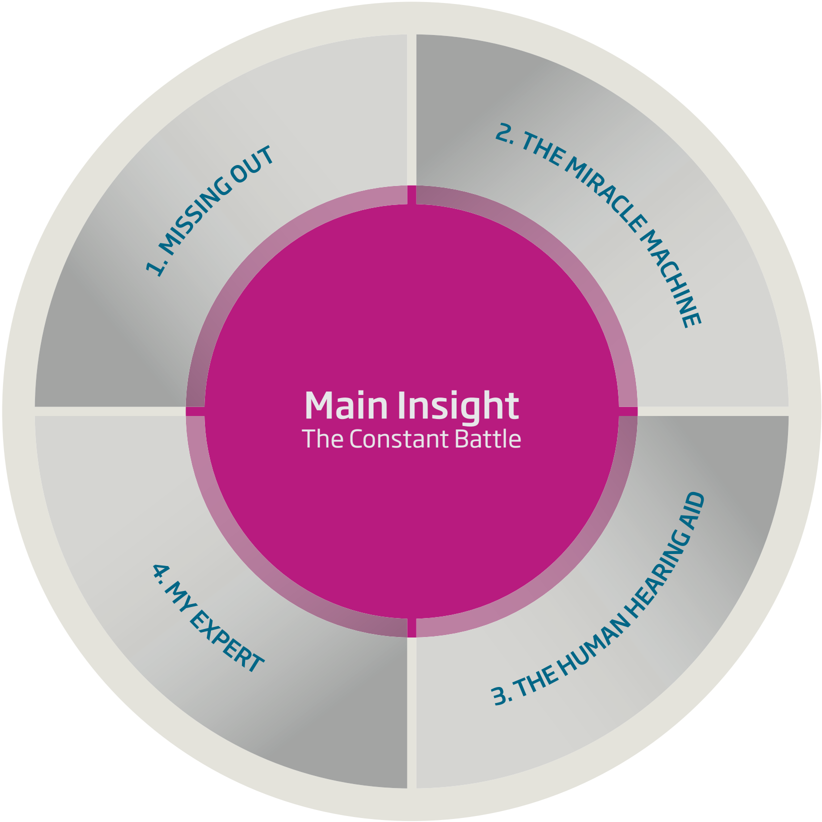
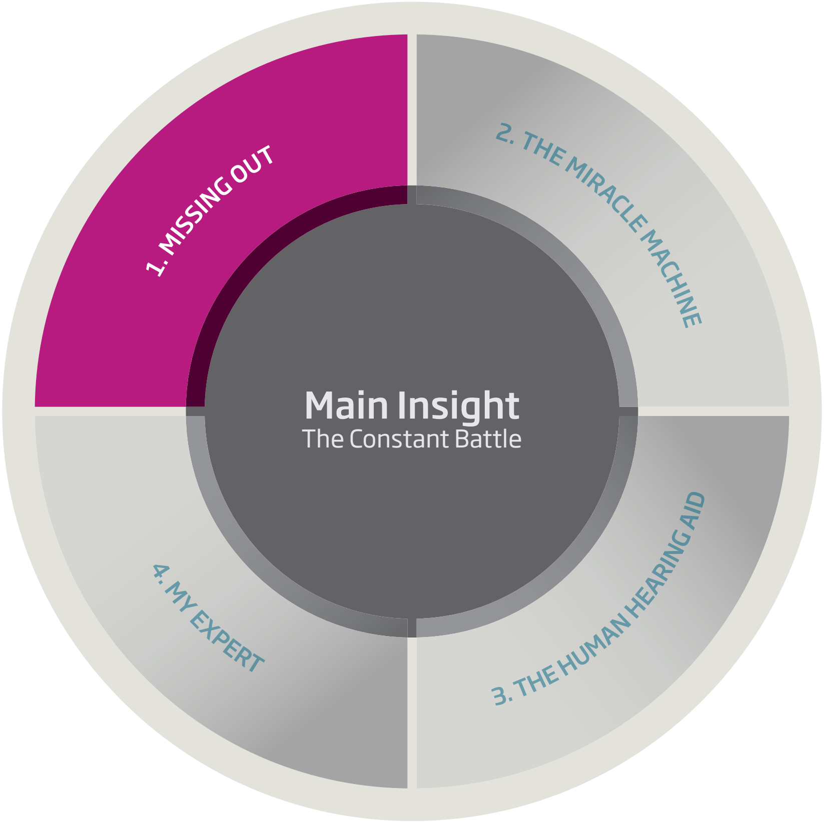
* A communication partner may be a spouse, parent or child, a good friend or another important person whom the Power User has confidence in and may use for assistance in personal matters.




