

Need to talk

Issue 2

Newsletter

Counselling and confidence building support for people affected by sight loss

If you or a loved one are experiencing sight loss, having someone who understands what you're going through can make a huge difference. During these times, many people find it helpful to talk through their feelings with someone outside their usual circle of family and friends.

Through the Need to Talk project, sight loss charities RNIB (in Scotland and Northern Ireland) and Fighting Blindness (Republic of Ireland) are working together to support people of all ages, including children and young people from the age of 11, and their family and friends, to access the emotional and practical support they need to adapt to life with sight loss.

Although the project is working across the three regions, there is a specific focus on providing support to those living in the more rural areas of western Scotland, Northern Ireland, and the border counties of the Republic of Ireland, where access to public transport and other support services can be limited.



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First year in review

"We are now almost two and a half years into the project and I really can't believe how fast time has flown. As with any journey there have been some wins and some challenges. I think some of the wins have been to see how much some of the services have been needed, especially in the border counties of the Republic of Ireland.

"It was in Dundalk, that we witnessed twice the planned attendees turn up for our first confidence building course. The group formed a strong bond and are now looking at connecting with each other in other ways to reduce the isolation they felt before they met each other.

"I think some of our challenges have been the low referral rates for the counselling side of the project, especially in western Scotland. We continue to work hard at developing referral pathways to enable people to access the support that they so desperately need. Part of the challenge is to normalise the negative feelings that occur from sight loss. If we see it as something that is normal, I think it becomes something that we more readily seek help and support for.

"Thanks to all that have been involved in the project to date, both our staff and volunteers for the work they have done, as well as they work that they will continue to do, in the next part of our journey."

Amanda Hawkins
Specialist Lead for Counselling and Emotional Support (RNIB)



Need To Talk Project Meets with Health Professionals in Ayr

The Need to Talk team organised its own one-day conference in Ayr, Scotland to bring together health and social care professionals to discuss the impact of sight loss on wellbeing.

The conference, which took place on 14 December, 2018, highlighted the vital need for emotional and practical support for those diagnosed with sight-threatening conditions.

Every day, 250 people start to lose their sight.

We explained that research by RNIB has found that people with sight loss are nearly three times more likely to report feeling depressed, constantly under strain and having low confidence and self-esteem.

The impact of sight loss

James Adams, Director of RNIB Scotland, told the conference:

"During these times, many people find it helpful to talk through their feelings with someone outside their usual circle of family and friends.

“The impact of sight loss can be devastating, and people experiencing it to whatever degree, may be worried about its implications for their future and the changes they are facing.

“Need to Talk supports adults of all ages, as well as children and young people over 11, in their own home, in their own way. We give reassurance to those with sight loss who are in emotional distress and socially isolated, especially those living in rural locations.”

The services are also available for family and friends.

The emotional effects

Dr Mhairi Thurston, an academic with Abertay University in Dundee, welcomed the Need to Talk initiative, having lost her own sight to the condition retinitis pigmentosa at the age of 40. Her experience prompted her to pursue a career studying the social and emotional effects of sight loss.

“There is no doubt that losing your sight impacts on your mental health. In fact, many people compare it to experiencing bereavement,” she said.

“Only a small percentage of people losing their sight will be offered counselling, despite the devastating effect it can have on people’s lives.

“Without proper support, people can rapidly lose confidence, leading to isolation, anxiety, depression and feelings of anger and confusion. Having appropriate support can make a huge difference to someone’s life.”

To better understand the process of losing one’s sight, Mhairi explained there were five key stages that most people go through. The first stage is the diagnosis of a serious sight condition, which is

often accompanied by shock, fear, panic and disbelief. During the second stage, many people want life to carry on as normal, for as long as they can, without appearing to be different from others. It is very challenging for people to engage with rehabilitation services at this stage. Stage three is where the sight loss impacts enormously on a person’s life and means enforced lifestyle changes and, with that, a sense of loss on many fronts.

