Knitting in the Dark

Susan Dale with Andy and Sarah

Sue Dale works for the RNIB as senior counsellor for the RNIB Bristol counselling project, which provides a face-to-face counselling service for people living, working and studying in the Bristol Area. She is also undertaking doctoral studies with Bristol University. Sarah and Andy are two ex-counselling clients who responded to the question ‘Is there anything you would like to share with others about your experience?’

Knitting in the Dark – The Stories

Sarah
I’m 58 quite assertive normally
I can’t believe how the hospital told me
Can’t believe it.
Even sitting in your counselling room telling you
I thought that I must have imagined it.
‘She’s got AMD’ he said to the student.
‘There is no hope of recovery the retina is damaged beyond repair’
Still they didn’t talk to me.
I blinked slowly.
‘What does this mean for me?’ I ask
‘We’ll make an appointment to get you registered’ he said
‘you don’t have to worry about it’
What! Me! Worry!
Then I was out in the street.
Should I drive home?
Did I really hear what they said?
If I couldn’t drive….
I started shaking then.
Uncontrollably.
I didn’t know where the bus went from.

[AMD age-related macular degeneration is a degenerative condition of the macular and the most common cause of vision loss in those over 60 (RNIB 2006:1)]

Sue
November 2005
‘It must be bloody terrible. I don't think that I could ever cope with it. I just couldn't go on living if it were me’. This was my taxi drivers thought for the day as we crawled through traffic towards my visit to a client at home. The driver is someone I travel with regularly, and regularly transports other visually impaired colleagues and members of RNIB. I am curious (although I didn't challenge him at the time) by his implication that sight loss was a tragedy. Certainly I don't consider it a tragedy, being born with a visual impairment which leaves me with tunnel vision it is just part of who I am as a person. I'm not suggesting that at times this hasn’t been frustrating, especially when I am entirely dependent on public transport—but having no peripheral vision has also enabled me to focus on one thing at a time, develop seeing through hearing, listening, and intuition possibly good attributes for a counsellor! I wonder about the different stories that I am hearing about sight loss and how prominent ‘tragedy’ and ‘medical’ stories are, and how little is told about peoples personal experience.

Andy
I use a white stick
I need it to feel my way through the streets
Like some kind of broken insect
Creeping round the ground
Tapping, poking, scratching, tasting.
I need it, yet hate it.  
How I hate it.  
It represents everything I hate and despise  
I have fantasies of smashing it, breaking it  
hacking it into a hundred pieces  
and then burning it.  
Burning it – seeing the flames lick it into dust.  
Then scattering the ash to the wind.

**Double listening**

Giving space and respect to stories of pain and despair and ‘how it is for us’, has enabled Andy and Sarah to move beyond being defined by these stories to finding new better descriptions of their life experiences.

It is not just the double listening to the individuals stories that is needed however, we hope that by sharing these stories with wider audiences that we can provide an alternative story which can stand alongside expert medical descriptions of sight loss and visual impairment and can hope to influence the practices of those setting up services to support those affected by sight loss and visual impairment.

**Casting Off**

Time to stop knitting,  
to cast off  
to finish this multi-coloured garment  
and wear it.
To move onwards, and outwards, sailing into the wind.
Feeling the spray on our faces, the breath of others speaking, shouting our names’.
(Sarah June 2007)

We would love to hear what (if any) impression these stories had on your own life and stories, and would be interested in sharing more of our work with you.

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