Songs at Twilight

Songs at Twilight:
A Narrative Exploration of Living with a Visual Impairment and the Effect this has on Claims to Identity

By

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To John,

For loving me

in sickness, as well as in health
and enduring the writing!

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PROLOGUE

Sue Journal June 2010
I have a certain amount of useful sight which means during the day I rarely think about what I cannot see. Because I have no night vision however the twilight hour is the time of day I remember my blindness. It is the sign that darkness will soon come and again and I will again be blind. It is a time of mourning, of lamentation, but it is also a time remembered of sitting around a campfire and singing songs and the warmth of the fire on my face where I felt drawn to others, not by vision, but by a sense of belonging, a sense of community.

A song my mother used to sing to calm my childhood fears at the onset of darkness comes into my mind:

"Just a song at twilight, when the lights are low;
And the flick'ring shadows softly come and go.
Tho' the heart be weary, sad the day and long,
Still to us at twilight comes love's old song,
Comes love's old sweet song" (Bingham 1927)

The beginning of a story about visual impairment

"Writing this book has made me blind" says Kleege (1999:1). She does not mean that in a physical sense she lost her sight whilst writing the book, but more that she explored her own relationship with blindness and how different her view of the world is than that of the majority.

Although night time has always reminded me of my visual limitations my journey into blindness and the relationship I have with being visually impaired really only came to the fore when I took up post as senior counsellor and project co-ordinator with RNIB (Royal National Institute of the Blind) Bristol in October 2005, and worked alongside volunteer counsellors to provide an innovative counselling service for people affected by sight loss. Until then I realise I had always lived my life as a sighted person without the sight and tried with moderate success to ignore what I could not see and to fit into the expectations that being sighted was "normal" and being visually impaired was definitely "not normal".

I have always written to try to make sense of the world I live and work in and this book is born out of my attempt to make sense of how I and other people who are visually impaired live in a world that prizes sight above all other senses. It is written from the perspective of considering that our sense of self and identity is socially constructed through relationship and the stories we tell of our lives.

The story of this book starts here; firstly with my own reflections on my work for the RNIB, then expanding to a small narrative research project I undertook with two ex-counselling clients who call themselves Andy and Sarah, which led to the emergence of a narrative entitled "Knitting in the Dark" (Dale 2006) which in turn led to a doctoral research project and then the text you are now reading.

Journal 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 that leaves me with tunnel vision 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.

Journal: December 2005

I have discovered there is so much I do not know about visual impairment, especially sight loss. Many of my clients report having "lost" their vision, and finding this a frightening isolating time; a time where there is so much grief for what is lost, at the same time as trying to learn new ways of living.

I want to understand something of what's happening to the people I'm working with. I look up various "conditions" on RNIB's website. I am struck by how calm and still the words on the page are, and how this contrast's with the person's experience. "Charles Bonnet Syndrome" is named after a Swiss philosopher who first described *this condition in 1760 when he noticed his grandfather who was blinded by cataracts describing seeing birds and buildings which were not there. (RNIB 2006:3). Tears prick the back of my eyes as I hold these words alongside the story of one of my clients (Sarah) who had thought for over 12 months that she was going mad.*

Apparently these visual hallucinations are common. If they are common, why are they not explained to people? I feel angry. Several clients have spoken of seeing things and being so afraid. Afraid they were losing their mind as well as their sight.

Journal: January 2006

There's so 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.

Journal: February 2006

Today I feel stressed and it feels much more appealing to go with the social model of disability and see people's sight problems as "going away" if we as a society promote more accessible services and communications. If we can give people the tools to live their lives by way of aids for living… I realise as I write this that although I do strongly agree that society needs to enable rather than disable others this is my feeble attempt to try to keep feeling in control.

