

Different horizons: Experiences of sight loss

Counselling people who are blind
or partially sighted

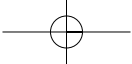
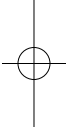
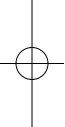
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RNIB

supporting blind and
partially sighted people



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Introduction

“

‘I need to talk to a counsellor who understands sight loss’.

In my role as a counsellor for the RNIB Emotional Support Service this is a comment which I and colleagues have heard time and time again from clients who are losing their sight and are seeking counselling as a result.

Every day 100 people begin to lose their sight in the UK, some of whom go on to seek counselling, yet there is surprisingly little literature available for counsellors on this issue.

To begin to address this, RNIB successfully applied to the Department of Health (Section 64 funding) to fund the development and publication of a ‘toolkit’ within a wider specialist counselling project in Bristol for people affected by sight loss. This publication is the result and uses data and learning from the counselling project. It is hoped that it will be of interest and value to counsellors working in a variety of settings, not only ‘specialist’ services, and will encourage further dialogue, debate and sharing of learning.

In setting about the task of developing this toolkit the big questions have been:

- What exactly is it about sight loss that people want their counsellor to understand?
- What would help our clients feel ‘understood’ at a time when their life is changing so irrevocably?
- How can learning from the counselling project be shared without pigeonholing or defining our clients by their vision alone?

Sight loss, visual impairment, blindness and partial sight are all labels used as a description of vision, which is considered less than ‘normal’ and is not correctable by treatment or glasses. However every person’s perception of what these labels mean is unique and depends upon their life experiences and how they perceive sight loss. This could be in terms of ‘medical’ understandings which see blindness as a physical impairment and place emphasis on diagnosis and treatment, or it could be that they consider their different vision as being ‘normal’ but feel disabled by society’s attitudes and inaccessible facilities and information.

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Since working for the project I have heard many descriptions of what being blind or partially sighted might mean, including:

“ ‘Blindness is the defining factor in my life; I am never just me but “that blind man”’.
 ‘A gift, part of who I am’.
 ‘I am part of a blind community and that is a cultural thing’.

Others have said:

“ ‘Isolation, that is my experience of sight loss’.
 ‘I can’t see the point in going on if I cannot see’.
 ‘It’s the worst, most traumatic thing which has ever happened to me’.

Some have likened it to bereavement, with feelings of grief, anger, and denial, others have described it as the beginning of a new life:

“ ‘When I knew that they could do nothing for me I cried and cried and raged, and then I thought this is a new beginning. I can choose who I am from now on’.

Society also has varying perceptions of what visual impairment or blindness might mean. These perceptions are often negative – Rebecca Atkinson, writing about her own sight loss says, ‘misconceptions start to spout from even your oldest friends’ mouths because negative attitudes about blindness permeate us all. You are about to cross over into the dark side and see what wriggles and writhes on the underbelly of society. Folk will see you as the sufferer, the pitiful, the afflicted, the subhuman’ (Atkinson 2007).

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In light of this myriad of responses and attitudes, it is difficult to respond to the seemingly simple request for ‘a counsellor who “understands sight loss” ’ and to produce a ‘toolkit’ which may help counsellors in their understanding. In describing the content of this publication it is probably easier to describe first what it is not.

- It is not intended to represent a specific model of counselling to work with clients who are blind or partially sighted.
- It is not intended to provide diagnosis or prognosis of how a blind person will think or feel.
- It does not intend to imply that all clients who come to counselling who are blind or partially sighted wish or need to talk about ‘sight’ issues.

It does, however, intend to raise counsellors’ awareness of their own pre-judgments and feelings towards disability (particularly sight loss), and to share experiences both from the perspective of counsellors, and from blind and partially sighted clients who have accessed counselling at the Bristol project.

This document is presented in two distinct sections:

Part one explores sight loss from societal, counsellor and client perspectives, including a narrative discourse based on both qualitative and quantitative data collected over the last three years from the counselling project. It is hoped this will help you think about the possible emotional responses to sight loss and to provoke thought about a client group who you might be unfamiliar with.

Part two offers more practical information and guidance on making counselling accessible to clients who otherwise may never ‘appear’ in the counselling room; how reduced vision could impact on the therapeutic relationship; a resource section; background and statistical information; and suggestions for further reading and research.

It is hoped that you will dip in to whatever section or sections are helpful to you in your work.

All the names of clients are pseudonyms and personal stories are included with permission.

