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COUNSELLING
for People with Dementia

Making Sense of Self



Danuta Lipinska

FOREWORD BY BRIAN THORNE

Person-Centred Counselling for People with Dementia

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Jessica Kingsley Publishers
London and Philadelphia

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First published in 2009
by Jessica Kingsley Publishers
116 Pentonville Road
London N1 9JB, UK
and
400 Market Street, Suite 400
Philadelphia, PA 19106, USA

www.jkp.com

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Library of Congress Cataloging in Publication Data

Lipinska, Danuta.

Person-centred counselling for people with dementia : making sense of self /
Danuta Lipinska ; foreword by Brian Thorne.

p. ; cm.

Includes bibliographical references.

ISBN 978-1-84310-978-5 (alk. paper)

1. Dementia--Treatment. 2. Client-centered psychotherapy. 3. Dementia--
Patients--Care. I. Title.

[DNLM: 1. Dementia--therapy. 2. Counseling--methods. 3. Nondirective
Therapy. 4. Professional-Patient Relations. 5. Spiritual Therapies. WM 220
L764p 2009]

RC521.L57 2009

616.8'3--dc22

2008036555

British Library Cataloguing in Publication Data

A CIP catalogue record for this book is available from the British Library

ISBN 978 1 84310 978 5

pdf eBook ISBN 978 1 84642 892 0

Printed and bound in Great Britain by
Athenaeum Press, Gateshead, Tyne and Wear

DEDICATION

In Loving Memory of

Gerard Pawel Lipinski

Gordon Holt

Jack and Barbara Whitsed

John Philip Jarvis

And the patients, clients and families who lived, loved and died with dementia

You have given me so much – may your spirits live on in these pages
Eternal thanks

Author's note on the cover:

Linden trees have always been a favourite of mine, and actually relate to my family name. In Polish, 'Lipa' is the linden, or lime tree, hence the name Lipinska.

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Foreword

This book is a tribute to the human spirit. It also constitutes a clarion call to a society where the average age of its citizens seems to mount inexorably with the passing of every year. For many 'senior citizens' their later years can be a time of unprecedented freedom and, not infrequently, of new-found interests and unsuspected creativity. For others, however, there is increasing physical diminishment and for some, the onset of various forms of dementia or the anguish of Alzheimer's disease. When mental decline sets in, the demands experienced by spouses, children, carers and medical staff can be acute and a corrosive despair can gradually permeate families and even whole institutions. In the demeaning language of many an establishment, the 'gerries' are nobody's favourites and the words used of them and the treatment they receive would scarcely be acceptable in the response to inanimate objects. When they are applied to human persons, they verge on the obscene.

Danuta Lipinska's beautiful book demonstrates how this state of affairs can be radically transformed. In the first place, she shows what it means to cultivate a deep sense of valuing and honouring the other no matter what that person's physical or mental state. Rooted as she is both in experiential knowledge and in spiritual wisdom, she offers an inspirational model of human loving and commitment. Second, she demonstrates, often graphically, the power of relationship to enliven, to engender hope and to bring light into apparent darkness. Relationship, she believes, can be the experience of the transitory moment or of the fleeting hour but is nonetheless life-enhancing. She even perceives the person with dementia as endowed with the rare capacity to live fully in the present – something which eludes most of us throughout the whole of our over-busy lives. Third, her

evident practicality makes it clear that her message is not addressed to would-be saints or those possessed of untold patience or forbearance. She is passionate in her belief that as individuals and as a society we have the often unacknowledged capacity to respond to the needs of those who currently languish for lack of care and that if we can learn how to do this effectively the whole of our social environment will be immensely enriched. As a start, Danuta Lipinska proposes with passionate conviction that people with dementia should have access to counselling. Her book is powerful testimony to the validity of this proposition.

For me, as someone who has committed the best part of his professional life to the theory and practice of person-centred therapy, it is, of course, a source of enormous satisfaction that Danuta has found in the person-centred approach the ideal means of relating to her clients. Its core emphasis on unconditionality of acceptance and empathic responsiveness provides a firm grounding for the work with people with dementia and their carers alike while more recent developments in such areas as the theory of configuration of the Self and the exploration of relational depth also prove highly relevant. Perhaps Danuta's most significant discovery, however, is the openness of the approach to the spiritual dimension of experience and its ability to transcend the conventional norms of time and space. Peter Conradi in his fine biography of Iris Murdoch¹ writes of her diagnosis with Alzheimer's in 1997: 'the simplicity of the child soon augmented the simplicity of the mystic'. In the pages of Danuta Lipinska's book I have detected both these 'simplicities'. What is astonishing, however, is how they combine to produce a study which is at one and the same time both eminently pragmatic and powerfully challenging to those who bear the responsibility of planning for the care and wellbeing of our ageing and often vulnerable population in the years ahead.

*Professor Brian Thorne
Emeritus Professor of Counselling, University of East Anglia
Co-founder, The Norwich Centre
Norwich, August 2008*

Acknowledgements

It has been a rare privilege and blessing to be invited into the lives and experiences of countless men and women living with dementia. I could not have written this book without your willingness to share your search for Self and the desire to make sense of it all.

My most deep and sincere loving thanks to you all.

Grateful thanks to the many people who have encouraged me and supported me in all the work environments we shared in the USA and the UK. You asked to see the book even before I had it written. Your visual thought inspired and encouraged me to make it a reality.

You had a part to play and you know who you are if you are reading this now. Carrie Hughes (whose sense of humour and nursing expertise extends the boundaries of ‘normal’) and Ellen Sheridan especially were crucial to the development of this work. And Leszek, without your belief in my ability and encouragement I may not have stepped back through the doors of a university.

To Lily Morgan, Karin Knudsen and all the team at Jessica Kingsley Publishers. Thank you for your vision and encouragement to fill this particular niche – I have been overwhelmed!

To my critical readers, without whom the manuscript would not have emerged at its editorial best:

Professor Brian Thorne, mentor and guide, whose wisdom, loving support and generosity of spirit encouraged me to keep going – you have blessed me beyond my hopes or imaginings.

John Killick, long time inspiration and loving supporter – you are so much more than words.

Professor Dwight Webb of the Counseling Department, University of New Hampshire who chaired my Master's thesis, my first writing about dementia all those years ago. Our Atlanta ACA soul reunion was instrumental in the process of getting the book inside of me – out.

Cynthia Ransley, author and my counselling supervisor, encourager and listener. Thank you all from the bottom of my heart.

My dear friends and colleagues, who lived with the manuscript and lovingly sifted the wheat from the chaff, believed in the book and my ability to get it written. A special thank you to Jane Robinson, dear friend and colleague in the quest for counselling of the highest quality, and fabulous Jude 'stardancer' who took me under her wing at a crucial moment and 'sparkled' me through writer's block.

An abundance of love and gratitude to all my family and friends near and far for your love, prayers and belief in me and the book:

My dear parents Mary and Gerard who bought me my first typewriter and rolltop desk when I was four, who always knew this day would come.

In particular my husband John for his endless support, love, sense of humour and unswerving belief in me; our sons Marek and Marshall who during the last of its writing crossed the threshold into manhood and just knew 'the book' would arrive at some point before they left home.

Madeleine and Jurek, best of neighbours, and all my wonderful family far and wide in the UK, USA, Canada and Germany. Sheba, night time companion and source of delight. You and Mimi have kept me playful and slept on my behalf.

Love, thanks and blessings to my 'Earth Angels' on both sides of the Atlantic whose faith in me never wavered and whose love, laughter and ability to treat and treasure me has blessed me for ever:

Karen, Elaine, Peggy, Susan, Teri, Patricia at Pevensy Bay where we cracked the book open so to speak.

Jennifer C. Kelsey, my fellow author and encourager. Swanbrother John, for dappled teatime with Mozart; you were a sanctuary.

My women's prayer group who have seen me through many years and Jean and Helen my prayer partners, Starfish Jude, Jacky M, Kerry, Sal and Sue to name but a few. Dear friend Carole Evans – and all the original Carers of the Elderly team who got me started in the UK.

To my spiritual Sophia home at Noddfa, North Wales, Sisters Patrice and Mary Jo, Pauline, Gwen and Mimi where I have been blessed and nurtured, strengthened and encouraged; where many chapters of the book were written and the First Draft completed in the wee hours of the morning.

To all of you, my love and thanks and above all,
To God be the Glory.

Introduction

Person-Centred Counselling for People with Dementia: Making Sense of Self has been written after many years of working in both the United States and the United Kingdom with men and women with various types of dementia, their families, caregivers and professionals at different stages along the journey.

The fresh urgency to write the book now, at this particular time in my life, coincides with my own process of self-reflection, self-exploration and assessment as I reach the half-century. It also follows two particular and unexpected experiences which demanded that I pay attention to how precious is the capacity for thought and creativity and how finite my time to be productive. The first was a minor head injury. This gave enormous but only partial insight for a few months into the complex tangle of emotions accompanying real and noticeable cognitive and accompanying physical changes experienced on a daily basis. These were brought on by microscopic and, thankfully, in my case, reversible changes in my brain. I have made a complete recovery, but I have a deeper sensitivity to some of the feelings and experiences associated with diminished memory and cognitive ability. Later I would find humour in saying that the experience was a way of adding authenticity to my work. The second was emerging unharmed from the tunnel at Edgware Road, a survivor of the 7 July London underground bombings in 2005.

Had I not survived, I would not have kept promises to the many men and women who were counselling clients, residents in care homes, attendants at day centres, lunch groups, respite centres; their families and fellow professionals, at home and abroad all have repeatedly and urgently asked me to write this book. Their expressed desire was that I advocate for counselling services to be widely available to

assist others in their lives with dementia. This request would have remained unfulfilled.

I then began a process of reviewing and recapturing the work and the relationships with clients, hours of my own reflections, journal writing, supervision, conferences, trainings, reading and studying, conversations with colleagues, family and friends, sometimes arguing – and always praying. Although the experiences have been with me for a number of years, the timely discovery of particular theoretical reference points and people to encourage me to evaluate my work in relation to the theory has been invaluable and I am grateful to have found them.

Of course you don't have to be a counsellor to be on this journey, and indeed the first part of the journey for me was as a nurse and further along the way as a stepdaughter of a dear and gentle soul with vascular dementia. As a student nurse my worst experiences took place in the psychogeriatric wards. We insensitively called the patients 'gerries' (short for geriatric). The experience was so traumatic for me and, I have little doubt, the patients as well, and there seemed little value placed on their lives, that I decided I could never work with older adults again. Of course when we make those bold declarations it is often precisely those situations in which God and the Universe conspire to teach us best. I was not, at first, an eager student of this new learning environment, but that was about to change. In 1980 I found myself back in the USA where I had spent considerable time as a child. I was in Graduate School at the University of New Hampshire, working towards a Master's Degree in Counselling (under the ever supportive tutelage of Professor Dwight Webb) after completing my BA in Psychology, begun at University College London. I had previously qualified as a registered nurse in England and Wales and earned a US nursing registration too. I was working as an agency nurse to help finance my degree and nearly every person I worked with had some kind of dementia, mainly Alzheimer's disease and vascular dementia.

At two o'clock on a very chilly New Hampshire morning as I was running around the block in pursuit of a man in his pyjamas and bare feet, who was in pursuit of his dog, I thought, 'there has to be a better way than this!' The dog of course, did not exist. It was a harrowing experience for both of us. I was amazed at how the families were coping and wondered where they found their information and support.

There was a new family support group as part of the local branch of the ADRDA (Alzheimer's Disease and Related Disorders Association) and I joined immediately in order to learn as much as I could and soon after became its President. During this time I was also reading and researching so that I could share with fellow nurses and helping professionals, and so began my training and public speaking career. This also led to organizing local conferences with renowned researchers and luminaries in the field in a part-time shared, paid position developed within the Department of Adult and Elderly Services at the State level. Many years later this would grow to a fully staffed office in its own right with numerous family support groups, social gatherings, volunteers, advocacy and training opportunities. Just recently I was given the gift of a book which in many ways brought the awareness of coming 'full circle' as I read Ann McLane Kuster's poignant journal of her mother's life with Alzheimer's disease.¹ I was living and working in New Hampshire during the time her mother, Senator Susan McLane's, passion and influence as a state senator was in its heyday. I recognized with fondness the many descriptions of life there. I shuddered anew at the paucity of dementia-specific resources and rejoiced in the early coming together of kindred spirits in the call to care for people with dementia, with Ellen Sheridan, pioneer, mentor and friend at the helm. I owe a great debt of gratitude to those hard but inspirational and formational early days, the wonderful people and our shared vision and determination to make a difference.

You do not necessarily have to be a person-centred therapist specifically, in order to be effective in counselling relationships or indeed day-to-day relationships with men and women with dementia. This is the approach I have found to be successful as I have ventured forward into counselling relationships with people with dementia and I can only attempt to share my experience as honestly and clearly as I am able from this perspective. The underpinnings, I discovered retrospectively, had shared foundations in the tried and tested methods of counselling practice which Carl Rogers,² Dave Mearns and Brian Thorne³ and others describe.

My Master's Thesis, *Alzheimer's Disease: A Wholistic, Interdisciplinary, Rehabilitative Paradigm for Caregiving*,⁴ opened the door to combining practical experience with the desire to be a different kind of counsellor. I had the opportunity to work exclusively with older people across the spectrum of years and life issues as well as mental health

‘diagnoses’ and early dementing conditions. I also had the benefit of counselling carers, family, partners and friends of people with dementia, and running family support groups and developing training for professionals and dementia-specific counselling services. I was seeing, hearing and experiencing within the ‘old culture of care’⁵ as Tom Kitwood described the ‘custodial’ or task-orientated care of older people. I knew at a deep level that there had to be another way forward as I worked with older people and their families on a daily basis. Persons with dementia are in touch with their medical community, general practitioner and mental health practitioners, and with the health and social service provision in their locality, which usually see dementing conditions as problems of old age. People may attend some form of community-based programme or have help and care at home and may ultimately live in a number of different care environments over the course of their experience with dementia. I have worked with people in most of these environments and with most health and social care staff across a broad spectrum of care and support, and with people much younger than 60.

It is as a counsellor that I write now in order to give voice to the extraordinary process that comes with the luxury of spending ongoing and uninterrupted time with men and women, on a one-to-one basis and sometimes in groups, who kindly invited me to be there. The opportunity came my way when I was hired to coordinate and conduct counselling services in a large community-based mental health centre. For the first time I was to see that older adults generally and those with significant emotional distress, psychiatric diagnoses and the beginnings of dementia could be offered counselling support and benefit from it, irrespective of their age or diagnosis. Later, in a small gero-psychiatric private practice I was to learn great lessons as the counsellor/psychotherapist for men and women in later life, in individual and group work. At the same time, I began and continue to work in private practice as a counsellor where the work continues. This crucial work in the United States instilled in me a desire and a belief to work towards a broader understanding and a new counselling paradigm. Having seen the evidence in practice, I was easily convinced that there was much more that the psychotherapeutic community could offer to prospective clients with dementia, and also to practitioners within the mental health field who may not have entertained the idea of working with these men and women.

Returning to England gave me the opportunity in 1997 to work with a charity for families and individuals with dementia – to develop counselling services, skills and relationships which fanned the embers to a flame and, I believe, did some measure of good for the clients and families concerned. These experiences encouraged the publication of journal articles and the opportunity to speak at numerous national and international conferences.

In writing this book, it is my belief that men and women living with dementia must be offered the opportunity to receive professional counselling if they would like it, to support them in making sense of their lives, and making sense of themselves in their present experiencing.

This opportunity does not often present itself to the person with changing cognitive abilities and the sometimes distressing limitations of communication and daily functioning which result. Combined with an often ageist society and the frequently nihilistic nature of a therapeutic and medical model that can presently find no cure, the expectation of the lives of men and women with dementia has been limited in many ways.

There also exists a pervasive myth, which though true in some cases is not in all: that all experiences of living with dementia are negative and based on disintegration, degeneration and diminishment. Although this may be one person's experiencing, there is also the person who sees this condition as another of life's challenges and is determined to make the best of it all. We must value each perspective equally if we are to obtain a true picture of what life with dementia might be. Just recently, the author Terry Pratchett, aged 59, has been diagnosed as having a rare form of Alzheimer's type dementia. He described his diagnosis and what he felt about it on the internet. He said that he would like it to be known that he is 'not dead yet'.

Frankly, I would prefer it if people kept things cheerful, because I think there's time for at least a few more books yet. I will, of course, be dead at some future point, as will everybody else. For me, this may be further off than you think – it's too soon to tell...⁶

And so, the counselling relationship is based, for me, on discovering who the person is and what he is thinking and feeling *about* what is happening to him. It has been rare for me to experience the client

speaking about dementia specifically or exclusively. Rather it is about how he is perceiving his world now that this diagnosis or label has been attached, rather than about the diagnosis or label itself.

It is similar to what Richard Taylor, a 59-year-old psychologist, describes in his essays on his life with dementia. He says when he talks to people about their dementia, 'I know they are telling me more about themselves than about the Alzheimer's experience.'⁷

So it seems to me in the various counselling relationships I have been involved in, I sense that I am encountering *how* the individual is experiencing, rather than the experience itself.

The chapters in this book have been written in such a way and in this particular order to demonstrate my own progression from my early relationships with men and women and their partners and families living with dementia, through the experience of counselling. They include the fundamentals of the counselling process and practice and those elements that I believe set this approach apart from others. This approach may act as a framework to build a new way ahead, as an encouragement to existing counsellors or as an heuristic to future endeavours.

The book seeks to highlight the possibility of effective counselling by bringing together several theoretical counselling processes. These are the core conditions of Carl Rogers, especially empathy, congruence and unconditional positive regard, and latterly, Rogers' belief in the role of the transcendent or 'spiritual' in the counselling relationship; Dave Mearns and Brian Thorne's working with configurations of Self, working at relational depth and working in 'not-for-growth' areas, and finally, my own exploration of essential spirit-core relating.

I believe the combination as outlined above can lead to a relationship and an environment conducive to positive experiencing and making sense of Self. It may be opposed to conventional wisdom and the usual expectations of counselling. In particular, it may shake the foundations of what we think we know and believe to be true about the nature of the counselling process and how aspects of Self are determined or defined by neurological health and cognitive ability.

After much consideration I made an informed, bold and deliberate decision not to follow the traditional style of the many books about dementia that are already in print. That is, to place firmly at the outset

and in the first chapter the definition and descriptions of dementia and the various types and how they are recognized and experienced. Helpful though it may be, the material shapes the reader's response to prospective clients on the basis of their condition, their diagnosis, their problems and disabilities.

I believe that it can be more helpful to introduce the whole person first, describing the individual as he or she is. Getting to know the person who becomes the client and experiences the counselling relationship in this way is more likely to strengthen the possibility of envisioning its effectiveness.

It may at first seem that the word 'Self' written with a capital 'S' is a typographical error that has escaped my notice. It is, however, another informed decision to attempt to identify, highlight, set apart and thus pay particular attention to the Self. In this case, Self is the person with dementia, the unique individual of infinite worth and value.

Many readers and especially therapists and counsellors of the person-centred approach will be familiar with this designation, the prizing of Self in its myriad forms or multiple configurations. The Self is much more than the merely physical and emotional, sexual, intellectual or social. There is a transcendent quality to Self that for me represents the whole of the individual brought together and mediated by the spiritual.

This use of Self is also an invitation to the reader to imagine the life, the voice, the experiencing of the person with dementia introduced in these pages as he or she engages with Self and attempts to make sense of it.

Wherever it has seemed most useful I have included a segment of dialogue that illustrates the point I am trying to make. The names of clients are made up and their identities protected by creating new ones and reconfiguring details. All are based on actual experiences and conversations. Some of the situations or experiences may be shared by many people with dementia, therefore it may be possible that readers recognize familiar traits or behaviour that seem to describe people they have known. In many cases the men and women on whom I have based some of the clients here are no longer living.

It is with humility and not a little excitement that I submit this offering and proposal that counselling, and especially person-centred

counselling when available, can support men and women as they Make Sense of Self and teach us valuable lessons about changing perceptions, abilities and relationships and, above all, the tenacity and splendour of the human spirit.

1

In the Beginning

Living with dementia, in whatever capacity, could be described as one of the biggest challenges in twenty-first-century western society. Most people will know of a friend's sister, or have heard about a colleague's father, read a book or seen a person on television or in a film, with one form or other of dementia. Some will have a parent, a partner, a sister or brother, or an adult child who has dementia. Perhaps that person is no longer alive. Perhaps in looking back we can identify what might have been the problem but assessment and diagnosis were not considered necessary in his or her lifetime.

I too, to a lesser degree, am living with dementia. In my work and in my friendships, with my colleagues and neighbours, and several years ago, within my family. For all I know, those of us who appear well now may have the seeds of dementia germinating within our functional selves at this moment. We would not know it.

Most of my professional life has been involved in many aspects of working with men and women with dementia, their partners, families, and the professionals who also support them. It could be expected perhaps that themes or patterns of how people cope might emerge over the years.

