

# WCB Roundup Supplement:

## Emotional Support, Wellbeing and Counselling for Visually Impaired People

Winter 2011/2012



## INTRODUCTION

Each edition of Roundup focuses on a theme: in this quarter we are looking at the whole area of emotional support, wellbeing and counselling for visually impaired people. To put the issue into context, we start with a personal experience of sight loss from Hilary Lester.

We have articles from several professional experts in this field: Dr Suzanne Hodge considers the emotional impact of sight loss; Dr Gail Bailey writes about the impact on children and young people; Dr Dominic ffytche explains Charles Bonnet Syndrome, an aspect of visual impairment which causes particular distress; Dr Susan Dale introduces an extract from her recent book based on research into the experiences of VI people, and Claire Nollett from the School of Optometry in Cardiff talks about depression, a new research study in this area and existing sources of support. We also have an article about Sight Support's counselling service.

Several organisations are now providing telephone befriending and support services for their members. We have a summary of recent research by Thomas Pocklington Trust into the lessons learned from provision of such services for visually impaired people, and provide a summary of the telebefriending services available in Wales.

We are very grateful to all authors for their contributions to this issue.

## A PERSONAL VIEW

*Hilary Lester is a trustee of Sight Support, and in this article she describes her own experience of coming to terms with sight loss.*

I have always been short sighted and learnt to cope with that as the years rolled on. I had a haemorrhage in my left eye in the early 80s followed by a detached retina in 1991 and then developed early cataracts in both eyes. After surgery for one in my right eye I then had a detached retina and following the operation for this, high optic pressure which was not able to be maintained, requiring yet another operation. My consultant was lovely but did not tell me that my sight would not improve. He just kept saying 'we'll see.....'.

When I was transferred back to my local hospital the consultant I saw was much more matter of fact and told me that things would not improve. I was registered initially as partially sighted but this was altered to blind/severely sight impaired in 2002. Although I knew in my heart of hearts that the situation was not going to improve, it still came as a shock and reduced me to tears. There were no Eye Clinic Liaison Officers (ECLOs) at this stage but one of the nursing staff approached me and asked what was wrong, and she gave me a card for Sight Support, formerly Gwent Association for the Blind.

It took me a while to pluck up courage to phone them but when I did they could not have been more helpful. They listened and then quickly arranged for a social worker and rehab officer to visit. I was soon equipped with symbol cane, blobs on my washing machine and cooker and advice about the blue badge scheme, benefits etc. I also had the opportunity to attend meetings and meet other visually impaired people and the staff of Sight Support.

Whilst I appreciate that my life has to be different it is still nice to be treated normally, however this takes personal acceptance that you

cannot do everything yourself and do need help for your own health and safety. I was also awakened to the impact that my impairment could have on friends and family. This was by a close friend who stopped visiting: she was finding it hard to accept what had happened to me and did not know how to cope. When she mentioned it we both had a good cry and have been firmer friends since.

To me the most important thing is not to pretend that you can see, but to tell people that you struggle - they are more than willing to help, and with guidance on the best way to do this, life can be great. I have recently trained and qualified with my guide dog, Yalena, so have reached yet another phase of acceptance of my situation.

It is invaluable to have contact with people who understand how you are feeling and so the telebefriending and counselling service now offered by Sight Support is vital.

It is also important that people are dealt with fairly quickly after diagnosis and so the ECLO service and low vision service are valuable. I will always try and stay positive but life can be extremely frustrating at times and could easily lead to depression.

I try and retain my sense of humour and have a network of friends that will listen on a bad day. However if you are not fortunate to have friends and family then counselling could be of benefit to you, as it helps your self confidence and shows you that you do not have to face things alone.

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# THE EMOTIONAL IMPACT OF SIGHT LOSS – AND WHAT CAN BE DONE ABOUT IT?

*Dr Suzanne Hodge is a lecturer in research methods at the Faculty of Medicine at Lancaster University, and has a particular interest in disability and mental health.*

Sight loss is often described as a ‘journey’, which implies a sense of travel, of movement from one place to another. It also carries an idea of adventure and optimism - a holiday or the start of a new phase in life. However, at the point when people first lose their sight any such positive associations are likely to be far from their minds. The kinds of feelings that people go through when they first lose their sight or realise that they are likely to lose their sight, are those associated with bereavement - shock, fear and a profound sense of loss. With the support of family, friends and professionals, many people learn to adapt to life with impaired vision and to cope with the many practical, social and emotional impacts that sight loss can have. For them, the metaphor of sight loss as a journey might begin to have some meaning as they learn to live differently, their lives taking different routes than they might otherwise have done had they remained fully sighted. However, others find it more difficult to adapt and cope, both practically and emotionally, and can struggle to come to terms with the loss of their sight and to cope with the changes it brings to their lives.

There is a growing body of research into the impact of visual impairment on people’s mental health, with studies consistently showing much higher rates of depression amongst people with visual impairments than amongst the general population. For older people, particularly, visual impairment can have a major psychological impact, with rates of depression in older people who lose their sight shown to be between 25 and 50% (Burmedi, D., Becker, S., Heyl, V., Wahl, H. W., & Himmelsbach, I. (2002) Emotional and social consequences of age-related low vision. In *Visual Impairment Research* 4(1): 47-71).

Interviewing people with visual impairments about their experiences of losing their sight over the last few years, I have been able to gain some

understanding of why these figures are so high. The impact of sight loss on people's well-being can be profound and wide-ranging, affecting virtually every aspect of everyday life.

One of the most obvious practical effects of visual impairment is on mobility. It can mean that people are no longer able to drive and instead have to rely on public transport, or on the help of other people to drive them about. For some people, being told they can no longer drive is itself a psychological blow, signifying a loss of independence. Having to rely on friends or relatives to take you to the places you want to go can create tensions in relationships, with the visually impaired person often not wanting to be a burden on others or feeling frustrated that they are forced to fit in with other people's arrangements.

Using public transport brings its own difficulties – despite progress made over the years to make public transport more accessible, many visually impaired people report a lack of staff awareness that makes travelling anywhere, particularly by bus, stressful and frustrating. Added to their fears of getting about with limited sight – fear of falling or of making themselves appear vulnerable by using a white symbol cane - this can result in a loss of mobility. This affects their ability to do many of the things that sighted people take for granted - going shopping, visiting friends and relatives, taking part in leisure activities and accessing the services they need. It can also result in them losing their confidence, as they go out less and less, and they then start to become increasingly isolated. This isolation can further exacerbate feelings of emotional distress related to their sight loss.