“In stage four, people find they must engage with some kind of rehabilitation services in order to move forward with their life. This is an emotionally challenging stage as it means that they are essentially “coming out” as a person with sight loss. This can lead to a change in self-perception and a change in how other people interact with them. The final stage is when a person accepts their sight loss and finds a new way of moving forward as their self. Understanding this process helps us understand that different types of support are needed at different points in a person’s sight loss journey.”

Dr Hazel McFarlane told the conference about South Ayrshire’s Sensory Impairment Action Plan while Dr Zac Khoshy from NHS Ayrshire and Arran discussed why vision is such a big deal for people.



Seeing the light

Heather Owens says the Need to Talk service saved her life and gave her back her confidence.

There is a direct link between sight loss and depression with more than four in ten people who attend low vision clinics reporting symptoms of clinical depression.*

Need to Talk is literally saving and transforming lives. Heather Owens, from Belfast, has been blind since birth and lives with her husband Alan, who is also blind.

Heather said: "I have always been very strong and positive, but I was dealing with so many things at one time and it all got too much. I was the primary carer for my mum, who had Alzheimer's, as well as going through health problems of my own. I've always been so independent and had never asked for help before but as I have got older, I needed some help in the home."

Heather went on to endure countless assessments from her local Health and Social Care Trust and each time, was refused help. Depression took hold and Heather admits to being in "a very dark place".

She said: "I felt humiliated, I felt worthless and mentally, I began to feel very low and weary. I was in a black pit of despair; I felt I had no way out. It got to the point when I felt like harming myself and ending it. I felt like I was a burden. I was being made to feel like I was wrong for asking for help despite having lived independently all my life."

She said: "I was at breaking point, I really thought I was going to have a breakdown. I heard about the Need to



Talk counselling service and I had eight weeks of counselling with a wonderful lady.

"Need to Talk saved my life. There's no doubt about it. If I hadn't received counselling, I believe I would've taken those tablets. I want to ensure other blind and partially sighted people know about Need to Talk."

Heather said: "There is a link between sight loss and depression as no matter how capable or strong you are, there's a big strain on you, day in, day out, as an individual, or as a couple. Even though my husband Alan and I are fully independent, it can be a strain.

"My blindfold never comes off. You're coping but it never leaves you. As you get older, it gets harder, especially if you have other health issues to deal with, like me. Everyone needs help and has their own independent needs."

Heather says as well as rebuilding her confidence and self-esteem, the Need to Talk counselling she received also gave her the strength to undergo one more final assessment to try and get the social care she needed.

"It did, I went through it one last time last April in 2018 and I won my case. Now, I have three hours of invaluable social care help a week and my dream is to become a counsellor myself someday soon."

"My counsellor helped me to understand that it was OK to ask for help, that it was fine to cry and that it was so important to talk."

Most importantly, however, Heather now has her pride and her confidence back and is enjoying life again.

*DEPVIT, 2016 - A randomised clinical trial of depression treatments in people with low vision. Read more at: ncbi.nlm.nih.gov/pubmed/27548898

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accessed counselling.

You will receive eight to ten sessions of counselling over the phone at a time that is convenient for you.

92

people accessed Need to Talk confidence building courses this year.

Interreg collaboration in Glasgow

Of the ten Interreg projects currently funded, six – including Need to Talk – operate in the eligible areas of western Scotland and representatives from these projects had a chance to come together at a stakeholder event in Glasgow on 27 November, 2018.



As it was the first such event to be held in Scotland, it offered an opportunity to learn what other Interreg projects are doing and hear what the Scottish government's aims are in supporting this programme.

In total, three workshops were held at the event, which allowed projects to explain to each other what they did. Need to Talk ran one in conjunction with Changing Lives, which operates in Louth, Belfast and Argyllshire, for families with a child with ADHD.

All in all, the event proved helpful to everyone present and promoted collaboration whilst offering ideas, plans for future action and a chance for people to meet one another.

Dundalk Living with Sight Loss course

By Amanda Kenny, Fighting Blindness

Our first Living with Sight Loss course in the Republic of Ireland took place in the Crowne Plaza Hotel in Dundalk from September to October 2018 and proved to be a great success.

The event attracted 24 enthusiastic participants living in County Louth over six consecutive Tuesdays and a wide range of topics were covered generating a great sense of empowerment and positivity amongst the attendees.