After many years of counselling men and women with various degrees and types of dementia on both sides of the Atlantic, it began to occur to me that there was a process taking place in the counselling sessions that happened again and again. No matter what the issues were, no matter what level of ability the person with dementia experienced, there was an ardent if not urgent quest to Make Sense of Self; to make sense of the past as it affected the present and collided with the silent brick wall of the future. The person's interior and exterior world shifted like the sand dunes in the desert, fleeting

new landscapes were created overnight, challenge upon challenge; momentary landscapes forgotten with the next breath of ill wind.

The once philosophical musings of 'Who am I?' 'Why am I here?' 'Where am I going?' now become literally essential to survival. The response of those of us who have the privilege to work with men and women with dementia is to make ourselves genuinely available to journey alongside these people in their attempts to Make Sense of Self in their interiority (what goes on inside and is often hidden), their exteriority (what goes on in the outside world) and their relativity (the inter-relationship between the two, mediated by the spirit).

As one client put it, 'if I tell you who I was maybe you will know more about who I am and who I might become'. This journey to Make Sense of Self inherently involves all aspects of the person including his or her spiritual Self. In the absence of so many of the usual markers for Self, what seems to emerge over time is the Existential Self, the Authentic Self, progressively more spirit-man and spirit-woman in its presentation and its experiencing.

Brian Thorne, the pre-eminent person-centred counsellor and author, wrote:

My spirit and your spirit are what ultimately defines us; it is our spirit that gives meaning and direction to our experience. It is our spirit that determines our identity and it is our spirit which bears the mark of immortality. We are body, mind and spirit, but it is the spirit that breathes life and gives light – or colludes with death and darkness. The existentialists' question 'who am I?' can only be satisfactorily answered in terms of the spirit.¹

Dr Oliver Sacks, the neurologist who reached the unreachable with all manner of neurological conditions, writes about the importance of 'narrative', our story, the journey of 'owning ourselves' and becoming ourselves that is essential to our existence.²

In this unique narrative called 'living with dementia' the names and places may be missing; the place where you were born, your school or career, the lovers, parents, even children may fade into the unremembered, made inaccessible by damaged cells resulting in impaired function. And yet, part of the determination to Make Sense of Self finds a voice in the telling of the narrative in verbal and non-verbal ways. The spirit finds a way to make itself known, in

accordance with or in spite of neurology, throughout the process of dementia until the very end of the journey and often beyond.

Sacks quotes correspondence from the renowned neuropsychologist Dr A.R. Luria concerning a patient with severe memory loss that serves to underscore these principles of a person-centred and holistic approach:

Do whatever your ingenuity and your heart suggest...[but] a man does not consist of memory alone. He has feeling, will, sensibilities, moral being – matters of which neuropsychology cannot speak. And it is beyond the realm of an impersonal psychology, that you may find ways to touch him, and change him... Neuropsychologically there is little or nothing you can do; but in the realm of the individual, there may be much you can do.³

The implication here for creating a response that is individual, developmental, spiritual and unconditional according to narrative and perception of Self is one that fits not only with my particular experience of counselling the person with dementia, but one that may also have an influence on how we provide care in the later stages. Sacks continues:

We have each of us a life story, an inner narrative whose continuity, whose sense, is our lives. It might be said that each one of us constructs and lives a 'narrative' and that this narrative, is us, our identities. To be ourselves, we must have ourselves – possess, if need be, re-possess our life stories. We must re-collect ourselves; re-collect the inner drama, the narrative of ourselves. A man needs such a narrative, a continuous inner narrative to maintain his identity, his self.⁴

Laura Sutton and Richard Cheston wrote about the importance of story-telling and narrative in their experiences of psychotherapy with men and women with dementia:

We believe that by providing opportunities for people with dementia to tell their stories and to be listened to in psychotherapy, so we are providing them with an opportunity to make sense out of the world in which they live and so grieve the losses they have suffered. Being able to tell a story and to listen to others telling similar stories, then, is an important part of the psychotherapeutic process.⁵

Often, in my experience, the narrative, the story is also about the perceived Self, which may be presented as story of determination, ability and humour, an essentially positive story even in the face of apparent multiple changes.

Facilitating support groups with people with dementia allows for a sharing of the story and narrative in a different but equally valuable way than the one-to-one relationship. I have observed a dual sense of sharing and uniqueness that affirms the notion of 'same though different' to the experience of the person with dementia. O'Leary and Barry, in their writings about Gestalt reminiscence therapy, say:

Storytelling is a means through which individuals become known to themselves and to others. They gain a sense of their own worth as their stories imbue them with status within the group. Gestalt reminiscence therapy is based in the assumption that older adults continue to develop in the emotional, social and spiritual dimensions of their lives up to the point of death. Through attending to this ongoing development, the approach endeavours to facilitate older adults in their journey towards enjoying full and satisfying lives. Factors such as personal choice and commitment to change are integral to this developmental process. Development is viewed as being contextually influenced – emerging from the interaction of people with their environment – and as being enhanced or constrained depending on the flexibility of both. Therefore, the context in which older adults live must be considered if their psychological needs are to be fully explored.⁶

If this is indeed the case, it would also be wise to venture that this process continues in parallel with the development of cognitive challenge irrespective of the age of the person with dementia. The counsellor can utilize this sense of ongoing development as part of the fabric of communication and adaptation within the sessions. The relationship between the counsellor and the client, over time, will develop assuming the sessions continue. There will be a development of how the person responds to her experience of dementia and how she adapts to the internal and external demands placed on her. The neurological changes that ultimately can create havoc in the person's life are a development of whichever form of dementia exists.

These ideas gives credence to the notion of the 'ongoingness' of things, not only a consideration of the past, but a commitment

to the present and, indeed, a vision for the future. This creates an underlying dynamic focus. Development implies movement, growth and change – descriptors that do not easily come to mind when considering the effects of dementia on the totality of the person. With development as a backdrop we can imagine that the very process of counselling, and the relationship itself and the environmental context within which it takes place, is not a static event.

O’Leary and Barry also quote Mearns and Thorne⁷ who tell us that contacting unknown aspects of self emerges through focusing at ‘the edge of awareness’. The authors continue that psychological growth will be enhanced when attention is paid to this inward experiencing and processing. I believe that this can and does happen when the client also experiences cognitive challenge. We are led back to the questions of how this kind of psychological growth is measured.

Counselling the person with dementia can encourage the process of psychological growth in the present experience of the shared narrative, the client’s perception of Self, some of which as a result of memory loss and other cognitive changes may seem to be at the edge of awareness. There will be various levels and degrees to which individuals engage in narrative and story-telling. This reprocessing of Self and its events allows the client to pay attention to his or her own experience as valid and worthwhile in relation to others. Counselling, then, may serve to bring to the fore, and support, a self-regulating, adaptive, developmental process.

Development inherently involves a state of ‘becoming other’, moving from what was to what is and what will come next. The person with dementia over the course of what may be an extended period of time develops formerly hidden or new and different aspects of Self in response to multiple changes. New and different strategies for relating, communicating, coping and meeting needs emerge. Often these are highly adaptive to the individual and may be met with an array of comment and emotion and correspondent behaviour depending on how appropriate the person with dementia’s behaviour is perceived by the cognitively well.

To view the client in an expansion of Rogers’ Unconditional Positive Regard⁸ means that I see the client as able to develop – to move forward, to grow and activate the ability to engage with Self

and others, the environment, and be purposeful about her wants and needs – even if they may be diametrically opposed to those around her. I believe this can be validating and affirming to the highest degree, and clients have confirmed this in many ways.

I have often wondered if the seemingly random monologue that one often overhears in people with dementia at the more advanced stages could perhaps be the externalizing of this internal narrative, which, when spoken aloud, provides an affirmation of one's existence: hanging onto the internal fragments of narrative, continuing the process of Self ownership, 'Making Sense of Self'. If one stops to listen and engage with the person, so many of the fragments make sense and are imbued with humour, laughter, pathos, grief, intensity, urgency and questions. They are fragmented but nonetheless very truly present for both of us to share and for us to 'bear witness' to this inner narrative, this life. Sharon Wilson helpfully contributes:

Have you noticed that the images hidden within everyday words can sometimes reveal their deeper meaning? Thus, 'recollection' becomes re-collection: a gathering of things together, and not only for the first time. Re-mem-bering conjures up the picture of a body once dismembered but now with limbs intact. And re-call suggests a summoning back of what has once been present. Associated as they are with the function of memory these words invite us to take an active part in the process of bringing the past back to consciousness. They re-mind us that when we re-collect the past we are giving back a primal unity to separated particles, and that when we re-member the past we are restoring to its original fullness a body whose limbs have been severed. And so history is given a second chance, a new beginning as our personal ongoing story.⁹

As one person put it, 'I want to tell you my story before I can't remember the words.' Counselling can provide the focused time and attention needed to explore this narrative and to offer the space and safety to say it aloud, re-claim the words and particular meanings, making it real, having a second, or often several, chances for a continuation of the story.

At the heart of my endeavour is a wish to combine a particular way of being a counsellor and plant it firmly within the person-centred approach to dementia care, placing the experiential within

the practical. The timing and development of the 'Person-Centred Approach to Dementia Care'¹⁰ is crucial because it means that having laid the foundation as a 'model of best practice' within the community of care for people with dementia, the notion of person-centred counselling may not seem as alien as it once might have been. Kitwood himself states in *Dementia Reconsidered* that:

As my work developed and deepened, I became increasingly involved with the details of dementia care, particularly drawing on the ideas and practices from psychotherapeutic work where the emphasis is on authentic contact and communication.

He and his colleague Kathy Bredin 'attempted to bring some of the fragments together. We called the whole approach "person-centred care", following the example of Rogerian psychotherapy.'¹¹

This revolution within the care setting generally for older people and more specifically for people with dementia of any age aptly demonstrates Kuhn's¹² criteria for a paradigm shift long overdue in health and social care, yet one that has broader and deeper implications. Perhaps we have finally come to recognize Rogers' inception of the 'Way of Being'.¹³ The fact that the approach can be applied almost everywhere and with anyone is further evidence of its appropriateness to human experience. It resonates with the underlying wisdom and sensitivity with which Rogers approached our human experiencing, and that have been the foundations for many since. What I experience here is what seems to be an elegant and natural 'fit'; an evolution or development of inclusion that can only benefit those for whom counselling might be an option, and those who invite me to experience their being alongside them.

This quest for Making Sense of Self takes place at many levels and with varying degrees of success. How indeed is success measured when our instruments for measuring are by and large developed for use within the framework of ability and cognitive function; where our milestones for counselling success in particular for non-institutionalized men and women, and older people specifically, are virtually non-existent. Our profession's often rigid adherence to a numerical formulation does not easily include outcomes like 'music of the heart', 'freedom of spirit' and 'joy of being'.

In his timely book *The Soul of Counseling*, Dwight Webb writes:

The *soul* [his italics] cannot be captured by boundary markers. No net may be cast to contain it. In therapeutic counseling there is no linear or quantitative measurement of the soul. We need to acknowledge that we don't have to measure everything. An act of kindness, for example, is a spiritual gift, and is to be experienced with savouring and rejoicing. Why try to reduce it to numbers? Such natural acts of love are too full of wonder to quantify.¹⁴

Must counsellors continue to establish their work's worth within the quantifiable parameters established by science? It is hardly a coincidence that the most notable, effective and popular type of counselling, based on quantifiable data (and therefore, 'real sciences') is currently CBT, Cognitive Behavioural Therapy. Its popularity in part is due to the fact that its outcomes are obvious and measurable and fit easily into a statistical, numerical framework.

It is another chapter in the same story that challenges, undermines and devalues much of the breakthrough improvement in 'quality of life' experienced by those taking the so-called 'anti-dementia' drugs, complementary therapies, person-centred approaches to caregiving, and indeed psychotherapy. The subjective reporting of people who have experienced many of the above and the reports of their partners, relatives and care staff fill unpublished volumes. How in fact do we 'measure' elements of the spirit, like spontaneity, joy, peace, love, creativity, sparkle, a return, however fleetingly, to Self?

Statements like, 'I feel more myself', 'There's more life in the old dog yet', 'She's got her old spark back', 'I can't quite put my finger on it, but he's better', 'It's something about her eyes', 'I know he knows it's me' do not readily lend themselves to statistical analysis. Does that make them less real or less valid? Not according to those who experience it this way, or to those of us who are acutely aware of the effects.

A quote from my Master's Thesis seems relevant here. Ms Whitcomb describes her mother's experience thus:

When my mother was given a mental status test several months before entering a nursing home, her score was zero. Her family knew that she still had cognition, but not the kind addressed on the test. Examples of the questions were: How old are you? Where is this place located? Who is the President of the United States? These were

precisely representative of the things she no longer knew. What did she know? Things I could not put into words at the time. She understood textures, fabrics, sunsets, birds at the bird feeder, friendly faces – when something was wrong. She knew me. She just didn't remember my name.¹⁵

Historically the neuropsychological community has preferred testing and results that emphasize left hemisphere function, which includes the linguistic, analytical and logical. These functions are most highly regarded in western education and society and fulfil criteria of success and adaptiveness. This is almost to the detriment of right brain emotional, creative, expressive, musical function and experiencing. Nurturing and express development of right hemisphere function are usually secondary and often an independent or extracurricular pursuit. This very synthesis of holistic experiencing, mediated by the spirit, is all but lost except on those who choose to enter into the labyrinth, hopeful and expectant.

We are still somehow bowed beneath the old Latin dictum 'cogito ergo sum', 'I think therefore I am.' Enlightenment it is not for those who don't 'think' in the ways our culture says we should and must, to be real people of worth. This is the dictum of exclusivity. Perhaps we could amend it to 'I am, therefore I am' or the Latin equivalent. Absence of thought, or expressed coherent thought, does not render us nothing, does not stop us from being who we are, from being our Selves.

We might perhaps agree with the ethicist Dr Stephen Post as he proposes an alternative:

Equal regard based on the cognitive, emotional, relational and symbolic-expressive aspects of persons with dementia (including advanced dementia) lead me to reject the notion 'I think therefore I am' and replace it with the less arrogant notion 'I feel and relate, and therefore I am'.¹⁶

Counselling is also hampered by our ageist culture and the ongoing stigma of mental illness across the adult lifespan, although for some people and in some places it is slowly beginning to change.

Dr Freud also did not help the cause of the millennial counsellor who might wish to work with older people in general, when he 'decided' that it wasn't worth doing analysis with people over 40

because they were incapable of change. His influence on the developing psychotherapeutic community in England has had lasting effects.

Our European and American counterparts developed alternatives to Freudian analysis, which has meant that working with older adults has not been dismissed in quite the same way. Problematic though it sometimes is, the field of older persons' services and the availability of counselling to the older adult as medical care consumer can be quite different.

So in light of the above, I began to try to put my questions into words. What forces are at work and how might I describe the client's efforts to Make Sense of Self within the counselling relationship? How do I Make Sense of my Self within that relationship? Where are the words that might translate these events into meaning and understanding and create a paradigm for counselling that would encourage further involvement with people with dementia, and provide a basis for qualitative research and guidelines for current and future work?

I began my own quest in parallel with the clients, who, by their own admission, reported feeling 'better'. They described feeling less anxious and depressed, more worthwhile, valued, heard and respected and able to express just how they were feeling during the sessions without needing to wonder if it was appropriate to do so. Some were able to experience forgiving and resolution. Others said how good it felt to be taken seriously and empowered to be themselves and assert themselves within their relationships and service provision.

2

‘Standing Tall’ and Other Lessons of Stature

In Chapter 2 we explore the fundamental principles I have encountered with authors presented here, persons with dementia, and also with clients. These encounters have called for a normalizing or ‘depathologizing’ (removing the pathology or disease focus from dementia) of the experience of dementia. Men and women living with dementia are becoming central to the quest for understanding and acknowledgement and development of appropriate services by speaking publicly and writing about their experiences. They are no longer willing to accept the designation of victim or sufferer of dementia and neither should we, in our public, private or professional interactions.

Not until the late Tom Kitwood and his person-centred approach to dementia care,¹ John Killick’s *You are Words*² and Malcolm Goldsmith’s *Hearing the Voice of People With Dementia*³ did we have touchstones that spoke specifically and with such urgency of the lived reality and intrinsic worth and ‘personhood’ of the individual experience in dementia, and the ways in which men and women communicate and long for us to communicate with them.

Of course there have been others since who have taken up the cause, but these early pioneers were the ones initially responsible for bringing this to our attention and changing the ‘culture of care’ for the better. They have forever changed the ways in which we enter into communication with and relationship with men and women with

dementia. Previously, our focus had been on the family carer almost to the exclusion of the person with the dementia. When the person with the dementia did appear it was often in terms of what was being done 'for' or 'to' him or her, rather than including the person in his or her experiencing life with cognitive change and concomitant changing ability.

It is essential that relatives and carers receive all the information, support and care that we have available. And yet, the person who walked out of the doctor's office having been told his 'diagnosis' was essentially the same one who walked in only a few weeks or months before. It will take many more months or even years for that person's abilities to diminish and deteriorate so dramatically that he will become dependent on another for all of his basic needs. Initially, very few of the health and social community of professionals are asking 'the patient' what it is like for him, and how he feels about what is happening. One former military person said rather emphatically, 'It's my brain and my disease. It's *my* mind that is going AWOL [Absent Without Leave], how about asking *me* what I think about it?'

We have now created a template, a standard against which models of best practice can be measured. We have been released from the exclusivity of the medical model in favour of multidisciplinary, inter-agency explorations that add the psycho-social and spiritual realms of experience. But within this 'new culture of care' (Kitwood) the complementary therapies with their inclusion of right hemisphere brain function, body as metaphor and the affective and spiritual modes of responding and behaving are encouraging the new paradigm. My belief is that there needs to be a merging of the medical/scientific with the psycho-socio-spiritual if we are to embrace this holistic approach to care and services we might like to profess.

It is one thing to respond to a person in a validating way, but when she wants answers to questions such as 'What is happening in my brain so that I can't remember things any more or can't find my way back from the supermarket?' we could be accused of patronizing and discriminating against the person by making a decision about what she can and cannot know about herself. Without the multiple interactive processes that create dementia chaos in the first place, we would not need to be creating alternative ways of responding, communicating, caring and being that are essentially multidisciplinary, integrative and holistic in approach. By definition, this includes

spiritual aspects of the Self, which we shall explore further as we continue.

My mentor in this work was a gentleman with dementia who taught me a great deal about the interiority of the process – what was happening from within; the inside out of things. He showed me the importance of shared laughter and tears, the essential humanity we shared in spite of differences in age, gender, culture and experience.

He shared with me his desire for normality, for things to be as much the same as he had known them. He had a terrific sense of humour, love of life, family and most things edible. There were many instances where even within aspects of confusion and disorientation he would laugh heartily and have most people around him joining in.

He taught me that 'standing tall' was essential not only to his physical stamina and posture, but to his 'personhood', his 'spiritual Self'. The phrase 'standing tall' is used often metaphorically to describe a presence of mind or attitude, one that invokes pride and self-worth, courage and integrity. It is no mistake that it is also what inherently defines us as Homo Sapiens and therefore is intrinsic to our sense of self and place in the world.

I will never forget when he pulled himself up to his full height, all 6 feet 1 inch of it; he grew into himself. A new and wondrous expression exploded onto his face and his eyes literally popped wide open in surprise as he looked down on his two nurses and beamed at us. As we proceeded down the hallway he made contact with every person and smiled and chatted and read every sign on every door we passed. He taught me an invaluable lesson here, that ability to read is different from understanding what the words mean, and that visual memory lasts longer than memory for words. A person with dementia is more likely to respond appropriately to a picture or photograph of a toilet than to the word 'toilet' or to a symbolic representation of male or female that in reality bears no resemblance to either man or woman. Neither does it give any sense of a place or an activity that only men or only women might do behind that door. These early lessons would affect my approach to communication and what indeed the person with dementia might be comprehending in very literal ways.

It was a moment of wonder and pleasure for all of us to see him this way and for him to experience himself in an orientation perhaps

long forgotten. Upright. Standing tall. In control. In charge. Walking. On his path. Although he could speak and use words, complete or intelligible sentences were not the usual mode of communication for him. It was more like a jumble of words just tossed together with the occasional appropriate words or partial phrases thrown in, or lengthy animated conversations with himself or imagined others.

Now, standing tall not only commanded a new position and different view of the world and Self, but it required a different and more coherent conversation, perhaps stimulated by this new orientation in space and time. I am reminded of that classic, never-to-be-forgotten scene in the film *Dead Poets Society* when, in an effort to encourage his students to see the world from a different perspective, the teacher, Robin Williams, stands up on the desk and the students follow one by one until the whole class is standing on desks and the collective penny drops. In this case also, perspective is everything.

This behaviour of seemingly becoming more orientated and engaged with the world around him and those people in it continued each time we helped him to stand up and to go for a walk with us. I have had numerous similar occasions since and others have also attested to this experience of renewed engagement, orientation and clarity. It also seems to be a way of restoring calm and control when a person may be highly anxious or agitated.

Psychologically, emotionally, spiritually, there were differences in the person's being. There also seemed to be cognitive changes in terms of communication, retaining information and socialization as well as the physical benefits of becoming more mobile and active. Several indicators of wellbeing as described by Kitwood can be confirmed through observation. People can participate more in their own lives, with a sense of purposefulness and agency; not only as recipients of our good intentions and care, but able to experience mutually enhancing relationships.