The day has gone pear-shaped. My taxi was late arriving to pick me up from a client's home, which meant I was late for the information day (for the newly diagnosed) my next client then arrived very distressed and talked of how he had tried to commit suicide using a carving knife. Hearing his pain was very hard, but I am amazed that he is still here, and is committed to "finding a way through this". His *talking was like an eruption which I thought would never cease "nobody has ever listened before", he says. "They have been marvellous at the hospital, and tried everything but they say they can't do any more...they don't want to know that I'm not coping". I wonder about the staff at the hospitals, how do they cope with giving others bad news, they see so many patients in a day, but I also wonder about the silent suffering.*

Journal: March 2006

My work sometimes seems like a drop in the ocean. As I sit here on the train I have been thinking about how I struggle between wanting to be "right in there with the client" and also working in a time sensitive way. At times I feel I am not allowing clients to tell me things that I think would be difficult to manage in a brief intervention. There are always more clients appearing on the waiting list which is a dilemma that haunts thousands of medical professionals all over the country. Do we offer this person more treatment at the expense of making this person wait? What are the priorities? Does the inevitable compromise mean nobody is getting a good service?

Identity seems a key issue, when we know ourselves as a "sighted person" who are we when we are no longer "sighted". I have read a very interesting article by Langellier (2001) which showed how the narrator transformed the effects of treatment for breast cancer (including mastectomy) with a tattoo over the scar. She moved from someone who was "treated" to someone who had transformed tragedy into a new identity. I wonder can the "eye care pathway" (jargon charting the patients through diagnosis, treatment and registration) make room for this kind of transformation?

Journal: April 2006

The narrative therapy practice of using therapeutic documents has taken a new turn today. In the past I often asked people to write journals and/or written to them between sessions, today I had suggested to a client that she keep an audio journal and she played part of it to me today. It was fascinating how by listening to the original story (which she had recorded) she was then changing and enriching the story as she talked to me. She was reconnecting with her skills as a writer (she had in the past written both poetry and short stories). I asked her "does this 'telling on tape' change how 'depression' holds on to you?" She replied "it can't touch me when I write, and I can write even though it is in a different way". She had called her original story "when the angels came" and now she had found a preferred alternative story of "knitting in the dark" but that knitting in the dark was ok. It was a bit "messy" and "complicated" but that the "multi-coloured garment" produced was worth it.

I’ve been thinking about my sight too. I realise that I have been effectively living as a "sighted person" without the sight. For the first time ever I asked the university to provide me with documents in large print. Their response was positive. I felt like crying.

Journal: May 2006

Frustration, anger, humiliation those are my thoughts for the day. I stood with fellow students at the crossing on Park Street in Bristol. 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!

Journal: June 2006

I have met today with two ex-clients Andy who I saw for 8 counselling sessions at the RNIB centre, and Sarah who I met with for 12 counselling sessions in her home. They want to tell their stories so that others might understand. I feel excited yet fearful. I don’t want to let them down. We have decided that the title for the research project will be “Knitting in the Dark”.

"Knitting in the Dark: an exploration of the experience of living with a visual impairment"[1] was my first tentative step on the doctoral programme which I had enrolled and was intended to augment the statistical data collected as part of the counselling project using CORE-OM which is a benchmarked research tool developed for psychotherapeutic practices, (Barkham et al. 2006). I had hoped that the stories would give sighted others some idea about what living with a visual impairment might be like and to act as a pilot project for a possible doctoral thesis.

I was taken aback by the wealth of responses I received, not just from sighted eye care professionals, but from other people who lived with a visual impairment. People emailed, telephoned, sent me audio-tapes of their own experience, and stopped me in the corridors of RNIB offices to talk with me about my writing. There was an air of excitement and enthusiasm about the stories that I had not expected. My doctoral project was born. I then worked with Adam, Mike, Dennis and Tony and we compiled an audio narrative exploration of our experiences of living with a visual impairment and the effect this had on identity claims. This was another life changing project. We used an audio-narrative medium to challenge the taken for granted text based academic practices[2]. Once again the stories emerging from the study were listened to and read avidly by people who were visually impaired who in turn sent in their comments, reflections and their own stories.

