

Communicating Emotions and Empathic Listening as part of Rehabilitation for Deafblind people.

Introduction

We often refer to the emotional impact of deafblindness. We use words such as grief, frustration, depression, isolation etc. What do those words mean in real terms, in real people's lives? We understand the words but can we truly empathise with those feelings? The only way that happens is when someone is prepared to share their feelings and someone is willing to appropriately listen. People are born with a sensory loss, some gradually lose their sight and hearing and there are those who undergo a traumatic loss. The impact on those people will vary greatly and their emotional response will be individual. In my work with deafblind people and as a trained counsellor I have had the opportunity of listening as three people have been able to talk frankly and honestly about the emotional impact of deafblindness in their lives. They have very kindly allowed me to share with you some of our taped sessions together.

David Genever

David is a 65 year old man who lives with his wife in the country.

He has had a hearing loss for approximately 10 years. He owns and manages a farm with his brother. In November 2004 David had an accident on the farm when he was working with his brother to straighten the bent leg of a cattle feeder. The leg was hollow and square shaped and had become compressed with hardcore. David's brother started to heat the metal leg while David was stood above

the leg ready to straighten it. What they didn't realise was that a gas had built up behind the obstruction. This gas ignited with the heat and the hardcore shot out of the leg and straight into David's face. He had severe facial injuries and lost both eyes.

David's expressive communication is speech and his receptive communication is clear speech.

Just a Blind Tractor Driver – David Genever

This is the transcript of an interview with David Genever. David is a farmer and in November 2004 he had an accident on the farm which caused severe and traumatic facial injuries. He lost both of his eyes. He already had a hearing loss due to the noise of the tractors he had driven.

David: From the accident which happened 18 months ago I am beginning to realise what a poor thing I was when I came out of hospital. Because I came out of hospital thinking that if I could have seen I could have gone back to work. But I think, my experience now is that even this time last year I had been out of hospital for over 6 months and I am having more trouble this year not being able to do the job that I used to do, than I did last year when I just took it for granted that I wouldn't do it. I went into hospital on November 18th 2004 and for 6 weeks I remember nothing.

Megan: Did you start thinking about what's going to happen when you came home, what's going to happen about your job?

David: Well, I suppose I wasn't really bothered about my job as I remember it. All I can remember was leaning very

much on my wife and relying on her to keep me going if you know what I mean, because basically I had got nothing and no prospects and I think as I look back, I think my only consolation in a lot of ways was that I am now 64 I should be 65 in October, and it's a good job that I have done most of the things that I have wanted to do already in my life because I wasn't going to get the chance to do them again. And that basically I was retired and I think in some ways, almost on the scrap heap. If it had got to happen it was a good job I was near retirement age because in fact, all it has done, is brought my retirement forward a couple of years.

Megan: Yes.

David: Or supposedly retirement, because Gail had said that the hours that I was working prior to the accident she was very concerned about the time I was working and the effect it was having on our lives. She was saying that she had even considered leaving me. I had never realised it was getting as bad as that, I know I was working a lot of hours.

Megan: So would you say you were a workaholic at that point?

David: Oh definitely. I have been for the last 50 years I suppose. Yes, and that was the biggest thing to come to terms with in a lot of ways, not being able to work. Which is one of the reasons why I talked to Shirley (rehabilitation worker) initially and she suggested that I talk to you as to whether there was anything I could do to help you. And I am still working along those lines, I am still thinking along those lines as to where I can find openings that are suited to a blind person that can talk..... and hear. I am lucky

that with the aid of modern technology I can hear conversations.

Megan: What has the difference been?

David: I think that I am recovering. I am getting back to how I was now I'm just a blind tractor driver whereas last year I was still an invalid, I think. I have got a lot of other things wrong, I know, I was recovering last year, shall we say. But, I think this year I'm getting that little bit more back to normal, if that's the way to put it, I don't know.

Megan: So you are saying it's easier this year than last year?

David: No it's harder.

Megan: How is it harder?