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Part one

Sharing our differences

I write from the perspective of being a counsellor who is herself partially sighted, working with clients who are blind or partially sighted, so often we share a common experience of living with low vision. However, I recognise that for many readers blindness and partial sight will be a life experience that is not familiar. One of the challenges we face as counsellors is how to work with clients who come with very different life experiences from our own, in ways that acknowledge the differences but do not diagnose or ascribe worth to a particular way of being. Thinking about producing a 'toolkit' for counsellors working in this particular field, I wanted to illuminate difference in ways that would enable dialogue and sharing of that difference rather than taking a position either within the 'world of the blind' or the 'world of the sighted'.

As a starting point I had a conversation with one of my sighted colleagues – let's call her 'L'. We talked about our work and our differences and I asked what she felt would be helpful to include in a 'toolkit'.

Sue: What's it like to be a counsellor, a sighted counsellor, with this client group who are not sighted?

L: It is different in some ways, but not in others, I don't like specialisms, labelling people, but there is something different here... Identity is the word that comes up a lot, if I think about it.

You can encounter this anytime with anybody in any relationship: what is the **same** about us? what is **different**? how we can **connect**?

What comes up time and again is that I am constantly reminded that I am sighted because I talk to people who are not. This is something which is common for them but not me.

Sue: In the course of their day to day, most people don't think about being sighted, it is one of life's 'taken for granted's'.

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L: I don't feel that I am an expert though – each person is unique, but what has been useful and is still useful to me is to come up against this difference, which I cannot change, cannot ever make equal...because I am sighted.

I ask myself the question: Can I work with someone when I haven't experienced what they experience?

It is possible, but it is sometimes uncomfortable. However, I value this feeling of being uncomfortable. It is as if I feel more connected through this feeling...it feels 'right' and 'true'.

There are different levels of engagement with people, and sometimes when I connect really well with someone who is blind, it's a bit of a paradox really, I get this really strong feeling that: 'I don't know what it is like'. There is no way I could ever know what it's like.

But being with this feeling, staying with it and accepting it sometimes makes me feel closer. There is this place of genuine facing that this is something that is profoundly different for both of us.

But somehow being able to touch each other, the genuineness about accepting that I will never know and saying so – that is ok and we can meet, 'touching' at this deep level.

Sue: So when someone phones up and says they are blind, it is better to be genuine about the not knowing what it is like and be curious about wanting to know?

L: Yes I think so, which is why I am ambivalent about what to say for this 'toolkit'. Does prior knowledge help? Perhaps we can only offer something that will provoke questions in others.

Living in a 'visual' world

The experience of being blind or partially sighted is not just about difference in a physical sense, but includes society's reaction to that difference. We live in a society which is influenced by particular ways of thinking about blindness and sight loss, and these will doubtless influence both your client's attitude to their visual difference, and how you respond within your counselling practice.

The most common way of thinking about blindness uses a medical model of understanding; which sees it as a disability, an illness, and works towards finding a 'cure' or medical intervention, which will restore vision. This may be how your clients view their situation, but it may be that they consider their differing vision as just part of who they are as people, and viewing their difference as a deficit may leave them feeling unaccepted or unacceptable.

Our views are also increasingly influenced by social models of disability which have encouraged society towards viewing disability as a social phenomenon where people are disabled by the ways in which society exclude them. Hence the political drive towards producing accessible public transport systems, and in the case of organisations such as RNIB, campaigning for accessible communications and support systems for those with low vision.

This in itself seems very positive, but many partially sighted and blind people also consider that it pays 'lip service' to their needs, and 'denies my feelings' (Tony).

We are also affected by cultural discourses for example: 'impairment is unattractive and unwanted' (British Council of Disabled People 2007:1); and, 'with genetic screening birth defects such as blindness could be eradicated' (Atkinson 2007).

These discourses surrounding visual impairment mean that people who are blind or partially sighted are often seen as 'tragic figures' to be pitied or patronised, or alternatively that they are some kind of 'super-hero' valiantly battling through life with a trusty guide dog or white cane with no needs or feelings. This can lead to frustration and anger. As 'Jo' said to me recently at a social function: 'If anyone else asks my guide dog if "mummy" is alright I think I will hit them!'

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These attitudes that permeate society do have an effect on everyone who is blind or partially sighted. For some it can be frustrating and challenging. Others have developed very hopeful creative ways of dealing with them. 'Mike' talks about how he enjoys his encounter with a stranger who offers assistance: 'At the moment a woman asks if I need a hand – I take her arm – I love that intimate encounter with strangers – the privilege of walking as one for a few moments on our shared journey of life' (Dale 2008b).

Insights from practice

In an attempt to 'offer what will provoke questions in others', I have tried to present ideas and information about emotional responses to sight loss in a way which is not prescriptive or diagnostic, but one that offers a flavour of people's lived experience. This draws upon quantitative and qualitative data that has been gathered from the RNIB Bristol counselling project (including CORE – IMS data), and offers a brief overview of client issues that have emerged.