Another fundamental aspect of life affected by sight loss is the ability to read. Again, the impacts of not being able to read are both practical and emotional. Reading is such a basic, taken for granted ability for most of us that, until we are unable to do it, we are probably not aware of how much we rely on it. Reading mail, recipes, food and medication labels and bus numbers are just a few of the very practical tasks that are affected by sight loss. Again, this may bring an increasing dependence on others which can add to the emotional impact of the loss of sight itself. For some older people it can be particularly difficult having to start

asking for help from grown-up children, suddenly becoming dependent on the people who, for so long, had been dependent on you. The loss of privacy involved in asking family members, friends or neighbours to read mail or other personal documents may also be difficult to accept.

For some people one of the hardest things about losing their sight is no longer being able to read books. And even though there is now a burgeoning supply of audio books available, this does not lessen the enormous sense of loss that people can experience when they are no longer able to read for themselves, to flick through the pages of beloved books that they might have collected over years and that have particular associations for them. As one man put it to me 'it would break my heart to get rid of my book collection, but is there any point keeping 700 books if you can't see them?'

Sight loss can affect older people particularly badly, coming on top of other losses, such as the death of a spouse. It can also increase the practical difficulties they have to deal with, as not only may they have to find different ways of doing things they had previously relied on their sight for, but they may also have to take on responsibility for tasks that had previously been taken care of by someone else. Physical ill health, either of the individual or of their spouse, may also add to the difficulties facing older people who lose their sight.

Whether people are able to cope emotionally and practically with losing their sight is partly a matter of individual personality and circumstances. However, it is also significantly affected by the kinds of social, emotional and practical support that are available to them. For most people with visual impairments, their main source of support is informal - family, friends and neighbours. In many cases this can be sufficient to enable them to cope, emotionally and practically. However, even people who, on the face of it, seem to have good levels of support, can be lonely and depressed. When the people around you continue with everyday activities that you are no longer able to fully participate in, such as watching television or looking at family photos, this can reinforce feelings of loss, creating a sense of isolation from the world that you used to be more fully a part of. Some of this may be lessened by family and friends adapting the way they interact with the visually

impaired person so that they are helped to feel included in activities, and to feel more in control of their environment. For instance, one elderly lady with virtually no sight at all explained to me how important it was to her that she was able to write out her shopping list in her own fashion, even though her son then rewrote it so that he could read it when he went shopping for her. Although she lived alone, she was enabled by the sensitive support of her adult children, to live as independent and fulfilled a life as possible. Between them she and her children had developed ways of interacting with each other in which her sight loss was not a barrier. She took great delight in describing her Saturday evening routine to me, which involved her son and daughter and their families coming round to her house to share a meal with her, and then doing a quiz together from the paper, an activity which always resulted in much laughter.

This individual benefitted from a naturally positive disposition and from sensitive, caring support from her family. Many visually impaired people do not have these advantages. With the link between depression and sight loss so well-established, there is a strong case for formal emotional support to be made more accessible to people with sight loss. Research that I have undertaken with colleagues has shown that people using a specialist low vision emotional support and counselling service gained significant benefit from the service (Hodge, S., Barr, W. & Knox, P. (2010) *Evaluation of Emotional Support and Counselling within an Integrated Low Vision Service, Final Report*, University of Liverpool/ RNIB). However, there are relatively few such services across the UK, and, in the context of current funding cutbacks, there is a risk that their growth will be halted before they have been able to really prove their worth. It is to be hoped that resources will be found for the further development of services that can be seen as being as important a part of the work of low vision services as rehabilitation and optometry.

## HOW CAN WE PROMOTE EMOTIONAL WELL-BEING IN CHILDREN AND YOUNG PEOPLE WITH VI?

*Dr. Gail Bailey, a Child Psychology Consultant based in Pembrokeshire reports on research recently completed at University College London.*

*When Gail became affected by Visual Impairment herself in the year 2000, she set about researching the factors that young people think helpful to children and young people adjusting to sight loss. It struck her that there are many practical issues that can lead to frustration, loss of self-confidence and sadness if unresolved. Here are some of the approaches highlighted by her research.*

Emotional well-being and motivation are underpinned by a sense of competence, autonomy and a sense of belonging. If you think about it, teachers, parents and practitioners supporting children and young people with visual impairments can do a lot of practical things to actively promote emotional well-being by ensuring support in these three areas.

For example, ensuring that a child is able to engage with and access the curriculum comfortably will enhance their feelings of competence and autonomy. However, ensuring access to parts of the curriculum such as personal and social education is particularly important to ensure that the child also develops the social skills to enable them to have confidence to engage socially in both formal and informal situations.

Of course, it is not all about education. The opportunity to take part in leisure activities is also important for building positive emotions and offsetting anxiety (we all know how much more relaxed we feel for having a chance to go for that swim or to go to the gym). Community services and partner organisations therefore play an important role in removing barriers to participation in such activities.

As well as social and emotional skills and opportunities to have fun and socialise, at times children need support to develop a strong sense of who they are. It is important for people around them to challenge any negative thoughts about what it is like to live with a Visual Impairment,

to help the child to accept who they are. Also, as with any child, it can help to identify the child's enduring personal characteristics to help them develop a strong sense of self-worth and positive identity. This will help them to be assertive should they need to combat any challenges they face as they develop and venture out into the world.

See the child, not the disability.

Sometimes, especially through periods of change, like a house move, change in school, adolescence or a deterioration in eyesight, children with VI may also need affective emotional support. At times like this it is important for people around them to remind them of past problems solved and help to encourage them to use their personal strengths to find solutions. A practical and optimistic approach will help in setting small steps towards future goals. Referrals to other agencies such as low vision services may help if there is a deterioration in sight. Mobility assessment involving parents may help to re-assure families that the child will be safe as they try to assert their independence in adolescence.

Should feelings of anxiety, sadness or frustration persist in spite of measures in place to meet need, a referral on for emotional support may be indicated. A referral to an educational psychologist who can work closely with their local sensory impairment team may be useful. In Wales, the Visual Impairment and Emotional Well Being project was set up in 2004-2008 by RNIB with Big Lottery funding. The objective was to deliver training in each of the 22 unitary authorities to a psychologist or counsellor in the specific emotional needs of children with VI. Several years on over 90 front-line practitioners have undertaken the training and work at local level to address concerns. To find out more about the route for support locally, a call to RNIB Cymru will help you in establishing the link person in your area. This information is currently being updated for the Welsh Eyecare Initiative website. In addition to this, the Welsh Assembly Government have a strategy aiming to place a school counsellor in each secondary school by the end of 2011. School counsellors in Carmarthenshire,

Ceredigion, Pembrokeshire, Neath and Port Talbot have received input on supporting children with visual impairments and other disabilities so far.

As far as support for parents is concerned, societies in Wales are working closely with Guide Dogs to pilot a new initiative to support parents who are having difficulty accepting or understanding sight loss in their children.