This book is autoethnographic, and yet also collective. Not collective in the sense of distilling the many voices to one, but collective in the sense of linking the experiences of unique individuals across a common theme to provide "thick rich descriptions" of a subject matter that is so often thought of in mono-dimensional terms. It attempts to sew together in a giant tapestry the stories emerging from the pilot project "Knitting in the Dark", my doctoral thesis and also stories from the many people who responded to these projects. It hopefully gives not the "truth" about visual impairment, or narrative research, or any of us individuals (who are so much more than visually impaired) but a glimpse of the lived experience of a group of individuals who are trying to make sense of their lives living with reduced vision. It is an attempt by us to develop an opportunity for people with a visual impairment to find a voice in a world that is predominately sighted in its outlook, and to challenge sighted communities about their taken for granted attitudes about sight. These are stories not of tragedy, but of hope and resilience.

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[1] See Dale 2006 2008a and 2008b for more details.

[2] The dissertation was submitted to the university as an audio-book with a text transcript (Dale 2009).

INTRODUCTION

The narratives you will find contained in the pages of this book will hopefully speak for themselves giving a glimpse of the lived experience of a group of people living with a visual impairment. Within this introduction I intend to give some context for the narratives with an overview of the book and the underpinning research methodology. There is also an exploration of some of the current literature relating to visual impairment research, and an introduction to the contributors.

Claims to Identity

The concept of "identity" and how we define ourselves is very complex. My own views (and practice as a counsellor and researcher) are influenced by post-structuralist understandings of how we make sense of our lives, where I see identity as constructed through relationship, and the stories we tell of our lives. As Brockmeier and Carbaugh state, "the stories we tell ourselves about ourselves and others organize our senses of who we are, who others are, and how we are related" (Brockmeier and Carbaugh 2001:10).

I am visually impaired and registered as partially sighted. One of the questions I have been grappling with recently is: If our identity is socially constructed, then how does this relate to being visually impaired? After all, as Kinash points out, "not being able to see is not socially constructed" (Kinash 2005:19), the "not seeing" is after all a physiological fact. The attitudes that society has towards blindness however are socially constructed; thus within a world where the majority are sighted, social interactions have developed to consider vision as "normal" and those of us who have different vision as abnormal. I suppose in some senses this is a democratic process, but in placing so much value on sight and in considering this constructed value as a "truth", the experience of those who are blind or partially sighted is often negated thus influencing research and how services are provided.

Literature relating to visual impairment

Literature reviews reveal that the majority of research relating to visual impairment comes from medical understandings of vision loss, with emphasis on diagnosis, treatment and rehabilitation. This has usually been undertaken by sighted "experts" speaking about people who are blind or partially sighted (Bolt 2005; Monbeck 1973; Scott 1969; Fitzgerald and Murray Parkes 1998) to name but a few. There is a growing collection of studies written about the emotional responses to sight loss (Burmedi et al. 2002; Butler 2007; Stephens 2007; Thurston 2010), and there are a number of non-academic memoirs and biographies including works by Ching (1980); Hull (1990); Kuusisto (1998); Knighton (2006; 2007) and of course the works of Helen Keller (1912; 1933). There are, however, few visually impaired researchers overtly using their personal experiences to influence research, with the exception of Kleege (1999; 2006); French and Swain (2000); Tuttle and Tuttle (2004); Krieger (2005) and Thurston (2010).

Deaf studies, and disability studies (Campbell and Oliver 1996; White 1997; Barnes and Mercer 2003; Hole 2004; Mintz 2007; French and Swain 2004; Barnes, Mercer, and Shakespeare 1999) give a different perspective, and have helped me consider how the social movement of disability has gained momentum, a movement which espouses that disability is not about physical difference, but about societal negative attitudes towards that difference. This movement has encouraged more public awareness of disability discrimination, and actively sought to change public attitudes. It has encouraged the promotion of inclusive practices within education, the workplace and social settings which has resulted in less overt discrimination and more accessible services being available for example, disabled toilets, lifts and accessible documents and signs, and workplace assistance being available to help both employers and their disabled employees. The issues of disability rights are now implemented through statute in the form of the Disability Discrimination Act 2005, and the Equality Act 2010 but despite these rights now being widely promoted, it does not always seem to have an effect on how people feel about living as "visually impaired", or their experience of discrimination. Tony (one of the contributors) said to me recently, "the Act is just a token really, people are more careful about what they say to you, but they still think the same! It only pays lip-service to my needs, and ignores completely how I feel or what I need".