Then follows a narrative text which is an excerpt from a collaborative research project conducted with two ex-counselling clients Andy and Sarah and was completed as part of doctoral studies with the University of Bristol. Publication details and further information on this study are also included within the resource section. It is hoped that this will give a unique glimpse of lived experience, which will encourage you to think about your practice, and how you might work with someone whose life experience may be very different from your own.

RNIB Bristol Counselling Project Findings

The service has now been running for over six years and the emerging data tells us that our clients are predominately white, single, and either retired or unemployed. Currently, nearly 50 per cent of all clients are over 60 (with the oldest client 102). Whilst this is perhaps unsurprising given that an estimated 95 per cent of people with sight problems in the UK are over 65 (RNIB 2008a), this is unusual in counselling terms, where in most mainstream services the majority of counselling clients are under 65 (CORE-IMS 2008).

The emotional impact of sight loss has traditionally been understood as a process of loss – closely akin to grief and bereavement theories. These see people as needing to grieve for what has been lost, and going through stages of denial, feeling emotionally numb, yearning for what has been lost, strong feelings of anger and agitation, and bouts of sadness and depression, before arriving at a place of acceptance and new life. Although clients often express many of these emotions these descriptions are too simplistic to describe what happens when they move from being part of a sighted world to becoming part of a blind or partially sighted one.

There are also:

- **Questions about identity**

People accessing the service frequently comment that they ‘do not know who they are any more’ considering that sight is the major factor that enables them to feel confident in themselves. There are also some identity claims which as a sighted person had been important such as ‘driver’, ‘reader’, ‘parent’ which were now lost or had to be redefined in response to losing sight.

This is not meant to imply that people who are blind and partially sighted do not have any identity claims, only that they have to find different, less visual ways of creating themselves, and as with all transitional processes this can be experienced as challenging and painful.

- **Feelings of isolation**

One of the most common themes repeated time and time again by many clients, are feelings of isolation.

Clients report ‘missing out’ on the visual signals and gestures we all make to each other over the course of an ordinary day. For example a smile, the raising of eyebrows, eye contact, or waving to someone you know on the other side of the road.

These issues, although predominately brought by clients who have recently ‘lost’ sight, are also raised by clients who have lived for a long time with a visual impairment. Feelings of isolation are often compounded, by for example, the practical challenges of travelling on public transport, and for

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older clients who may be living alone, the absence of day to day contact with others.

● Relationships

Many clients comment on how difficult sight loss is for their partners and other close relatives or friends, and how it impacts on their relationships by changing relational dynamics and upsetting long held roles and expectations for the future.

A high percentage of clients attending the service are single. This is perhaps a reflection of the age of clients (many are widowed) but also may perhaps reflect the findings of research (Monbeck 1973), that people who are blind are less likely to find a partner.

● Work

Working age clients report high levels of stress and anxiety connected with employment issues.

Although the Disability Discrimination Acts have given legal rights to disabled people, and the Access to Work scheme enables employees to obtain equipment and support in the workplace, discrimination is still widespread and unemployment rates amongst working age blind and partially sighted people are extremely high.

However, client issues are not only about being excluded from employment but are often about having to change career path as a result of disability and the loss of standing in an existing role.

● Depression and anxiety

A high percentage of clients (over 90 per cent in 2006/7) report feeling 'depressed' and feel that this depression is affecting their quality of life to a major extent.

Research has shown (Burmedi, D, Becker, S et al. 2002) that depression rates in people who are blind or partially sighted are far higher than in the peer population, with a higher incidence of suicidal thoughts and feelings, and this has certainly been reflected at the Bristol Counselling Service where

53 per cent of clients accessing the service during 2006/7 were thought to be at a moderate to high risk of suicide (at assessment), which is a far higher percentage than in mainstream counselling settings. The assessed risk following counselling reduced to fewer than 5 per cent of clients.

Reports of anxiety and panic are frequent, with some situations commonly being identified as highly stressful. These included hospital visits, the experience of diagnosis, treatment and registration, going out alone, eating out, and 'not knowing what the future holds'.

- **Travel and mobility**

Many people mourned the loss of independent travel, especially having to give up driving and becoming reliant on public transport. Rehabilitation and training aimed at enabling people to develop new ways of living may be experienced as liberating, but feelings of ambivalence are also common. For example learning to use a white symbol cane as an aid to walking down the street may be experienced as enabling independence, but also as being singled out as 'different'. As Knighton says, 'a cane is a permanent commitment to blindness, more final than a diagnosis even' (Knighton 2007: 69).