It was some time later that I was to learn the real significance of the cephalo-pedal reflex, the nervous pathways that connect the head to the feet. This is stimulated by walking, running, any weight-bearing activity including pushing against a footboard at the bottom of the bed. The reflex also acts to give feedback as to our whereabouts in time and space and where our limbs are located; our kin-aesthetic and proprioceptive abilities. It tells us which end is up and stimulates general awareness and orientation. When not stimulated,

even cognitively unimpaired humans soon become confused, disorientated. Many people in care homes and day centres, hospitals and hospices are deprived of this stimulation, often unintentionally, in order to minimize risk.

Humans also intuitively seem to wish to walk, pace, run, jog when undergoing stressful situations. Anxiety seems to provoke the need for action. Some people need to pace and walk when stress erupts or have a profound need to get out of the house, to run, to flee from the pressure in a real and physical way. The same is true of clients and yet there may be limited opportunities to do so, including restrictions to prevent harm and falling, escaping, getting lost, all with the best of intentions, yet inadvertently undermining autonomy and sense of Self and an inherent calming, restorative functioning.

There is little doubt that living with dementia can be more or less stressful at different stages and in different people at different times; perhaps this might be a clue to the seemingly endless pacing, walking and wandering seen on a regular basis. When so many other means of self-soothing, self-righting activities are unavailable for whatever reasons, getting up and moving through physical space and the environment seems to help.

Of course there are people for whom walking and bearing weight may not be possible or advisable. It is essential then to provide every opportunity for weight bearing to take place and pushing against 'terra firma' in the form of a footboard can help with the reflex stimulations.

What I learned many years ago about 'standing tall' helped me to realize that there is an inherent psychological and spiritual dimension to this behaviour. People step up into themselves when they stand tall. There is a subtle shift of power and control. They own themselves and their integrity when approached from this perspective. They can maintain their unique perspective on the world, and demand and expect to be treated as equals. The individual can reclaim the agency of change in her life and domain.

With this in mind, I imagined what might need to be maintained for the person as client to 'stand tall' in our counselling relationship. I need to view the client from her perspective of standing tall and respond accordingly, offering a respectful sense of her personhood, imbuing her with her sense of Self, whatever she perceives that to be in the moment. I made the decision early on that there would be very

few differences between how I worked and related with my clients who had dementia and those who did not.

Clients forget my name, the name of the office building, where they left their glasses, what happened in the last session. Those are the clients who don't have dementia, so there was going to be a great deal of scope within which to work.

'What we lack in distance we make up for in height, and once in a while we stand tall enough to touch the sky, look the sun straight in the eye and laugh', Linda Ellerbee – American journalist (b. 1944).⁴

3

The Purpose of Counselling

Why Counsel People with Dementia?

Making sense of mind or brain seems to be of utmost importance to us humans. The questions concern philosophers and thinkers, and equally to the woman with dementia in residential care, cited by John Killick, who says ‘After all what is this lump of matter if you can’t make sense of it?’¹

Attempting to make sense of the ‘lump of matter’ is part of the focus of counselling and what is explored in this chapter. It explores the aims of counselling as described by several counselling ‘authorities’ and makes the case for why people with dementia may benefit from the counselling relationship in spite of increasing cognitive change.

The more important question to be explored in Chapter 3 seems to be, ‘Why not counsel people with dementia?’ If we are told that talking therapies have a positive effect on reducing feelings of depression, anxiety, grief, loss, isolation; that new neural pathways can be encouraged, then why wouldn’t we want to offer counselling to people with dementia if they would like it? One could argue that this kind of specifically focused interaction of a sustained and uninterrupted hour over a number of weeks could be nothing but beneficial, and therefore potentially a placebo effect; that without any particular therapeutic skill or training, there could have been a

positive outcome. However that need not diminish the importance of having the opportunity in the first instance.

Of course, counselling is not for everyone. For those who choose to engage in counselling the rewards and benefits can be truly life changing. There is, however, still an unhelpful amount of misunderstanding and stigma associated with the process and practice and outcomes of counselling, further limited by ageism and attitudes towards disability. Counselling and psychotherapy services for older adults specifically are not easy to locate, but are beginning to be more available in some places, yet with significant regional differences.

The *Journal of the British Association for Counselling and Psychotherapy* dedicated an entire issue to counselling and older people.² However, counselling people with dementia specifically is in its infancy, and yet there are encouraging projects and committed individual therapists beginning to emerge. Counselling is and can be available if we choose to look for it, keep asking for it and encourage others to do the same. This book is a testimony to those efforts and the men and women who engaged in the counselling relationship with me and who asked me to write this book on their behalf. It is also an invitation to encourage other practitioners to explore the possibility that counselling might be helpful, and furthermore, that they could offer it.

This approach seeks to support men and women with dementia, their carers and the professional community to ask for counselling if it is what they want and need. It is also an attempt to 'de-pathologize' dementing conditions in the very person-centred way that Tom Kitwood has described, eschewing that which he identifies as 'malignant social psychology'.³ He means here, the ways in which he observed people with dementia being 'demeaned and disregarded'. I, too, have experienced men and women who have become socially exiled and excluded from their own being, or Self; their relationships, families and communities, indeed, at times, set apart from humanity altogether. Holistic experience will and must include all aspects of Self including spirituality and sexuality and in particular those aspects of Self that are yet unaffected by disease process. The focus shifts to residual strengths rather than apparent weakness. As Kitwood says later, 'people who have dementia for whom the life of the emotions is often intense, and without the ordinary forms of inhibition, may have something important to teach the rest of humankind'.⁴

The other focus of person-centred counselling as I experience it, with its frame of reference beginning and ending with the person (client), is a framework that encourages the counsellor to be with and alongside the client from her very central place of experiencing. As Mearns and Thorne suggest, 'be with the client in her experiencing', not outside of it.⁵ This skill and this privilege are not for the faint-hearted. It requires the risk of 'working at relational depth' discussed at length by the above authors and presented here as a way of being inside the experiencing of the person with dementia as client. It is also an elegant fit into the present culture of dementia care, indeed a parallel to the person-centred care that Kitwood introduced, and has become a model of best practice for those who provide care and services for people with dementia and their relatives.

My experience of working with clients has grown from a belief and a commitment to the person-centred way of working. I have come late and through the back door to the work of Mearns and Thorne and now Mearns and Cooper⁶ and can see how deep and how simply elegant their theories are when applied afterwards to the process I have experienced with clients first hand. The interplay between body, mind and spirit is never more keenly apparent and at work than in men and women whose usual ways of working and presenting themselves and their personal and private experiencing are available so readily for others to witness. The trust this person is unknowingly and perhaps unwittingly handing the counsellor is quite extraordinary. The client has turned himself inside out without even being aware that he has, and said 'here I am'. And I must do my very best to prize all aspects of what he shares. This is where the 'configurations of Self' and 'working in the not-for-growth areas' support and encourage the process and the outcomes.

For at least two decades now we have been reaping the benefits of dynamic and revolutionary approaches to understanding dementia and supporting men and women who are caregivers and, latterly, those experiencing the specific problems of dementia. We have been able to apply those lessons to the 'relational' (our relationships with the person with dementia) within the area of service provision and family support, but, to date, rarely within the realms of counselling and psychotherapy.

When we consider the aims of counselling, it would appear that this client group would not fall outside of the remit as written by two pre-eminent accreditation bodies in the fields of counselling. The British Association for Counselling and Psychotherapy (BACP) states that the aim of counselling is to: 'provide opportunity for the client to work towards living in a more satisfying and resourceful way'.⁷ The American Counselling Association definition is: 'The application of mental health, psychological, or human development principles, through cognitive, affective, behavioral or systematic intervention strategies that address wellness, personal growth, or career development as well as pathology'.⁸

In a similar way, I, the counsellor, can express the core conditions of person-centred counselling, namely empathy, unconditional positive regard and congruence, to provide a safe basis from which the client can begin to reconstruct Self from the fragments of the remembered past. The reconstructed Self becomes the real Self in the relationship with the counsellor. The counsellor's responses and reflections and way of being offer the client the opportunity for feelings of self-worth to emerge and expressions of mastery, control and choice to be validated, however briefly.

In the trusting relationship that ensues, it also encourages the less favourable, often negative and sometimes hated and hateful, shameful and disgusted Self to be heard and accepted, validated and included. Making sense of Self, if only for the moment and if only for a moment in time, acknowledges, affirms and accepts the client's real Self by being able to share who she once was in the context of who she has become. Sue Monk Kidd⁹ writes of the experience of being 'nowhere' as actually having the same letters as 'now here' and certainly for the person with dementia in particular there is an especial truth to this word play. It is a reminder to pay attention to living in the moment, whatever it holds for us, and by so doing, come ever closer to experiencing our authentic self. It is also an invitation to me as counsellor to pay attention to the here-and-now experiencing of the person with dementia lest I miss an opportunity for engagement, relationship, sharing and supporting.

Experience has led me to believe that clients desire many things: acceptance, not being judged, to be able to speak the unspeakable, confront the unimaginable and yet hold onto Self – the Residual Self

– the Emerging Self, ‘owning the narrative’ and in some instances reinventing the narrative. This may occur when a former narrative has become at times fragmented or forgotten, or the reconstructed perceived Self is preferred to the former Self.

David Howe echoes this sentiment in *Counselling and Older People*:

In bringing the past into the present, experiences are reconstructed to make sense in the individual’s current framework of understanding... We continually reconstruct the way we understand ourselves. This is what clients seek to do in therapy, hence the need to talk and tell one’s story.¹⁰

It seems that this process is no different for the person with dementia. There is, however, no pressure on the client to say the right words or in the right order or to be smart, logical or even understandable. It is enough to give voice or simply give presence to Self; to laugh, cry, shout, sulk, be numb. The client can come ‘Just as I am. Wholly accepted, wholly acceptable, truly prized.’

With some of the usual signposts to Self missing, without these markers and maps to remind us of our own journey, is the narrative of our particular journey diminished? Or does it take on another meaning at another level on a road less travelled? Who are the intrepid explorers who will bear witness to this new exploration, who will be alongside as we discover the ‘new world’?

The counsellor might be one of those persons who may be able to co-navigate the way forward into these uncharted waters; the quest of Making Sense of Self. I have faith and trust in who you were, who you are and who you are becoming. I have faith and trust in the counselling process and the relationship we develop to get us to where we want to go. If I am alongside you to hear your narrative, to bear witness to your story, your re-membling, or sometimes your un-remembering, maybe we will discover something new and unexpected that will change our understanding and appreciation of who you perceive yourself to be now and who you might become in the future. In the absence of a distinct and clear map, as cognitive abilities change, we trust the spirit and feelings to guide us to truth and acceptance the way the stars may have guided our ancient vessel to its farthest shores.

4

The Process of Counselling

How Does It Work?

Chapter 4 looks closely at the inspirational person-centred work of Brian Thorne and Dave Mearns within the context of three specific areas: working at relational depth, configurations of Self and working in 'not-for-growth' areas within the counselling experience. This work has provided the basis for the continued development of what may be described as a new paradigm for counselling and people with dementia.

It was a slow process that brought me eventually to the discovery that the counselling work I had been engaged in for some time with men and women with dementia encompassed a familiar expression of their search for Self. In the face of apparent cognitive change and at times seemingly debilitating self-doubt, self-loathing, depression and anxiety and the general expectation that nothing could be helpful, something positive was happening between us that opened the client to experiencing Self in ways that were essentially affirming and empowering, positive and nurturing. Not only did we recognize it, but partners, family and other professionals were aware of the changes as well, even though at times they may have been at odds to describe or explain exactly what the changes were. In my journal writing, talking and discussing with colleagues and friends and my own supervision I was intrigued. I asked the following questions: What is it I am experiencing? What is the client experiencing? How can I give voice and meaning to what I know is real and be authentic

and congruent in the process of its explanation? Could I risk describing the process without forever altering the experiencing?

I discovered that at the heart of this dilemma existed a huge discrepancy between three key areas:

- My previous experience of 'traditional' counselling and its purported outcomes. What this meant to me was that clients without cognitive impairment usually experienced the anticipated outcomes of growth and change, feelings of being heard and valued, increased feelings of positive regard for themselves and others, and an ability to manage their difficulties in more meaningful ways.
- What I had learned about the impact of progressive degenerative cognitive impairment associated with dementing conditions and the impact of 'malignant social psychology'¹ which meant that the person with dementia may not be able to benefit from counselling at any level and that those around him or her would not anticipate any positive change.
- The reality of what the client and I had experienced within the counselling relationship seemed far removed from what I and others had imagined. There was a subtle and interactive transformation taking place in which power and control, judgement and dismissal were not exerted by the 'other', in this case, me, as counsellor. This shift may sometimes be in sharp contrast to the view of individuals in health and social care disciplines generally. The client can become empowered and encouraged to be fully her-Self or him-Self within the affirming, accepting safety of the relationship.

The collaboration of Dave Mearns and Brian Thorne and their dedication to the person-centred relationship provided the place of safety for me to be able to take the risk of identifying in words for the first time, what I knew at a deep level to be true. I had read Brian Thorne's books on Christianity and spirituality in person-centred counselling² and was enthralled and encouraged. Thorne's writings have created a place of safety and sustained energy for my explorations. There is a sense of awe and wonder at the spiritual connectedness with clients that I value and treasure, and, I believe, that partially underpins my notion of Making Sense of Self.

Some time ago I heard Dave Mearns speaking about his work with Brian Thorne concerning configurations of Self; working at relational depth; working in not-for-growth areas, and my soul took flight as my thoughts grew wings. Here at last was the theoretical language that described my practical experience on three levels – the cognitive (thought and behaviour), affective (emotional/relational) and the spiritual (the soul, or spirit, mediator of all aspects of Self, in the broadest non-religious sense).

I believe that in the light of fragmentation and disintegration of cognitive and physical abilities, clients' expression and experience of themselves and my relationship with them, a new expectation, or hypothesis, was necessary. Positive outcomes were emerging in a consistent way and on a regular basis and flew in the face of what was usually predicted for this client group. Interestingly, affect or emotion – how the person is feeling – is often fairly intact and easier to access than mere cognition or his or her spoken communication or thoughts about what is happening most of the time. The diminishment of role, history, pretences and masks, as well as a fair amount of disinhibition creates a 'Way of Being' – to borrow Rogers' phrase³ – for the client, which is immediately engaging and alarmingly undefended and vulnerable. The counsellor has to stay focused and open to whatever may happen and be willing to risk her own vulnerability as our deep connection is made.

What has been immensely helpful and fundamentally affirming is the discovery and observation of Mearns and Thorne's theories and seeing how they come to life in my working with men and women with dementia. These are: working at relational depth, working with multiple configurations of Self, working in 'not-for-growth' areas, and working with the available spiritual essence of the person.

When a client is met at relational depth and enters her existential process she takes an 'inside' view of her Self. From that perspective she sometimes experiences her Self in terms of different 'parts' rather than a single 'whole'.

Staying 'in the moment' with the client 'working with the client in his existential process' means:

- he gives his Self as he experiences Self
- what he gives is not dominated by the Self-protective strategies (often he will oscillate between the Self-protective

mode and his direct experience of his Self, in such a way that undermines the Self-protective strategies)

- he finds it impossible to lie.

Creating conditions for working at relational depth includes:

- high levels of therapeutic conditions in mutually enhancing interaction
- the 'stillness' and 'fearlessness' of the therapist
- listening to the 'expressing' rather than the expression
- meeting the client inside his experiencing.⁴

The person-centred way of being means that the counsellor is experiencing the client at relational depth, which allows the client to experience himself in his own unique way. This experiencing of Self, where according to Mearns and Thorne the counsellor meets the client 'within' his experiencing in the present ongoing moment, is crucial to our valuing the other's diminishing sense of Self and 'personhood' or emerging 'other' Self. It allows me to accept and validate the existential Self and the conflicting configurations of Self as they emerge.

This continuous process of deconstruction of Self seemingly without any way back to wholeness or fullness of being can create a silent desperation in many. It is often shown in anxiety and depression and spiritual longing. It could be compared to an experience of wandering in the wilderness. Many psychotherapeutic models emphasize the ability for change and growth that give evidence of a successful therapeutic encounter. Here, the emphasis is on the client making sense of Self in this present moment and sometimes for a limited time into the future. Perhaps this model can create an active goal of acceptance and peace through reconfiguring the parts or in some cases allowing them to fade into the background, replaced by others that might be more necessary to the client's survival.

Clients who would not have been expected to learn new information can frequently remember, retain, store and recall that information and use it appropriately later on, and have done so to my surprise and their delight.

One client was becoming extremely anxious and upset when words couldn't be found or when the words that came out were

inappropriate for the situation. The anxiety became panic and he felt stupid and exposed. He thought it would be better to withdraw from all occasions where he could look stupid, but this resulted in an increase in isolation and loneliness. He wanted to find a way out of the problem but to stay connected with people. Hearing how he encountered each situation, and what it felt like to him, showed us the way forward. He decided he had to slow down and take charge of the situation himself. Together we were able to come up with the notion of 'go with the flow' and he wrote it on a piece of paper and tucked it into his wallet. He decided he would take this piece of paper out and read it aloud whenever he was stuck for words.

What delight there was in his telling me that he was able to use this strategy to help him out of a tight spot in a few occasions between counselling sessions. As he read it aloud, it slowed him down and relieved his anxiety. He said he could hear my calming voice reading the words, and the person he was speaking to was able to be part of the process of word finding and caught a glimpse of what he was experiencing. It sounded very much as if he was on the receiving end of empathy, as he described it. This was encouraging a greater desire in the client to communicate and much less frustration or impatience on the part of the listener. Together they calmly tried to find the right word. Sometimes it worked and the word was found, and sometimes it didn't, but the client was not at the mercy of the dilemma; he was able to regain some of the lost control he perceived over this word-finding problem. He felt he could do something about it, felt in control of it rather than *IT* being in control of him.

This new-found ability surprised his family and friends and it lasted for as long as he was aware of the problem. There came a time when it didn't seem to create the same anxiety and feelings of stupidity as it had before and so the need for the piece of paper and what it offered was no longer important or necessary.

These were all ways in which I had been experiencing and relating to the client yet had not been able to name them or identify specifically in theoretical terms how change and growth were taking place. It seems to me to have a natural home within these models of 'working with configurations of self and at relational depth' and further examples will be noted later.

A configuration is a hypothetical construct denoting a coherent pattern of feelings, thoughts, and preferred behavioural responses symbolized or pre-symbolized by the person as reflective of a dimension of existence within the 'Self'.⁵ In summary, the counsellor needs to commit to and engage with all aspects (configurations) of the Self as if including the voices of all members in the intra-psychic family. Some of the voices denote positive attributes and others negative ones. We would deny those family members a voice, at our, and their peril. Neither should we refuse admission to alternative expressions of Self. We often prefer concentrating on those aspects of the client which will bring the ultimate growth and change, engage the actualizing tendency and thereby the positive outcomes which are most encouraging to us and to the client.

On occasion, the client may not be able to express herself with words the way she might once have. This can occur for many reasons and sometimes language is replaced by sounds or facial expressions, or added to them. Primary language (mother tongue) may replace the language of the community the client has resided in for many years and in which she was fluent. This can present significant difficulties for the family in particular. I remember one incident where the father immigrated from Poland after the Second World War and married an English woman. Together they decided they would speak English to their children in order that they would be fully integrated into the community and their schools. When Adam developed Alzheimer's disease and reverted to his mother tongue, neither his wife nor any of their three children could communicate verbally with him. They creatively discovered other ways of communicating with one another effectively for a while.

Although verbal communication may be lost or changed, there are aspects of communication that emerge from a pre-symbolic self, which is nonetheless a valuable aspect of the communicating. It may be expressed through tone of voice, sounds, crying, facial expression, body posture, gesture. Mearns and Thorne also describe this the following way:

some of the most absorbing person-centred work occurs when the client is at the presymbolic stage in relation to a configuration of Self. Here, the client and therapist cannot talk about the configuration, they can only be in the configuration. The client is dimly and

partially expressing himself from the configuration but the material is not neatly organized. For the therapist whose listening requires coherence there is only confusion. What is required is a listening that hears the person rather than the content. The listening is to the existence and expressing of the person. It is the expressing which is being listened to rather than the expression.⁶

Mearns and Thorne's contention is that we are being fully congruent when we spend as much time with the client in his or her expression of negativity and 'stuckness' and self-loathing, self-doubt, and so on, which create the 'not-for-growth' experience. What actually happens when we hear the client's multiple configurations of Self irrespective of their merits, and value and prize those configurations as much as we would others?

The person as she experiences the changes and losses that accompany dementia begins to dwell in a place of paradox. On one hand, she has the ability to still be the person and do many of the things she used to, and on the other hand, she has the encroaching awareness that all is not as it seems and that there are many 'parts' to the once known Self that are newly emerging and causing trouble, an unwelcome or unruly guest at a family gathering. Sometimes aspects of Self that once seemed so vital, so important are let go as they recede into the mists of the unremembered. In order to proceed as 'normally' as possible, the person will cover up and rationalize the new feelings and behaviours, will blame others for those feelings and behaviours in an effort to save face. We are, all of us, so good at this, but this skill becomes even more developed under the specific conditions dementia promotes.