Duckett and Pratt in 1999 and 2007 conducted reviews of visual impairment research and called for research practices where there was empowerment and "greater inclusion of visually impaired people" (Duckett and Pratt 2007:7) and French and Swain called for research (with people who were disabled) to be emancipatory, and that "supported people in their struggle against oppression and inequality" (French and Swain 2000:35). This book is a response to these calls and intends to give voice to those living with a visual impairment. It also hopefully opens up a space for further conversation between visually impaired and sighted communities in order to empower and give voice to those who are visually impaired, and to encourage research which does not negate their experience.

This book intentionally moves away from “expert” and “medical” opinion, or even “social theories” of disability. It uses a collaborative, narrative, methodology that enables myself and 30 contributors to explore our personal experiences of living with a visual impairment and in doing so “gives voice” to people who are blind and partially sighted. The themes contained in each chapter are those contributors felt important to share with readers. This means that you may not necessarily get answers to the questions you may have about the experience of visual impairment, but it does try to redress the balance of research activities which have been up until recently weighted to the curiosity of the sighted researcher as opposed to what visually impaired people think is important.

Narrative approaches to research

The use of narrative within social science research has been documented by researchers such as Richardson (1990; 2000); Ellis (1999) Ellis and Bochner (1992; 2000); Ellis and Flaherty (1992); Clandinin and Connelly (2000); Etherington (2000); Richardson Taylor et al. (2000); Langellier (2001); Reissman (2006). Oral history and life story projects have also used narratives to document the history and give voice to marginalised groups (Smith 1999; O'Neill and Harnindranath 2006; French et al. 2006; Cloke et al. 2000), and Pelias has spoken of how performance and arts based methods can be used to explore social processes (Pelias 1999) and indeed I, and others, have used narrative approaches to explore counselling processes (Dale 2010; Etherington 2000, 2001; Speedy 2007).

Within this book, narrative is used to “show” a dynamic process of research, through conversation, rather than a “telling” of a research process that has happened. The focus is firmly on the experience of visual impairment rather than a review of methodological approaches and conclusions. It uses narrative, specifically outsider witness practices (Myerhoff 1982) and definitional ceremony (White 2003) as a means to construct and convey identity.

I was introduced to outsider witness practices and definitional ceremony whilst studying narrative therapy as part of a Master of Science Counselling award. These practices and the phrase “definitional ceremony” were used initially by anthropologist Barbara Myerhoff to describe the way in which people could generate richer identity claims by telling stories of their life experiences and having these witnessed by others. For example people belonging to religious communities such as Jews or Christians (within worship ceremonies) tell the stories of God's relationship with people in the past to enable them to understand God's relationship with them here and now, and it is in the witnessing and sharing of these stories that people gain a sense of their own identity and worth. Sometimes however, as in the group of elderly Jewish people Myerhoff was working with, the natural occasions for this kind of witnessing did not happen, and individuals became increasingly isolated and the community fragmented.

> "when cultures are fragmented and in serious disarray, proper audiences may be hard to find. Natural occasions may not be offered and then they must be artificially invented. I have called such performances 'definitional ceremony'" (Myerhoff 1982:105).

Witnesses were not asked to "evaluate" the stories they heard (either in terms of praise or criticism, but rather to allow the stories to resonate with their own life experiences and the stories from their own lives that were evoked. These practices have been developed by Narrative therapists such as White and Epston (1990), Payne (2000) for use within their therapeutic practices and developed also by researchers such as Speedy (2007; 2004).

Isolation is one of the commonest "issues" cited by people with a visual impairment (Burmedi et al. 2002; Stephens 2007), and the opportunity to "witness" in this sense to each other is limited by the fact that people who are blind are a minority, and the practicalities of living with low vision means we often have to rely on others to facilitate meetings. Also, there is often the expectation from sighted communities that people who are visually impaired should be integrated into a sighted society rather than meet with each other. One manager at a local society for the blind responded to my suggestion of a support group for people affected by sight loss said,

> "we don't want to start a blind ghetto here, you never know what they might get up to if they meet in groups! The need is for them to become part of our community not a separate one".