David: I wish more that I was there (on the farm). When the jobs need doing, especially when they are short staffed and it looks as if they want another, if you'll pardon the expression, another bum on the seat, I could be that bum on the seat if I could see, but I can't see so that's it. But it doesn't stop me wanting to be there.

Megan: So are you saying that you feel you are letting people down?

David: In a way yes and I am also a real pain to my wife because I am all the time wanting her to take me to different places as I did yesterday. I wanted to go and see what was happening, how they were getting on and all that sort of thing. Doing the job as I should have been doing.

Megan: Right. So it's having impact on both your lives then?

David: Oh yes, yes definitely. Yes, Gail works wonders to look after me the way she does and to remain cheerful. I am sure I get on her nerves no end of times but we're still together. I think, I suppose if I've changed at all I'm more sentimental than I used to be, I feel myself choking up at certain times and that sort of thing, which I don't think I did before.

Megan: And what causes that?

David: Different things I hear, stories about what's gone on with certain people and the way that events build up and all of a sudden it gets a lump in my throat, and that's how it affects me.

Megan: Is it particularly to do with other peoples hardships? What other people go through?

David: Yes, I think you could be right there. Yes it's other people experience of life and how they are shaping up and that sort of thing. Yes.

Megan: Do you think that is because you have had a taste of that yourself?

David: I suppose that's a nice way of putting it but you could be right Megan, I don't know. But I am certainly a lot more aware of those things and I think I am more aware of people, it's a funny thing to say, of people dying.

Megan: Do you think there's anything good to come out of your accident and what's happened?

David: Well from what my wife has told me since the accident happened what sort of trauma she went through while I was in hospital I don't know. Because I, people say to me I came to see you in hospital and I say "did you?" I can't remember, I can't even remember people coming to visit me. Nobody at all, other than the one coming I think once before round about Christmas time and she took me out for a walk. That's the only thing I can remember. But I think that the good that has come out of it is that I am still here living with my wife and I think there's a risk that the way things were going I might, work might have taken over, and she might have slipped away. I hope not but I think there's a risk that that might have happened. And that would have been terrible.

Megan: Do you ever feel angry about the accident?

David: I haven't done, but as the accident happened there was only myself and my brother there when it happened. He was working the torch, warming up the metal and I was pulling on the middle bar that I suppose the people that came to see Paul after it happened have suggested it was the ignition of methane that had caused the explosion and shot the stuff into my face and we both should have known better. I could be angry but I try and avoid that. Because I think it would be very much counter productive.

Megan: Umm, umm, ok

David: I do have "why me" days though

Megan: Do you?

David: Yes, because you know, when you think about it, it could have gone over me shoulder instead of hitting me in me face.

Megan: And how do you think round that one? Or don't you?

David: I don't. No I think there is somebody somewhere that organises these things and it was my turn. It's a sad thing to say but I think that was it. But I still go to church.

Jo Stimson

Jo is a 54 year old deafblind woman who lives with her husband in a village location. Jo has one married daughter, age 30, who lives nearby and who works full time. Jo's sight has been deteriorating since the age of three and her hearing since the age of 17. She is registered blind and she has a severe hearing loss. She also has tinnitus. When she left school she worked for an agency as a Nanny from the age of 16 -23. When her daughter was born and Jo's hearing and vision deteriorated further she had to give up working.

Jo's expressive communication is speech. Her receptive communication has had to change over the years due to the progressive hearing loss. Jo can still access clear speech in a noise free environment but is also learning to receive deafblind manual alphabet.

Treading Clouds with Glued Feet

This is the transcript of an interview with Jo Stimson about her emotional response to her sensory impairment and about the grief she feels over losing the ability to hear music.

Interviewer: Megan Mann

Jo: I always felt that I had got the problem, the fault was with me. I was having to slow down, file down because of my problems. It never entered my head that I should be thinking about, well what about me in all this. All I wanted to do was be a mum and a wife and lead the appropriate lifestyle that everybody else does. That's all I wanted to do and its only since Sense came into my life and made me start thinking about the way things have been that I have realised that I have missed me totally. I was taking such a back seat, that most of the time I didn't exist. I was the one with the problems, that's the only thing I could see. I was that one. That's where the big guilt issue really has driven me on, if you like, it's guilt.