Finally, it is also worth remembering that the many children and young people with visual impairments adjust successfully with time. In order to help this happen, timely support from the Welsh Low Vision Service can help to replace lost skills with practical support such as low vision aids and even electronic magnifiers. The most important thing is for people around the child to be positive about the future. After all, no matter what happens to us in life, we always have control over the attitude we take towards it.

If you would like to know more about training available to front-line practitioners aiming to support EWB in children with VI, please contact Gail at [gail.bailey7@btinternet.com](mailto:gail.bailey7@btinternet.com).

Gail is the author of 'What Can you See? Resources to support the emotional wellbeing of blind and partially sighted young people'. Produced by RNIB Cymru, this book includes a range of activities suitable for primary and secondary school aged children and young people, as well as the adults who work with them. The resources are designed to encourage the development of social skills, empathy and emotional literacy, and can be used when providing individual support or in a group setting with peers, and also include activities to help sighted people gain a better understanding of the impact of sight loss.

What Can You See? is available in a range of formats from the RNIB online shop <http://www.rnib.org.uk/shop/Pages/home.aspx> and costs £12.50.

# CHARLES BONNET SYNDROME

*Dr Dominic ffytche, a clinical senior lecturer at the Institute of Psychiatry, explains this condition.*

Some people with visual impairment see things that are not actually there – a condition sometimes referred to as the Charles Bonnet Syndrome (CBS). This causes significant distress to a large number of people, not necessarily because the ‘visions’, more correctly termed visual hallucinations, are a problem in themselves, but because people fear they may be developing a serious mental illness or dementia. In this article I hope to dispel these myths by highlighting the fact that visual hallucinations are a normal response of the brain to failing vision.

Charles Bonnet (1720 – 1793) was honoured by the medical community in the 1930’s by having his name forever associated with visual hallucinations; yet, perhaps surprisingly, he was neither a medical doctor nor had a particular interest in the symptom. Bonnet had been fascinated by insects as a child and became in 1740, at 20 years of age, the youngest corresponding member of the French Academy of Sciences for his observations on aphids. He went on to study issues as diverse as insect metamorphosis, the regeneration of tape worms and photosynthesis. However, at the height of his scientific career, he was forced to abandon experimental work because of eye strain and pain when using a microscope. He turned to philosophy, focusing first on the relationship between brain, mind and religion, and in 1760 published his ‘Analytical Essay on the faculties of the soul’. Today ‘mind’ is perhaps closer to what Bonnet was referring to than ‘soul’ and ‘essay’ belies the fact that the work covers two large volumes. Bonnet’s Analytical Essay made a major contribution to our understanding of how different functions are localised to different brain regions; yet, it is not this that led to a syndrome being named after Bonnet. Instead, it was a few paragraphs hidden in Chapter 23 where, to illustrate his philosophical theory, Bonnet described an elderly man who experienced visual hallucinations in the context of failing vision. The man was not named in the first edition but it subsequently emerged it was Bonnet’s maternal

grandfather, Charles Lullin, a retired magistrate from Geneva whose diary revealed further details of the story.

Lullin had undergone a cataract operation on his left eye in 1753, aged 84, which had been a success and allowed him to read with glasses until September 1756. By January 1757 he could only perceive light in his left eye, vision in his right eye was starting to deteriorate and he could no longer read or write (he dictated his diary). Although his ophthalmological diagnosis will never be known, it is likely he had age-related macular degeneration. In 1758, Lullin started to experience visual hallucinations. These were silent, appeared in front of him wherever he looked and were seen in far greater detail than he was able to see real objects. The hallucinations fell into four main categories.

**Simple hallucinations** - Lullin's most frequent hallucinations were a multitude of, what he referred to as, 'atoms', varying in size and whirling about his field of view. He also described a blue handkerchief with four yellow circles with black borders in the corners and one in the centre; a spinning hexagon that looked like a component of a weaving machine and a white satin sheet covered in black shapes with golden roses. Sometimes his walls took on an orange tinge and were covered with pale blue, spinning, oval shapes about two inches long.

**Patterns and grids** – these included hallucinated walls and buildings of bluish cut stone with the line of mortar visible between the stones; scaffolding made from an assortment of beams; off-white and golden clover patterns, antique books or tapestries covering his walls.

**Figures** – these included neatly dressed and coiffured ladies carrying caskets or inverted tables on their heads; 8-10 year old girls dressed in yellow silks with rose coloured ribbons, pearl collars, golden buckles and diamond pendants who danced around the room; two well-dressed men, one with a red the other with a grey dress coat and hats bordered in silver. The hallucinated men and women were sometimes giant-sized with their heads reaching to the ceiling. Looking towards a fountain in the street from his window he hallucinated crowds of people or a

procession of three men in grey wearing hats walking into the fountain.

**Objects and animals** – these included a carriage complete with driver and horses which expanded to the size of a house; golden-framed paintings of different sizes covering the walls from floor to ceiling; giant pigeons, flocks of larks or white fluttering butterflies.

Charles Bonnet realised that his grandfather's descriptions would be dismissed by others as attributable to either senility or mental and physical illness. He therefore took great pains to assure the readership that, despite Lullin's age, other than his eye condition he was in excellent physical health, fully awake during the experiences and that his judgement, memory and understanding were faultless. To further emphasise the truthfulness and accuracy of Lullin's report, in 1759, when the hallucinations had resolved, Bonnet arranged for the diary to be signed as legal testimony by four witnesses, one of whom was Lullin's physician.

### **Visual hallucinations today**

One can find people with almost identical experiences to Charles Lullin in any eye clinic in the world. All of the hallucination categories he described are still reported today, with the addition of hallucinations of disembodied faces, often with a grotesque or gargoyle-like quality. We do not know exactly how many people are affected but there are likely to be 20,000 - 100,000 people in the UK with visual hallucinations caused by a single eye disease (age-related macular degeneration) and since they can be caused by any eye condition, overall the numbers are likely to be much higher. The hallucinations start in the context of failing vision and are worst in the first weeks and months following visual loss. They tend to improve over time and more than half of people affected no longer have hallucinations 1-2 years after they started. Stress makes them worse and they tend to be more frequent in the later part of the day or when relaxing, for example while seated listening to the radio. The hallucinations generally last a few seconds or minutes but may be continuous throughout the day. Only a minority of people will tell anyone about the hallucinations for fear of what it might mean and

this 'suffering in silence' is an important cause of distress. Some people also find the experiences distressing in themselves, for example, seeing a grotesque face leering at you or a brick wall obstructing your path while walking. Others find the hallucinations distract from visual tasks they are trying to perform, leaving them unable to make full use of their remaining visual abilities.

Brain scanning studies over the last decade have begun to explain the symptom. Loss of visual input to the brain through eye disease results in spontaneous and random firing of brain cells in visual parts of the brain. The location of this random activity defines what is hallucinated. For example, activity in an area that normally processes visual objects will lead to a hallucination of an object while activity in an area processing patterns will lead to a hallucinated pattern.

