

HOLISTIC COMMUNICATION WITHIN THE FAMILY

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INTRODUCTION

This paper seeks to identify the different methods of communication that may be used for families who have a "hearing-impaired Usher type 2 or 3 person". An evaluation of a real-life situation will be used to illustrate how different forms of techniques may be used to assist the family so that their quality of life can be improved.

Communication is a two-way process where changes are taking place for the Usher person. Receiving feedback from people within the family unit and friends, can be difficult, thus leading to misinterpretation, isolation, frustration and conflict. For example parents, relatives and friends need to be aware of how to improve their own methods of communication to the Usher person. This may be in the form of developing gestures, finger-spelling, pointing or even to learn Sign Language as this will assist the Usher person to have a direct contact with people, in the long term future.

The ideas have been developed due to the meeting of these two people, who became aware of the different forms of communication being used as a couple. Their main forms of communication are as follows:

- English Spoken Language
- English Deafblind Manual Alphabet
- Sign Language (Mixture of English/Finnish)
- Body Language and own Gestures
- English written Language

COMMUNICATION SITUATION

Russ uses two high powered hearing aids and has an 80% hearing loss in the middle and high frequencies, he uses his voice and lipreads. He is learning to use Sign Supported English. His sight is very restricted about 2 - 3% field of vision, when walking, a red and white guide cane is used to assist mobility for his own safety.

Riitta has full hearing and sight and has communication skills in English and Finnish Spoken Language, Sign Language (including "Hands-On") and the English Deafblind Manual Alphabet.

Their main form of communication is English Spoken Language when Russ uses his hearing aids and is lipreading. Russ also uses a radio microphone to cut down background noise in crowded and noisy environments. When it is dark the Deafblind Manual Alphabet and "Hands-On" Signing is used, when lipreading proves to be more difficult.

COMMUNICATION PROBLEMS

(a) The Usher View

Using Sign Language is difficult at present since Russ was taught the 'Oral Method' of communicating whilst attending deaf school from the age of 4 to 7. He attended hearing schools thereafter, integrating with hearing people, contact with deaf people only started from the age of 22, just after he was diagnosed with Usher Syndrome (deafness, tunnel vision, nightblindness).

Now having accepted his limitations, Sign Language and the Deafblind Manual Alphabet are proving to be the most useful forms of communication, especially when the lighting

situation is very difficult. The hearing aids and radio microphone are only able to pick some speech and lipreading is proving to be too exhausting over long periods of time. It is important to understand that people with Usher's have to use a large amount of energy to communicate because of the concentration required. This applies to both deaf and hearing impaired Usher people who use Sign Language and lipreading. The use of hands-on and tactile communication becomes the main source of communication especially as the vision deteriorates over time. However development of 'Tactile, Touch and Sense' is a slow process if one is used to speech.

Group discussions are impossible and this is an important area particularly if a person wishes to study on courses. One to one contact and appropriate lighting conditions are important, to ensure the Usher person is able to see and follow properly.

Contrasting colours both in the home and outside and suitable lighting are also a major problem in the real world and sometimes the Usher person has to constantly change to the adapting environment. An Usher person finds it difficult to change their environment as one builds up a mental picture of where things are placed.

Co-ordination of objects and people's movement can affect the Usher person's self-confidence. If anything is moved or replaced, it takes more energy for that person to find things again. No Usher person likes to feel his or her independence is becoming more and more restricted.

Recognition of the partners body language is difficult due to the narrow field of vision for example. It is only possible to see the other persons face when looking directly at them. This situation becomes impossible when lighting conditions are difficult. Sometimes a deafblind person needs to have some kind of confirmation that they are being heard and understood when talking to another person.

Hearing and visually impaired people need to maintain eye contact while they are talking, compared to hearing people who can still continue talking, even when in a different room. A visual sign, signal or response is necessary during the conversation to prevent feelings of anger and frustration.

(b) The Hearing/Sighted View

Hearing/Sighted people use their ears, eyes and Body Language to communicate and do not have to use any tactile forms of communication. If a partner's spouse is deafblind, there are many situations where the hearing person may not be aware of, especially regarding the changes of the hearing and vision. This can lead to misunderstanding, frustration, stress, pressures on the relationship and can cause friction. Some of these situations are outline below:

- Repetition of own words can prove to be very slow and takes much energy.
- Repetition of other people's words can be time consuming.
- Different forms of communication may have to be used in different environment .
- If a couple is not used to Tactile Communication, the speed of communicating can be very slow.
- The Tone of the voice can be very difficult to hear, when teasing and joking with each other.
- Items in the home environment such as furniture, books, kitchen utensils etc. have to be kept in the same places.
- The hearing/sighted person needs to tell the Usher person, where they are moving to in settings (home, outside home).
- Partners are often bumping into each other.
- Guiding becomes a necessary way of life.

- Concentration on one thing at time is necessary if an Usher person is doing something on their own such as reading, watching TV, so communication can be difficult as eye to eye contact is required.

HOW TO IMPROVE COMMUNICATION

The Usher person must learn to be independent as far as possible and not to rely on other people to do things for them. It is important to consider that as the demands placed on the hearing/sighted person increase, more energy is required causing tiredness. This can cause stress and pressure in a relationship or marriage. So the Usher person must learn to help in the daily living chores and to have specific responsibilities. Another consideration is that both people should learn to be more open with each other to explore communication techniques and discuss problems. Some suggestions follows.