Megan: Tell me what the guilt was like. I understand what the word guilt means but how did you actually feel?

Jo: It's heavy, It's heavy, It's heavy, It's a very heavy feeling, quite mentally debilitating. I had a phase where I was quite low and the path to getting into that situation is very slippery and very quick and you hit an all time low and mentally what happened to me, was that I couldn't see the wood for the trees. But the turning point was when I realised that it was me again, this is the thing, it was me again that was letting this happen. It is a sheer luxury, this sort of self pity, is not too mild, that was happening to me. It's the only time in my life that I have

ever thought, “Why me, why is this happening to me?” To be honest, I have no right to feel like that. I should say, which I have always said and I always will say, is “Why not me, why not me? We live in such a confident world that somebody that slightly deviates from the norm, people can’t deal with it and people justify – I have heard it, I have heard it, I have had it said to me, that I am very difficult to be with. And yes I am. There would be nobody who would applaud that more than me. They justify not coming by saying that, but they don’t stop to think what it does to your confidence and that your confidence knocks your self esteem and you go in that knock on line, one thing affects another.

Megan: As you were talking you sounded quite angry.

Jo: I am now, I am. I could do damage, physical damage when I think about it because I have let this happen to me. I have let it happen without knowing that it’s happening and it was only when Sense came into my life, and we started talking things through in a black and white way, this is the most wonderful thing. I have been able to be really honest, I think for the first time in my life, or the first time in a very long time, be really honest about the emotional side of it, because nobody wants to know, nobody has got the time. Humanity itself is so busy, and I applaud that, that’s the way it should be. You know, everybody’s got problems of their own, nobody wants to stop and listen, they see that you look all right, fine, end of story. That’s why I spend half of my life being totally invisible, because people see me as I am which, for the most part looks OK. They don’t want to look underneath that. So now, now I have been able to talk things through properly and be totally honest about the way I feel and too, getting very good honest feedback, this is the ultimate

thing, it is getting it said as it should be – no frills, just black and white.

Megan: Has that been uncomfortable at times?

Jo: Yes very, very. It is one of the things that it did for me was that I had to confront me for the first time in years. It made me realise that I actually exist and that was an amazing feeling, an absolutely amazing feeling, I cannot tell you what that was like. That was treading clouds but with glued feet. You know there was something still pulling me down and yet there was this elevated bit that this was me.

Where had I gone? My mind's just saying that sort of lovely feeling when it dawned on me that, why hadn't I thought about me?.... It was just.....**(Jo gets upset and interview stops).**

(Break)

Jo: One of the things that has played a tremendous part emotionally with my hearing loss is that I can't listen to music any more. I could cry buckets full every time I think about it, because I used to listen to music quite a lot. I mean music's magic, you know, its pure magic. It lifts you up when you need to be, it calms you down. You know you can sit down with something that you're familiar with; it doesn't matter whether it is a classic or The Wombles, as long as you're at one with it, and it just totally relaxes a body. One of my most favourite pieces of music is the 'Slaves Entrance' from 'Aida', and it's such a strong piece of music. You know you can feel really uplifted and ready

to go.(Jo rubs her arm)..... look at the goose pimples..... just thinking about it. But now I can hum it, I can whistle it but I can't hear what I whistle, this is the thing, so there is no point in doing that.

And one of the awful things, not so long ago actually, I was in the sitting room, we were actually having a TV dinner which we don't do very often. David had got the television on and he had got, I cannot think what the programme is called, but they have got children, or teenagers, and they were pretending to be somebody else. I said to David "Who is he going to be?" and David said "He is going to be Jackie Wilson" and my mind said straight away um what's it called?....[Jo hums the tune] I cannot remember, but this song used to be one of my ultimate favourites and I would dance my way through that in no time. So I got near to the television on my hands and knees to see if I could hear this. I couldn't hear it and my mind was singing it, but I just had to sob my way through and in the end I just came out of the room(Jo gets upset)..... and thinking to myself, you know a world without music not very pleasant. But, the upside of it is, well for me, I am not quite sure about everybody else is that I sing quite a lot, [Jo laughs] I go through my days singing, or David will say to me [laughter] "you're humming".