## **Treatments**

There are practical measures that can be tried to stop hallucinations while they occur including eye movements and alerting techniques. Counselling has a place for people who find their hallucinations particularly distressing. It is also important to consider other possible contributing factors such as particular types of medication or other illnesses. Advice from healthcare professionals should always be sought if the hallucinations are not typical of eye disease, for example if they are heard and seen or the person experiencing them is unable to understand they are not real. Yet, the most important treatment for visual hallucinations takes us back to Charles Bonnet's realisation that his grandfather was not suffering from mental or physical illness and that visual hallucinations can occur in someone who, other than having an eye condition, is entirely well. Education and raising awareness will solve much of the distress caused by a misunderstanding of what the symptom implies. Visual hallucinations are a normal brain response to visual loss - there is a 250 year old sworn testimony in Geneva to prove it.

*Factsheets on CBS for are available from RNIB (0303 123 9999) and the Macular Disease Society (0845 241 2041).*

## **'SONGS AT TWILIGHT' BY DR SUSAN DALE**

*Susan Dale completed a doctorate in education specialising in narrative and life story research at Bristol University in 2009. Following three years as senior counsellor and project co-ordinator for the RNIB Bristol counselling project she now works in Machynlleth as an independent counsellor, trainer and researcher. She has published in leading national and international academic journals on counselling, narrative practices and visual impairment and is author of "Different Horizons: Counselling People Who Are Blind and Partially Sighted" (RNIB Publications, 2008) and "Where Angels Fear to Tread: An exploration of having conversations about suicide in a counselling context" (C-S-P Publishing, 2010) and is Vice Chair of VINCE (Vision Impairment Network of Counselling and Emotional Support).*

*Her latest book is "Songs at Twilight: A Narrative Exploration of Living with a Visual Impairment" (C-S-P Publishing, 2011). It is based on a qualitative research project undertaken by Susan together with thirty contributors. Both Susan and the contributors are all registered as either sight impaired or severely sight impaired, and together they talk about their experiences, and discuss what it means for them to live with a visual impairment. What follows is an excerpt from the book. We join the discussion as thoughts turn to the provision of emotional support for people who are diagnosed with untreatable sight loss.*

### **What is meant by Emotional Support?**

All of us need emotional support as we go through life, as John Donne commented "No man is an island entire of itself". Even if the emotional support is in the form of talking to a friend or going out with the lads, most of us from time to time need to talk with others about thoughts and feelings that are disturbing us. Whether we need more formal kinds of emotional support is dependent on: our existing relationships and support structures; our ability to access the above; and the severity of the turmoil we are experiencing. More formal emotional support can be accessed in many different forms including telephone help

lines, joining with others who are experiencing similar issues in a local support group, joining an on-line forum or accessing one of the talking therapies such as counselling or psychotherapy.

Most of us need more emotional support from others in situations where we face significant:

- Loss or bereavement – losing something or someone that is precious to us can result in overwhelming feelings of sadness, despair and anger.
- Trauma – when we are subjected to situations that shock us or challenge everything we thought to be safe or true about life or our lives.
- Transition – where we move from one life experience to another. To give a couple of examples; the life transitions we all experience from childhood to adolescence, from adolescence to adulthood, or transitions in our social or work experience; from working to unemployed, when our relationships with significant others encounters problems or changes.
- Oppression – where we feel that we have no control over our lives and others take no account of our needs and desires or we are socially excluded.

Needing emotional support from others from time to time in our lives does not, in my view, mean that we have mental health difficulties. If however we are unable to get the support that we need, at the time we encounter these difficulties, then this could lead to major problems such as acute anxiety or depression.

Research has shown us that people with a visual impairment are more likely to suffer from mental health issues such as depression than the general population [1, 2] but there is little research available to consider what it is about visual impairment that results in these mental health issues, and what we can do about it.

Losing sight or living with a visual impairment can lead a person to

experiencing any or all of the above scenarios. Sight loss brings with it an experience of bereavement. As many contributors point out there are many losses: loss of sight; loss of “who I was” (Sarah); loss of driving; loss of independence; loss of visual interaction with others. Many describe their diagnosis and treatment as “traumatic” and often display symptoms akin to post traumatic disorder: “I keep having flashbacks of the moment he told me” (Stephen). “Every time I go for injections it gets worse, I feel deeply traumatised and afraid and have nightmares. It is like being tortured and told, ‘It’s for your own good’ and yet nothing changes. I find myself often re-living the moment of the injections” (Annie). “I feel afraid all the time, sometimes I shake, it’s like the world is a totally different place, one I don’t know or like at all.” (Peter).

People have often talked of “transition”, feeling they are moving from a sighted world to a blind one. Some experience this in positive ways. George, for example, considers losing sight as a way for him to choose to engage with society in a different way: “suddenly I had choices, I wasn’t labelled as a junky or alcoholic, but as visually impaired. Strangely this gave lots of different possibilities”. Others have found the transition extremely difficult: “I’m too old to start changing my ways, and actually I don’t want to!” (Mo). Some (myself included) find themselves in between the worlds of the sighted and the blind. We do not have enough sight to get by in a sighted world, but we have too much to be considered truly blind. As Dennis’s dilemma about using the white cane highlights: “If I use the white cane, I feel a fraud because I’m not really blind. If I don’t use it I am kidding myself that I am ok visually when I’m not”. There are also changes and challenges in relationships, for example when we move from the “carer” to the cared for.

Many people who are visually impaired, whether recently diagnosed or living with a visual impairment for a long time feel oppressed by their interactions with a society that has very negative attitudes towards visual impairment. They are often isolated and without a voice. As Tony comments, “many people feel marginalised, isolated and unable to change that position”.

It would seem therefore a natural conclusion that visually impaired people would need some kind of emotional support (either informal or formal) at some time in their lives. I asked contributors what they thought about this and received a wave of responses:

“ I would have liked to have had information given to me about where I could find some support, e.g. contact details for a support group or even counselling service. I would have also liked my family to have more information about my condition and what this might mean for me psychologically” (*Michael*)

“I went to my GP who diagnosed depression, and gave me anti-depressants and offered counselling. The counsellor however did not get the sight loss issues at all. She thought they were totally separate from the depression.