(a) One to One Communication

Speaking clearly in a suitable lighting environment when communicating with hearing impaired Usher people allows lipreading to be much easier. If the lighting conditions are difficult, the Deafblind Manual Alphabet can be used. For example: the first letter of every word eg. "p" for pizza.

This method saves a lot of time and energy in having to repeat words in conversation. Depending on the situation or environment (in dark places), the Usher person can receive some form of feedback through 'touch'. A gesture such as tapping for 'yes' ('okay') and a rubbing from side to side for 'no' ('what'), can be done wherever suitable on the body. There are other methods such as placing the hand on the side of the face and feeling the head nodding for 'yes' or moving from side to side for 'no'.

Maintaining body contact allows the Usher person to feel safe and to know where the other person's is for example, touching the person leg with a foot. The use of a video camera can be used both at home and by the professionals when running specialised Usher Rehabilitation Courses to help identify what forms of communication are or could be used.

(b) To Get Attention (Distance and Direction)

Here are some examples in order to attract the other person's attention before speaking that saves both their energy, time and misunderstanding:

- Get into the line of vision first.
- Place the palm of hand onto the Usher persons face and position head, so eye to eye contact can be made. Some people find it difficult to co-ordinate where a sound or a vibration is coming from.
- Banging on a Table or Floor, with a hand or foot to create vibrations.
- Waving a hand slowly from side to side at a distance.
- Blowing towards the persons face. This is particularly useful in a public place to avoid attracting attention.

If an object is dropped onto the floor the Usher person finds it difficult to see where it has been dropped. To save both partners energy, one can use different forms of communication such as speaking, signing or using gestures as to where the object has fallen, eg. left, right, up or down.

To indicate a direction or obstacle or even an aeroplane in the sky, the partner can get the Usher person to hold onto their hand or arm and point in the direction of the subject concerned. In the home environment it is necessary to indicate by a signal or sign, which room or direction the other partner is moving to. One must realise it takes a great deal of energy for the Usher person to sense where someone is in the room or house, as they are unable to hear or see things outside their field of vision.

(c) Loving Relationships

An Usher person has to take off their hearing aids during the night time and communication may prove difficult. This is where both the Deafblind Manual Alphabet and hands-on gestures/signs are important to avoid any frustrations or misinterpretation.

If an Usher person develops a special loving relationship with a partner, it is very important for both people to understand and recognise the body language and responses that will develop as time goes on. Both partners should be open with each other, develop their own signs and gestures so communication does not become a problem.

Both partners need to show and express their feelings openly to each other particularly in a sexual relationship. The words 'I love you' can have a deep emotional effect on both partners. It can also give the Usher person reassurance, security and self-confidence. It is difficult to pick up the signs and sounds of responses so each partner has to work out their own methods. A suggestion is to discuss openly anything which may have been misunderstood so both partners can learn about their body responses.

The need for human contact and companionship can be considered as a major priority for an Usher person. For example, on an Usher course in Birmingham, England, a 19 year old male asked, "How can I ever have a girlfriend if I cannot take her to the cinema or a Disco, or drive a car? How do I tell her that I cannot see in the dark?"

One has to be flexible according to the situation and perhaps to be open when the time is suitable, if she is a nice girl or a good friend, she will help you.

Usher people are very sensitive, they need to feel loved, reassured and to be able to share in a loving relationship and probably regard this as an important area in their lives.

Very often the Usher disability can be an obstacle especially when one considers their quality of life. The need for social groups and clubs have a vital role in providing friendships for Usher people.

CONCLUSIONS

We think that the important priority for families is to have a Common Language, whether it is a spoken, signed, deafblind manual alphabet or gestures, so that both partners are able to communicate in the best possible way. This language should allow both people to communicate in any environment whether at home or in noisy atmospheres. To find this language requires patience, understanding, listening and a willingness to be open and share experiences.

Both partners need to work out individual signals, signs and gestures, using different forms of communication. They need to practice regularly and learn from each other, this is a two way process of learning.

Relationships and marriages may very often break down, where there is an Usher person involved due to a lack of Communication between partners. It is necessary for couples to become aware of the changes and adaptations that will happen when the Usher person's vision or hearing starts to deteriorate. They have to be able to share and talk openly about the little problems which they have to cope with during any changes of sight and/or hearing.

It is important that Professionals working with Usher people are trained to understand the different methods of communication and for Local Authorities to provide the necessary support services, such as interpreters, counselling, rehabilitation and mobility.

Furthermore, the acquisition of technological devices such as computer hearing aids and radio microphones should be made more widely accessible for a hearing impaired usher person.

Each partner need to have own time alone. Other friends and social groups are necessary so they can pursue their own interests with other people. They must not feel totally dependent on each other, this can in many ways make a relationship or marriage stronger. Neither people in a relationship should be dominant, they should try to give and take, help each other doing domestic chores like washing dishes, clothes, cleaning the house. No matter how small it is, Usher people are not 'disabled' (in their own thinking), they just have restrictions in their hearing and sight, and need to have additional support if they get into difficulties. They are quite capable of doing anything, it is a matter of learning to change, be encouraged to do things in a different way and have faith and courage.