- **Am I 'going mad'?**

Clients have expressed fears of 'going mad' and this is commonly related to experiences of visual hallucinations. These hallucinations or illusions, known as Charles Bonnet Syndrome, take all kinds of forms from simple patterns of straight lines to detailed pictures of people, animals or buildings. Charles Bonnet Syndrome (CBS) usually affects people who have lost their sight later in life, but can affect people of any age, often appearing after a period of worsening sight. The visual hallucinations often stop within a year to 18 months.

As CBS is still not readily spoken about by medical practitioners, people are often unaware of the syndrome and reluctant to disclose hallucinations as they may be fearful they are a sign of Alzheimer's disease or mental illness.

CBS hallucinations are not accompanied by hearing voices or by tactile hallucinations and are not signs of psychosis. A factsheet on Charles Bonnet Syndrome is available on RNIB's website (RNIB 2008b) and there is also further information in the BMJ (2008).

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- **Feelings of anger and rage**

Many clients express anger and rage both at losing their sight, and how at times they feel overwhelmed by these feelings. Anger is directed towards family, hospitals, 'the sighted', drivers and cyclists (one client reported assaulting an unknown cyclist who was riding on the pavement).

Many also talk of feeling angry and frustrated with themselves for not being able to do the things they want to do, as well as towards a society which is perceived as excluding them from normal activities.

- **Feelings of shame and uselessness**

Clients often talk about feeling ashamed; of their failing eyesight, of losing their dignity by having to ask others for help, of not being able to do tasks such as 'reading letters' or day to day activities such as driving, housework, even 'putting on make up'. Many speak in terms of being a 'burden' or a 'nuisance' to their friends and family, and of how 'useless' or 'purposeless' they feel. The tensions between the need to be 'independent' and 'dependent' have commonly emerged.

Knitting in the dark: narratives about the experiences of sight loss

These are excerpts from stories emerging from counselling conversations that took place between November 2005 and September 2006. They were originally presented for an academic research project which used a narrative methodology to explore the experience of sight loss both from the position of client and counsellor. Andy's and Sarah's stories are compiled from conversation and audio journals kept at the time of counselling and 'my story' comes from extracts taken from a written journal kept during the first 10 months of the counselling project.

They have been included, not to give an 'absolute truth' about the experience of sight loss (or of counselling), but to give you a glimpse of the real, lived experience of people affected by issues you may not be familiar with. Andy and Sarah had only recently been diagnosed with sight loss, I have lived with a visual impairment all my life.

Perhaps as you read and reflect on these stories you can consider how they resonate with your life (and counselling) experiences, and how they differ. You could ask yourself whether there are any themes in particular that struck a chord with you? Was there anything that surprised you? And how you might have felt or worked if Andy or Sarah were your clients?

Part one

Sarah

“

The angels appeared soon after my vision left.
‘Do not be troubled’ they say,
all I can see sometimes is their sad eyes.

I spent about six months wanting to die thinking;
“I’ve had my life”,
but the angels kept coming;
crying in my eyes.

I can’t see the point any more.
I know they say at the hospital “there is always hope”
and “it could be worse”;
but I’m not sure that they are right.

Last year when he (my husband) died
My first thought was “freedom”...
Then the angels came.
Guilt came on me.
Weighed me down.

My first thought when I knew he was gone was “freedom”
so much of the world to see,
even going out to the bingo without his voice
shouting in my face.

Then the angels came;
“gambling is the devil’s work” he would have said.

Him dying seemed to open the gate for me;
I stood on the threshold.

Then the angels danced in my eyes;
he took my sight and sent me the angels to spy.

Now I have discovered that my angels are not madness
but are shadows, and that many people have them.
The brain tries to make up for not seeing.

No-one told me though,
I thought I was going mad,
but angels they are, and they haunt me.

Part one

Sue

Journal January 2006

“ There are many things which I thought I knew about not being able to see very well that I realise I don't know at all. How do you cope if you are elderly, alone and then you lose your vision? How is it when your whole life has been reading, writing and you can no longer do these things? The hours in the day must seem so long and endless.

Often there seems to be a battle between learning new skills and the 'not wanting to go on'. I had a conversation with (Andy) today who is a 60-year-old man with diabetic retinopathy. His rehabilitation worker referred him as he seemed to have "got on well to start with, but now was refusing to go out". "He seems really fed up" she said. Andy talked to me about how hard it is for him to keep up an act of "coping well" and although he knows he can learn new ways of doing things, he feels so angry and despairing.

"The only thing I have control over now is if I live or if I die" he says. Suicidal thoughts seem top of everyone's agenda at the moment and sometimes I feel like the little Dutch boy who puts his finger in the dyke only to find more and more holes appearing.