I think that if I had been offered some kind of support alongside the medical treatment then I wouldn't have got so depressed.” (*Peter*)

“I did have some telephone counselling with the RNIB some time later, and that was helpful, mainly because the girl I spoke to was also visually impaired. If she hadn't been I think it would have been a waste of time.” (*Annie*)

“When I went through a very bad time at work I did access the work's counselling service, and actually she was really good, even though she wasn't visually impaired she didn't make assumptions, but I still would have preferred to have talked to someone that was visually impaired.” (*Emma*)

“I thought I was going mad, the “Charles Bonnet” was not explained. My family really did not understand – apart from wanting me to go in a home! If I had been offered counselling I would have snapped it up.... I think my family also needed re-training so they knew a bit more about what I was going through. All they saw was mum going mad.” (*Pauline*)

“I think that there needs to be a change in the attitudes at eye clinics such that when families are delivered with the news that they are going to have to live with little or no vision they are supported – I know my family were totally traumatised by being told that their child would be blind, and I can imagine being told in later life would be no easier.”  
(*Caroline*)

### ***Developing Emotional Support Services for People who are Visually Impaired***

As stated previously, all of us have times in our lives when we need emotional support, and this is often provided informally by friends and family. Isolation however is one of the most common issues cited by people who are visually impaired [1, 3]. This sense of isolation could be due to mobility issues, age (the majority of people who are visually impaired are over 65 and have been affected also by other age related health problems [4]) social factors; as we have seen in previous chapters societal attitudes often have a profound effect on how people who are visually impaired relate to sighted others. Many people who are visually impaired also live alone [5], both in the older age group where a partner may have died, but also in working age people where the proportion of single people is significantly higher than in their sighted peers. There are also issues regarding sighted friends and family members not being aware of the issues connected to living with low or no vision, or losing sight. This means that natural occasions for emotional support are often reduced. It seems imperative, therefore, to consider how professionals involved in services interacting with people who are visually impaired respond to this deficit.

This does not necessarily mean that everyone who is visually impaired “needs” counselling, or has a psychological problem, more that perhaps there should be more options available for people to access formal emotional support. If we consider losing sight as a transitional process [6] then different levels of emotional support will be needed at different

stages of the visual impairment journey [4, 7, 8]. The RNIB is recently developing a “thresholds framework” clarifying levels of emotional support needed at different stages of the eye care pathway which it is hoped will ensure that terminology is consistent across the field (for more information, see [www.rnib.org.uk/emotional support service](http://www.rnib.org.uk/emotional-support-service)).

If diagnosis is the beginning of the sight loss journey then provision for emotional support should begin with ophthalmology clinics. Despite the recognition of this need [9] and this being highlighted in various national standards and guidelines it is rarely implemented effectively. (For example, Low Vision Services Consensus Group 1999, NHS Eye Care Services Programme 2007, NICE 2004, Vision 2020 2008). Some changes have started to emerge, for example in some UK ophthalmology clinics ECLO staff are appointed to support patients to provide “emotional support, advice and information, guidance about registration, explanation of eye conditions, and family support” [10]. However most see their role as being involved with practical issues and few are trained in basic listening or counselling skills which would then enable them to support people emotionally. As Nyman comments, “the potential for ECLO’s to provide emotional support has yet to be realised”. [3:199].

Although there is some evidence of good practice in ophthalmology clinics with the majority of attendees being satisfied with the treatment they received [8] there are still people who find their consultants’ attitudes unhelpful [11]. One man told me “the consultant would often come with his entourage of students and discuss me without even saying one word to me. I just felt as if they didn’t see any purpose in talking to me at all, or listening to my concerns”. Certainly this ties in with the experiences of several of the contributors to this book, and also my own. Surely the first step in emotional support is that we at least listen to people’s concerns and acknowledge them as people rather than just conditions?

Although the focus of work within an eye clinic is on medical care

and retaining sight, perhaps clinicians need to remain aware of the psychological impact that diagnosis and treatment has on their patients. One way of addressing this would be that when a diagnosis of untreatable sight loss is made it needs to be followed up by a psychosocial assessment which would identify both practical and emotional needs of the person such that appropriate referrals could be made. Improved training on the psychological impact of sight loss may also enable clinicians to support their patients better when delivering a life changing prognosis.

Often people find themselves with a diagnosis and possibly registered as severely sight impaired (blind) or sight impaired (partially sighted) but once they are discharged by the hospital are not supported at all. Within some areas social services will follow up registration with a visit or information about services, but this does not happen routinely in all areas of the UK leaving many people unsure of any services in their area.

Despite the evidence that visual impairment has a “profound negative emotional impact on individuals” [1, 3,6] and that there is some evidence of a demand for emotional support that is not being met [3] funding is often not available to set up sight-specific services. This is partly because as yet there is no conclusive evidence of what kind of support enables people to have a better sense of emotional and social wellbeing [3]. Most of the services currently set up to support those who are visually impaired are run within the voluntary sector, and do not have the resources or expertise to run research projects as “random controlled trials” which are considered necessary to secure funding for treatment from NHS. To address some of these issues VINCE (Visual Impairment Network of Counselling and Emotional Support) has been set up. This is a multi-agency network established to: develop collaborative working between counsellors and emotional support service providers; share good practice, service developments, evaluation and research outcomes; influence the development of counselling and emotional support services for adults, children and

families affected by sight loss.

In my view there needs to be a multi-tier approach to providing formal emotional support for those who are visually impaired provided over several years following diagnosis. This would include:

- Support being available within ophthalmology clinics at times of diagnosis, and registration. This could include better practices from clinicians, a psychosocial assessment to determine needs, improved ECLO provision, and signposting.
- Practical and emotional support being offered to both the person with the visual impairment and their family, together with opportunity for referral to sight-specific support groups or counselling services.
- Funding for sight-loss-specific therapeutic services, to include counselling, telephone support, peer support, therapeutic group and family support.
- Ongoing follow up and support for people and their families post-registration and discharge from hospital clinics to review needs.

### **References:**

*For reasons of space, the references in this document (signified by numbers in brackets within the text) have been excluded. They can be read on the author's website, [www.susandale.counselling.co.uk](http://www.susandale.counselling.co.uk), in the section 'Publications', which also has details of how to order her books.*

# **DEPRESSION AND VISUAL IMPAIRMENT BY CLAIRE NOLLETT**

## ***Depression***

Depression is a serious condition in which a person may feel sad, low or worthless, or they may lose interest or pleasure in things they used to enjoy. These emotional feelings are generally accompanied by physical feelings such as a change in appetite, disturbed sleep and loss of energy and motivation. People with depression may find it hard to continue to work or do household tasks, pursue leisure activities or socialise. Although it's not often talked about, depression is a relatively common condition. In 2007, researchers interviewed a large number of people in the UK in their homes and found that around 9% of men and 14% of women were experiencing either a depressive episode or a mixture of anxiety and depression (McManus et al, 2009). Whilst depression is common in the general population, there is evidence to suggest it is even more prevalent in people with a visual impairment.