1. MISSING OUT
2. THE MIRACLE MACHINE
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4. MY EXPERT
Main Insight
The Constant Battle

Power Users feel that they are missing out at several different levels

Power Users often feel left out in many different situations and aspects of life and they constantly have to strain themselves to keep up. This endless array of situations – especially the unpredictable situations – plays an important role in the constant battle. Power Users' lack of understanding often leaves them unable to make sense of the social interaction they participate in.

The three typical areas where Power Users miss out:

1. Communication
   Constantly missing information in every day situations.

2. Fulfilling personal dreams
   A feeling of not being the person they might have been without their hearing impairment.

3. Social life
   Feeling alone even when being together with other people.

> "Conversations like this – what am I doing – STOP – I didn't hear what you said, I didn't hear what you said. I just let it go – I cut and paste. I miss out of everything and I..."

> "It has taken a lot of me away."

> "When we have parties, I must admit I go into the kitchen or another place to hide out to get some peace."

> "I only get 40-45% of the words as it is, and the other 50-60% - whatever – my brain makes up, that is why it melts sometimes. It is struggling to make sense of what you say."

Missing out on communication

Direct communication
Situations where the Power User is in direct dialogue, typically one-to-one conversations where the Power User has the possibility to improve the chances of understanding, e.g. by asking questions. However, misunderstandings might not be discovered until at a later stage.

Examples of direct communication:

- Conversations
- Seeking knowledge
- Short messages
- Jokes
- Calling your attention

Indirect communication
Information from different sources not exclusively targeting the Power User but a wider audience. People with normal hearing obtain a lot of information and knowledge through indirect communication, adding to the full picture of what's happening around them. Power Users miss a lot of this information and thus feel left out and "the last to know". This leads to embarrassment, annoyance and insecurity.

Examples of indirect communication:

- Small talk, all the communication going on around you
- Radio, television, movies
- Parties, restaurants
- Meetings, conferences, school
- Announcements, warnings

Missing out on fulfilling personal dreams

Power Users often feel that they do not have the same opportunities in life as people with normal hearing, e.g. when choosing education and career. They typically have to find a job where the hearing difficulties do not interfere to much with performance and thereby, the options are limited. Many Power Users clearly express that they do not have the life they might have had, if they did not have a hearing loss.

Examples of areas of compromise:

- Limited choices of education
- Manual work
- Potentially lower income
- Refrain from having children
- Limited choices in sports

> "I can't go swimming with my hearing aids."

> "I'm good with my hands, I like to have small projects."

Missing out on social life

We all need to relate, participate and be social but Power Users often do not benefit from participating in social activities because they have problems keeping up with what is going on. This feeling of being outside and being lonely tends to make the Power Users more introvert: A social event that most people would look forward to is often perceived by the Power Users as a major battle. Often, the close relatives, too, feel these limitations in their social life.

> ”I’m more introvert. I used to be really into politics. It’s not comfortable asking for repetition in large crowds.”

Preventing ”Missing Out”

Power users constantly use many different tactics (coping strategies) to keep up as much as possible – to prevent missing out on events, opportunities, information, etc. The tactics are often experienced as a battle because it is something the Power Users need to prepare, consider or make an effort to do.

The three types of battles are:

1. The battle of understanding
   To fight the risk of missing out on communication, the Power User uses various individual coping strategies like lip reading or asking themselves the five Ws*. In general, Power Users can understand much of a conversation but need more “processing time” to reconstruct meaning from the bits and pieces they hear. This leads to a permanent lagging behind in conversations and a feeling of missing out.