Andy

“

People stand in the way
and make encouraging noises.
The sweat trickles down my arms.
Why do they stand in the way?
Stupid, stupid,
the silent watchers waiting for my slip;
the condescending murmurs of encouragement.

Finding my way now takes all my concentration
I find my way by learning the route.

I record in my mind every dip in the pavement
each lamppost,
each fence,
I physically reach out with my stick
like a bomb disposal expert searching for mines
tap, tap, tap.

Never ever just walking and thinking about something else
concentrating so hard that
I break out in a sweat.

Someone stops me
I lose the plot.
Where am I?
The person – afraid, backs off at my angry response.
I am alone.

Part one

Somehow losing my sight has changed all my senses
my body is constantly tense
trying so hard to notice the least change of sound.
Loss of vision makes it harder to hear to link in with others.

I am so angry all the time
angry bitter thoughts
consume me.

Sarah

“

Each night I pray that I won't wake up,
but I always do.

It's always the same just at that moment of waking;
hope then despair.

The angels still have hold of me.

I always felt part of the community,
on committees and the church PCC (Parochial Church Council),
running a jumble, for red-cross.

Used to help in the charity shop.

Didn't do a lot, but it was good to feel useful.

I'd go down to the shop and stop to chat
with anyone and everyone.

Now they all walk past me.

I can't see them to say hello,
and it hurts so much.

It's bad enough that shopping is so difficult
without that;
without the silence.

I still go to church.

When someone comes to take me that is.

Otherwise I stay at home,

I can't ask.

It would be too humiliating to ask.

The priest did say he would come and give me home
communion

Part one

if I needed it.
Do I need it?

I think I need the people more, and they are
no longer around;
busy I should think. Too busy.
Never mind!

I get so angry with God sometimes
why can't he just let me be.
Now I feel I am such a nuisance,
I hate being such a nuisance.

Everyone is in such a rush,
and I'm so slow now.

I just want it all to end.

I've always been so independent
doing things for others,
being the one people relied on.
Now I'm just useless.

I'm expected to accept this thing
But I never will.
Never.

Every night I say my prayers
I pray that He will take me
He doesn't.
Just sends the angels
To torment me.

Sue

Journal May 2006

“

Frustration, anger, humiliation those are my thoughts for the day. I stood with fellow students at the crossing on Park Street. The lights weren't working. The rest of the group crossed leaving me stranded on the other side of the street. They wait talking amongst themselves as taking a deep breath I plunge into the traffic. A driver hurls an obscenity through the window. "Sorry", says my friend "I forgot", and charges forward through the throng of students. I say nothing, but feel everything. The fault however lies with me. My white stick, as normal, lies folded neatly, zipped in my bag.

A funny (?) incident happened today. I came out of my client's home to find no taxi, so waited patiently by the side of the road. Ten minutes later a car drew up and I jumped in. Fortunately it was the taxi. He was horrified. "You shouldn't wait by the side of the road here" he said "This is the street where ladies of uncertain reputations pick up their clients". A salutary lesson – check the taxi credentials before jumping in, and be careful where you wait. One of the many challenges for those with poor eyesight!

Part one

Andy

“

I live a lie

“I’m ok”

I tell my friend

“I’m coping well”

I’ve got a stick

and this guy who comes and tells me I’m doing ok,
and I am.

I get out, walk the walk, talk the talk.

Stumble my way through pavements strewn with
bins, people, cars.

So cheerful – “well done” they cry.

The lie kind of protects me,

like the stick I suppose;

moves people away from me.

Being vulnerable is something I’ve always dreaded.

Reality though is that it’s shit.

I’m not ok.

I hate it.

I’ll never accept it (never? no never, never? well hardly ever –
my head bursts into a refrain from the Pirates of Penzance)

Life isn’t worth living;

but I live it because I’m too afraid not to.

I wish I didn’t have to.

She – at the hospital – told me that living without sight
doesn't have to be a tragedy
that I can go on and have a "fulfilling life"
that I need to put a "brave face on it"
and I do – I think.
What the hell does she know though?
She doesn't live my life.
She just wants me to say I'm ok
so that she can feel better about it all.

I can't do this.

I don't want to.

I think about dying sometimes
it seems like a kind of relief to think
that it will all end one day.

Who am I as a man anyway?
I run my hands over my body,
my fingertips can explore and know these things;
the stubble on my chin,
the chest hair.

But am I a man to you?
I hear your voice
I catch a smell of something feminine
a glimpse of orange – skirt I think
but I can't see your face.

I can't touch your body.
I have to follow the etiquette of the sighted;

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if I could see, I would see in seconds what it takes me for ever to tell.

I can only be a man if I can gauge myself against you as a woman or perhaps someone else as a man.