## ***Depression and Visual Impairment***

A large UK study of people aged 75+ found that almost 5% had depression, but this figure rose to nearly 14% for people who had a visual impairment (Evans et al, 2007). In the USA, about 30% of people with AMD who attended a low vision clinic had symptoms of depression (eg Brody et al, 2001; Rovner & Casten, 2001). There is currently little information on the rate of depression in people attending low vision clinics in the UK and no study of possible treatments for this group. For this reason, Cardiff University, supported by Guide Dogs for the Blind, has recently launched a research study entitled 'Depression in Visual Impairment Trial (DEPVIT)'. The aim of DEPVIT is, firstly, to estimate the rate of depression in people visiting their optician for a low vision assessment and, secondly, to compare three treatments for depression in this group. The treatments we are investigating are: a follow up assessment 6 weeks after the first low vision assessment; a follow up assessment plus a referral to the GP for

help with depression or a follow up assessment plus a psychological talking treatment called Problem Solving Therapy (PST). PST aims to help people identify and solve problems they are encountering in their lives, which can help to lift their depression.

The study is taking place across ten opticians in South Wales and at a hospital in London. If your optician is part of the study and you see them for a Low Vision Assessment in the next two years, you will be given more information on the study.

If your optician is not taking part in the study but you suspect that you may have depression and would like help to overcome it, the good news is that help is still available.

### ***Visit your GP***

Firstly, I recommend that you visit your GP. It can seem daunting to bring up emotional issues such as depression with your GP, but remember, it is a common condition and they will be very used to discussing it. In fact, it's the third most common reason for people visiting their GP. It may help to prepare yourself before you go and Age UK recommend the following useful tips:

- Make a list of your symptoms, when they started and when they are worse eg. first thing in the morning.
- Take a list of your medications.
- Consider taking someone with you to your appointment for support.
- Think about questions you might want to ask the GP and write them down.
- Be honest – try not to feel worried or embarrassed as your GP will have heard similar stories before.
- If you really don't want to see your usual GP, consider asking if the practice has someone who specialises in mental health, or ask to see the practice nurse.

Treatment for depression has a high success rate and your GP may be

able to offer you several options for treatment. Anti-depressants are not generally recommended for mild depression but may be an option if you have moderate depression. It's not uncommon for people to be wary of anti-depressants, believing they are addictive in the same way as anti-anxiety medication such as Valium, but this is not the case. Discuss any concerns you have about taking medication with your GP. If you have mild depression, or you do not wish to take tablets, your GP may be able to refer you to someone for a talking therapy or give you information on sleep or self-help routines. If talking therapy is not available through your practice and you would like to see a therapist privately, contact the British Association for Behavioural and Cognitive Psychotherapies (BABCP - 0161 705 4304) or the British Association for Counselling and Psychotherapy (BACP - 01455 883 300) for a list of accredited therapists in your area. An explanation of the different therapies available can be found at [www.iapt.nhs.uk/silo/files/which-talking-therapy-for-depression.pdf](http://www.iapt.nhs.uk/silo/files/which-talking-therapy-for-depression.pdf)

### ***Information, advice and support***

You may wish to speak to voluntary organisations which specialise in supporting people with depression.

'MIND' has an infoline which is available Monday to Friday 9am-6pm. They can send you information on depression and where to get help. Call them on 0300 123 3393 or visit [www.mind.org.uk](http://www.mind.org.uk)

Alternatively, 'SANE' offers an out-of-hours helpline everyday of the year from 6pm until 11pm and can offer emotional support as well as information. Call them on 0845 767 8000 or visit [www.sane.org.uk](http://www.sane.org.uk)

In Wales, 'Journeys' provides information as well as an audio book on recovering from depression and has support groups in many towns throughout the country. Call them on 02920 692 891 or visit [www.journeysonline.org.uk](http://www.journeysonline.org.uk)

If you would like to learn more about ways you can help yourself,

Northumberland, Tyne and Wear NHS Foundation Trust have produced very good self help leaflets on depression. They are available free of charge and come in large print and audio format so are a very useful tool. Call 0191 223 2545 or 0191 223 2546 to order a copy or download from <http://www.ntw.nhs.uk/pic/selfhelp>

Remember, you are not alone. Depression is common in people with visual problems, but it is not inevitable and can be treated. If you suspect that you may be suffering with depression I encourage you to seek support today.

### ***For health and social care professionals***

If you would like to know more about screening people for depression and evidence based treatments, I recommend reading the National Institute for Health and Clinical Excellence (NICE) “Depression with a chronic physical health problem” quick reference (CG91) which can be downloaded from [www.nice.org.uk](http://www.nice.org.uk) or ordered on 0845 003 7780. For more information on DEPVIT please contact myself using the details below.

Claire Nollett  
School of Optometry, Cardiff University  
[nollettcl@cardiff.ac.uk](mailto:nollettcl@cardiff.ac.uk)  
02920 870 571

# **SIGHT SUPPORT - COUNSELLING & EMOTIONAL SUPPORT**

Sight Support has been offering a counselling service since April 2008 to all their service-users who feel they need someone to talk to. It provides confidential one-to-one counselling by skilled counsellors in Gwent and the service is offered in the comfort of their own home.

Sight Support's Emotional Support Telephone Service is also available to provide confidential telephone support and information to people who, because of sight loss, are experiencing emotional difficulties. It gives the client an opportunity to talk about their situation and feelings, and an opportunity to work through some of their feelings as well as gaining support. All our counsellors receive visual impairment awareness training and are subject to enhanced CRB checks.

## **What is counselling?**

Counselling is a purposeful relationship in which one person (the counsellor) helps another person, (the client) to help themselves. Counselling takes place when a counsellor sees a client in a private and confidential setting to explore any difficulties the client may be having. By listening attentively and patiently the counsellor can begin to perceive the difficulties from the client's point of view and can help them to see things more clearly, possibly from a different perspective. Counselling is a way of enabling choice or change or of reducing confusion. It does not involve giving advice or directing a client to take a particular course of action.

## **What concerns can a client bring to a counselling session?**

In the counselling sessions the client can explore various aspects of their life and feelings, talking about them freely and openly in a way that is rarely possible with friends or family. Bottled up feelings such as anger, anxiety, grief and embarrassment can become very intense and counselling offers an opportunity to explore them, with the possibility

of making them easier to understand. The counsellor will encourage the expression of feelings and as a result of their training will be able to accept and reflect the client's problems without becoming burdened by them. It can help people who are adjusting to life events such as sight loss, bereavement, depression, illness, disability or loss.

## **How are clients referred to the Service?**

Clients are referred to the service by from many different routes, for example, Rehab Workers, Social Workers, Support Workers, GPs, Optometrists, Eye Clinic Staff and sometimes from friends, family and relatives of the client. Clients can also self-refer. Counselling sessions are arranged by mutual agreement with the counsellor, usually once a week. The total number of sessions varies from person to person, but is usually between 8-10 sessions.