What I discovered when I started to present or published stories about people's experiences of living with a visual impairment to audiences of blind and partially sighted people was that stories evoked stories. When stories were told those listening talked about; how what they had heard evoked strong feelings linked to their own experiences and they in turn told me stories about their own experiences. When I relayed these new stories to the original storytellers they expressed feelings of their experiences being validated, and felt a strong connection to these others.

Through the process of the telling of stories, these being witnessed by others who in turn have told their own stories there has been movement from individual fragmented voices to a collection of linked stories that are presented in this book.

There has been a growth within feminist traditions of what is described as "collective biography" which is as Speedy states: "work that draws the memories that people hold to in their lives through a process of telling, re-telling, writing and re-writing stories" (Speedy 2005:31) and through the re-telling and writing "reveal the ways in which we were (and are) collectively produced" (Davies et al. 2001:169). This book is not a "collective biography" (Davies et al. 2001) in the sense that the stories are not written collectively, with individual stories distilled into one collective voice, but they are a collection of stories connected across shared themes, thus instead of the process being one of reduction, the opposite occurs; many voices are added which give thick rich descriptions (White and Epston 1990) of a subject matter that is often thought of in very narrow terms. Our sense of community is being re-membered (White 1995). There is what White (1999) describes as "commutas – that unique sense of being present to each other in entering liminal circumstances, betwixt and between known worlds" and out of the unknown is born something new.

The narrative is presented as a tapestry of voices which challenge the privilege of medical and academic knowledge and will hopefully inspire other people who live with a visual impairment to tell of their experiences. The book is set out in three parts:

Part 1 Transitions will set the scene, introduce the contributors and include themes relation to transition from sighted to visually impaired. Chapter One "Diagnosis to Registration explores the experiences of being diagnosed with an incurable eye condition, and the journey from diagnosis through treatment possibilities, to losing sight and registration and includes part one of the commentary "the etiquette of the sighted". Chapter Two "Living with incurable sight loss" explores the experience of losing sight, in terms of emotion and practical issues that arise in daily living. It also includes part two of the commentary "the etiquette of the sighted". Chapter Three "Changing Relationships" focuses on how the dynamics of personal relationships change with loss of sight, and includes part three of the commentary "the etiquette of the sighted". Chapter Four "Employment, Study and Benefits" explores the experience of changing patterns in employment study and what living on benefits is like and includes part four of the commentary “the etiquette of the sighted” Chapter Five “Am I going Mad?” considers the experience of living with visual hallucinations and societal attitudes that link losing sight with deteriorating mental health. It includes a commentary that explores current literature relating to visual hallucinations and “Charles Bonnet Syndrome”.

Part 2 – Living Life as someone who is blind or partially sighted; will consider the societal attitudes towards blindness and what it is like to live, long term, with limited vision in a world that values sight above all other senses. Chapter six “Societal attitudes towards blindness” explores how societal attitudes about visual impairment affect perceptions of self and identity. It includes the first part of commentary entitled “re-authoring blindness”. Chapter Seven “Who am I if I cannot see you?” explores identity issues related to gender, sexuality and relationships and includes part two of the commentary “re-authoring blindness”. Chapter Eight “Blindness and Disability Discrimination” explores how disabling practices have disempowered contributors and includes part three of the commentary “re-authoring blindness”. Chapter Nine “New treatments, ‘A step forward for humankind’, or not?” explores whether visual impairment is always a medical condition that needs treatment or whether it is just a different way of being. It also includes part one of the commentary entitled “living in the twilight zone”. Chapter Ten “Differences between blindness and partial sight” explores from different perspectives the experience of blindness and partial sight and includes part two of the commentary “living in the twilight zone”.