The other thing that terrifies me, I am terrified of losing the memory of the music that I already know. If somebody said to me about something that's recent, I haven't the vaguest, I never will have, but I have years of experience of music, which in essence at this point is keeping me going because I can still sing, I can hum, it drives David mad, you know I am sure that there might be divorce proceedings in the offing because I am driving him mad

because I am always humming or I am always singing. I even do it when I go to Abigail's. Marcus said to me, not last weekend the weekend before, "You're humming Jo" **[laughter]**

But now, because I am trapped in, if you like, this noisy world without seeing properly, without hearing very much, now my mind goes into overdrive and I go on mental journeys with that particular music and everything just comes flooding back.

Megan: What was the song?

Jo: Yes, it was Jackie Wilson, "lifting me higher" I think it's called. You know it is really a dance tune and I sang it Meg, I sang it.

Megan: How did it go?

Jo: **[singing]** "Your love is lifting me higher, than I've ever been lifted before, just keep it up, you're my desire, I'll be at your side for evermore. Your love, your love keeps lifting me up, just keeps lifting me higher." **[lots of laughter]**

Jimmy O'Hare

Jimmy is a 37 year old man who lives independently as a tenant in self contained flats. Jimmy was a child of deaf parents, born with a profound bilateral hearing loss and partially sighted, Jimmy is deafblind as a result of the Rubella virus contracted by his mother during pregnancy. Jimmy learnt and used British Sign Language (BSL) with

his family and through his early school years, although his vision was deteriorating all the time. He was registered blind at the age of 10 and started to learn Braille and Deafblind manual. He now only sees light and dark. Aided by his hearing aid, Jimmy can identify environmental sounds such as aircraft, loud traffic, babies crying and the telephone ringing, and he can also hear shouting and loud laughing. He cannot hear speech.

Communication

Expressively, Jimmy uses the following methods of communication:

- Deafblind manual
- BSL
- Occasional vocalisations – loud laughing, “ya” for yes, and” no” for no
- Facial gestures and body language
- Actions – when other communication fails, Jimmy takes direct action eg. after repeatedly and unsuccessfully asking for a replacement vacuum cleaner he took a pair of scissors and cut the plug off the flex!
- Braille, using his “Versa Braille” equipment to phone and write to people. He writes frequent letters to express his feelings and opinions.
- Touch – Jimmy likes to feel actual objects, animals and people and then reproduce them through the medium of clay.

Access to Information

Jimmy receives information via:

- Deafblind manual

- Hand under hand signing (although he prefers to receive manual)
- Touch – Jimmy loves to explore objects using his hands, and to have them described, using deafblind manual. In a familiar external environment, Jimmy uses his hands rather than a mobility cane to find his way around.
- Smell – Jimmy has a highly developed sense of smell and will reject people or objects if he does not like the way they smell.
- Residual hearing – Jimmy will query why people are laughing or whose phone is ringing when he hears it.
- Braille – Jimmy can read Grade 2 Braille but finds Grade 1 easier. He also prefers the refreshable Braille on his Versa Braille machine to paper Braille.
- Taste – Jimmy will identify food by taste, but prefers to be told what it is first (via Deafblind manual)
- Sight – but only to identify if it is a sunny day, night time or if he is going from a light environment to a darker one e.g. entering a building.

Baby Love – Jimmy O’Hare

This is the transcript of an interview with Jimmy O’Hare about his desire to find a partner and have a family.

Interviewer: Megan Mann

Communicator Guide: Janet Mc Neill

Megan: What do you want in a partner? What will your partner be like?

Jimmy: Caring, loving, like having fun, laugh, like animals, cooking, go out for meals. I want a partner who can see

or Deaf or hearing. I want big, cuddly build because-comfy.