Loving relatives, partners and friends will continue the process of filling in the blanks of the unfinished sentence, making sure the right clothing is worn for the right occasion, doing more planning and protecting. Partners make excuses for social withdrawal, preferring to order a takeaway rather than risk potential difficulties at the local restaurant. Feigning physical illness, sudden dislike of an activity or its organizer, or seeming lack of funds all allow for disengagement from social occasions and friendships for reasons other than the obvious.

Yet throughout this early coping, which it is indeed, few, if any are yet giving voice to the anguish or the embarrassment or the panic

accompanying the changes. As humans we are all very good at covering our tracks and some of us have many allies in this particular narrative of staying the same as we have always been. Distancing ourselves from the enormity of what lies ahead is essential to our coping and survival. Denial is one of the defence mechanisms called into play here, and it can be seen also as an adjustment process to loss, and in the case of persons with dementia, multiple changes and resultant feelings of loss and grief.

The person who comes for counselling at this stage may be aware of the beginnings of disintegration and the multiplicity of selves, some of which are too frightening to consider alone. It is my experience that the person with dementia will tend to reveal these configurations earlier in the counselling relationship than those clients without dementia. Perhaps this is partly motivated by a sense of finite time, or the push towards the authentic Self that changing roles and emotional and spiritual vulnerability elicit. And yet these parts or configurations of Self are very real and present to the person and, at the same time, paradoxically alien, but familiar.

Margaret Warner's sensitive and powerful notion of the 'fragile process' can be aptly and helpfully applied to the experiences of persons with dementia. This fragile process, as she describes it, is:

a style of process in which clients have difficulty modulating the intensity of the core experiences, beginning or ending emotional reactions when socially expected or taking the points of view of other people without making contact with their own experience. Clients in the middle of a fragile process often feel particularly high levels of shame and self criticism about their experience.⁷

I have witnessed the client as he experiences aspects of Self that seem to be at odds with the known Self. Sometimes other members of the family, home care workers or neighbours might be blamed for behaviours that don't make sense to the person with dementia.

For example, a client might relate a situation akin to this one:

I know the milk goes in the fridge. How did it get into the oven? I know that I could not possibly have put it there, that is far too silly a thing to do and I am not silly. So, it had to be YOU! YOU are doing these things to confuse me, to trip me up to make me look silly.

These statements could also be called 'introjects', as Warner describes them; they 'potentially carry a protective function in the unlikelihood of lasting change'.

As the person with dementia experiences this seemingly 'alien' behaviour at times, I wonder if their configurations of Self (the silly part, the Alzheimer part, the ashamed part) are actually invested in the protection of Self. These configurations may be an organizing principle that can lend structure and function to individual thoughts, feelings and experiences.

Those experiences and thoughts that just don't make sense are either disowned or blamed on someone or something outside of the Self. Of course there are those more potentially harmful and distressing thoughts, feelings and behaviours where elements of paranoia with its fear, suspiciousness, and capacity for harm of self or others must not be ignored. In some cases, counselling alone cannot help. It would be inappropriate however to leave the reader with the idea that dementia always equals delusional, aggressive, paranoid and out of control, difficult to manage behaviour and experiencing. This is not the case, but it does affect some people in those ways and we have a responsibility to make appropriate referrals for additional support and/or treatment should the need arise.

Mearns and Thorne also speak about the Self that has endured, survived, and adapted to pervasive and sometimes contradictory conditions of worth. The client also needs to find ways to respond to 'self experiences' that are inconsistent with the rest of Self.

Rogers pointed particularly to 'the protective mechanism of denial whereby experiences dissonant with the rest of the Self are disowned'. He further states that 'Behaviour may in some instances be brought about by organic experiences and needs which have not been symbolized. Such behaviour may be inconsistent with the structure of the Self but in such instances the behaviour is not "owned" by the individual.'⁸

In the example given above, when faced with actual observable reality, there needs to be an externalized explanation, and therefore someone or something else is to blame and needs to be responsible. These accusations, blaming and denials are often the pitfalls in communication and relationship that the person with dementia, relatives and professional careworkers fall into.

Observers of this dissociated behaviour or apparently disorganized way of thinking have been known to admit these as testimony to the 'organicity' or the 'pathology' of the condition, the unravelling of the mind, rather than the Self-protecting abilities we see in action here; part of the need to make sense of the apparently nonsensical events in one's previously sensible life.

It becomes painfully and regrettably easy to see that when we reinforce these actions as essentially negative, we lose sight of the alternative as outlined above; an alternative that actually speaks of a functional, protective, organizational and wellness-seeking endeavour.

How different the scenario and the experiencing of it would be if, assuming the above to be correct, our responses might rather be:

'Tom it sounds like it would really bother you if it had been you and not me that put it there? So you get angry at me because there has to be some reason why it's in the oven, right? And I'm the only other person around at the moment. I wonder what that would feel like if it had been you who put it in the oven?' [NOTE: not that you DID put it in the oven]

'It might mean that I'm really losing it, off my trolley.'

'You would feel like you were really losing it? And what would that be like?'

'Freaky, really scary.'

'Scary that you didn't remember doing it?'

'Yeah.'

'Do you still feel scared when I'm here Tom?'

'Not so much.'

'It happens sometimes, though, doesn't it, not remembering things?'

'Too much. But that's forgetful Tom, stupid Tom. I don't know what to do about it.'

'Kind of separate to other parts of Tom. [Pause] I think I see what you mean.'

[He nods]

'So, would you like to put the milk back in the fridge now?' [pointing at the fridge]

[Puts the milk in the fridge smiling] 'Sure! I can do that!'

The Self isn't able to take in the event all at once because of its stark and potentially threatening meaning. It is pointless to focus on

the milk being in the oven, the observable flawed reality. Rather, it would be more valuable to shift the focus to the intrinsic meaning and what it feels like to the person. In the end he is able to focus on his ability to be 'heard' and to rectify the situation. That feels validating, reorienting and positive. It also doesn't focus on how bad or sad it might make the other person feel to be accused, or blamed. I might need to talk to someone else about how it feels, but it wouldn't be particularly helpful to add my feelings to the current dilemma. Nor is it even really necessary to examine why or how the milk ended up in the oven.

We could learn to respond in much more validating and affirming ways rather than taking umbrage, arguing back with logic, becoming angry and defensive. Those are some of the pitfalls I mentioned earlier. Rogers has explained that the configuration may become an organizing principle that can lend structure and function to individual thoughts, feelings and self experiences.

So the person with dementia experiences this seemingly 'alien', incongruous or inconsistent behaviour and needs to make sense of it. It can be either embedded or encapsulated within a configuration of self⁹, and wouldn't our communication and responding to individuals demonstrating these behaviours take a completely different and much more supportive response if we recognized this as a possibility?

The way in which we respond to these events in the client's life can be key in our staying with the not-for-growth areas and getting a real taste of the role that configurations and dissociating might play as a form of resilience and Self-care.

The client Tom cannot speak of some of these parts of Self at home, as they might scare his wife, family and friends and possibly the dog too. The one who is providing all of the care and support is the one most often blamed. The client knows at heart that because of the emotional bond they have, this 'other' is less likely to desert him, scream at him or remove her love and care. Sadly, there are cases where it all becomes too much for the main carer and understandably so, when we hear how relationships are stressed to capacity.

Interestingly, pets who have been lifelong friends and companions also come into the 'realm of forgetting' and the relationship as well as the pet's name may be forgotten by the person with dementia. As long as pets have memory however, they will continue to be non-judgemental, fully accepting friends and loving companions that at

times are a great compensation or additional support for us humans who find this all so very difficult.

Being able to include the voices of 'all members of the intrapsychic family'¹⁰ to participate in the counselling relationship allows the person with dementia to experience herself as she 'perceives' herself to be, within her subjective reality. This perception forms the person's sense of Self and informs her making sense of what is going on in and around herself, free of judgement and the need to make it right, better or just different.

Perhaps the partner or the family member finds this change in personality and behaviour almost intolerable. This is not the person he has known to be mother, lover, friend, and the task of observing or living with this person as she changes is one of immense forbearance, care, love and self-sacrifice and above all, courage. In many other instances, the emerging person is one with whom the husband or adult child has a new, real and refreshingly unencumbered relationship. These constitute some of the 'gifts' of dementia. There is real joy and relief in people's faces and voices to know that after all, and at last, they might have a few years being the beloved. It is amazing to me how the ability to forgive sometimes horrendous abuse or at least feeling not wanted or never good enough is generously given in the reality of this new-found 'person'.

A woman proclaimed, with tears in her eyes:

I never imagined I would be grateful for any illness. But my mother, who never was a real mother, never baked cookies after school or told me she loved me, never played with me or thought I was pretty or bright. She was jealous of me and my dad, said mean and hateful things...she wanted a son, you see. I guess I was the competition. She never really took to me. Now she loves me, she really does! She stands at the door and throws her arms open and smiles and smiles and hugs me tighter than I could ever imagine. 'Here's my girl,' she says.

For this daughter, the gift is immense – and returnable!

As the counsellor, I only know the client as she is now. I have no previous emotional involvement, history or engagement with the client and am in the position of being able to allow this person to simply be who she perceives herself to be in the moment and how she is

experiencing herself in her world as it shifts and tilts around her. Although the importance of life history work and knowing about the client has profound benefits in certain situations, it seems to me that I can be primed into a particular way of responding or experiencing the client as other than who and where she is in the 'here and now', which may be less beneficial to the client in the long run if I am to truly enter into her perceptions of self. This is ultimately more important to the client than the 'reality' that has been forgotten and that everyone else wishes would return. Where does that leave her? – outside of her own and others' reality and experience! This is indeed something of a 'double bind' for the client.

Mearns and Cooper also write about experiencing the client in the here and now:

In the here and now exploration, clients also have an opportunity to find out from a (congruent) other how they are experienced, and this can help them develop their ability to engage with others as they actually are, rather than as the client (or in this case, the client and the carer) might imagine them to be.¹¹

Further, the authors advocate four basic ways in which we can facilitate an in-depth encounter with our clients as part of a 'co-presence'. Presence in this sense encompasses enhancing our expressivity and our receptivity and encouraging the client to enhance his/her expressivity and receptivity.

There are of course, in the early days, long periods of lucidity and awareness and insight that far outweigh what might be missing. They are related to the unaffected parts of who the person is and how he or she continues to be. These times are often rich, detailed, truly poignant and humbling to witness.

One client was determined to unburden longstanding feelings of regret, shame and guilt about an extramarital affair a long time ago and emphasized the need to 'do it now before I forget all the words'. He wanted to rage against himself, that 'cad', 'bastard', 'sneak', 'cheat', 'phoney', before eventually forgiving himself and making peace with himself over this issue. His wife had died many years previously and he imagined her own pain and unforgiveness as weighing down heavily on himself as well. He was eventually able to imagine a number of scenarios that included his wife as she might have been had

she found out about the affair. In time he was finally able to work through to her forgiving him and their being reconciled.

Others view their configurations or parts with great tenderness and grieving, some with contempt or fear of who they might become or what they might say or do in a moment of unknowing. They speak of being stupid, an embarrassment, useless, worthless, an impostor, pathetic, disgusting, vile, hateful, a burden, a drag and a drudge, childish, infantile and more and more, but essentially negative. By being fully present, accepting and validating of these parts of Self I can welcome these negative parts as I would those more positive aspects of Self.

Observers of this way of behaving have historically used it to describe or underline the further unravelling of memory and agency, rather than the possibility that we are observing unmasked, the organizing and self-absolving process of creating protective configurations necessary to survival and making sense of Self. Our hope would be not to pile any more sense of guilt or shame onto the person for his or her apparent mistakes, or their need to 'figure it out' or apologize because of an angry outburst.

Clients often speak of their experiences in these terms within the counselling session. What actually happens when I respond to this 'fragile' Self within his experiencing and engaging with his configurations of self, is that the client feels included, heard and valued for who he is 'within his experiencing'. This can give a great sense of relief and respite from the pressure to change or to hide or to condemn the less than perfect Self. I can stay with the client, alongside, and bear witness with him to these parts and work with them and him to help make sense of the whole.

5

What Is the Counselling Experience Like?

This chapter gives an overview of the counselling experience from a number of perspectives: the person with dementia as client, the family or partners, professional staff who work with people with dementia who have engaged in counselling and myself as a counsellor. It also gives examples of involvement, from initial referral to ending the counselling relationship.

One of the emerging themes I have observed seems to be an urgent desire and motivation to Make Sense of Self. So familiar and so reliable has it been in its expression, that it had to become incorporated into the title of this book. This is not an unusual quest, as many of us are engaged with this on a daily, even momentary, basis. In the life of the person with dementia, however, the urgency stems in part from the unpredictable nature of the neurological process, and the question of when and for how long all of its complexity will be available. This desire forms the basis and the motivation to do the work of making sense of Self.

The counsellor is able to appreciate, acknowledge, value and prize the client as she is now, who has been lost and who she might become. Family members and care staff may throw their hands up in despair at the thought of my not knowing who this person is at home who has turned their world upside down, who is lost on her way from the bedroom to the dining room in her own home.

If I am aware of how the client is at home, because the family member has told me, how would this presentation of one aspect of reality help the client make sense of Self? She perceives and believes herself in one moment to be well and capable and in the next diminished and lost. By being present to these often conflicting and self-defeating configurations of Self the client might create a tangible whole that can be experienced with the counsellor together in the present moment.

In an attempt to explain and illuminate our experiences in the counselling relationship and its outcomes, I wanted to pay attention to what it was that we shared in counselling. These were some of my thoughts: From the outset of the relationship we share the formation of our therapeutic alliance, the confusion, the pain, the vulnerability. We share at a depth that is risky and that transcends observable reality. We share the essence of our humanity, within the spiritual context that transcends and underpins our experiencing. There is a breadth and range of emotional and intellectual responses to what is happening to us and between us. We share in the confidentiality of the relationship, secure in knowing that this is a safe and private environment in which to talk, be silent, be heard and accepted. We share the prospect of surprise and anticipation of an outcome. We share the beginning and the ending, the holding on and the letting go. It is hoped that the outcome will be a positive one, but it may simply be an acknowledgement by another of the client's most vulnerable Self, as the client perceives it to be.

Some partners and families report that their relative's depression or anxiety are the observable changes they become most aware of initially, and not memory loss in particular. Older people with dementia may have already begun the developmental tasks of later life, including evaluating their joys and disappointments, planning for their future, grieving change and loss. Some people find this process depressing in itself, without the onset of dementia. Younger adults may have been used to talking out their issues either with a counsellor or friends and partners and find this time just for themselves, talking with someone from outside their known group, particularly useful and supportive as they too attempt to Make Sense of Self.

It can be challenging to identify positive outcomes observed in someone who may be described as 'non-communicative'. Families, partners and staff members comment on the general mood and

disposition of the person, there is often a willingness and attempt to communicate with the other, there may be more smiling and laughing, more spontaneous use of words or brief sentences in appropriate ways. There may be less calling out or crying, increased relaxation and sleep, improved appetite, less need for medication, increased interest in activities, music and social contact. The indicators for anxiety and depression begin to diminish. One can also apply the 'Indicators for Ill Being and Well Being' as identified by Tom Kitwood through the process of dementia care mapping, a detailed evaluation of a person with dementia's psycho-social expression and interactions.¹

I will still always ask clients if it is all right for me to sit with them and spend time with them. I will say what time it is, how much time we have, and when we might end, but let them know that they can end the session at any time. I watch very closely for any signs of distress or withdrawal and will give feedback as to what I am observing, and ask if I am doing that correctly. As the session progresses I will check with the client especially if I observe an increase in distraction or restlessness or disengagement, will ask the client before deciding if we stop or carry on. At the end of the session I ask if the client would like me to make another appointment. Often the person is able to communicate as usual, with only one or two confused moments or words in odd places. Sometimes it is 'yes' or 'no' either with words or sounds, smiles of assent or dissent, the non-verbal behaviour becoming a vibrant and essential part of the communication.

For the most part I will work with people with dementia the same way I work with all adult clients. The same protocols and arrangements are involved regarding adherence to the British Association for Counselling and Psychotherapy code of ethics and the verbal contract that constitutes our agreement to work together. I will tell all clients the same things regarding the way in which I work, my background and training, that I attend monthly supervision, and my commitment to confidentiality and its exceptions. I will tell clients about the length of the sessions, that they are free to end whenever they feel they would like to, and, in private practice, my fees and the client's preferred method of payment.

The need for clarity takes on even more significance for the person with dementia. I try to be as clear as I can about the expectations, goals, responsibilities on both sides, making sure the client understands all of this and that attending is voluntary on his or her

part. Although I can appreciate the reasoning behind it, I don't agree with family or professionals who cajole the client to attend counselling because I am a friend and we can have a nice chat. Clients will be under no illusion as to my role and our purpose when we meet. It is important for clients to be aware that agreeing to come for counselling is their choice alone.

Often the opportunities for persons with dementia to make simple determinations and choices about their lives are diminished or may be limited by others' concerns or assumptions about them, often well intentioned but not always well founded. I will endeavour to make choices available to the client, such as: Where would you like to sit? Where would you like me to sit? Would you like something to drink? Water, tea or coffee? At the end of the session I always ask the client if he or her she would like to come back for another session and when. At the beginning of each session I introduce myself and tell the client what my role is and how many times we have met so far. In situations where it seems important to the client to remember what happens from one session to the next, I assure the client that we can review what has happened at the end of one session and at the beginning of the next, and where we have been, and that I would be willing to take care of that part of the work if he or she agrees.

When I become the keeper of the memories (as one client described my role), it helps to move the session along and more importantly saves the client from endless searching and embarrassment. For example:

- C:** I can't remember if I told you this before, did I?
- D:** It sounds like you're not sure if we spoke about this before, would it be helpful if I told you?
- C:** [Client nods]
- D:** Yes, I do remember it. Would you like to spend some more time on that this week?
- C:** No, I think I'm done with that if you've heard it before. We can move on now. (OR: Yes, there's something else there I think.)

And so we go forward from there.

I ensure that the client knows that I don't expect anything of him between the sessions, and that we will go from wherever he is when he arrives for the session on the day. It is not essential for him to feel the stress of wondering what we will talk about each time.

We also talk about the timescale for counselling, which can be whatever the client needs it to be. The client knows he can come for one session or as many as he wishes. I do tell the client at the first session that I offer a review when we get to session six so the client doesn't feel he has been dropped into an endless stream of appointments with no end in sight. I let him know that at any time, or at the review session, he can decide if he wants to continue and if it is at all helpful, if there be something else we need to discuss, if it be more helpful if we did things another way. There are some situations where there are a limited number of sessions because of funding or the requirement of a project and the client will know how many times we can meet from the outset.

The client needs to be and to feel involved in the process of creating the counselling relationship and agenda. The sense of having some control over the sessions is crucial since there may be fewer and fewer aspects of daily living, and indeed daily being, over which the client is able to maintain control and choice. This constitutes part of the empowerment that emerges as a result of the counselling relationship. It is of course important to ascertain that the client has capacity to agree to the conditions of counselling. According to the Mental Capacity Act² we are to assume that the person has capacity unless and until proven otherwise.

When setting up the next appointment I always gain the client's permission to share this with the person who has brought her or who looks after her appointments. If I make the appointment over the telephone I always ask to speak to the client first and then gain her permission to share this information with the person who will bring her. In this way, the person with dementia stays at the centre of her counselling experience. This may seem odd to some relatives and professionals at first, but when I explain the reasons behind it most are helpful and supportive. I do not want in any way to intrude on, interfere with or undermine the family carer or residential home staff in their efforts to support the client. So far, nearly all of my relationships have been congenial. Although there is quite a bit of

information to share, I keep the language concrete and the sentences short, checking with the client to make sure I have been clear enough and that I am making sense in what I say rather than having the expectation that the client should be trying to make sense of complicated, wordy pronouncements.

There may already be several professionals involved in the care, wellbeing, support and treatment of the client, from the general practitioner, old age psychiatrist, social worker, day care provider, home care service, befriender, Meals on Wheels, volunteers from Age Concern or the Alzheimer's Society branch to name but a few. The person with young onset dementia may not as yet have many services available to her, but nonetheless needs to stay firmly at the centre of all care provision and the opportunity for counselling. There is a professional commitment to confidentiality within the broad sphere of professional services. It is often important for the appropriate and smooth delivery of services that members of the team are in consultation with one another on a need to know basis. Often more is known to more people than actually need to know it to be in the client's best interest. Yet within the counselling relationship, and perhaps with a Catholic priest in confessional, a faith leader in pastoral care or with one's legal advisor, confidentiality, with few exceptions, is truly maintained.