Part 3 – Enabling practices and transforming identities considers how people’s negative experiences of living with visual impairment can be minimised. Emotional support, counselling and emancipatory research practices are explored and how people can support themselves and enable dialogue with sighted professionals in ways that promote enabling rather than disabling practices. Chapter Eleven “Emotional Support” considers the emotional support needs of those who are losing sight and includes part one of the commentary entitled “developing emotional support services for people who are visually impaired”. Chapter Twelve “Tales from the Counselling Room” explores contributor’s experiences of using formal counselling and other psychological interventions and includes part two of commentary “developing emotional support services for people who are visually impaired”. Chapter Thirteen “Joined up Voices” uses excerpts from group conversations between people who are blind and partially sighted to explore what moves them from feeling isolated, marginalised and without a voice to a vibrant community who have a degree of control over services.

Chapter Fourteen “Narrative Perspectives on Research” explores the use of narrative research practices to research the experience of living with a visual impairment and the impact of the research project on contributors. It also includes part two of the commentary “emancipatory research practices. Finally there is an Epilogue which is entitled “The re-grilling of Mr B”.

Terminology

I have used the descriptions “blind or partially sighted” or “visually impaired” interchangeably to mean someone who is registered as either seriously sight impaired (blind) or sight impaired (partially sighted). I have also used the terms counselling, therapy, and psychotherapy interchangeably to mean a therapeutic undertaking agreed upon by someone who is commonly called a client and someone who is called counsellor, therapist, or psychotherapist.

Poetic representation

Representing conversation as text is always challenging, and much has been written on this subject for example within the works of Richardson (1992; 2000; 2003; 1990; 2000). We do not normally speak in the formal language of prose, but in what has been described by Tedlock (1983) as “dramatic poetry”. I have therefore - as others have before me (Richardson 2003; Speedy 2005; Etherington 2000) presented conversation in stanza format. For a fuller discussion of my use of stanza format and how conversation is turned into text see Dale (2010) where a full discussion and examples of the process are included.

Introduction to contributors

Some contributors have chosen to use pseudonyms others have preferred to make contributions under their own names, they have all been part of the editorial process, but following consultation I have taken most of the decisions about what material to use and where to put it. Some contributors have been involved with the research project since 2005, others have joined the journey in the intervening years. Some have written much and others only a little. All their contributions however big or small have been valued and are, I consider, the vital element of the book which you are about to read.

All the contributors introduce themselves in ways they feel appropriate, and tell you the reader what they would like you to know about them, possibly not always what you would have chosen to ask! Their ages range from 22-89 years. All are registered as either sight impaired (partially sighted) or severely sight impaired (blind). Some have lost sight relatively recently others have always lived with a level of visual impairment. Sixteen are male fourteen are female. Most have varying degrees of residual vision, three have no vision at all. They are all developing a voice.

In alphabetical order they are: Adam, Andy, Ann, Anna, Annie, Beth, Caroline, Chris, Claire, Dennis, Emma, George, Jane, Maria, Martin, Matt, Maureen, May, Michael, Mike, Mo, Patrick, Pauline, Phil, Peter, Ray, Sarah, Stephen, Tony and Will.

PART 1

TRANSITIONS

CHAPTER ONE

DIAGNOSIS TO REGISTRATION

Sue: Journal February 23rd 2007
Coming home from work on the train on a cold day in February 2007 May's words rattled round in my mind and I write them (as much as I can remember) in my notebook. These notes were May's current description of her life, and are the backdrop against which our future conversations took place. It started me thinking about the way in which people are diagnosed, treated and then registered as either sight impaired (partially sighted) or severely sight impaired (blind) and the ways in which these moments often defined people within "thin problem saturated descriptions" (White and Epston 1990) that were difficult to escape from, and little support was offered to enable psychological adjustment or hope for the future.

May says of herself[1]:

I sometimes think I have lived too long;
I was well up to my late 70's,
never had even a twinge.
Then everything fell apart at the same time.

This is not living,
it is just enduring

I coped with the arthritis,
the Parkinson's,
losing my son (that was the most awful time),
even the cancer.
But losing my sight is the **biggest insult**;
being looked after like a baby!

I've always had my pride.
The **shame** of it.
I am just a "blind woman" now
I even have a certificate to prove it!