2. The battle of behaviour
   The need for coping strategies requires good planning and many Power Users feel a huge need to prepare in order to control situations. At the same time, this constant high level of focus and concentration results in a need for small breaks and occasional withdrawal from demanding situations.

3. The battle of identity
   Unable to be the persons that they really are and unable to become who they want to be, Power Users often develop strengths within other areas like do-it-yourself or creative skills.

* The five Ws: Who, what, where, when and why

> ” At meetings I often ask people to repeat, and cross-talk I don’t tolerate; “You want to cross-talk, you have to wait until I’m finished” – that was my rule.”

> ”Because I’m hard of hearing, I don’t hear things well – I ask myself the five Ws and the one H: Who, what, where, when, why and how. That gives me the story.”

> ”I spend more time catering than I do socializing.”

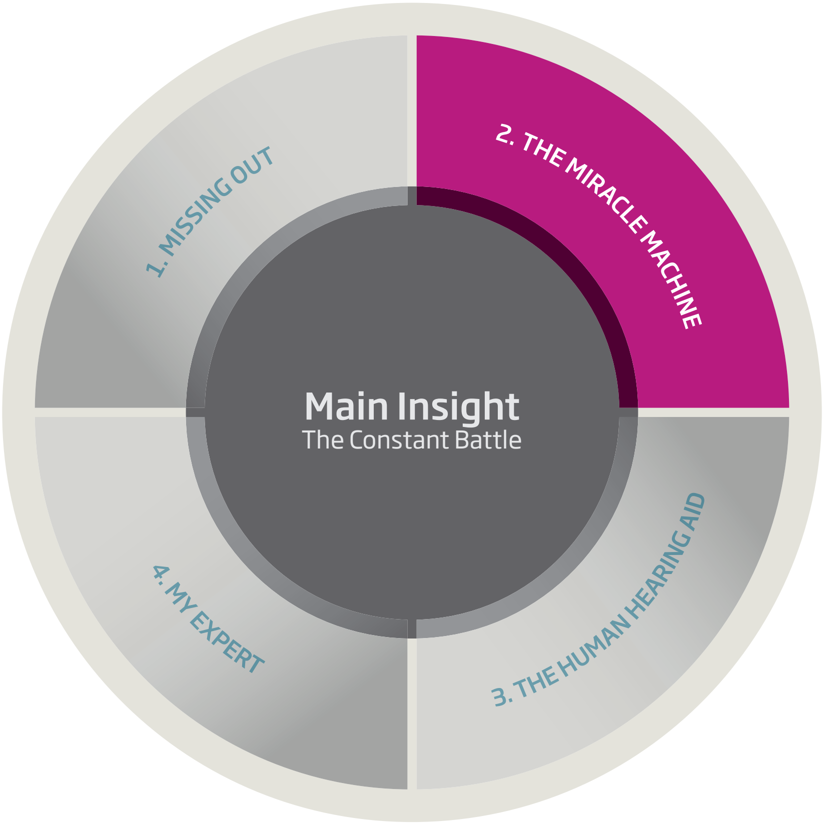
Coping with ”Missing Out”

Modern technology has brought groundbreaking opportunities for the severely and profoundly hearing impaired to improve their possibilities to communicate and connect to people.

The preferred media are:

- Texting, primarily used by people under 60
- Mobile phones are used a lot by some while they are not an option for others
- Internet is generally highly preferred, e.g. Chat forums, Facebook and Skype

However, the preferred media for obtaining **knowledge** about new hearing instruments is the **HCP**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Power Users see their hearing instruments as Miracle Machines

Power Users do not want to wear hearing instruments but they can't live without them. Power Users get a lot of benefits from their hearing instruments. They often see them as small miracle machines. But it is a relationship based on love and hate due to the many daily battles.

> " Sometimes I just want to step on it and throw it out the window."

> "I don't need my ears for that! I turn the hearing aid off in the street."

> "Then she gave me these. And oh my God, I have loved them since day one!"

It is a love/hate relationship

Reasons to love

Functionality
In the moments where everything comes together, the hearing instruments are a ticket to become part of the hearing world.