Other health and social care professionals as well as family might find it difficult to understand my complete conviction that the client alone will dictate if and what to share with anyone outside the counselling relationship. I will always attempt to gain the client's permission to speak to his or her GP or a relative if it seems that would be important or helpful to the client. I talk with relatives about the 'process' of counselling and the reasons for which I will not be able to share with them what their relative talks to me about. To the response, 'Oh I know, but I just want to know if it's going all right', I might say, 'Do you see any signs at home that might indicate that coming to the sessions is stressful to your dad?', 'Does he seem to want to come to the sessions?', and talk of how the client was being affected once he left the session. Most of the time the relative sees that a problem at home may indicate an issue about coming to the sessions. I welcome their observations. Many times relatives say that they see that confidentiality has been a real benefit to their relative,

and also to them as they no longer feel they have to do it all; there is someone else there to hold the psycho-emotional pieces together.

There will, of course, be times when counselling will not be the most helpful or appropriate relationship for the person. For example, a person with dementia had been referred to talk about depressed feelings over a broken relationship from the past, which he talked about to staff on numerous occasions accompanied by great distress. Whether the person the relationship was with is alive or dead, the material that surfaces can be too painful. Going over it can cause prolonged anxiety, grief and sadness and a sense that the incident or problem is happening 'for the first time' at each session. When the client is unable to make sense of the experience the events remain raw, exposed and overwhelming. In one session we were able to recognize and conclude that this process was not particularly helpful. The person with dementia told me:

I don't want to think about it any more, it is too hard and then when you've gone I just sit here with it and have nowhere for it to go. It does me no good. I end up feeling more depressed. I want something to take my mind off it. I don't want to think about it or talk about it any more.

He did like me and my visits, he assured me, but the talking was not having the results we had all hoped.

I was able to ask his permission to have staff contact his social worker, who was able to plan pleasant, engaging social activities with the client that indeed did occupy his thoughts and emotions in a more productive and meaningful way.

Many readers may have worked with clients with severe depression, anxiety, psychosis and many other difficulties. When we wonder about the effectiveness of counselling people with dementia, we need to reflect, as I believe I have elsewhere in the text, that reaching therapeutic goals in many counselling relationships may take a long time. For example, there may be subtle and incremental changes in a severely depressed person, which might include the client making eye contact with the therapist for the first time in weeks or months. This should be heralded as a breakthrough indeed, and worth patiently and expectantly waiting for.

As clinicians we would not consider ending counselling with clients with chronic depression because of their failure to communicate

in recognizable and sustainable ways. The encounter is not to be reduced to mere communication exercises because we believe therapy is inappropriate or would be lost on the client. We continue being invested in the relationship, for the agreed time, irrespective of the outcome, yet being clear about the nature of the relationship and its boundaries.

The following are some examples of what has been said about the counselling experience from the client's perspective.

- 'You have really helped me to get control of myself and what's happening to me.'

This person was struggling with feelings of being overwhelmed and anxious when episodes of forgetfulness involved language and word-finding difficulty.

- 'When I talk to you, I feel a whole weight lifting off me.'

For many, the burden of carrying this condition is enormous. There may be no one else to tell their story to, to live their narrative with them. Conventional wisdom tells us that 'a burden shared is a burden halved'. The opportunity for the 'unburdening' of the present experiences without interruption or fear of failure or of needing to be corrected is a great relief and an affirmation that it is acceptable to continue to be oneself even in the 'not-for-growth' areas and within configurations of Self that may be particularly negative.

- 'I never thought I could ever forgive him, but talking to you about it has really helped me to do it!'

Resolution and forgiveness are experiences that traditionalists would say require working memory and awareness, and the ability to choose to respond differently. Of course, that is true for the most part, yet people with dementia often retain enough skill and motivation to be able to make a complete or partial and valuable attempt towards forgiveness and reconciliation when they have set their mind to it. I can attest to the fact that this can and does happen even within the so-called limitations of cognitive change.

Clients are able to forgive and experience resolution if given the opportunity and the desire to do so. A woman was able to talk about her childhood and forgive an alcoholic uncle for sexual abuse and her mother for not having believed her or taken steps to protect her from him. She had lived with

these memories her whole life and although referred because of high levels of anxiety, this issue was raised by the client as she shared her narrative.

There was a tremendous experience of freedom, peace and wellbeing for this woman after she was able to express her narrative for the first time at age 82. We will not know whether this unforgiveness might have created any particular problems as the dementia progressed had it not been brought into the open by the client, yet the experience as it affected her in the present moment, and into the immediate future, made it so worthwhile for the client who was able to describe feeling 'free and happy' for the first time in years.

- 'I could never tell my wife how I feel, she has so much to deal with just looking out for me.'

Even the beginning awareness of how confusing and frustrating life was becoming for him did not cloud this man's awareness of what his diagnosis was doing to his wife and family. His concern was more for his wife's wellbeing and ability to carry on into the future with him, and the pain of imagining her without him. His gratitude to and concern for his wife prevented him from expressing his own fears and anxieties at home. Speaking freely in the sessions and allowing himself to experience the fears and concerns for himself as well as for his wife, he was able to be more available to her and their relationship.

- 'It's not just the talking, it's the silence too.'

Being able to bear witness to clients' pain, their moments of unknowing, their unravelling and letting go, their holding on and holding tight without necessarily having to use language can feel incredibly supportive, accepting and validating. Sometimes there are no words. We communicate within the realm of symbolic and emotional experiencing, no less powerful in the absence of words. The counsellor takes the lead from the whole of who the client is. Even in the absence of words in particular, I can meet the client at relational depth, and in the use of empathy, unconditional positive regard and congruence, a dialogue of sorts ensues. This takes a great deal of patience and vigilance and an awareness of what might also be going on in me at the same time. I may mirror the person's body language and comment on what it feels like to

me, all the while watching for the briefest of flickers of facial movements and sounds, smiles, frowns and eye movements.

There are moments with the client where we actively and attentively share the silence between the lines, which are the essential spaces where the penny drops, the light goes on and the shoe fits – making sense of Self and our shared world. This is not just about focused communication and validation techniques alone, it is my commitment to the relationship as a counselling relationship, with an ongoing investment of time and an expectation that ultimately there may be a positive outcome for the client, in her ability to make sense of Self, or at the very least, to have shared who she is in the moment.

It requires risk and a quietness and stillness within the counsellor to allow this process to emerge and exist. It has always surprised me to learn so much by connecting to the spiritual core of the person in this alternative, often silent, way of being.

- ‘Don’t you remember? I’ve told you before I don’t want your stupid counselling.’

This client had been referred for severe memory problems and anxious and withdrawn behaviour. We had one session at the end of which he expressed that he didn’t think he wanted counselling after all. I made an appointment with the plan of offering a session to him if he had changed his mind in the intervening week. When he saw me from the other end of the corridor it was very clear to the client that I was *not* what was needed and obviously I was the one with the memory problem. Rejection had never sounded so sweet. He had remembered not only who I was or what I did, but more importantly he remembered his decision and I confirmed with him that I understood and would not be expecting to see him the next week.

- ‘Are you here to do my hair?’

This woman’s identification of me with her hairdresser was not as far-fetched as it may at first seem. When I reflected on the relationship hairdressers and their customers share, I could really appreciate what she was telling me. Most women, and perhaps men too, look forward to having their hair done by a stylist or hairdresser. Most women feel so much better afterwards and may have spent the whole time letting off

steam and chatting to the hairdresser, telling them all kinds of things about themselves and their lives. This is how I believe this lady felt after our sessions. She was always glad to see me, even after I told her that I was her counsellor and we had met last week. She remembered there was something about how she felt during our time together that made it seem worth taking the risk. She always grabbed my hand at the end of the session and said most furtively 'You are coming again next week aren't you dear?'

- 'I know I can talk to my family, but counselling gives me the chance to have some time for myself to talk openly about what is bothering me that I wouldn't want to share with them. I'm still my own person and I don't want them to know all my secrets.'

Some family members and partners have been particularly keen to share their views of how their relatives experienced the sessions. Some of what has been observed and experienced includes changes in behaviour, mood, spirit and ability to communicate and remain more 'themselves'. I can honestly and gratefully report that to date, there have not been any negative responses from partners or relatives:

She is much more relaxed when she has been to see you and seems to sleep better at night.

You will never know how much the sessions have meant to him and to me. I just couldn't cope with all he had to get off his chest.

It has given her peace of mind again. She doesn't tell me what you talk about and I don't ask. We just both know it's better.

She still insists on coming even though it takes her everything to get here.

Counselling has given her an outlet so I don't have to be the one to listen all the time. I've heard so much of it before I just run out of patience when she starts up again. I say, why don't you save that for your session? Yes, I think I will, she says!

Professionals across the spectrum of care services have mostly been surprised by the outcomes of counselling, and some have been able to

include these outcomes as evidence for good practice. Over the many years there have been very few men and women for whom counselling hasn't offered a positive way of experiencing Self, and equally importantly allowed others a window into their reality and more person-centred ways of offering a service:

I never thought he would carry on coming to see you, it really has made a difference.

She doesn't seem as needy of staff attention since she has been coming to see you. It gives us more time for other residents.

There are many caring staff members who feel robbed of the opportunity to enter into more meaningful relationships with the service users because of staff and time shortages and other priorities the job imposes. It often gives a sense of relief that someone can offer time and a special place to 'be'. Also:

I doubt very much that he'll talk to you, he is such a private person, but I'm going to refer him anyway. [We met for many sessions and he did talk a great deal]

The staff have started to look at other clients differently and make their own suggestions for referrals at meetings.

I wish this was something every client with dementia had access to if they wanted it.

The son tells me it has made a world of difference to how they get on at home, his dad is much less irritable and frustrated.

These are just a few of the responses and reactions from persons with dementia, their families and the professionals who work with them. Feedback of the formal and informal kind has provided some illuminating insight into the experiences of clients and those who live and work with them.

So what is it like to come to the end of the counselling relationship? As in all counselling relationships, the ending is with us at the beginning. There may be a review at the end of six sessions where we will discuss how the sessions have been going and what has been covered and how it has felt. It may be that a different direction needs to be taken, or something repeated, or a change of pace or simplification of language as the client's needs change. The review may occur

on a more frequent basis, other than six weekly, so that the person with dementia can stay up to date with the process and content of the sessions. It is important to know whether clients want to return, or whether or not they feel they benefit from the sessions. Ending will not be unexpected and will not usually be undue cause for distress or concern. During that last session we shall have a chance to talk about what it has been like to work together, what it has meant to each of us and what it might be like for us not to be seeing one another again. This session usually includes laughter and tears, kindness and gratitude on both our parts.

There are rare occasions, within a time-limited funded project for example, when the ending takes the form of a referral for ongoing or perhaps more specialized in-depth work that will need to take place. This will have to be discussed with the client and his or her consent given to identify an appropriate counsellor and to give referral information. This has happened in my practice on a couple of occasions. The person with dementia made a good adjustment to the new counsellor and productive work took place.

At other times, ending happened as a result of the person being hospitalized in an emergency. Clients sometimes change their living environment and counselling will not be pursued because of distance from the counsellor or transportation issues for the family. On occasion, clients die from accident or sudden illness and this can cause quite a sense of loss and grief for the counsellor, with the need to work through this in supervision and sometimes in his or her own therapy.

6

Who Is the Client?

In this chapter we explore several aspects of the life experiences of men and women with dementia who may become clients. Assumptions about clients may be made in line with our expectations and/or prejudices regarding the effects of dementia on the person and his or her abilities, and engagement with the counselling process and anticipated outcomes.

We do not often associate words like rehabilitation, recovery, re-enablement, reorientation, relaxation, reassessment, reappraisal, restoration, remembering, returning home with people with dementia. It seems as if the whole approach and often the expectations are those that fall into line with ageism and in what Kitwood describes as 'malignant social psychology', the way in which people with dementia are 'demeaned and disregarded'.¹ To put it in my own words, the all-pervasive attitude of negative and growing badness (malignant) with which a person's relationships, community (social), behavioural and emotional (psychology) experience are viewed.

A holistic and person-centred focus will embrace all of who the person has been, is and is becoming. The person with dementia has a past, a present and, indeed, a future. How a person experiences each aspect of Self throughout time is unique to each person and those who are in their lives. Who are we to predict what the future will be like, what it will hold? For as long as possible and even within the limitations of changed abilities, my hope is to support individuals in making sense of what they experience and to believe that they are able to continue having an impact on their experience of Self, on others and on their lives until they are no longer living. In some cases the impact of the person will continue for the family and community in sharing memories, stories, legacies of learning for others

with dementia, and through creating rituals of commemoration and celebration for many years to come. One person said, 'I know why I am going to die now, unless I get hit by a bus or something. But I'm not dead yet. I want to live my life to death.'

To see someone you love changing so dramatically right in front of your eyes is almost unimaginable. I watched my mother caring for and grieving over her husband of a few short years as vascular dementia changed him from moment to moment and the future they had planned into old age together was cut short. Loved ones and families need all of our concern, support and practical help. People with dementia require our engagement with all of who they are in the moment and not to deny them the rest of their life. I believe that as counsellor I am called to stand in the gap for them, the gap between who they were and who they are becoming; the gap between their home and the care environment; the gap between family and professionals; the gap between members of the family; the gap between life and death, joy and misery; the gap between heaven and earth. I want to continue to value and encourage that person's right to be here still, and still making an impression. The counsellor can offer this in the relationship.

Marlis Pörtner describes some of these aspects well in her person-centred approach to caring for older people. She describes seven ground rules for accompanying older people:

1. 'clarity creates security and trust'
2. 'what is decisive is not what is lacking but what is present'
3. 'the person is more than her present condition'
4. 'experience is the key to understanding'
5. 'development is a life-long process'
6. 'there is not only one reality'
7. 'self-responsibility has existential meaning'.²

I can attest to incorporating these attitudes almost without realizing it, within my working with clients with dementia, whatever their age and experience. The fact that Pörtner is describing her experiences of older Swiss men and women encourages an appreciation

of inter-connectedness across international borders, the boundaries of ageing and barriers of ageism. We can be encouraged also, that what we might strive to offer within the counselling relationship can be a testimony to precisely these fundamental and widely applicable principles.

There are, however, explosive and difficult to hear expressions of grief and loss, loneliness and anger, of being cheated out of remaining years with this person and fear of not knowing how to live on without 'the One'. 'Oh she's just not there any more', 'He's not the man I married, he's gone and left me here', 'She's just a shell of who she used to be', 'It's like a slow death, an ongoing funeral', 'It's like the lights are on, but no one's home'. We hear these and other much more difficult statements all the time in living with and sharing the journey with others.

In many respects, what has been expressed seems true to the speaker, and is often more a reflection of that person's emotions than of the actual state of the person with dementia. The person that was known and loved and shared a history, a relationship, a home, has changed. When I meet your relative, who is to become 'client', I have the considerable luxury of meeting her just as she is now and can begin my relationship with 'who is'. There may be a great sense of sadness and loss over the person as you knew her and the person you always imagined would be there for you to share your life with. With knowledge, support and sometimes counselling, partners and relatives may ultimately grow to develop some good and positive feelings about being with this new and changed person, beginning a different kind of relationship for as long as they can.

Some people feel it is all just 'too much' and in order to survive may withdraw and ignore what is happening to the person. Denial, at its most protective and adaptive, sets up home in the heart and thoughts of this person. I have encountered some for whom it is the only route they believe they can choose given their particular personality and relationship with the person with dementia. This is even more so if their shared history was difficult or abusive. It is not for me to judge, or to blame, but to attempt to experience from within their world.

What follows next are some of the assumptions I have learned to consider and be exceedingly sensitive to within the clients' experiencing of their lives. I need to be aware of the ways in which I might

be tempted to overlook a need or behaviour or way of being, thereby doing the prospective client a real injustice. These are assumptions I have most often experienced with older clients in general, and with men and women with dementia across the age spectrum.

Appearance

The first contact with the person as client may belie how the individual feels about himself or herself. It is crucial in these early moments not to jump to conclusions or make assumptions that could lead us to formulate inaccurate opinions and inappropriate views of the person. Prejudice can rear its ugly head and judgement can enter at this point. Whenever possible I prefer to meet the client without access to her GP's referring notes or previous medical history and will ask for the briefest of details from the referring person so that my introduction to the individual with dementia (who will become 'client') gives her as much control over her situation as possible. She is free to engage with me however and as much as she is able and on her terms.

Let me give an analogy of how this first meeting is usually set up: imagine arriving at a dinner party only to discover that the other guests have been given detailed information about you that begins with all of your problems, bad habits, things you cannot do for yourself, your living arrangements, bathing and toileting habits, medical and psychological problems, the kinds of medication you might be taking, financial, social, relational and sexual status. All of this before a brief and almost 'by the way' mention of what kind of person you are, and your positive attributes and qualities, likes and dislikes and strengths. It might be a challenge for those fellow diners as well as yourself to engage in a conversation that might actually include a desire on their part to get to know you. There would hardly be anything you could say or do at that moment to create a keen desire for anyone to get to know more about you. I imagine the negative impact would be hard to shift.

And yet this seems to be the way in which referral information is usually accrued and shared 'in confidence' with other professionals. Perhaps this isn't so important if you and I are able to set the record straight, and by the forceful personality and communication skills we possess, we are able to demonstrate who we really are to the coun-

sellor. Then of course, all is not lost. In the case of the person with dementia, however, it may not be quite so easy.

It may be helpful at a later date to know about a person's biography and medical history, as it might impact on our working together. But I prefer clients to let me see who they want me to see. Their perception of who they believe themselves to be is critical to the 'Self' they want me to engage with and believe to be their real Self. It often transpires that the way in which clients experience Self is quite different to their husband or partner, grown children or staff in the residential home where they now live. Their '36 hour day'³ reality of the person's abilities and difficulties cuts into all their lives, leaving jagged, raw and tender edges, gaping holes, perilous relational pitfalls, and worrying difficulties for fellow service users and staff alike. My intention within the counselling relationship is to value those narratives separately so I can get a true glimpse of what is happening for the person with dementia first, and from the inside out. Often, partners and relatives will benefit from their own support groups, Alzheimer's Society branch support workers, carers' networks, one-to-one counselling and/or services from an 'admiral nurse' (a nurse skilled in supporting carers of people with dementia) and dementia-specific training for the workplace.

People with dementia have the right to be seen and heard from their point of view. Most of us feel quite differently inside than others would imagine; including what we believe others see when they look at us and how we feel about our age, race, ethnicity, gender, size and shape and so many other issues that appearance alone belies.

People with disabilities including dementia have an added dimension to deal with. I recall running a group for residents in a residential home and the topic we were discussing was ageism in society and how it affected them as older adults. One of the questions was, 'What age do you feel on the inside?' I said that I felt like an 80-year-old woman, and what did they think that meant? Sadly, most of the connotations were negative ones apart from one person who was brave enough to say that it might mean that I felt wise and free and doing what I wanted with my life, spending time in the south of France, driving a sports car to the beach. Indeed, that was the positive image I was imagining, but one that is often missed in our own stereotypical notions of what being 80 is like within a given culture.

One white-haired lady, very thin and frail looking, sitting in a wheelchair declared, 'I feel like a 16-year-old nymphomaniac on the inside but no one will believe me.' This was followed in almost equal measure by hoots of encouragement and laughter and also loud 'tutting' and gasps of disgust from her peers.

This is the part of the client that I want to meet; not only the one her GP, psychiatrist or her daughter knows. What others have to share is valuable and important, but not as important as how the client perceives her 'Self'. Over time, in counselling, it will become more clear where those lines of Self become blurred or are testing the patience and skills of others. In some cases, the client's determination to hang onto Self (and perceived abilities) can be risky, unsafe and inappropriate to those around and indeed to the status quo. This requires sensitivity and skill in hearing an alternative view of Self the person with dementia may be unwilling or unable to accept, and to allow that part equal access to the counselling relationship.

Lifestyle

This can include, but is not limited to, biography, culture, ethnicity, relationship, sexuality, career choices, family, community, hobbies, creativity, spirituality, education. It is therefore helpful to know as much as the client is willing to share in these areas. Diminishment and depletion, or enhancement and inclusion of these areas can undermine or enhance feelings of worth and value and make the experience of dementia more or less difficult to live with for all concerned.

In some cases, men and women whose same sex partner develops dementia may find themselves on the fringes of care, concern, services and legal provisions if there is not a civil union or clear 'Advanced Directives' to indicate who can make medical and care decisions if the partner is not 'next of kin'. Gay and lesbian sons and daughters may be marginalised by parents and other family members. The partners of gay and lesbian adult children with dementia may be excluded from family discussions and decisions concerning their care.

Some health and social care staff still struggle with their own stereotypical beliefs and even strident homophobia which present barriers to communication, support and services.

Expectations and assumptions that are taken for granted by health and social care professionals and the community at large may create obstacles in communication and barriers to provision of support, funds, services and a person-centred approach to care.

Finances

There is such a diversity of experience in this area, and it is also the one in which older adults experience the most abuse.⁴ Assumptions are also made about ability to choose to pay for services privately. Where financial constraints exist, arrangements will be made so clients can pay what they are able to afford for sessions if the service is not part of a project or a trust that has been budgeted.

Counselling can be paid for by the individual, the social services department (if the social worker can make a good enough case for the need for counselling), or by the individual's family or friends. Individuals can also be referred to counselling services within some health authorities, mental health trusts, hospital and university pilot projects and voluntary sector programmes offering counselling. Direct payments for some individuals allow them to purchase care and services as they choose, and counselling could be one of those services.