I took it for granted when I could see.
Constantly taking in what you look like
and the differences between us.

This leads me to know who I am, and who you are,
and whether we can be together or share any level
of intimacy.

Postscript

These are only excerpts of the narrative text, and stories from where Andy and Sarah were at the time of writing. Since completing this study and having the stories presented to many different audiences they have both reported that their lives have changed (for the better) and that they feel very differently.

Sarah now regularly gives talks about her experiences to local groups and schools, and gives guidance on how they can make their activities accessible to people who are blind and partially sighted. Andy is undertaking counselling training hoping to work specifically with disability issues. He considers that he has re-defined himself as “a feeler, someone who feels their way around and who feels anger, rage, sadness and joy. Feeling is being. I am because I feel” (Dale 2008a).

The purpose of writing these stories was to give voice to those who **live with**, rather than those who **treat others** affected by sight loss, and to “enable sighted others to understand something of our experience” (Dale 2008b). They are included here with the intention of provoking discussion and enabling others to consider life lived in a different world from their own.

For further information about the therapeutic and academic uses of these stories see Dale 2008a and 2008b. To obtain a copy of the original research project email the author sd2510@bristol.ac.uk

Part two

Making your practice accessible

Practicalities

Making a first appointment to meet a counsellor can be daunting for anyone and the hurdles can seem even greater for people who cannot see. Leaflets may be in small print and therefore difficult or impossible to read, and it may be challenging for a client to find their way around a new environment such as a counselling centre.

Making your practice accessible is good practice, as well as an important part of ensuring compliance with the 'Disability Discrimination Act 1995 Access to Goods, Facilities and Services'. This requires that 'reasonable adjustments' are made so that services are accessible to people with disabilities.

The following suggestions are to help you ensure that people who are blind and partially sighted can find out about and access your service. It is recommended that this guidance is read in conjunction with the BACP Information Sheet G11 'Making Therapy Accessible to Disabled People'.

Accessible information

It is good practice to ensure and publicise that you can respond to requests for service information in alternative formats, for example service information, appointment details, and codes of confidentiality. There are many ways that people can access printed information, including:

- **Large print**

Many people with low vision can read print if it is in large bold print. By increasing the size of the print to the required font size and 'bolding' it as a Word document, information can be produced easily on request. Clear fonts such as Ariel are generally easier to read.

- **Email and internet**

Many people use accessible computer technology such as screen magnification software that enlarges text, or screen readers that 'read out' text on the screen. Clients who use accessible technology may prefer you to email appointments or electronic versions of documents (in Word not as a

PDF as this cannot be read by most screen readers). If you have a website, you will need to ensure it is accessible to people with disabilities – an important aspect of website design and layout. RNIB's Web Access Centre (RNIB 2008c) can offer guidance and training on website accessibility.

- **Audio**

Some peoples' preferred format is audio-based, and you may need to record information onto a cassette or CD for them. Depending on the complexity and length of the document and how many copies are needed this may be done simply on a domestic machine or professionally transcribed by a transcription centre.

- **Braille**

It is often assumed that everyone who is blind or partially sighted will use braille but this not the case. Many braille users also use access technology, so may prefer to receive information via email (as above) especially long documents. However it is important that you know how and where to get material transcribed into braille if you need to. For more information see (RNIB 2008i).

Completion of documents by clients

Many services invite clients to complete documents, such as evaluation and client satisfaction questionnaires. For example at Bristol Counselling Project, in order to use CORE outcome measure questionnaires, we created large print, audio and electronic formats with permission from CORE IMS.

If you use text-based materials within or between counselling sessions you will need to discuss possible solutions with your client and whether the method of working may need to be varied. For example completing a diary can be difficult for someone who does not use access technology or printed materials, so an audio diary may be an alternative. Online CBT programmes, for example 'Beating the Blues' are not currently accessible to many blind or partially sighted people.

Further detailed guidance on making printed information accessible can be found on the RNIB website (RNIB 2008d).

Part two

Invoices and money

For services where fees are payable, it is helpful to discuss preferred methods of payment and invoicing. For example writing cheques or differentiating between denominations of bank notes can be difficult. Invoices may be needed in alternative formats, and payment methods may vary from individual to individual.

Guiding and assistance

A client arriving at a counselling service may require some assistance in finding their way around an unfamiliar environment, so do ask if any help is needed. Clients may wish to take your arm or hold your elbow, and for you to 'guide' them to the counselling room. Further guidance is available from the RNIB website at the 'How to guide people with sight problems' page (RNIB 2008e).

If a client brings a guide dog with them remember that it is a working dog, not a pet, so do ask before interacting with it.