Topics included assistive technology, local support, eye health, mindfulness, sport and leisure and mobility. We were delighted to have speakers from Irish Guide Dogs, disABILITY Louth, the Louth Leader Partnership, Dundalk Library, Sight and Sound Technology, Fighting



Blindness and Vision Sports. We were also inspired by Eleanor Burke, Need to Talk partnership board member, who generously shared with us her personal journey of sight loss. We are very grateful to all our speakers who provided their time and expertise so willingly in the delivery of this important programme. The course was co-facilitated by Richard Craig from RNIB together with John Delany and Mahon Carmody from Fighting Blindness.



Build your confidence

Confidence Building Coordinator Richard Craig tells us about three Living with Sight Loss courses delivered in Northern Ireland throughout 2018.

If you have just received a sight loss diagnosis, you will have questions, you may feel scared, alone and anxious about the future. This is where the Need to Talk project's Living with Sight Loss courses are really making a difference to people's lives.

Living with Sight Loss courses take place regularly across the regions. Forty-one people with sight loss took part in face-to-face Living with Sight Loss courses in counties Tyrone, Derry/Londonderry and Antrim in Northern Ireland.

A range of different themes were covered each week over a period of six weeks on each course. These included mobility and daily living, emotional support and wellbeing, assistive technology, eye health, peer support and leisure time.

As well as providing an opportunity for people with sight loss to meet and connect with each other, family and friends also attended and participated in the course and found it hugely beneficial.



"I wasn't sure what to expect from this course but ended up receiving so much support and realised there is a lot of help out there."

Michelle Boyd, Dervock

Build your confidence online too!

Need to Talk also offers a free eLearning Living with Sight Loss course to rebuild your confidence and support you in learning new skills and techniques to deal with sight loss.

The online course is in two parts; eye health and confidence building. In both parts you will have the opportunity to explore a range of topics covering eye health, emotional support, technology, benefits, daily living, and social and leisure.

And because it's online, you can take the course at a time and pace that suits you.

This course is also suited to family and friends of anyone affected by sight loss as sight issues affect all aspects of a person's life – including those closest to them.

This course is available to anyone living with sight loss residing in Northern Ireland, the border counties of the Republic of Ireland and western Scotland. To register and begin this course, please visit: rnib.org.uk/needtotalk

For further information or support in accessing this course, please contact the Need to Talk Team on: **0303 123 999**, or rnib.org.uk/needtotalk

“Those six weeks were so important for me”

Gill Jackson, from Moira in Northern Ireland attended the Need to Talk Living with Sight Loss course in Lisburn in November 2018. Alongside finding new skills and confidence, she is cherishing her new friendships.

Gill has a condition called keratoconus which has involved her undergoing regular cornea transplants over a period of 25 years. However, despite losing the sight in her right eye after an unfortunate complication during surgery, Gill still had perfect sight in her left eye.

Now 52, Gill is happily married to Adrian and has two children – Ross, 27 and Zoë, 22. She taught Primary One children for 30 years but in November 2017 she suddenly lost the vision in her left eye as well. She recalls:

“One minute I was leading an active independent life teaching P1, driving the school minibus and managing the over 50s Irish Masters Hockey team,

and then the majority of my sight just went overnight.

“My left eye was my rock. I had a transplant on it 25 years previously and ever since that, the sight was very good with the aid of a contact lens and then, my cornea failed and my eye clouded over, just like that. I had to grasp the concept of becoming partially sighted overnight.”

Challenging Times

In the months after her cornea failure, Gill found it very difficult to adapt to the radical change in her life. Her resourceful husband Adrian set about adapting fixtures in their home to practically help her with day-to-day tasks. She said: “I was being led about by the arm and I had blisters over the surface of my failing cornea and the pain was unimaginable.”

Gill tried to remain upbeat though and even went skiing. She said: “I had always skied so I learned how to ski with my limited vision at We Are Vertigo – an indoor artificial ski centre. Skiing was very challenging at times but I refused to let it hold me back.” Gill is also a regular at her local gym at Edenmore Country club



“The Living with Sight Loss course is essential. I would challenge anyone to go on that course and say they didn’t get something from it.”



where she takes part in spin classes and a number of other group classes.