Health issues

Past and present levels of wellness or mental and physical illness will have an effect on and be affected by dementia. If medications are being taken for pre-existing conditions there may be an interplay of their possible side effects and the developing dementia. It should not be assumed, however, in the case of older adults that ill health exists primarily as a corollary to age.

Medical model and 'sickness' role

The majority of older adults do not conform to the medical model where their needs are presented as illness-related in order for them to be taken seriously and given the attention they crave. However, our ageist views in western society expect that to have their emotional needs met, the person may adopt this role. They have, often without

conscious premeditation, over time become 'successful' in having their needs met while expressing physical pain or disability. In our stereotypically ageist society it has become more acceptable for older people to complain about arthritis or constipation than being able to speak about their broken heart or lost dreams.

Stigma of mental illness

In spite of some positive changes over the past 20 years, mainly through education, awareness raising, service user involvement and hard work of many charities such as Mind and Age Concern and the Alzheimer's societies and associated organizations across the globe, many older adults with dementia are dealing with a double stigma: first, that of ageism and second, that of mental illness, or beliefs and prejudices accorded to people whose behaviour belies cognitive functioning and does not 'measure up' to standards of 'appropriate adult functioning'. Interestingly, 'ageism' in dementia also applies to those under 65 where the common reaction is 'Oh, surely not! You can't be "old enough" to have Alzheimer's!' The person of 42 or 56, or even 39, with dementia experiences ageism of a particularly cruel variety. Through lack of information, awareness and our own fears, dementia is still considered part of what happens as a result of ageing.

There still exists no small amount of real fear regarding 'losing one's mind', being 'locked up in the nut house', 'sent to the loony bin' or being 'crazy'. Some clients will have had first-hand experience of appalling treatment as a result of mental illness, misdiagnosed illness or socially unacceptable behaviour (e.g. having children before marriage, homosexuality) for which the treatment of choice was hospitalization or imprisonment, often against the person's wishes, including restraint and involuntary commitment, drugs, ECT and other 'treatments' now considered barbaric, inhumane and inappropriate. These individuals were lost to their families forever, or were too institutionalized to function normally if and when they were released, and some were confined to lifelong tranquillizer dependencies and worse.

The idea of living in a residential or nursing home also invokes all kinds of fears, not least of which is the notion that it marks the 'end of the road'. With the bad press care staff and residential homes receive, it's hardly surprising. Yet, because it doesn't sell stories or papers, we

don't often hear of the excellent care that happens on a regular basis, the commitment and pride that many staff bring to their work, which may offer little in the way of advancement and not much validation. Neither do we hear of the people whose time in residential care is so restorative and positive that they are able to return home for a little longer. There are also men and women who return to a more fully functioning life within the safety and continuity of care provided in the home. These people can feel 'at home', a sense of belonging, fun and enjoyment living in community with others.

Generational context

How does the person see himself within his own generational context? Does he see himself as a product within or outside of his times? These exigencies will also affect sense of Self and wellbeing and how well adapted he feels to twenty-first-century living.

'Survivorhood'

For the two generations of older people we may work with, one of the many things they all have in common is that they have 'survived'. Many have 'thrived' well into the third age and have long and often incredible stories to share. They will have developed a repertoire of coping skills and strategies that have been more or less successful over the years. These individual strategies must be explored and validated and seen as the standard against which present strengths and needs can be measured.

During the counselling sessions it is important to find out from the client's perspective how she experiences the changes and differences that have rendered those formerly reliable strategies less than helpful at this time. For the client there has been a noticeable shift in her using a previously helpful skill or strategy. It has not worked this time, or for a while, and the accompanying stress and anxiety have created real difficulties for her. Often it is because she cannot remember what it was she was doing. Finding this out can really give insight into what the person is experiencing and how she might want to talk about it. Sometimes it is about co-creating a new strategy, and the person can often learn and retain and make use of a new strategy for a limited time.

Sometimes it makes sense to model my language according to the client's experiencing and expressing. I remember asking a survivor of lifelong domestic violence, poverty and sexual abuse what it felt like to get up every day, having been beaten and sometimes raped by her alcoholic husband of 40 years. She looked at me quizzically for a few long moments and in a voice and with an expression I shall never forget, she replied, 'What do you mean how did I feel? I didn't feel anything. I just got up and got on with it like I did every day. I don't know what it was like to "feel" anything.'

This lady had been referred for counselling for depression alongside her Alzheimer's disease. She literally spat out the word 'feel' with utter disdain or disbelief, I don't know which. All I knew was that, this word did not exist in her survivor dictionary and she would not be able to talk about feelings in ways that I had been trained to use them. We developed our own language and frames of reference that, for her, included a great many physical pain references, or 'somaticization', the physical-izing of emotional, psychic or spiritual pain. It is well known that pain is pain, irrespective of its origins or locations, and it seemed essential for this woman to be able to recognize it, express it before coming to terms with it.

Contrary to many beliefs about what counselling a person with dementia can achieve, she was able to express forgiveness of her dead husband. She was able to reach resolution of her 'view' (not her feelings) of her circumstances, and the willingness to see herself in a different light as a result was very liberating for her. Over time, her symptoms of depression decreased and she smilingly said she 'felt better' than she had in years 'in spite of my memory being like a sieve'.

Surviving a wonderful life is also replete with problems for some older adults as they reluctantly face multiple life changes and the loss of partner, adult children, friends, family and pets to illness, accident and death. Their own mortality and associated fears loom large. This emotionally hazardous cocktail of events often leaves clients staggering under the sheer weight of it all, adding to the stressful experience that dementia may often precipitate.

Psychological sophistication, commitment to therapy and motivation

This varies from person to person, but again our assumptions may be that the person with dementia may be new to the realms of counselling. Yet, in my experience, before they had dementia, clients may have had times in their life when they were involved in one-to-one or group counselling, couples work, pastoral counselling, or a lifelong commitment to analysis.

There have been, in my experience, high levels of commitment to the counselling relationship and process and equally high degrees of motivation to achieve change, adaptation or emotional relief. As one person expressed it, 'I have no time to waste', or 'time isn't on my side', 'I've got to get this sorted out before it's too late.'

Abilities and strengths

It is especially difficult for men and women with dementia to experience positive responses to obvious abilities and strengths when the message seems to be that all the damage will happen in one fell swoop, like switching off a light, and now suddenly the person and all that they have been and are and might be, no longer exists. Family and health and care staff may begin to behave 'as if' this has already happened.

In spite of alterations in cognitive abilities and resultant behaviour change, the brain is still capable of immense resilience and adaptation – as neuropsychologist Norman Geschwind named it, 'brain plasticity'⁵ – even within the limitations of dementia. As Kitwood has implored, assume that dementia is equal only to neurological impairment to our peril and the diminishment of the life of the person with dementia.

Imagine this analogy, that brain function can be likened to your driving the car along a busy main highway. There is an accident ahead, the road is blocked and so you decide to pull off and use the A roads and B roads and back roads to get to your destination. The message the brain needs to send to meet a goal has been blocked somewhere along the usual pathway. Your brain can decide which 'other routes' will get the message to where it needs to go and so it does it!

The whole brain does not shut down in one moment, but over time and with unique configurations of change for each individual.

The timing and types of abilities to be affected may also vary from person to person and within the subtleties of types of dementia.

I have observed that clients are to varying degrees able to remember, recall, process information, learn and retain new information, creatively respond and interpret long into whatever form of dementia they might have. The person's ability to 'surprise' relatives and me as counsellor is an additional means of encouragement and validation for all of us.

Even though we can identify certain types of change with particular forms of dementia, each person will experience dementia in his or her own unique way. This is the result of a combination of factors over the course of the condition. It is influenced particularly by the individual's personality, history, health and present relationships and supports.

Types of problems and issues

These are as varied as the people who bring them to counselling. They range in intensity and severity, covering the whole gamut of human experiencing, as well as the 'diagnosis' of dementia. Additionally there will be concerns and fears for their own impending disability, increased dependency, death and what the long-term effect of the condition will have on their quality of life and their relationships, and the concomitant stress for their nearest and dearest. The experiencing of fear and panic associated with the onset of loss of control, mastery and choice are often harbingers of depression, free floating anxiety and rage, to name but a few.

Spirituality

The human spirit is at the existential core of the person, whether expressed within formal religious traditions or not. Some may say this is a humanist approach, and as a fellow human I suppose that would be true inasmuch as I want to connect with the person for whom the usual mode of communicating and experiencing Self and others may be diminished at times.

There may well be other assumptions that we make unknowingly. I have included here those that I have become most aware of and have

experienced in my working with men and women with dementia, their families, friends and professionals who work with them.

Here is a potentially frightening and somewhat challenging idea. We and the persons with dementia are essentially the same. We mark different places along the birth to death continuum; we may occupy different places along the health/ill health continuum, we have had unique life histories and experiences, and in spite of our unique genetic make-up, we share more than we differ. We have a few absolutes in common. We have been born, we are alive now and someday shall die, and we pay taxes. If someone was to stick a pin in you and in me, we will have the similar flinching and the hole in our skin will react the same way regarding how it closes up, our blood will be the same colour even if we are not. We will more than likely not be very happy with the person who did it to us. We may both want to have counselling to help us sort out our feelings about this nasty person, or how it is that we have allowed ourselves to be bullied in this way. There is not a 'them and us', there is only 'us'. The heart of Tom Kitwood's person-centred approach to dementia care resonates with the work of person-centred counselling's founding father, Carl Rogers.

In identifying the psychological needs of the person with dementia, Kitwood draws a flower with the centre called LOVE and five surrounding petals called Attachment, Identity, Occupation, Comfort and Inclusion.⁶ Many would argue that these are the needs we all share, whether we have dementia or not. Interestingly, Rogers later explained that his use of the now familiar words 'unconditional positive regard' was his attempt to make the notion of love more scientific and therefore more acceptable to the scientific community at large at the time. Now we find we are seeking to give and receive love and forgiveness as reference points more and more in our lives and in our professional encounters. It is very apparent in my relationships with clients and their families, that love, as it exudes empathy and acceptance, attachment, comfort, inclusion, is no less than what we would also wish for ourselves in the absence of changing cognition.

In 1988 I wrote this in my Master's Thesis which for me still summarizes how we work together within the therapeutic alliance:

From this bag of assorted bits and pieces (memory) we pull together the pieces of the puzzle that have become uniquely your puzzle. When we have lost the pieces it is almost impossible to fill the gaps

that remain. But from the general outline and form of the puzzle that remains intact and from the shapes of the pieces that remain in the box, we try to complete the puzzle. Collaborators. We gather round as we would around the table on a rainy afternoon irresistibly drawn by the desire to find just the right pieces. We sometimes even cheat a little and squash the wrong piece into the empty hole. Sometimes it works for a little while and no one really minds. After all the delight and triumph of the shared moment is in almost getting it right.⁷

7

Communicating with One Another

Many volumes now line the shelves of countless libraries, public and private, resounding with the complexities of communicating with people with dementia and extolling one method or another. Most have inestimable worth and value and several have enthralled and encouraged me and shown me skills and filled me with gratitude for the patience and tenacity of the writers.

Chapter 7 provides a brief encounter with communication, particularly from the perspective of counselling and the person with dementia rather than just communication in the everyday sense. Of course, many of the principles underlying everyday discourse are the foundation on which communication in the counselling session relies. Some of those will be enlarged on. There are examples of ways in which our communication demonstrates the intent and feelings of the client and emphasizes how knowledge about the process can steer the interaction away from feelings of ineptitude and stagnation towards a place of validation and movement within the session.

People often ask me how to talk to a person with dementia, and wonder how counselling can actually take place. Interestingly it is in much the same way as I counsel anyone, but with a few exceptions and additions.

Each individual will have his or her own particular way of communicating, even within the limitations of the spoken word. I have to discover this with the person and together we co-create a way in which communication can happen. I cannot profess to know all the answers, and create a checklist or matrix of how to communicate,

because I must take my lead from each client. As I listen to clients I am profoundly aware of the subtlety of symbolic meaning and metaphor as a means of supporting and enhancing their communication. People often use extremely creative and imaginative ways to share their feelings and thoughts. There may be a quality of free-style or free flow, words that tumble out and over themselves no longer reined in by the refinements of conventional speech. In their book *Communication and the Care of People With Dementia*,¹ Killick and Allan have expanded our understanding of the subtleties and nuances of communication and persons with dementia. It is fascinating to read segments of conversations and to see the way in which fairly sophisticated and highly symbolic yet wildly free and imaginative language is used to describe the observations and inner processes of men and women trying to make sense of Self and their surroundings. Cheston and Bender's thorough and sensitive approach to understanding people with dementia is replete with references to this way of communicating.² Cheston highlights the use of metaphor specifically in his 1996 paper 'Stories and metaphors: Talking about the past in a psychotherapy group for people with dementia'.³

This seemingly sophisticated use of language is often not a conscious choice on the part of the client, but when I can truly focus in on meaning and tone of voice and non-verbal behaviour expressed through the face and body, I may have more success in understanding the whole of the person. This may seem like a given, but there is a heightened sensitivity towards this process when the spoken word may be inconsistent with what is trying to be communicated. It may have a different meaning for the client, and the very process of articulation may be lost so that only a sound or a series of sounds comes out.

In 1983 I heard Naomi Feil lecture on what she believed to be the precepts for communication through the use of validation therapy,⁴ an approach she developed to correspond to stages through which a person with dementia may progress as his or her abilities and also communication skills change over time. It is essentially person centred in its attempts to focus in on the emotional tone of what the person with dementia is trying to communicate rather than on the words alone. My process explores beneath the words or the behaviour to experience the feeling tone of the person, by reflecting back to the person statements, words, sounds and feelings that I can hear and

see. In the immediacy of our contact I initially seek to acknowledge, affirm and accept the person as well as, or in spite of, what he or she may be saying or how he or she may be behaving.

Garry Prouty highlights the importance of using validation and contact work techniques in communication as pre-therapy.⁵ This is a careful, sensitive and practical approach to acknowledging, affirming and accepting the means through which the person with impaired cognition is communicating. It offers communication methods that encourage the positive role all of us who have contact with the person can play. In transcripts at times poignant and full of meaning, Prouty shares his experiences of communicating with patients with significant cognitive impairment.

Penny Dodds, in the *Contact Work Primer*, an introduction to pre-therapy, does not seem to envision a place for therapy as described here, because the 'progressive neurological and cognitive changes mean that a person with dementia is not going to recover and progress to traditional psychotherapy'.⁶ Although this is in fact true regarding the progressive and irreversible nature of most types of dementia, the abilities of men and women with dementia in general are sustained for many months and years, with only subtle cognitive and therefore communication differences attributed to a particular dementia type.

It has also been observed that reduction in the symptoms of depression and anxiety can seemingly also reduce, for a period of time, what appeared to be dementia-focused disability in communication and function. Dodds presupposes that for prospective clients, 'conversations with people with dementia which, due to the nature of the illness, are unlikely to be presented in coherent, logical patterns of speech' and that 'knowledge and skills in validation therapy or the ability to piece together disjointed narratives'⁷ will be prerequisites for counsellors and therapists. This is true in part, but I wish to encourage the view that this is not the entire picture, and that trained counsellors and therapists can indeed work successfully with men and women in various stages and with varying degrees of dementia.

One need only listen to the eloquent and impassioned presentations by people with dementia at international conferences and congresses and read their published books and articles to know that here are people for whom the opportunity to engage in psychotherapy and counselling could indeed be fruitful.

We must move carefully and courageously into this newly emerging territory by expanding the parameters of our expectations. We can include the validation therapy techniques of Naomi Feil, including reflection, advanced listening, immediacy, mirroring and empathy, to lead us forward as ways in which counsellors and therapists communicate and develop our therapeutic relationships. Working at relational depth, with configurations of Self and in 'not-for-growth' areas, are precisely the uncharted waters I navigate with clients, a place that is unprotected and opens us to our own shared vulnerability.

Dementia can be described as an eyeball to eyeball, heart to heart, spirit to spirit and often mind to mind experience. Business and marketing studies tell us that if a pie graph represents 100 per cent successful communication regardless of age or gender, then we can slice the pie up into pieces representing aspects of how we communicate. Rounding up the percentages, they rate the spoken word as worth roughly 10 per cent of the total value of the effective communication, with the tone of voice at 40 per cent and non-verbal behaviour as a big 50 per cent. People with dementia who may have difficulty with the verbal components of communication either because of disease process or because I don't speak their native language become very attuned to the other 90 per cent available to them. The good news about this representation of communication is that there is still 90 per cent possibility remaining that I may be able to communicate successfully with a client in the absence of words. I will be able to reflect and affirm, validate and respond to the person's non-verbal behaviour, his or her body language and facial expressions, when speech is limited because of either cognitive impairment or a different spoken language.

Given sufficient time and patience, clients can express themselves and make themselves understood even when others may have thought they were 'non-verbal', 'mute' or unable to communicate. Deep-seated concerns and fears can emerge in short but compelling, understandable statements when we listen with our 'third ear' and observe with our 'third eye' and engage our spirit with the spirit of the person as 'client'.

When speaking with a client I may speak more slowly and be more deliberate in what I say, using more concrete words, less nuance and euphemism and fewer embedded sentences. It is more expedient and more appropriate to the situation to use one sentence instead of

five to make the same point. Once I have had an opportunity to talk with the client I will ask about my pace, am I being clear enough, rather than putting the onus on the client to understand me. I will ask if my language is too complicated or overly simplistic. I always take the lead from the client. Many clients are well able to continue using complex language skills and may also be bilingual or trilingual for a long time to come. I will always assure clients that I really do want to know what they are experiencing and ascertain if they would be willing for us to work together on how we develop our unique way of communicating.

Clients may lose their memory differently and not all at once so there are parts that are still working well and types of memory that last longer than others. For example, short-term memory loss seems to be commonly experienced in the beginnings of Alzheimer type and other forms of dementia. Although short-term memory is initially affected, ultimately long-term memory will be as well. A person living with Pick's or fronto-temporal types of dementia, however, may retain good memory and verbal function but demonstrate disinhibited behaviour and extreme personality change that is little noticed by them, but shocking, upsetting and difficult to cope with for family and friends.

Memories for pictures, shapes or colours can last longer than memories for words alone. Memories that are particularly emotionally charged will last longer than simple factual information. Memories of sound, taste, smell, touch, feelings and body experiencing are less often included and explored as robust indicators of intact memory in the presence of such apparent decline in more cognitive (and therefore more valuable?) aspects like recognition of names and faces, use of language and so forth.

Killick and Allan refer to this overemphasis on a particular type of memory as a tendency to lean towards 'hypercognitive values'. In so doing, we may miss the holistic function of memory that, in its most expansive form, helps to hold our fragile Self and our world together:

The whole concept [of hypercognitive values] is orientated towards seeing memory for information, which can be consciously recalled, verbalized and integrated with other knowledge, as being of primary

status. We have a long way to go in fully exploring the value of other sorts of memory.⁸

Yet, within this relationship the counsellor has the special opportunity afforded by uninterrupted time to share with the client, and the identified role prescribed by this joint activity to become aware of and inclusive of the many ways in which memory is sustained.

It has surprised me on numerous occasions how much a client has remembered from our sessions. There is also something about the quality of the relating that remains and allows us to build on the last time we were together.

Here is an example of communicating with a client who was accustomed to being dismissed on the basis of apparent communication deficits.

Let us imagine Professor Janet Green, an accomplished academic and lawyer, with journal articles and books to her name as well as a string of letters behind it. She was still teaching until Parkinson's disease was diagnosed and some time later the onset of dementia with Lewy bodies. Her life changed gradually but dramatically and her silent rage became her tower of imprisonment. She was 64 years of age. Speaking was laborious and often hard for others to understand because of changes in the muscle control of her mouth and almost constant drooling from the effort to make words and the side effects of anti-Parkinson's medication. Janet was continuously and laboriously wiping her mouth with her handkerchief in between trying to form words. She was particularly aware of everyone's verbal and non-verbal behaviour around and towards her and understood most of what was being said at any given time. The gap between what was said and her response or feedback was misinterpreted as a sign that she did not understand. People had a tendency then to shut her out and carry on talking without checking with her if she was understanding them.

She was becoming less steady on her feet and had a tendency to stagger or fall, even when using a stick. She needed help with personal care, dressing and meal preparation. There were friends who came to check on her and some who still invited her out for a meal or a trip to a concert or for coffee on occasion. She was determined to stay in her own home as long as possible. She had been referred by her GP for counselling as she was depressed and anxious. Her

daughter (Janet was divorced many years previously and had no contact with her ex-husband) had come from Chicago to take care of her.

After the preliminary introductions of myself and the way of counselling, confidentiality and all the usual elements of a first session, I gained her voluntary and verbal agreement to work with me. All this was done with slow precision and a great deal of effort on Janet's part and on mine as I had to focus very hard on what she was trying to say.

D: I can see how much effort this is for you, Janet. I really want to be able to hear your concerns and to support you the best way I can. Would it be OK if we talk a bit about how we can communicate the best way for you and for us both?

J: It takes too long. [These few words took several seconds accompanied by much contortion of facial muscles and drooling and her wiping her mouth in between]

D: [Nods] For you or for others?