## **A counsellor's perspective by Lee Hale, Volunteer Counsellor**

I have been working as a voluntary counsellor for Sight Support for almost four years. My job entails working on a one-to-one basis with people who experience visual impairment or blindness in one or both eyes. The conditions not only have a devastating impact on the person, but family and/or close friends can be affected too. In such situations, I work systemically with both the client and the person or people involved with him/her.

I am essentially a Person-Centred counsellor but have been trained integratively, which means I also utilise the theory and practices from the Psychodynamic and CBT approaches. I also incorporate aspects Problem Solving Treatment Therapy – a brief therapeutic approach, that can help some people with focus and prioritising issues. Over time, I have found a combination of these approaches, used in accordance with needs, have been of benefit to the people I meet. Although a combined and flexible approach can help, I have found that all people really want to do is to vent their frustration and have someone to listen to their concerns about the disabling magnitude the eye condition is having on

them/their lives.

In respect of this, I often provide counselling in relation to the person's fears, anxieties, depression, sense of loss, isolation and anger. Further, the clients frequently present a diversity of issues unrelated to the visual impairments that also have a negative impact on their lives. In these situations it is necessary to adopt a holistic approach but to also support the client to identify a primary issue, as well as the eye condition, that is having the most impact on his/her wellbeing. I initially offer ten counselling sessions with a view to reviewing progress from week five. As time progresses, goals can be identified to enable the client to move forward in his/her life. Alternatively, there is also the option for clients to be referred to external specialist services if the client and I understand this to be a more beneficial need.

I have worked with many people who have experienced different eye conditions. The conditions include: Glaucoma, Coloboma, Macular Degeneration, Iritis/Uveitis, Retrobulber Neuritis and Stargardt's Macular Dystrophy. Each one presents its own challenges to each person as they try to absorb and anticipate the enormity of the changes being forced upon them. With each person I connect with, I experience new challenges too. My challenges are related to thoughts and feelings about my own ability and competencies to 'hold' the experiences that the people are enduring – which for some, can be on a minute to minute basis. I feel this perhaps because I feel that my own visual short-sightedness and eye 'floaters' do not equate to the severity of the conditions that my clients experience - thus, I am not 'worthy' to understand the situation from their perspectives. However, through accessing solid and enlightening supervision and a process of my own therapy - I became realistic and aware that this attitude could make empathy redundant. It is this understanding of empathy/advanced empathy that enables me to work effectively with the people who need psychological input around the conditions experienced and to derive a 'real' understanding of what and how each person is experiencing.

Given this, I approach and endeavour to understand each person's

concerns from their perspectives/frame of reference – as I would any other person's. However, perhaps one of the primary considerations that should be considered when working with people with sight problems or blindness is to ensure that eye contact and head direction is maintained, as this communicates to the person's sense of hearing that you are actually looking towards him/her, paying direct attention – and are making the effort to understand the concerns being shared.

Both the clients and I are realistically aware that counselling is not going to elicit any 'magic wand' cure for any eye condition, but the aim is to minimise and/or alleviate the psychological suffering that is associated with the conditions. This was reflected when working with a person who experienced 'Charles Bonnet Syndrome.' This neurological/occipital condition manifests through the person distinctly 'seeing' people, children and /or animals in the contexts of their lives – at home or in social/community settings. The images have varying degrees of impact on the person's life and can range from being pleasant to devastatingly terrifying, frightening or horrific. Complex and convincing scenarios can be 'acted' out with the 'people' carrying out different roles. They are always reported as being physically vivid – as if they are actually happening, but quintessentially without sound and interaction for the person experiencing Charles Bonnet. The input from counselling and conveying a sense of acceptance, without collusion, that the images were very real for the client, was/is very different from family and friends who discouraged talk of the images. The client's ability to freely speak of the experiences and to explore possibilities, including scientific views, as to why the images occur and combine this with past experiences, can help to alleviate the psychological impact – and also reduce the frequency and intensity of the images/visions.

Counselling people with sight problems has metaphorically 'opened my own eyes' with a literal understanding of individual needs. I help in probably the most basic way where I can. Essentially, though, I feel very honoured and privileged that I am invited into what can be describe as 'darkened' worlds – and invited to work and walk together towards a psychological 'lightening.'

## **TELEBEFRIENDING AND TELEPHONE SUPPORT SERVICES**

*The Thomas Pocklington Trust recently produced a report 'Telebefriending and telephone support services for people with sight loss' which looked at the lessons learned from existing services, the attitudes of services users and those involved as providers, and considered areas which required further research. This article gives a brief summary of the report.*

The term 'telebefriending' refers to a one-to-one social telephone conversation between a person who may be socially isolated and a trained caller (usually a volunteer). It can be seen as an end in itself – providing a social contact – or as a way to enable access to other resources.

People with sight loss generally valued the befriending service, and reported a variety of benefits. These were mainly associated with an improved feeling of wellbeing: a reduction in loneliness and isolation, and an increased sense of social inclusion. The call gave service users a social structure and something to look forward to, and the caller's interest in their welfare increased feelings of safety. They could also be a source of valuable information about other relevant services or sources of support.

The service user's experience of telebefriending could be improved if he/she shared a common interest with the caller, although this was not essential as long as the caller was friendly and empathetic. It was important that the caller was reliable and called at the agreed time – or let the service user know if this was not possible. There was also a perception that female callers were better communicators and were more understanding.

For volunteers and staff, the research showed the importance of training such as role play and communication skills, and an understanding of the boundaries of the telebefriending service. Callers must be able to recognise the limits of what they can offer and refer

service users to other sources of support when necessary – this could be a particular issue when there was a need for emotional support, for example when a health condition is deteriorating. However, many callers reported that they benefited from the calls themselves in terms of increasing their own self-confidence and skills. The use of people with sight loss as volunteer callers was seen as having the potential to be of particular benefit to both parties.

The report describes a number of challenges faced by those wanting to develop a telebefriending service. These included the problem of identifying socially isolated people with sight loss who may benefit from the service, particularly those from diverse communities. Establishing good relationships with GPs, eye clinics, hospitals, sensory teams and other organisations which might be in contact with people with sight loss was important, as was establishing a strong profile for the service, and involving service users and referrers in its planning. Whilst language was a particular problem in establishing links with diverse communities, it was not the only one – providers needed to take account of cultural preferences and the community attitude to sight loss when planning telebefriending services. The report also addresses the challenges of finding and training callers, and emphasises the importance of flexibility – for example, allowing callers to make calls from their own homes, rather than requiring them to visit the organisation's base.

Good management of the service was also regarded as essential. Confidentiality is a crucial issue, and a clear confidentiality policy must be in place from the outset of the service to guide staff and volunteers. Volunteers needed to be given a clear understanding of the policy for paying expenses; particularly if they were making calls using their own phones. Managers needed to have a clear understanding of what the service was intended to achieve, and mechanisms for monitoring success.