Despite her grit and determination, Gill is the first to admit she was still struggling. "There were times when I thought, 'I don't know how to practically do this.' I welcomed someone saying, 'this is what's available for you; this is what you can do'. You don't know what you need until someone shows you what's out there," she said.

And that's what Richard Craig from RNIB and his team did when he met Gill at the Living with Sight Loss course.

Recommended by her social worker, Gill knew the course would be good for her and she also knew that she wanted to go to it alone. She said: "My husband, friends and family take me everywhere, but I wanted to go to this on my own. I felt I needed to get to know people by myself; I felt it would be good for me. Throughout my time on the course I learned to do more things for myself, rather than totally relying on others.

"Various speakers talked to us about transport, home security, benefits, counselling, opportunities in sport and local groups and from attending the course, I was also inspired to get involved in opportunities run by RNIB's Olive Rodgers and I'm now involved in the Hillsborough Castle and Gardens Community Access Scheme (CAS), amongst others."

Reassurance

"Richard's session on transport and travelling was very informative. The whole course gave me a new confidence and I've even set myself a few goals for this year. Inspired by Richard's talk, I would like to learn to use some form of public transport on my own."



Gill enjoyed the course immensely and praises its benefits. "Richard is such a lovely guy; he taught us so much; including handling money and various apps; the magnifying one is fantastic! I often struggle with money, particularly with loose change, so it was so nice to know others experienced it too. To find people who have exactly the same issues as you, is reassuring. Then to realise that there isn't just one solution to your problem, but two or three, is even better."

With new confidence and skills came new relationships and Gill said: "Everyone knew each other by the end of the course. We built relationships, we shared stories and we all became friends."

"I felt those six weeks were so important for me," she added. "I sat beside a lovely lady called Louise and we started to talk and built up a great friendship. We text each other all the time and now meet up for coffee."



Need to Talk NEWS

Rugby Legend Shane Byrne launches Need to Talk's Emotional Support Vision Champions' initiative.

As well as Counselling and the Living with Sight Loss courses, Need to Talk also delivers the Emotional Support Vision Champions' training programme, which was launched at the annual Retina Conference in Dublin on 6 October, 2018.

Sight loss can be devastating, and its emotional impact can be profound for the individual going through this life-changing event, and for their family and friends. Vision Champions recognise the emotional impact of sight loss, have a high level of empathy and understanding, have knowledge of services available and provide support and information to people affected by sight loss. A free online course has been launched for those working or supporting people affected by sight loss and who wish to be trained as a Vision Champion.

The launch welcomed Dr Mhairi Thurston of Abertay University, Scotland, and Amanda Hawkins from RNIB, who

presented on the day. Dr Thurston outlined the importance of identifying the practical and psychological impact of sight loss and explored some of the challenges that commonly arise, with examples from her own life as someone who is affected by vision impairment. The power and honesty of Dr Thurston's talk resonated with many in the audience.

RNIB's Amanda Hawkins spoke about the importance of the Emotional Support Vision Champion's role in supporting all those directly and indirectly affected by sight loss. She outlined how a diagnosis of a serious eye condition can have a devastating impact on the person affected and the people with whom they share their lives.

Shane Byrne

Also at the launch, Irish Rugby star Shane Byrne shared his family's experiences with sight loss. He said: "My grandfather, who was a surgeon, tragically lost his sight and hearing in his early 40s in the space of just nine months. During this difficult time, he spiralled into depression; he did not know what way to go with his life and felt he was a burden to his young family."

“Following a trip to Lourdes he came back a completely different man. His motto was, ‘I am the same man I was before this all happened, it’s just my eyes and ears don’t work!’ He had decided then to grab life by the scruff of the neck and became the world’s first visually impaired and deaf physiotherapist.”

Online course

Our online course is now available and is designed to train volunteer Vision Champions to support someone at such difficult times.

The Emotional Support Vision Champion course is part of the Need to Talk programme delivered in partnership with RNIB Northern Ireland and Scotland. This

cross-border project is funded by the European Union’s Interreg VA Programme, managed by the Special EU Programmes Body (SEUPB).