Socially
The instruments enable the Power User to engage in social interaction. It makes them feel part of something.

Emotionally
The sum of situations where the hearing instruments make a positive difference makes the Power User more relaxed, happy and confident. These are important factors to help the Power Users cope with the constant battle.

Reasons to hate

Functionality
If the hearing instruments do not perform satisfactorily, Power Users are forced back in the corner where they are missing out and where they do not want to be.

Socially
It is annoying and very uncomfortable for Power Users if hearing instruments attract attraction, e.g. if they whistle or moulds slide out of the ear.

Emotionally
In situations where the hearing instruments do not make a positive difference, the Power User becomes stressed, angry, disappointed and insecure. These factors all add to the constant battle.

If insecure, would you go to a friend or a total stranger?

"Anything new?" is a question often asked in the clinic. Many Power Users are always looking and hoping for better hearing aids. Even so, going from a 'known friend' to 'a stranger' can be a challenge.

Because the hearing instruments are so important to the Power Users they are perceived as "a well-known and good friend". The Power Users depend on their hearing instruments and they know exactly what to expect from them and what to be prepared for. The sound picture becomes familiar and a natural part of the Power Users experience of life.

The Power Users' hearing instruments are:

- A life line for interaction
- A help to maintain focus and have full attention
- A security blanket
- A familiar world of sounds

Having used a specific hearing solution for many years, the instruments almost become part of the Power User's body like a cyborg*. This perspective illustrates how big an issue it is, when the Power User changes from one hearing solution to a new one. You change a vital part of the organism.

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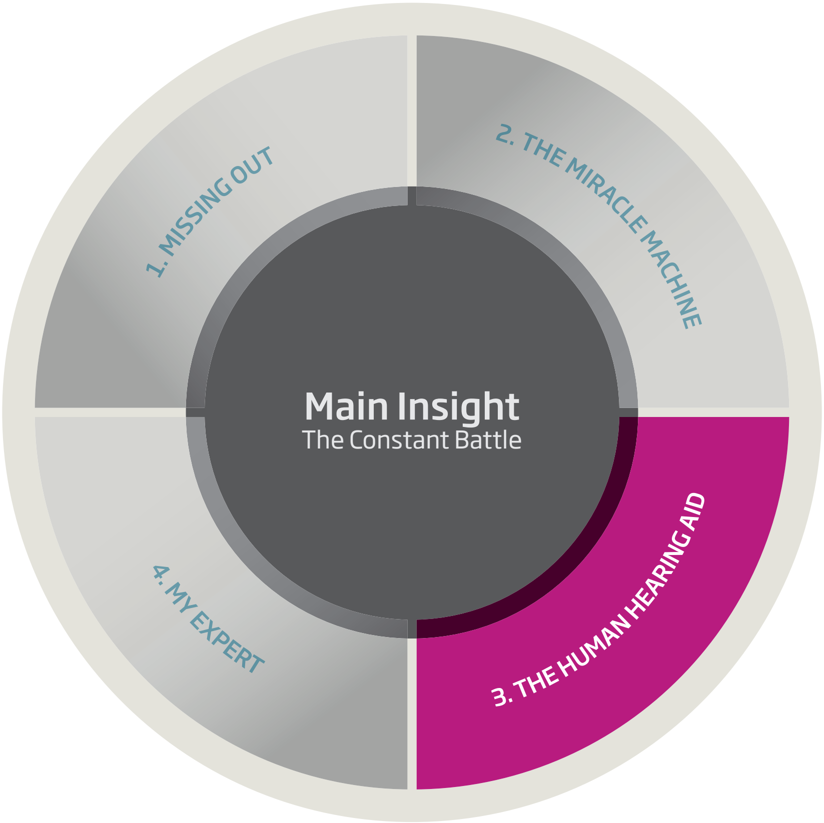
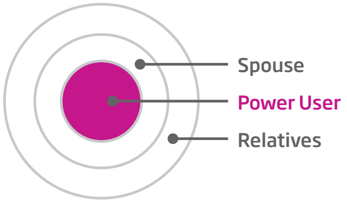
* A cyborg (cybernetic organism) is an organism that has both artificial and natural systems