The most important thing is to ask your client if they require any assistance, and not to assume you know what they require. When meeting always introduce yourself, and if you have to leave the client for any reason then tell them you are going so they are not left talking to an empty room.

The counselling room

Simple adjustments to the counselling room, such as to the lighting or layout can be important in helping clients familiarise themselves with the environment, as well as making the most effective use of their vision.

When meeting a client for the first time it is helpful to describe the room layout, (including where the exit is in relation to where they are sitting and any unexpected obstacles) and invite your client to ask questions about the room. This will encourage your client to ask for what they need, and show that you are open to suggestions about things that you may not have thought about.

Common adjustments include:

- **Lighting**

Lighting is very important and diffuse room lighting, such as two or three small lights, which can be angled, is generally better than one strong central source. A flexible lamp that can be adjusted can also be useful, as can a window blind to reduce glare.

Where the client is sitting in relation to lighting sources is also important. Some people may have a problem with glare from windows, whilst clients with cataracts can have difficulty if light is shining into their eyes, and some conditions such as macular degeneration can cause sensitivity to light.

- **Room decor and use of contrast**

When you next decorate your counselling room or practice this is an opportunity to implement some simple good practice guidelines. The walls of the counselling room itself are best decorated in a light colour, such as white, with the carpet or flooring in a contrasting colour. Painting the doorframe a deeper colour than the door and walls, offers a stronger contrast that can be seen more easily by someone with low vision.

- **Adapting counselling delivery**

Some people are unable to travel independently, perhaps because of health conditions. Consider whether you are able to provide telephone counselling, online counselling or sessions in a client's home. New ways of working of course need to be thought through, including from a health and safety perspective, but can reach people who would not otherwise be able to access counselling.

Part two

How sight loss may impact upon the therapeutic relationship

Non-verbal communication

Non-verbal communication is important in a counselling relationship, but however much empathy you may think you are displaying, a client who is blind or partially sighted may not be able to pick up on routine visual clues such as nodding, facial expression, or maintaining eye contact. As we have heard from Sarah and others, losing sight often makes it harder to form or gauge relationships, so you will probably need to say and describe more than you normally would.

Personal space

You may need to review your standard counselling practices regarding touch and seating arrangements in response to the needs of a client who is partially sighted or blind. For example, sitting in carefully angled chairs across a coffee table may be ideal for most sighted clients, but is not always appropriate for a person who can only see you if you are sitting directly next to them.

Touch can sometimes be very important to people who have lost their visual sense and conventional counselling practices may need to be reviewed. For example, Andy sometimes wanted to hold my hand in his when we spoke together and commented: 'when I touch your hand it pulses with life and I sense your meanings' (Dale 2008a). Touch is also a necessary part of guiding, but touching unexpectedly without forewarning your client can be unwanted or can cause shock.

Tony recounted, 'I walked into the room not knowing who was there. I was pulled into a "bear hug" I felt panic – it took me a few minutes to recover and realise that it was only my brother's wife'.

There are no absolute rules, again ask your clients what they would like, and be prepared to revise your conventional practices.

Relational dynamics

The power dynamics within any therapeutic relationship need to be considered carefully, and are especially important when working with a client who is blind or partially sighted. For example, your client could feel vulnerable because of being dependent on you in practical ways, such as getting in and out of the counselling room, or if because of the client's mobility difficulties you meet with them in their home, you may feel vulnerable as the environment is out of your control. Recently a counsellor reported visiting a client at home in the late afternoon to find the room they were meeting in was dark – the client had no working light bulbs as she did not need them.

How we respond to difference, and our own thoughts and feelings about being 'blind' will affect the therapeutic relationship, and being genuine about our not knowing seems key to enabling blind and partially sighted clients to engage with the therapeutic process. It is important to remain self-aware, and discuss with your client what sight loss may mean to them, and what (if anything) they need from you, or (as in the case of the light bulbs) you need from them.

Working with young people, families and partners

As discussed in the previous section, when a person loses sight this often has a profound effect on relationships, and frequently partners and families of those affected by sight loss will request counselling support. Although the remit of this toolkit is specific to working with clients who are partially sighted or blind, it seemed important to include a small section on working with 'partners' and 'families and young people', and it is hoped that it will at least highlight these areas for further exploration.

For partners, family and friends, sight loss can lead to uncertainty about the future, financial pressures, changing roles (including negotiating or taking on a role as a 'carer') and can put considerable pressure on relationships. Parents with a child or children with a visual impairment may also seek counselling as may young people, who may have very varied experiences of family expectations, education provision, and peer or family support.

Part two

If you are working with parents, young people or families affected by these issues, further information is available on the RNIB website (RNIB 2008f).