If you are in the border region of the Republic of Ireland (Donegal, Sligo, Leitrim, Cavan, Monaghan, Louth) and would like more information about the initiative, or are interested in becoming a Vision Champion, please contact: **needtotalk@fightingblindness.ie** or phone: **+353 1 674 6496**.

Alternatively, if you’re from Scotland or Northern Ireland, email: **needtotalk@rnib.org.uk** or phone: **0303 123 999** or **rnib.org.uk/needtotalk**



Common emotional reactions to sight loss

Amanda Hawkins, Specialist Lead for Counselling and Emotional Support at RNIB, outlines the various reactions and feelings when coping with a sight loss diagnosis.

Reactions to losing sight can vary enormously. When and how we begin to experience sight loss can make a difference, and so can our personality and usual ways of coping with difficulties, or how much support is available. However, there are a range of feelings and responses that many people experience.

Who does this apply to?

Anyone affected by sight loss – whether that is yourself or a member of your family; whether you have ever had sight, or never had sight.

What might I expect?

The process is often compared to bereavement and the same range of thoughts and emotions can come into play. As with grieving any other loss, the reactions do not necessarily happen in a particular order, nor does everybody experience the whole range – although they might.

Sometimes we can be aware of several of the feelings in a short space of time; sometimes one dominates our mood for a longer period. Sometimes feelings we thought we had “dealt with” return, either at random or in response to further changes in our circumstances.



“It was so helpful to talk to someone privately, outside my family and friends. The counsellor had time to listen and helped me talk things through. This has made so much difference to my life.”

"Isolation has not been a feature with most of my clients but being able to have telephone counselling without the need for someone else to be involved has been a recurring theme.

"I have worked with a number of clients in Scotland who have reacted like this. Most of them live in close-knit communities and many have a lot of support from friends and family. However, they have benefited from talking to someone outside this group, privately and independently on the phone. Together, over a period of eight weeks, we have talked honestly about their feelings. We also explored different ways of adapting to their situation and finding ways for them to live their life in a way which feels right for them."

**Dorothy McColl,
Sight Loss Counsellor,
RNIB**



Common feelings

Shock and denial – whether sight loss comes on suddenly or a diagnosis is confirmed after experiencing gradual change, shock is often the first reaction. It can be hard to take in the news; we can find ourselves carrying on as if nothing was different; we can forget anything has changed and experience the shock all over again (for instance on waking in the morning). We may continue to do things as if we had our old levels of sight and find reasons not to try new methods of doing things.

Maybe we disbelieve the news or think the doctor has made a mistake. We may find ourselves frantically seeking further

diagnosis even if we are told the same each time or trusting in miracle cures that have no evidence to support them.

Denial may be the mind's way of buying time to get used to a new situation or experience, but should give way over time as we gradually find ways to adjust to our situation.

Anger and questioning – we may get angry or upset with those around us for not doing enough to help or not helping in the right way. The changes are new for them too so they may not know the right way to help, or may not fully appreciate how we are affected.

Perhaps there are legitimate targets for anger – for instance if the sight loss was caused by an injury; or if information, diagnosis, treatments and support services were not as timely or accurate as they could have been. Sometimes, however, we feel angry when there is no obvious external target and this can make us self-blaming or short-tempered with others.

Anger can be a natural response to unwelcome changes in our circumstances. Being justifiably angry can give us strength to fight back against such difficulties. Questioning how the situation happened is closely linked to this – we are searching for ways to make things better, and trying to prevent similar problems in the future. We seem to need time to explore whether we have the power to change the situation before we can feel ready to move on to adjusting to it.

Helplessness, fear, anxiety – these feelings can follow on from a period of anger and searching and are part of the process of accepting what cannot be changed. Temporarily accepting of our lack of power to change or restore our circumstances can in itself be scary and may even send us back into denial. »

Or we may have genuine fears about how we will manage areas of our life that have always been sight-dependent. For many of us, the last time we could not do things for ourselves was in childhood. Not being able to do things that others can do, and that we have been able to do since childhood can feel intensely embarrassing, even shaming.