Power Users are surrounded by "human hearing aids"



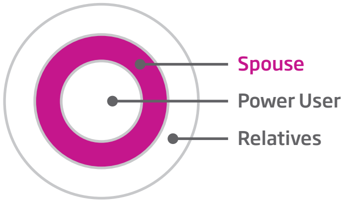
In many situations, the spouses and relatives are the Power Users' ears. They translate what is said, they answer on behalf of the Power User and make excuses related to the Power User's hearing loss. They are – actively or passively – part of the Power User's coping strategies.

To the Power User, this situation is a constant, fine balance between feeling secure and feeling alienated. This puts a strain on the Power User's relationship and interaction with the relatives and it adds to the constant battle.

> "I don't need to bring an extra hearing aid on holidays because I have my wife at my side the whole time".

> "I am the interpreter. He needs one constantly – I am just like one more program on the hearing aid."

Being a "human hearing aid" is challenging, first of all for the primary communication partner



Being dependent on a human hearing aid and being a human hearing aid often causes problems of defining who is responsible for a successful communication.

Communication often takes place on the hearing impaired person's terms, which can be very frustrating for the relative. For the spouse it can be a fine balance to take responsibility for interaction without pitying the partner with hearing loss. Many relatives make huge efforts to fulfil their role as 'human hearing aid', but find that their hearing impaired partner does not acknowledge these favours.

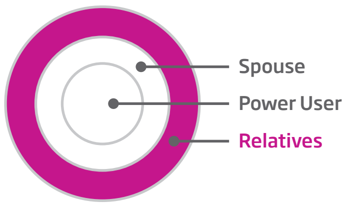
> "I was sitting on my husband like an albatross."

> "But he is saying something completely different – I just try to fix the situation."

> "Don't answer for me!"

There are many "human hearing aids"…

A severe to profound hearing loss affects the whole family – adults as well as children. Everybody has to make an effort to make daily communication succeed. Often the hearing impaired person is not quite aware of how affected the close communication partners are – emotionally, practically and socially.



When the extended family is gathered, e.g. with grandchildren present (playing noisily and yelling as children do), being together in one room can be a challenge for the hearing impaired person. This fact may lead to a great sadness and annoyance for all members of the family.

> "I am afraid what will happen when my mother's hearing gets worse. How will she manage when I move away from home?"

> "We sleep at a hotel when we visit our daughter and her family because Edward gets tired and needs to rest."

The "human hearing aids" use tolerance to overcome difficulties

Persons with severe or profound hearing loss are always under pressure in the constant battle. Consequently, many Power Users may appear bad-tempered, grumpy and stubborn, and their way of using coping strategies may seem very demanding and controlling to an outsider.

Many spouses of persons with severe hearing impairment need to be very tolerant and patient in order to make things work in the daily life, just as a strong devotion in both parties in a relationship seems to be necessary. The hearing impairment heavily affects the partner of the affected person as well.

Some persons with severe or profound hearing loss have been born with this condition. In young couples, the person affected by hearing impairment as well as the spouse may consider whether this will affect any children they may have together.
Other spouses feel that the personality of their loved one changes with progressive hearing loss and that the person they fell in love with disappears as his hearing ability progressively disappears.