J: Mainly me. No one waits long enough to hear.

D: No one waits long enough to hear you?

J: [Nods, looking sad]

D: It seems to make you sad, not being heard, not being given time.

J: [Nods, still looking sad]

D: I would really like to hear you. [Pause] I have time to hear you now. [Pause] We can meet for an hour every week if you would like and we can take our time.

J: [Nodding and smiling slightly] I'd really like that. [Again this took several seconds with much the same process as before, with great effort and wiping her mouth]

D: You'd like that? And I would too. [Pause] How would it be if I help you with a word if you seem stuck, or if I go over something

to make sure I understand you? You can tell me to stop or to 'shut up' any time if you find it annoying. How does that sound to you?

J: [Smiling, head tilted to one side, eyebrows raised] We could try it.

D: OK, we'll try it. What would you like to talk about today Janet?

J: My daughter. I'm so angry at her. She thinks I'm HER daughter! [Voice is raised and she looks angry too, this has taken her about 30 seconds as she also dropped her hankie down the side of the chair and had to get it back out again] Tell her to go back to Chicago. She's driving me CRAZY!

D: You're angry with your daughter? [Pause] She's driving you crazy? [Pause] How is that?

J: [Nods] She tells me what to do all the time. Treats me like an idiot.

D: It sounds as if she's being the one in charge and treats you like you don't know anything?

J: That's right. [Nodding slowly]

In this example Janet had the opportunity to express her feelings and experience a sense of worth and value in her experiencing. She had been heard and acknowledged without being judged. More importantly, the client was given the time she needed to gather her thoughts and work at the physical demands needed to sit relatively still and form the words and movements required to get her tongue and mouth to cooperate.

Here is a further example from a man named 'Bob'. He said to me, with genuine warmth and apparent 'appreciation', 'You have beautiful breasts.' My immediate response was simply 'thank you'. There was nothing lewd or suggestive about Bob as he stated his 'fact' and observation; a private thought he was having to himself. Perhaps his brain's ability to engage the 'inhibiting mechanism' that keeps us socially and culturally appropriate was not firing on all cylinders

(neurons) today. It would be fair to hazard a guess that in normal circumstances this is not the kind of comment Bob would have allowed himself to make, except perhaps having had too much to drink at the Christmas party when he was 30 years younger. In the present circumstances he might have been very uncomfortable and embarrassed if he had been aware that what had crossed his mind had now also crossed his lips.

To have focused on how what he said might have affected me, or the possible inappropriateness of the remark would be moving in a less than helpful direction. It is of course important in other circumstances to acknowledge and validate the individual's ongoing sexuality and need for appropriate sexual expression even within the experience of dementia.

The core of his feelings at this point was about loss of control and being shamed by his wife and feeling ashamed and embarrassed and not really knowing why, when he believed he was being 'truthful'. It was almost like a betrayal of Self, being out of control of Self and then having to deal with the consequences, which made things feel even more confusing to him. You can no doubt imagine that this conversation could go a number of ways. Here's what happened:

D: I imagine that's not what you would usually say out loud Bob.

B: No. Not really.

D: I wonder what it's like for you, saying things out loud that you wouldn't want a person to know.

B: I don't know it till it's out and then it's really embarrassing. She yells at me or when I see how the other person looks when I say it. I think I do it all the time. But it's the truth. My wife tells me not to say those things to people. [Pause] [Looks up and smiles impishly] Well, she did have an ugly hairdo. My wife agreed with me. She said I'm not supposed to say it out loud.

This behaviour is reminiscent of a child learning how to be appropriate; appropriate social interaction becomes part of what is 'inhibited' in our culture and society. Children whose skill is developing may anger and embarrass their parents when they repeat what they heard over the dinner table to unassuming friends or relatives, and

when met with vehement denial or anger then insist they are only saying what mum or dad had declared earlier. Memory for this kind of learned subtlety can disappear fairly early on and in inconsistent patches for some. Knowing that it is not deliberate can help family and friends cope with the sudden exclamations.

D: So it can be a bit embarrassing for you and your wife too? [Pause]
Even if it's the truth. That could be a bit confusing?

B: Yeah. [Looking down at hands, slightly flushed and seeming embarrassed]

D: Is that how it feels right now Bob?

B: Yeah.

D: [Nods slowly] Yeah. Embarrassing, confusing. [Pause] And I might yell at you?

B: Will you?

D: No, Bob. I think I sense where you're coming from on this one.

B: [Looks up, makes eye contact] Not everybody does.

D: Not everybody does. [Pause] Am I on the right track Bob?

B: [Smiling] Yup.

Perhaps inconsistent with some of the ways we learn to use questions, clarification, giving choices, not limiting the client's responses by framing them within our own expectations, you can see here that I intentionally do the opposite. I may limit the choices for responding to one-word or few-word answers so as not to inhibit responding through confusion or over-stimulation, or because sentences are too long, too involved or contain too much nuance or too many ideas.

Questions with more yes and no responses or statements with only two choices can be used helpfully to encourage responding and staying in communication rather than outside of it. Inclusion and comprehension are the goals.

I could have added to Bob's embarrassment and confusion by diminishing and over-sexualizing his intention, which was in fact a compliment to me, based on his observation and perception.

When I venture into the deep place of relating, beneath the words and sometimes even the behaviour, we can venture forth together into the place of our authentic selves and experiencing.

It seemed important to Bob to be able to make sense of what he was experiencing as 'disinhibition' although he may never call it that. He decided he was going to give himself a way out of the consequences of his straight talking by saying before the conversation began, 'I'm sorry if I say things that might be upsetting, I really don't know that I'm doing it and don't seem able to control it.'

Communicating the way we had gave Bob a sense of understanding that what happened was something beyond his control and that couldn't be helped. Overall, his sense of worth and wellbeing was affirmed in spite of the words that had run away with themselves. You can see from this short interaction how this communication works in the face of a moment of disinhibition.

Sometimes the inhibiting mechanism in the brain is affected, while under normal conditions it keeps us socially and culturally appropriate and safe. (It keeps me from pinching the waiter's bottom, even though I may really want to.) People may have only fleeting and random control over what he or she say or do. Formerly private thoughts, feelings, behaviours, including deepest prejudices and darkest secrets, unmediated by this mechanism are set free to wreak havoc in the family and the world at large like the proverbial cat among the pigeons: 'Oh, I don't like that jacket dear, much too drab!', 'You're not my only child you know', 'Go back to where you came from. I don't want the likes of you anywhere near me!', 'You have beautiful breasts'. These and other comments can seem hurtful, scandalous, obscene or simply rude or upsetting, the list of potential hazards could be alarming. Moreover, if the person saying them was aware of what he or she were saying in terms of consequences of behaviour, they might be highly embarrassed or upset or humiliated. Our response needs to bear in mind the need to protect the person's dignity rather than convey our shock or disgust. Responding this way is far from easy within relationships and the family setting. This can be rather disarming for the counsellor too as it was for me in the beginning, yet awareness of how this can happen and a desire to focus on the client's need for expression and being understood, can fit appropriately into the space the client has invited you to share.

The next dialogue depicts the sometimes repetitive nature of speech and communication. Often part of a theme or a whole piece of narrative comes round again. Sometimes a client will say, 'I've told you all this before, haven't I?' Sometimes he hasn't, but he has learned to hedge his bets. He is often quite relieved to have a first-time audience for one of his stories. If the same content keeps coming round, it may be because there is some intrinsic worth in it for the client. Something needs to be communicated that I have been missing, perhaps, or because he can tell this particular story and does it successfully, it will become part of the repertoire of social engagement.

Perhaps the client is seeking a particular response or affirmation and will keep going until it presents itself. My instinct might be to minimize any possible embarrassment or shame by pretending I haven't heard it all six times already and run the risk of falling off my seat with boredom, feeling frustrated and resentful, and lose our connection, my empathy, and congruence. My feelings of unconditional positive regard will certainly be tested. The client relies on my ability to stay genuine, honest and congruent, to be able to move forward.

Bill and I had been working together for some time when this emerged:

D: You're wondering if we have been down this road before, aren't you Bill?

B: Yeah.

D: Yes Bill, you have told me about your boss before, but if you feel you'd like to tell me again that's OK. [Pause. Bill looking anxiously around and fidgeting with his fingers] You seem a bit worried?

B: Just seems important to tell you.

D: I'm wondering if there's something you are trying to get at, and I'm missing it?

B: Yeah.

D: Shall we see where we go with it Bill?

Note that each time the theme is the same, the hypercritical, 'bullying' style of the boss, but the action is different. What emerges with

each re-telling of the narrative are the underlying feelings of being devalued, judged, dismissed, made to look foolish in front of work-mates, feeling he was letting his boss and himself down. One day, the particular tone of his voice, his demeanour, got us into the heart and soul of his need to keep telling the story.

D: I'm looking at your face and at your eyes. You seem so sad.

B: [Nods]

D: Your body is kind of slumped, like this [mirroring his position and facial expression]. It looks like a heavy burden and feels like one to me too. [Silence as we sit, mirror images of one another]

B: Stupid, feels stupid. I'm stupid.

D: You're feeling stupid and that's kind of embarrassing? When your boss would get mad at you in front of your friends? [He's nodding, but not moving] Like maybe how it is when your memory doesn't work like you want it to?

B: Yeah. [BIG sigh]

D: That's a big sigh Bill, from way down deep. [I sigh like he did] It feels like here... [I put my fist in my gut]

B: [Looks right at me and straightens a little] That's right.

D: [Nodding slowly] Right. [Silence] I think I get what you want to say Bill. Can I try and say it back to you?

B: Yeah, OK.

D: OK. Stop me if I get it wrong or go too fast. The feeling you get when your memory doesn't work is like how you felt around your boss when he was mad at you?

B: [Nodding]

D: You feel stupid, embarrassed?

B: Yep. [Moving now, changing position but still making himself small in the chair]

D: Is it like shame?

B: [Looking down and away] Yes, that's it. Shame. I feel ashamed.

D: [Nodding] Mmmm.

B: Stupid and ashamed. I can't do anything about it.

We were able to go on to talk about having memory problems and feeling so helpless and unable to effect any change over the situation, feeling stupid and anxious. He wanted to let people know he couldn't help it, but was overwhelmed by the former fears of standing up for himself to his boss, when he always backed down and the boss always came out on top.

O'Leary and Barry⁹ also support this notion and this client's experience well:

Repetitive story-telling may be either an indication that the hoped-for response has not been obtained from the listener or a sign of unfinished business. Some emotion experienced at the time of a significant event was not dealt with and remains with the individual many years later. These emotions can be either toxic or healthy. The recounting of stories holding positive affect can be a source of satisfaction and self-esteem. However, negative affect resulting from unfinished stories can sap energy. These stories can be distinguished from healthy recollections in that the latter are devoid of resentment, anger and guilt.

When I asked what he would like to say to his boss, or to other people, Bill was able to say that he would tell people 'up front', 'Hey, my memory doesn't work the way it used to' and then chuckling, with a boyish grin on his face, added, 'so take it easy on me, OK?'

Occasionally, and more often than I would have at first thought possible, our communication takes place within the myriad realms of silence. In those positive encounters I imagine it akin to a beautiful prism being held aloft between us; tantalizing in its elusive beauty, inviting wonder and interest. As a prism reflects multiple facets of light and colour, alighting here and there, so too silence can reflect multiple facets of personality, meaning and spirit, separateness and communion. In sharp contrast and often in conflict with the potential for beauty and benevolence, silence can be hard, mean, painful,

hurtful and punishing, rejecting or simply thoughtful. Is it merely coincidental that in the English language, the word 'LISTEN' is made up of the same letters as 'SILENT'?

As Killick and Allan encourage, we must first stop talking in order to listen.¹⁰ We listen to the unspoken words between the lines of the narrative instead.

The following quote from the Taoist philosopher Chuang Tzu elucidates this idea in a much more eloquent fashion and encourages us to see beyond and beneath the words to the richness and depth, the light and the colour, the reflected spirit and substance of silent communication. Relationship and understanding, communication and validation can take place at this essential and fundamental core, even in the absence of the words whose loss we so often grieve:

The purpose of a fish trap is to catch a fish and when the fish are caught the trap is forgotten. The purpose of a rabbit snare is to catch rabbits. When the rabbits are caught, the snare is forgotten. The purpose of the word is to convey ideas. When the ideas are grasped, the words are forgotten. Where can I find a man who has forgotten the words? He is the one I would like to talk to.¹¹

Perhaps it is possible, then, to embrace the words and the silence and the wordlessness equally, as part of the newly emerging configurations of Self. Rather than mourning speech's absence, there may be a sense of awe and privilege, discovery and meaning that has heretofore eluded us. Perhaps it has been lost in life's clamour and is inviting us to explore it, just beyond the shadow of the last word.

8

Essential Spirit- Core Relating

This chapter explores the essential spirit-core relating that exists within the realm of psychotherapy and the world of living with dementia. By this I mean the central force or core of 'being' or being human that we share. From Buber's 'I-Thou' relating and the transcendence Rogers speaks of, to the writings of Brian Thorne and others, there is a spiritual aspect to the experience of counselling as there is to the experience of living and dying. It is the manner in which we do it that engages the spirit or the soul of who we are.

My experience of working with all clients affirms that there is another force at work. My experience of counselling men and women with dementia expands to another dimension where growth and change can take place that is somehow pre-verbal, pre-symbolic, non-intellectual, essentially spiritual. Whatever it is, it seems to exist in the absence of memory, history, role or functionality. It exists even in the absence of adherence to a particular religious denomination.

I come face to face with my own stark reality, my own frightening vulnerability and choose to stay in the room and 'enter into solidarity' as Nouwen suggests,¹ with the client's and my own potential unravelling. I will not flinch or flee as others might, and as he fears that I will. I will stay and face our moment together. If I were to develop dementia I would wish that someone would be fully present to me as I am to him now. This will require commitment and it will require risk. It will also require an attitude of acceptance and generosity of spirit that expands the realms of the possible and reaches beyond the boundaries of diminishment and present expectation.

In his later writings Rogers stated:

A vast and mysterious universe – perhaps an inner reality, or perhaps a spirit world of which we are all unknowingly a part – seems to exist. Such a universe delivers a final crushing blow to our comfortable belief that we all know what the real world is.²

This notion is crucial to my working with the clients' 'perception' of Self, their reality, their truth and the real world as they actually find it. This is not the same as colluding with a delusional or hallucinatory experience. It is affirming reality as the client perceives it. I must admit that this interpretation of events does seemingly little to support the family carer who is with her relative through thick and thin, all hours of the day or night, endless week on endless month. Often the relative is longing for her brand of reality to be the same as the individual with dementia – but usually preferring the value and safety of her own. Understandably, she grasps tightly to what was and what might be, in an effort to block out the ensuing panic that accompanies the often inconsistent and unpredictable confusion that 'is'.

Reality does, however, matter very much to the son whose father believes himself to be still in primary school and that his mother is shortly coming to get him. The son may think:

This is my father, for goodness sake, he drove a Porsche and was executive of a huge company, a multilingual jet-setter. He could strip car engines down to nothing and make them back up again. He made kites on the beach, taught us to drive and played football with us. He loved us passionately and unreservedly. How can we allow this imposter be in this place?

I have heard and have seen and known the implications this has. But for this dad, it is important to know that what he feels and imagines and 'perceives' as real for himself in this moment in time is part of the 'now here' rather than the 'nowhere' his children think he is. In validating what he is experiencing I can use his narrative or his silence as a bridge to communicating with the feelings and with the spiritual elements at the core of his being.

Clients with dementia are generally more readily available for intense and immediate work because of the lowered psychological defences and disinhibition that often accompany damage to the brain.

There is vast and sometimes stark openness and sincerity of purpose, with few or no masks or pretences to social status or meaning that is not readily available to most of us. We usually have to work at removing those masks or layers, one by one and over prolonged periods of time.

I have always believed that the counselling relationship was one of sacred privilege and responsibility. This has not held me in a paralysed grip of awe, but rather is an energizing and active engagement of all of me (mind, body, spirit) with all of the client, in a truly holistic context with whichever parts he or she allows. In the face of changed cognition, altered perceptions, accompanying physical challenges, the one constant is the indomitable human spirit. Because I choose to believe in God, I also choose to believe that the humanity we share is God-breathed, God given, that the spirit of creation lives in both of us, client and counsellor, and lives on in eternity after our physical bodies have died.

Mearns and Thorne, instrumental to the ongoing practical and theoretical development of my work, share differing views of what 'spirituality' means to them. Brian Thorne is a committed Christian within the Anglo-Catholic community and Dave Mearns is a self-professed atheist/agnostic. Yet both use spiritual or existential language to recognize and describe this experience and quality of Self that takes client and counsellor to a unique and in-depth place of relating.

Vast and wonderful volumes have been written about the nature and experience of spirituality. I cannot do them justice here. What I want to emphasize, however, is that in the face of apparent diminished functioning, disordered thought and disappearing language, there is left a real and wonder-ful 'spirit being' that is, indeed, 'larger than life' and holding onto that life with tenacity. Rogers has described the place of transcendent experiencing where the counselling relationship takes place, and his unconditional positive regard is clearly another way of describing Love. Indeed, his last writings speak of Love as the catalyst of his unconditional positive regard, in the refined and more mainstream language of the community of psychologists and therapists at the time.

Tom Kitwood also speaks of the Love that is the keystone to the psychological needs of the person with dementia. Indeed, we are all in great need of it. Perhaps it is this spirit of life and humanity that

propels the individual forward into tomorrow when neurology might dictate otherwise. The spiritual lover, spiritual survivor or indeed spiritual warrior can be seen every day in the halls of residential and nursing homes, the apartment down the street, the café on the corner. Often these spiritual configurations are embodied in one very present individual.

When all else seems a shadow of what it was, who is the person who remains? I can choose to engage with the spirit of the person with my spirit. Words can and often do fail both of us, but our feelings or emotions, as mediated by our spiritual selves, are there for us to share. The connection between spirituality and emotion is not lost on people with dementia. To deny its presence and refuse its participation would be a grave injustice and a waste of an opportunity for mutual experiencing, expressing and enrichment. The propensity for joy, delight, affection, fear, anger and lonely desperation touch our hearts and spirits in places the mind only imagined.

I desire that our human spirits, face to face, should count for something other than what is reduced by language alone to mere words and syllables of sound. My hope is to co-create an encounter, a relationship where, even in the absence of speech, our spiritual, soulful selves that are uniquely yours and mine, may meet in a sacred moment that is uniquely ours. Experience, observation and reflection show me that there is another force at work. Something is taking place within the relationship that is somehow pre-verbal, pre-symbolic, essentially spiritual and according to Rogers, 'transcendental'.

You and I may differ on what we call spirituality, but many believe it is fully present in the person with dementia and is calling for our attention. In his essay 'Helping the flame to stay bright: Celebrating the spiritual in dementia', John Killick, writer, poet and creative communication force in dementia care, says:

memory loss may have the effect of confining the person to present experience, but it may also give those without the condition the opportunity to appreciate qualities associated with being rather than doing. It opens up a positive approach to dementia, including the possible enhancement of creativity and spirituality.³

This tangible vulnerability, this disarming openness and honesty, are also home to the sacred and the spiritual. I see, reflected in the searching, worried or sometimes wise and peaceful eyes, my own

vulnerability, the pain of exposure to ridicule or exploitation, the desire to be thought well of and be accepted, prized and loved. Perhaps the quality of presence that I bring to the relationship is essentially spiritual and by its nature therapeutic, healing, helpful and loving. These conditions can move us into relational depth not because I am a perfect person, extraordinary counsellor or a super-soul. Perhaps it is because I am recognizing, prizing and learning to accept and love my spiritual God-given Self and to love my neighbour (client) as myself.

To engage in this way with the client I must, as Henri Nouwen says, 'enter into solidarity' with the client. I believe this solidarity goes even beyond empathy in that the person with dementia is in many respects holding up a mirror for me to see myself reflected in the most vulnerable aspects of my humanity. If this is an older person, I know that I too am ageing and that with ageing comes an increasing vulnerability to dementia. Sometimes the client with dementia is my age or younger than I am. These are times when the mirror has been polished to a sheen and I see myself even more clearly and shockingly reflected. To be fully present I have to engage with this aspect of client and Self in a place of solidarity. My body can't stay present as my spirit runs from the room. I need to move actively beyond the fear of that moment so that the empathy, unconditional positive regard and congruence can flow and I might risk taking a step across the I–Thou divide into the realm of 'we', at once frightening and enthralling.

Debbie Everett, a Canadian hospital chaplain, says: 'We must not fear the unknown, or the insufficiency or powerlessness we feel when we are with someone with dementia. Yes, we can experience, but we must not allow the fear to keep us away'.⁴ Kitwood reflects that where dementia creates an emotional intensity for some, the person can become less bounded by the inhibitions of the status quo. Here, he encourages, there are essential lessons of the soul to be shared with humankind. When the client gives me the gift of him or herself, without reservation or compromise, I have indeed been prized and taught by the client in extraordinary ways; ways that are too precious to be held tightly, but need to be shared to give life to others.