Anxiety can be very strong under these circumstances and is a natural reaction – an internal signal of danger that makes us stop and take care until we have learned new ways to deal with our circumstances. Anxiety should reduce gradually as we get more confident. Panic attacks are not uncommon but can be managed with the right help and information.

Helplessness and fear should recede as we allow ourselves to see that although we cannot do things just as before, we can learn to do things in new ways. We may even find new capabilities or interests that we might never have found the time or opportunity to discover otherwise.

Sadness and grief – most people would see these as obvious reactions but might be surprised by the strength or depth of what they feel.

There may be a background feeling of sadness that seems to be there all the time, or the feeling may arise suddenly in response to a particular situation, or a new realisation (for instance, not noticing a friend in the street; dropping something and not being able to find it; realising we won't experience looking at nature, or art, in the same way again).

This can be especially difficult for people who see themselves as "practical" and "good at coping". Some people think that expressing sadness is just self-pity and means they are not as strong as they thought. At times the feelings can seem overwhelming, but it is important to know that with time they will get less intense and affect us less often. We are unlikely to be happy about losing something we treasure but we can gradually learn ways to live with the changes it brings.



Depression – when sadness lasts a long time and stops us from seeing any chance of hope, or if we turn anger in on ourselves and become self-blaming, we can get depressed. Depression is a normal response in grieving a loss; it is perhaps a mixture of the feelings of sadness and helplessness, but if it lasts for more than a few weeks and is severe enough to stop us getting on with normal life we may need professional help to overcome it.

So if you persistently feel unable to get up, eat normally, or have disturbed sleep; or if you have no motivation to see friends or family, or otherwise do what you would normally do, it is important to seek support. Talk to your GP about it, or seek support from a counsellor, especially if you get so low that you have thoughts of harming yourself.

Loss of identity – the changes we experience can feel so drastic that we wonder if we can maintain a sense of who we are. Maybe we will have to change the work we do; maybe it no longer feels safe to babysit young grandchildren alone; maybe we worry about sight loss being genetic and feel concern that we might pass it on.

Without the opportunity to do the things we've always done we may wonder who we are anymore.

It can also be that in time we discover new careers, interests, pastimes that we would not have found time or opportunity to try without the changes that losing sight brought about. This may seem a long way off when we are still at the early stages of coming to terms with sight loss, but it is important to hold in mind that new possibilities often arise just when we are ready for them.

Adjusting our sense of identity is a major change – and we might resist at first. This ability to manage a new sense of self does not usually happen overnight and each of us will have our own way of getting there. It is quite likely that we will have been feeling better for some time before we realise, by looking back, just how far we have come.

Grieving – this is a process; whether it is bereavement or the loss of something else that is precious to us, it is a natural process and takes time. Most of us do need extra support of some kind when grieving and when adjusting to major changes, whether practical or emotional or both. Seeking and accepting support of some kind is a healthy response to a change in circumstances and not a sign of weakness or failure.

Here is a quote from 'William' who chose to use the RNIB Sight Loss counselling service: "It was so helpful to talk to someone privately, outside my family and friends. The counsellor had time to listen and helped me talk things through. This has made so much difference to my life. My sight isn't any better than it was but the time of being depressed has gone."

"It's a great feeling to support clients who have been feeling isolated and alone in Northern Ireland - the area of the UK that I cover. It never ceases to amaze me when they realise that there is support out there for them and they are able to utilise the support to move from feelings of fear and anxiety, to ones of independence and empowerment."

**Miguel Wiggans,
Sight Loss Counsellor,
RNIB**

Need to Talk is a five-year project delivered through a partnership between RNIB in Northern Ireland and Scotland, and Fighting Blindness in the Republic of Ireland.

The project is supported by the European Union's INTERREG VA Programme, managed by the Special EU Programmes Body (SEUPB).

All aspects of Need to Talk's counselling services and Living with Sight Loss courses are provided free of charge.

For more information please visit: rnib.org.uk/needtotalk

Get in touch

You can get in touch with Need to Talk's counselling and Living with Sight Loss team by telephoning or emailing RNIB or Fighting Blindness.

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