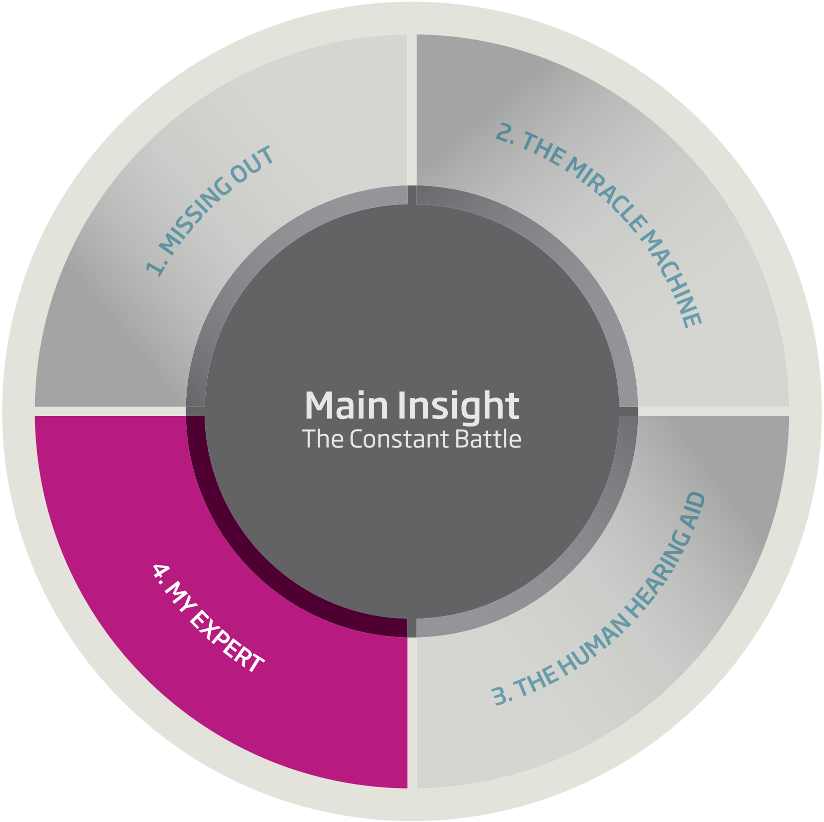
> "I have chosen him as he is…"

> "It is stressful sometimes – you have to have the right partner who is willing to say: Okay, he has a hearing problem."

Human hearing aids are not seen by a hearing care professional

Despite the fact that the communication partner is very entangled in the Power User's problems and challenges, communication partners very seldom involve themselves in the knowledge seeking process and interaction with the HCP.

- The Power User typically sees the hearing care professional alone because this is the one person in the world that the Power User believes understands him or her completely, so they do not see any need for bringing anyone.
- The close relatives typically respect that the Power User prefers to see the HCP alone. However, in reality they would prefer to be much more involved, only they do not wish to overrule the wish of the Power User.
- In general the HCPs also appreciate it when the Power Users bring a communication partner but sometimes they, too, find it sensitive to convince the Power User about the benefits in doing so.
- The close relatives also do not share knowledge with relatives to other hearing impaired people. It seems like the relatives in the same way as the Power Users think that there are no others like themselves with the problems they experience.



The Power users need to rely on an expert

The HCP must show experience within empathy and technical skills in order to be accepted by the Power user as an expert. Power users depend on the professional's understanding, time and skills.

The Power users need an expert to share the responsibility of his or her hearing and they also need a person in their life who knows the exact nature and consequences of the hearing loss. This is the one place where the Power users do not have to pretend.

However, once the Power user has confidence in a HCP, this could very well be a match for life. When the Power user trusts the HCP, the expertise is not questioned.

"I like that I know I can leave everything in their capable hands."

"A good professional is one who can offer knowledge about equipment and has choice of equipment."

What the Power users expect from an expert

In order for the HCPs to be perceived as expert in the view of the Power users, they need to:

- Show understanding of the user
- Treat the user as an individual not an object
- Translate words into fine-tuning
- Convince the user about his or her technical skills
- Not talk "tech-language"
- Allocate plenty of time
- Pay full attention
- Present and explain different possibilities
- Acknowledge the user's anxiety

"One who tries to help me hear better, feel better and let me go through life easier."

"One that takes my concerns into consideration and compromises on what she thinks is best."

[about the fitting situation:] "One who is willing to try repeatedly."

APPENDIX
RESEARCH
DESCRIPTION

Research description

Study:
Interviewing and observing 9 severely or profoundly hearing impaired hearing instrument users in the US and in Denmark.

Ethnographic approach:
- In-depth interviews with the Power Users
- Observations of everyday life situations
- Conversations with 8 spouses/relatives and 9 Hearing Care Professionals from the US, Germany and Denmark

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interact naturally and
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