The report concluded that telephone befriending services can significantly improve the quality of life for visually impaired people by

reducing feelings of isolation and putting them in touch with helpful services – and also by using them as volunteer callers.

You can read the full report by going to [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk) and looking for Research Discussion Paper Number 7. If you do not have internet access, or require it in alternative formats, contact The Pocklington Trust on 020 8995 0880.

## **TELEPHONE BEFRIENDING SERVICES IN WALES**

Several clubs and societies offer telephone befriending services. If you are aware of any other providers which may be of interest to visually impaired people in Wales, please let us know and we will include them in the next edition.

### **Cardiff Vale and Valleys – Contact Line**

Contact Line is a free service provided by CVV for all of their blind & partially sighted clients to see that everything's OK and if they are in need of anything, either from CVV or from their local Social Services - but for most clients it's just having someone to talk to. Calls are made approximately on a weekly basis by volunteers who are sighted, blind or partially sighted, and can last from a few minutes to over half an hour.

CVV has a database of several thousand people in the Cardiff, Vale of Glamorgan, RCT, Merthyr, Swansea & Neath Port Talbot areas, and all of those for whom a telephone number is held are contacted at least once per year. CVV can be contacted on 029 2048 5414.

## **Ceredigion Association – Telephone Visiting Project**

Registered Blind or partially-blind persons (clients) join the service through recommendation by the County Council Social Services department and are telephoned once per month, from a centre in mid-Ceredigion. Eight volunteer callers, who themselves are also vision-impaired, attend on one Wednesday afternoon a month (on a rota of two each week accompanied by a sighted co-ordinator) and they, understandably, empathise with their clients more easily than would be the case with sighted persons. Calls to each client last between 10 and 15 minutes. Currently around forty persons are called each four-week period and the Association would welcome an increase in this figure to fifty or more provided that Social Services are able to continue recommending additional names for inclusion in the project.

Confidentiality must be ensured and any matters of concern, welfare or otherwise, are recorded and referred to the appropriate officers in the county social services department for follow-up. The vast majority of clients are most appreciative of the service – but, exceptionally, the odd one occasionally will say that there is no need for further calls! Some clients are, of course, more talkative than others and, typically, the weather gets an airing, and politics or local/family matters affect the mood of the day!

## **Sight Support – Ring Around Service**

Sight Support offers a Ring Around Service to blind and partially sighted clients in the Gwent area, who live alone and who are socially isolated, on a weekly basis. Trained volunteers call the clients for approximately 15-20 minutes per person and have a friendly chat. For many clients this service offers a lifeline to those who get minimal support from friends and family. Many of our clients have reported feeling less lonely and isolated due to this service and many have formed meaningful relationships with the Ring Around volunteers. For further information please phone John Beavan on 01495 763650.

## **Vision Impairment Merthyr – Telebefriending**

Newly registered VI people are seen quickly by the local authority rehab officer and are asked if their names may be passed to VI Merthyr, who carries out a telephone interview, looking into their needs, and into how the society can support them. Where appropriate, the telephone befriending service is offered. Referrals are also received from the Action for Blind People mobile information service and from the families of people not registered but challenged by poor sight.

Calls are made monthly to participants, usually lasting about five minutes. Calls are made by visually impaired volunteers, from an anonymous centre, to protect the callers, who may be themselves vulnerable. VIM is currently calling 37 people. One elderly lady used to go to church regularly, but is no longer able to attend and looks forward to VIM's calls as a friendly understanding chat, which she is now deprived of on Sundays. VIM often picks up problems during calls, many of which it can resolve. If not, with the participant's permission, the problem is referred on as necessary. This is a befriending service, not a counselling one, with mutual support from understanding people who have similar challenges. VIM can be contacted on 01685 473954.

## **Vision Support – Let's Talk**

Many of Vision Support's Service Users receive a regular call from a Let's Talk Volunteer. As well as putting Service Users in contact with any of Vision Support's other services that they may enquire about, they chat about, well, everything under the sun really. As most of the Volunteers are phoning from the comfort of their own homes, calls can be arranged for a day and time convenient to both Service User and Volunteer. Most calls are on a weekly basis but can be less frequent if that is the Service User's preference.

As it is the Volunteer who makes the phone call there is no cost to

the Service User. One person who has been receiving a call for the last 5 years said: "I so look forward to our weekly chats as I live alone. My Let's Talk Volunteer has also encouraged me to go along to one of Vision Support's clubs, which means that I am out of the house one day a week."

If you are interested in receiving this service or would like to refer someone please contact Liz Withington on 01270 873691 or send an email to [lwithington@visionsupport.org.uk](mailto:lwithington@visionsupport.org.uk).

## **The British Retinitis Pigmentosa Society – Telephone Befriending Service**

People with RP who are aged over 18 may be interested in the BRPS's Telebefriending Service (TBS), which links people who would welcome a friendly phone call from a trained person with knowledge of dealing with RP with a team of volunteers willing to share their experiences. The TBS is completely confidential, calls are not discussed with anyone else and no record is kept of the content of befriender's conversations. Calls can be stopped at any time.

If you would welcome a friendly phone call once or twice a month from one of the team, please contact the office on 01280 821334 or by email on [tbs@rpfightingblindness.org.uk](mailto:tbs@rpfightingblindness.org.uk).

## **RNIB - Talk and Support service**

RNIB provide a Tele Befriending service, providing valuable peer support, friendship and social contact to adults with sight loss across the UK. Participants require only a landline telephone and an interest in talking to other like-minded people. Small groups of six people meet together over the telephone for 55 minutes each week. The groups

are carefully matched together based on the participant's age group and interests. Tele Befriending groups have no set agenda for discussion but are used by participants as a way to meet new friends, to socialise and share practical information and support about living with sight loss. An active community of approximately 800 people from across the UK ranging from 22 to 104 years of age currently take part in our telephone groups each week. The service is available free of charge to participants (RNIB covers all call costs). Telephone book clubs are also available.

To find out more about Talk and Support, call the Helpline on 0303 1239999 or visit the RNIB website [www.rnib.org.uk](http://www.rnib.org.uk). To speak to someone in Welsh, please ring 02920 450440.

## **Feedback**

If you have used counselling, telebefriending or other emotional support services, we would be interested to hear about your experiences - please send any comments to the address below.

Roundup is published quarterly by Wales Council for the Blind. It is also available in audio CD format. Further copies can be requested from Richard Bowers, Wales Council for the Blind, 2nd Floor, Hallinans House, 22 Newport Road, Cardiff CF24 0TD.

Telephone 029 2047 3954

Please send articles and news items to the above address and mark the envelope "Roundup". You may also send to [richard@wcb-ccd.org.uk](mailto:richard@wcb-ccd.org.uk).

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