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[1] My conversations with May were initially published in the article "The Grilling of Mr B: Using the narrative therapy practice of 'externalising' conversations to co-research the experience of blindness" Therapy Today 2009. 20 (7) and are reproduced here with permission.

"Blindness" is a real bugger!

In my conversations with many people who are visually impaired the starting point is often their descriptions of diagnosis and registration and these are often recalled and remembered vividly; perhaps in the way that people often remember a loved one's death, or where they were when J.F. Kennedy was assassinated, or when the planes crashed into the twin towers on 9/11.

The experience of these moments are often recalled with emphasis on "where I was, who I was with, what they said to me, how they or I behaved" and often linked with feelings of acute anxiety, despair, anger, disbelief and isolation, followed by depression. This ties in with research such as (Burmedi et al. 2002; Douglas, Pavey, and Corcoran 2008; Stephens 2007; Thurston 2010) where the points of diagnosis and registration are highlighted as key moments when people report feeling particularly anxious and depressed.

They are perhaps moments and turning points in life which come unwanted and unasked for, and are often delivered in ways that are not always helpful or supportive.

A journey into conversation

Dennis: A journey

Sue: into conversation

Dennis: thinking about
untreatable sight loss.

"there's nothing I can do
I don't need to book another appointment
I'm sorry but I've got a busy clinic.
Can you go now."

I know they don't say that
but that is what they imply.

Sue: That was the implication I heard
When I was sitting
talking to this very eminent professor.
Him saying:
"there is nothing we can do
so we can discharge you"-
That's it.

Such a sweeping statement.

Sue: Still left wondering,
"what are they telling me?"

They were purely focusing on "you" as an eye condition.
Not "you" as a person
and how it may impact.

Dennis: I'm just remembering my diagnosis
He said three things:
"There's nothing can be done
you've got macular degeneration".
Why not?
"YOU won't go completely blind".
What the flippin heck does that mean?
Can you explain?
and you've used that word
BLIND!

"You must make provision for the future".
At the time, I couldn't even think,
I had my wife and a two-year-old baby
sitting in the room with me.

How the flippin hell do I do that?

How do I make provision for a future which you've just told me is going to be
damaged permanently by loss of sight?

That was the one that made me
more angry than any..

Literally was:
"I won't need to see you again".

Sue: Goodbye!

Dennis: I don't think it was insensitive
But don't think it was necessarily friendly
It was just ..
Professional.

The etiquette of the sighted (Part One)

One of the comments that has touched me most relating to blindness was spoken by Andy (an ex-counselling client). He said, "we have to live within the etiquette of the sighted" (Dale 2008c:25). He was speaking of the ways in which people communicate using eye contact, body language and facial expression which were lost to him as a person with partial sight. He wanted to, "run my fingers over their faces and bodies to see who they were" but to do so would break social rules of etiquette, so in conforming to these rules he was deprived of the means to understand using other senses. Kinash says:

> "If you are sighted, close your eyes and what do you see? You see darkness. Try to walk around and attend to daily life and you are disoriented and crash into things. This is not the blind person's experience" (Kinash 2005:1).

95% of people who are registered as blind or partially sighted have some residual vision (RNIB 2008), so although many of us are registered as "blind", or are referred to, or refer to themselves as "blind", only a very small number of people have no vision or light perception at all. It is also worth remembering that even those with no vision at all do not see darkness, (Kinash 2005) but nothing.

The general public's perception of blindness or visual impairment, however, is often that those who use a white cane or a guide dog live in permanent darkness, and are either to be pitied and patronised, or, we are some kind of super-hero. People who are blind and partially sighted are in fact just that, people, they are not a homogenous group "the blind" but all have different levels of residual vision, and unique perceptions of what their visual impairment means to them, for some this is a positive experience, for others it is not.

Adam Hahn is an artist whose grandmother had macular degeneration (MD). Following a detailed interview with Dennis, who also has MD and is registered blind, Adam painted a picture, shown here with Dennis alongside, depicting a typical image of one of the main MD symptoms – the inability to recognise people:

> "By representing the person as they would see themselves these paintings engage the viewer in trying to understand how other people see" (Hahn 2008).