Another essential discovery for me as I contemplated the spiritual in counselling was meeting (people always talk about 'meeting' her), or being introduced to the 14th Century mystic and counsellor,

Mother Julian of Norwich, while circle dancing with the Sisters at my spiritual home in Wales. The first woman to be published in the English language, Julian was no stranger to the notion of the spiritual in counselling relationships. For her, its embodiment was Love; and Love was not only transcendent of human misery and distress but its all-pervasiveness would in the end make everything well.

She was no Pollyanna to the horrors of her day, she was a woman of her time, but also outside of time as she ministered to the troubled who came to her cell 'anchored' or built onto the church of St Julian in Norwich in fourteenth-century Norfolk. Her counsel was no mere pat on the head and desire to pacify or patronize her client. It was transcendental experience as she had lived it, in the spiritual realm of God's gracious, unconditional goodness and Love that she desired to pass on to her 'client' at the wall.

Possibly her most famous statement, 'All shall be well and all shall be well and all manner of thing shall be well'⁵ brings hope and peace and a sense of the possibility of wellbeing. I think this notion pre-dates our current models of best practice in dementia care by about six hundred years. It also includes the images of 'wellness and wellbeing' as the touchstones of desired outcomes.

When I began to contemplate what it is I most desire for clients to experience as a result of their counselling, I first of all thought it was Hope. We often hear that as long as there is Hope, there is Life. Yet I have witnessed Life in the perceived absence of Hope and in spite of an apparent abyss of Hopelessness. I have come to believe that although Hope is good, Peace and the sense of Wellbeing are even better. If one cannot escape the storms of life, what better than to experience Peace within the storm. To feel peaceful in the midst of mind-numbing chaos, feeling that wellbeing in the moment and perhaps in the future is possible and attainable if we focus on the here and now, the 'now here', are elements of these particular counselling relationships that have guided me and encouraged me more times than I can say.

Together in the counselling relationship perhaps we can explore what it means for the client to experience peace and wellbeing. What are these elements of being, if not music of the heart written on the wings of the spirit? Carl Rogers, late in his writings, and then Tom Kitwood have unashamedly identified love as one of the feelings generated between counsellors and clients and the lynchpin that holds

Kitwood's psychological needs of people with dementia together. Person-centred therapist, writer and inspirational presenter Suzanne Keys, speaking about the politics of counselling, states that in spite of who the client seems to be at the beginning of the counselling relationship, the growing intimacy we experience with clients will generate feelings of warmth and caring. My own experience with clients would support this observation. And to echo Ms Keys, almost in spite of ourselves, 'love occurs'.⁶

Epilogue

My experiences as a counsellor have been many and varied over a period of more than 20 years. The years I have spent listening to and sharing with men and women with dementia have presented me with a particular kind of experience, requiring more patience and commitment to listening and learning than I had imagined.

The rewards have been great, the encounters truly humbling and often joyful. It has been essential throughout to seek regular and skilled supervision, to give a voice and sometimes tears to the changes, loss and grief I was carrying alongside the client.

As the counsellor, I have had to be flexible, reliable, congruent, humble, able to tolerate incompleteness, and 'one session only' clients. I have learned to negotiate attachment, detachment, being seen as the good parent, bad parent, good daughter, peer, bad son or husband; the hairdresser.

Clients and their caregivers have become ill and died during our counselling relationship and I have had to grieve them and move on, committed to blending their narratives into the writing and giving them the final word. This kind of relationship is not for the fainthearted or the ingenue, or the person who needs to see quick and definitive results. It requires holding lightly the moment and the future. A sense of humour and the willingness to be surprised or put in your place are essential.

I have had to return to the seat of learning time and again in my own reading, journal writing, studying conversations with colleagues and training, to stay current with the ever-evolving world of dementia. I need to continually nourish, replenish and enrich my heart, mind, body and spirit. For me this often occurs during times of solitude at a retreat house in Wales, walking on the beach of my spiritual

home where many pages of the book were conceived, birthed and celebrated.

My husband and sons, my family and friends, on both sides of the Atlantic, have encouraged me to rest, relax and to engage in play and laughter. My cat Sheba has watched over me, enticed me to take a break by bringing her toys and encouraged re-writing, having stood on the keyboard erasing the text as she purred.

Above all, I try to stay open to God as the provider of my strength and the grace and courage it sometimes takes to share this burden of dementia. I take these words of the New Testament of the Bible seriously. Jesus says:

Come to me all you who are weary and burdened and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart and you will find rest for your souls. For my yoke is easy and my burden is light. (Matthew 11:28)

The Message, an updated version by Eugene H. Peterson,¹ translates the end of this passage as 'learn the unforced rhythms of grace'. I feel most truly that I am still learning these unforced rhythms of grace and that it is grace abundant that often leads me into the posture and attitude of peaceful attending, where the client feels safe to take the risk of unburdening him- or herself. It is also a perspective that allows me to hand over that which could overwhelm or dispirit me. I can unburden myself and walk lightly into the next session.

When I finished the first draft of the book, I was overwhelmed by tears; a great torrent of them, which came in huge gulping sobs from down deep in my heart and soul. I was taken completely by surprise and had no choice but to give in to the wails and torrents. About three hours later I stopped sobbing with a shuddering and final breath. After a while, I realized that I had experienced an out-pouring of grief for the people and their narratives that I had brought back into my consciousness as I thought about them and imbued these pages with their gifts to me. The gifts of themselves; real, true and courageous, willing to take the risk of sharing their tentative and vulnerable selves with me.

There was a greater freedom in the writing thereafter, and I know I have now completed the task many had asked me to do on their behalf, which was, 'Please tell others about counselling and how it can help us.'

I had mourned them well, one and all.

Now is the time for commemoration and celebration for all that they were and are, and all that they taught me. Their struggles have not been in vain. Perhaps you already counsel people with dementia and have been validated in the work you are doing. My hope is that you may be encouraged to continue and to enlighten others to the benefits of counselling. Perhaps you have discovered that you might be the next counsellor in your community to support a person with dementia in Making Sense of Self. I am delighted if you are now considering counselling men and women with dementia for the first time. Then I know that the process of sharing with you in this way has been as fruitful as I had dared hope, and that the people's lives I have been privileged to share will not have gone unwitnessed.

A Blessing

May the light of your soul guide you.

May the light of your soul bless the work you do with the secret love and warmth of your heart.

May you see in what you do the beauty of your own soul.

May the sacredness of your working bring healing, light and renewal to those who work with you and to those who see and receive your work.

May your work never weary you.

May it release within you wellsprings of refreshment, inspiration, and excitement.

May you be present in what you do.

May you never become lost in the bland absences.

May the day never burden.

May dawn find you awake and alert, approaching your new day with dreams, possibilities and promises.

May evening find you gracious and fulfilled.

May you go into the night blessed, sheltered and protected.

May your soul calm, console and renew you.

John O'Donohue²

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Additional Recommendations

I realise that not everyone will have access to a computer, so I have included telephone numbers where available. Most of the sites will have links to books, journals, films, chat rooms as well as a wide variety of information, helpful hints and current research, fundraising and volunteering opportunities.

Contacts for Information on Alzheimer's Disease and other forms of Dementia

United Kingdom, Scotland and Ireland

National Alzheimer's Society – www.alzheimers.org.uk (0207 423 3500)

HelpLine for a confidential telephone contact providing information, support, guidance and referral.

Dementia Positive – www.dementiapositive.co.uk

News and Reviews, Creative Arts and Dementia with John Killick and Kate Allan

Alzheimers Scotland – www.alzscot.org (0131 243 1453)

Alzheimers Ireland – www.alzheimer.ie (1 800 341 341)

Helpful information of the brain – www.howstuffworks.com (Go to the Health link, then Anatomy link, then Brain.)

European Contacts

Alzheimer International – www.alz.co.uk (44 207 9810880)

Alzheimer Poland – www.alzheimer.pl (48 22 622 1122)

USA

Alzheimers Association – www.alz.org (312 335 8700)

Helpline 1 800 272 3900

The Tangled Neuron – www.tangloneuron.info

A lay person's guide to memory loss, dementia and Alzheimer's Disease. Lots of useful links and reviews, helpful hints, movies.

Person-Centred Counselling for People with Dementia

Canada

Alzheimers Society of Canada – www.alzheimers.ca (416 488 3778)

Australia

Alzheimers Australia – www.alzheimers.org.au (61 (2) 6 4233254)

New Zealand

Alzheimers New Zealand – www.alzheimers.org.nz ((04) 381 2362)

Counselling Organizations

If you are interested in counselling for yourself, or you would like to refer someone, you can read the FACTSHEET at the Alzheimer's Society (UK) website (co-authored by Danuta Lipinska and Jane Robinson). Most of the sites below will have links to 'finding a counsellor' and 'what is counselling'

British Association for Counselling and Psychotherapy (BACP) – www.bacp.co.uk (01455 883316)

United Kingdom Register of Counsellors (UKRC) – www.ukrconline.org.uk

United Kingdom Council for Psychotherapy – www.psychotherapy.org.uk (0207 014 9955)

American Counseling Association – www.counseling.org (800 347 6647)

Counselling Association of Scotland – www.cosca.org.uk (01786 475 140)

Irish Counselling Association – www.irish.counselling.ie (00353 127 23427)

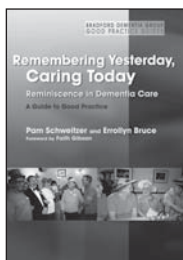
The Norwich Centre for Person Centred Counselling – www.norwichcentre.org (01603 617 709)

European Association for Psychotherapy – www.europsych.org (431 5131729)

Canadian Counseling Association – www.ccacc.ca (613 237 1099)

Counselling Association of Australia – www.theaca.net.au (07335 64255)

Counselling Association of New Zealand – www.nzac.org.nz ((07) 8340220)



Remembering Yesterday, Caring Today Reminiscence in Dementia Care: A Guide to Good Practice

Pam Schweitzer and Errollyn Bruce

Foreword by Faith Gibson

Paperback, ISBN 978 1 84310 649 4, 224 pages

Reminiscence is an invaluable means of promoting confidence and supporting identity in people with dementia. This practical guide explains how creative reminiscence work can stimulate and enrich communication and contribute to positive relationships between people with dementia and those who care for them.

Based on ideas developed and tested internationally over a period of ten years, the book offers imaginative approaches to reminiscence and a wealth of resources for use in a wide range of situations. It provides a useful planning tool for organising and structuring group and individual reminiscence work, with detailed descriptions of activities that can be used to improve quality of life in a variety of care settings, the community or the home environment.

Remembering Yesterday, Caring Today highlights the value of combining good practice in reminiscence with a person-centred approach to dementia and is an essential guide for professional and family carers.

Pam Schweitzer has many years' experience developing reminiscence work both in the UK and internationally. In the 1980s she founded Age Exchange Theatre Trust and Reminiscence Centre and remained its artistic director until 2005. For the last decade she has been actively developing reminiscence projects for people with dementia and their carers. In 2000, she was awarded an MBE for services to Reminiscence and she continues to direct the European Reminiscence Network. **Errollyn Bruce** is a lecturer in Dementia Studies at the University of Bradford. She joined Bradford Dementia Group to work with family carers and in 1997 met Pam Schweitzer and became involved in the *Remembering Yesterday, Caring Today* project as an evaluator.

Bradford Dementia Group Good Practice Guides

Under the editorship of Murna Downs, Chair in Dementia Studies at the University of Bradford, this series constitutes a set of accessible, jargon-free, evidence-based good practice guides for all those involved in the care of people with dementia and their families. The series draws together a range of evidence including the experience of people with dementia and their families, practice wisdom, and research and scholarship to promote quality of life and quality of care.



Involving Families in Care Homes **A Relationship-Centred Approach to Dementia Care**

By Bob Woods, John Keady and Diane Seddon

Paperback, ISBN 978 1 84310 229 8, 144 pages

Families often wrestle with the decision to move a person with dementia into a care home. The decision can be highly charged and emotional, involving feelings of loss, sadness and guilt. This accessible guide offers practical strategies for developing a good relationship between the family and the care home in order to ease the transition.

The authors take person-centred dementia care a step forward by outlining ways in which care homes can help families to become partners in the caring process. Using case examples, quotations and research-based evidence, the authors offer practical advice and good practice guidelines for supporting families who choose to be involved in the care of people with dementia, as well as highlighting the value of this involvement. The book contains useful features such as checklists for reviewing current practices and summaries of key points for each chapter.

This book is an invaluable resource for care home managers and staff, and also provides useful information for families of people with dementia, as well as students and researchers with an interest in dementia care practice.

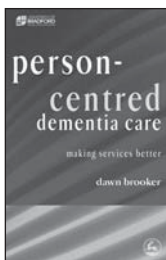
Bob Woods is Professor of Clinical Psychology of Older People at the University of Wales Bangor, and co-director of the Dementia Services Development Centre Wales.

John Keady is Professor of Mental Health Nursing and Older People at the University of Manchester/Bolton, Salford and Trafford Mental Health NHS Trust. He is Co-Editor of the Sage journal 'Dementia: the international journal of social research and practice'

Diane Seddon is a Research Fellow in the Institute of Medical and Social Care Research at the University of Wales Bangor.

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Person-Centred Dementia Care

Making Services Better

Dawn Brooker

Bradford Dementia Group Good Practice Guides

Paperback, ISBN 978 1 84310 337 0, 160 pages

The term person-centred care has been widely used, misused and ill defined. It is used frequently in the aims and objectives for dementia care services and provision, although in practice what lies behind the rhetoric can be questionable. This book gives fresh definition to the important ideas behind and the implementation of person-centred care for people with dementia.

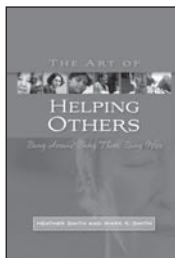
Dawn Brooker explains the four key elements of person-centred care that comprise the VIPS model: Valuing people with dementia and those who care for them (V); treating people as Individuals (I); looking at the world from the Perspective of the person with dementia (P); and a positive Social environment in which the person living with dementia can experience relative well-being (S). With an emphasis on practical application, *Person-Centred Dementia Care* provides care organisations with clear, accessible guidelines on how to put the VIPS model into operation for effective care that is 'fit for VIPs'.

This is essential reading for practitioners working with and policy makers responsible for people with dementia at all levels.

Dawn Brooker is Professor of Dementia Care Practice and Research at the Bradford Dementia Group, University of Bradford. She has twenty years' academic and clinical experience of working in the field of dementia, during which her particular research interest has been the improvement of quality of life and of services for people with dementia.

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The Art of Helping Others Being Around, Being There, Being Wise

Heather Smith and Mark K. Smith

Paperback, ISBN 978 1 84310 638 8, 176 pages

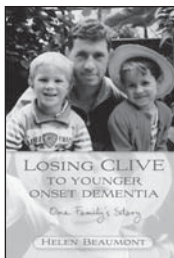
When searching for someone to help them reflect upon and improve their lives, people tend to be drawn towards those who are compassionate, committed and wise. This book is aimed at those who recognise these qualities in themselves and wish to develop their capacity to engage with and help others.

The authors argue for ways of approaching helping and counselling that are rooted in care and commitment, drawing upon the experiences and practice wisdom of youth workers, housing support and hostel workers, the clergy and those working in a religious setting, educators and settlement and community workers. They explore the key characteristics of those who counsel and teach and examine aspects of the helping process, focusing on living life well, knowing and being oneself, relating to others and working to make change possible.

This book is essential reading for students on professional training programmes in youth work, community education, ministry, social care and counselling.

Heather Smith has worked in youth projects, a special school, a residential centre working with families where a child has a very serious or terminal illness, and in a housing scheme for younger people. Currently she is a lead tutor in a London further education college. She works both with students experiencing difficulties with studying and participation in college activities, and the staff who teach and support them.

Mark K. Smith has worked as a careers officer, youth and community worker and project worker. He is now the Rank Research Fellow and Tutor at the YMCA George Williams College. Amongst his publications are *Developing Youth Work*, *Local Education* and *Informal Education*.



Losing Clive to Younger Onset Dementia One Family's Story

Helen Beaumont

Paperback, ISBN 978 1 84310 480 3, 144 pages

"[The author] has managed to combine an appreciative memoir, a gripping narrative and an informative account of an illness, and each of these is presented with everyday vividness, and totally without sentimentality"

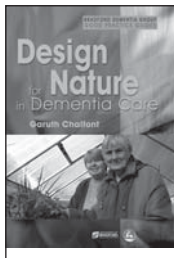
*– Terri Apter, PhD, psychologist, writer and Senior Tutor
at Newnham College, Cambridge University, UK*

Clive Beaumont was diagnosed with Younger Onset Dementia at age 45, when his children were aged just 3 and 4.

Clive had become less and less able to do his job properly and had been made redundant from the Army the year before. His wife, Helen, tells of how she and the rest of the family made it through the next six years until Clive died: the challenge of continually adapting to his progressive deterioration; having to address the legal implications of the illness; applying for benefit payments; finding nursing homes; and juggling her responsibilities as a wife, a mother and an employee. She also describes her sense of sadness and fear as her formerly gentle husband became more erratic and aggressive as his health deteriorated.

This story offers understanding and encouragement to younger people with dementia and their friends, families and carers.

Helen Beaumont is a founder member of The Clive Project, a registered charity based in Oxfordshire and set up by Helen and others in a bid to establish support services for people with Younger Onset Dementia. She lives in Oxfordshire with her two children.



Design for Nature in Dementia Care
Bradford Dementia Group Good Practice Guides
Garuth Chalfont
Paperback, ISBN 978 1 84310 571 8, 176 pages

Maintaining a connection to nature is increasingly recognised as essential for personal health and well-being. *Design for Nature in Dementia Care* demonstrates how people with dementia can benefit from nature through meaningful activity and environmental design.

The author suggests practical ways to include nature in care environments by integrating the design of the building and landscape with the routines of care practice. He describes a wide range of activities both indoors and outdoors, such as caring for house plants and pets, gardening, cooking, housekeeping, going outside and taking a walk. Supported by research evidence from environmental psychology, nursing, neurology, therapeutic horticulture and occupational therapy, as well as findings from his own research, the author provides a comprehensive holistic approach to including beneficial nature in everyday life.

The book is illustrated with images, diagrams and insightful quotations from people with dementia and their caregivers. Ethical issues are raised and addressed. It is a practical and informative resource for care providers and design professionals who aim to improve physical, mental and spiritual well-being for people with dementia through connection to the natural world.

Garuth Chalfont, PhD ASLA, is a researcher at the School of Architecture, University of Sheffield and operates Chalfont Design, a research and design practice in the US and the UK. He is a member of the American Society of Landscape Architects, a Fellow of the Royal Geographical Society, a visiting teacher at Bradford Dementia Group, University of Bradford and a trained care assistant.

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'We've been waiting a long time for someone to write a definitive text on counselling persons with dementia. Now Danuta Lipinska has done it, and it is even better than we had hoped for.'

– John Killick, *freelance writer and researcher, and co-author of Communication and the Care of People with Dementia*

'With warmth and humor, Danuta shares the clarity of her vision of honoring the wholeness of the person, and the unique experiences of their history, always encouraging full expression of their feelings and frustrations, their strengths and their struggles. This book will open your heart with hope. If you are a caregiver, a family member, a friend, a therapist or allied medical professional, it will offer you a fresh perspective to consider, and be a great resource.'

– Dwight Webb, *Professor of Counseling, University of New Hampshire, and author of The Soul of Counseling*

'This valuable book...challenges us to raise our expectations, to believe in a person's capacity for growth and change despite – even because of – failing memory. This is a book about hope, respect and love.'

– Cynthia Ransley, *Lecturer in Social Work, Integrative Psychotherapist and Tutor, Metanoia Institute, London*

This book explores the value of counselling for people with dementia and how it can enable them to make sense of their lives and their notions of themselves. The author explores the pervasive myth that all experiences of living with dementia are entirely negative and shows counsellors and carers how a person-centred counselling experience can have positive outcomes for those with dementia and the people who care for them.

Based on the author's own experiences of counselling people with dementia, this book covers the fundamentals of the counselling process and precisely what a person-centred approach entails. Accumulating findings from over 20 years of counselling experience in both the UK and the US, the book explores the importance of the Self and recognising each individual's worth and value. Dialogue from the author's counselling experiences is also used to illustrate the effectiveness of the person-centred counselling approach.

Providing a comprehensive guide to person-centred counselling for people with dementia, this book gives an illuminating perspective on the subject and will be of value to counsellors, health and social care professionals, carers, people with dementia and their families.

Danuta Lipinska has worked with people with dementia in the community for many years. She has a BA in Psychology and MA in Counselling, both from the University of New Hampshire, USA and is an accredited member of the British Association of Counselling and Psychotherapy, and the UKRC Association of Independent Practitioners. Danuta currently works with clients on a referral basis and as a training consultant in the area of mental health and older people, particularly those with dementia. She is a qualified nurse and has previously worked as a Director of Nursing in a residential care home in the USA. She now lives in London, UK.



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116 Pentonville Road
London N1 9JB, UK

400 Market Street, Suite 400
Philadelphia, PA 19106, USA

www.jkp.com

Cover design: Black Dog Design

ISBN 978-1-84310-978-5



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