Megan: Are you sad because you don't get enough cuddles?

Jimmy: Yes, yes.

Megan: How do you feel if somebody cuddles you?

Jimmy: I feel happy when lady cuddles me and puts arms around me and kiss because it makes me very happy and I cry because I want partner.

Janet: I agree it is very nice to have a partner to cuddle. It does make me feel happy too.

Megan: Did you have a lot of cuddles when you were a little boy?

Jimmy: Yes

Megan: Who cuddled you?

Jimmy: A lady named Sue, I loved her because I think she is my mummy. I want to cry because my mummy cuddled me when I went to bed.

Janet: You thought Sue was your new mum but Sue was a lady at school. She was a very kind lady who used to look after you when you were very small?

Jimmy: Yes

Megan: Do you want any children?

Jimmy: Yes I would like one child.

Megan: Do you think what it would be like to have your baby?

Jimmy: The baby will be very small and will sleep a lot. It will need lots of changes of nappy and will need feeding and bathing. The baby will need washing and changing clothes. If the baby cries it will be because it's tired or maybe hungry or has wind or wants something. Maybe because it has a dirty nappy and needs the nappy changed.

Second Part of DVD

Verbal description

Jimmy is visiting the home of Alex Oram. Alex is a lady who three weeks ago, gave birth to a baby boy named Luke. Jimmy is accompanied by Janet McNeill and a male support worker named J.J. Jimmy is on the settee, with J.J. sitting on his right side and Janet sitting on the arm of the settee on his left side. Janet is holding the baby. She slips the baby carefully into the arms of Jimmy. He cradles it in his left arm and with his right hand he immediately begins to feel the baby's arms, hands, tiny fingers and very gradually moves down exploring the baby's body and legs. Janet reaches over and strokes the baby's head and touches his nose with her index finger. She moves her hand from the baby to Jimmy's hand. She lifts Jimmy's finger and guides it towards the baby's little nose. Jimmy feels the nose and then touches his own nose as if comparing the size. Janet touches Jimmy's nose as if confirming his observation. Jimmy then feels and strokes

the baby's head and soft dark hair. Jimmy starts gently rocking sideways. J.J. taps Jimmy's right hand and he holds out his hand in readiness for communication. J.J., using deafblind manual makes a comment to Jimmy about the baby. The baby moves slightly in Jimmy's arms, stretching and settling. Jimmy continues rocking and at the same time he makes noises as if singing to the baby. Jimmy has a look of contentment on his face. He again uses his right hand to feel the baby's cheek and arm. He has a very intense expression on his face. He feels the tiny little fingers again. Then he smiles, a big broad beaming smile of satisfaction, a look of great contentment.

Conclusion

We have seen a mix of emotions expressed through these interviews both positive and negative. David, Jo and Jimmy have had the opportunity to talk about and express their feelings. Not everyone would want to or need to do that but everyone should have the opportunity offered to them. Often, practical assistance is given in the form of rehabilitation. One-to-one support offered, new skills taught and technical aids provided. These measures do a lot to alleviate the practical issues but what about the emotional impact? I mentioned in the introduction the situation of someone wanting to share their feelings and having someone who will appropriately listen. The word 'appropriate' is vitally important. People need to feel safe in that setting. That is not just about confidentiality but it is also about how someone will respond to their emotions. In my experience there is very little offered in the way of counselling. Counsellors who have the communication skills or understanding of deafblindness are few. What could be done to improve this situation?

I believe that there are three ways that this needs to happen.

- Basic counselling skills should be included in the training of all professionals working with deafblind people.
- Existing mental health services should have deafblind awareness as part of their on-going programme of staff training.
- Access to specifically trained counsellors specialising in issues related to dual sensory impairment.

Finally, we need to recognise that there are no magical solutions to be offered. No one can heal the emotional scars of another. People should have these services available so that they feel supported and listened to, enabled to tap into their own inner resources and to make progress as they see fit.

Megan Mann 10/10/06