The website also hosts a number of peer support forums for young people and parents: RNIB Parents' Place Forum (RNIB 2008g) is a forum to help parents support one another. There is also a forum for students (RNIB 2008h) and a forum for young people aged 11-16 (RNIB 2008j).

Background information

Statistics

There are an estimated two million people with significant sight loss of whom approx 364,000 are registered as severely sight impaired (blind) or sight impaired (partially sighted). There are an estimated 25,000 children in the UK with sight problems; about 12,000 of these children also have other disabilities.

It is estimated that 49 per cent of blind people and 80 per cent of partially sighted people can recognise a friend at arm's length, so blindness does not necessarily mean 'living in total darkness' as is often assumed.

Eye conditions

Some people will be affected by a sight condition from birth, while others may have an inherited condition such as retinitis pigmentosa, which gets gradually worse over time. Sight loss can occur as a result of accident or injury or as a result of other related conditions, for example diabetic retinopathy. Sometimes an eye condition may have no known cause and could develop at any age, as in some cases of uveitis.

Age-related eye conditions are the most common cause of sight loss in the UK. Some 95 per cent of people with sight problems in the UK are sixty-five or over. Conditions such as macular degeneration or cataracts are the main causes.

Eye conditions affect vision in many different ways: for example some people will have no central vision or no vision to the sides; others may see a patchwork of blank and defined areas, or else everything may be seen as a vague blur.

Diagnosis and registration

Diagnosis of a specific eye condition usually follows a routine eye test or after someone noticing something different with their vision.

An ophthalmologist (eye doctor) will investigate and diagnose the eye condition. Some eye conditions are treatable but many are not, and some conditions deteriorate very slowly over time whilst others may affect sight very quickly. An ophthalmologist will decide if and when someone can be registered as 'severely sight impaired/blind' or 'sight impaired/partially sighted'. This register is held by the individual's social services department. Many people do not register, either because they are unaware of the benefits of doing so, or through choice.

Services and support

A person who has been diagnosed with an eye condition whether or not they are 'registered' can request a community care needs assessment from their local social services. Services and waiting times vary greatly across the UK, but may include support from a rehabilitation worker or mobility worker. For example, services may include training and support in learning new ways of carrying out everyday tasks; orientation and mobility skills to enable safe and independent travel; communication methods including keyboard or braille; and assistive technology training for IT.

An assessment by a Low Vision Service may also provide equipment, such as magnifiers, and training to enable a person to make the most of their residual vision to help with detailed activities such as reading or writing.

Part two

Sources of additional support

There are a number of national and local organisations and charities that provide a range of information and support services for and by people with sight loss. Further information is available from **RNIB's Helpline 0845 766 9999 or 020 7388 2525**.

Counselling and emotional support specifically for people affected by sight loss is provided by a small but growing number of national or local organisations. These currently include:

RNIB (Royal National Institute of Blind People)

www.rnib.org.uk

Helpline 0845 766 9999 or 020 7388 2525

Emotional Support Services ess@rnib.org.uk

Bristol Counselling Service 0117 9341720

Low Vision Service Counselling Pilots

susan.coulson@sightservice.co.uk

RNIB provides telephone counselling and emotional support and is currently piloting face to face counselling in some local areas.

NALSVI (The National Association of Local Societies for Visually Impaired People) 01302 571888

www.nalsvi.cswebsites.org

Some local societies offer counselling and or emotional support as one of their services.

The Macular Disease Society 0845 241 2041

www.maculardisease.org

The Macular Disease Society provides telephone counselling to people affected by macular disease.

VINCE – Vision Impairment Network for Counselling and Emotional Support

VINCE is a developing 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.

For further information please visit the VINCE WebPages at www.vision2020uk.org.uk

VINCE is listed under Special Interest Groups.

Part two

Researching practice

Research conducted with clients from the Bristol Counselling project was conducted in accordance with BACP ethical guidelines. You can find out more information about research on www.bacp.org.uk.

The **CORE System** (Clinical Outcomes for Routine Evaluation) has been designed in the UK for use in psychotherapy, counselling and other psychological therapies to measure outcome and provide for service audit, evaluation and performance management.

CORE IMS is authorised by the CORE System Group to offer a quality support service for both existing and prospective CORE System users. This includes training and management support for counselling and psychological therapy services using the CORE System, and CORE-PC software. More information is available at www.coreims.co.uk. The outcome measure questionnaires were developed for use by visually impaired counsellors and clients by creating an audio and electronic format with permission from the CORE team.

The research project 'Knitting in the dark: exploring the experience of sight loss' was conducted using narrative inquiry as part of doctoral studies with the University of Bristol. The full study can be accessed by emailing the author on: sd2510@bristol.ac.uk with full details of the methodology used.

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