

Arts Therapies and
Progressive Illness

Nameless Dread



Edited by Diane Waller

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Arts Therapies and Progressive Illness

Arts Therapies and Progressive Illness is a guide to the use of arts therapies in the treatment of patients with diseases such as Parkinson's and Alzheimer's. In the last few years arts therapies have been used in an increasingly wide range of applications with new groups of patients, such as patients in palliative care, or with learning disabilities – Diane Waller has been a driving force behind this expansion.

This book covers treatments such as art therapy, dance movement therapy and music therapy. In addition to dealing with a wide range of debilitating diseases, it focuses on the issue of the care and treatment of dementia and the effects on patients, carers and staff and the role of the arts therapies in improving the quality of life for the increasing number of patients who will sadly develop this distressing illness.

The broadly focused, multi-disciplinary book will be of great interest to arts therapists, arts therapy educators, medical, social work and other staff who are concerned to devise care plans for these patients and their relatives.

Diane Waller is Professor of Art Therapy at Goldsmiths College. Her previous publications include *Becoming a Profession: the History of Art Therapy in Britain 1940–82* (1991), *Group-Interactive Art Therapy* (1993) and *Treatment of Addiction* (1998, co-edited with Jacqueline Mahony).

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diagnosis of Parkinson’s.

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Like one, that on a lonesome road
Doth walk in fear and dread,
And having once turned round walks on
And turns no more his head;
Because he knows a frightful fiend
Doth close behind him tread.

Coleridge,
The Rime of the Ancient Mariner

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Contributors

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Jill Bunce is a dance movement therapist whose MA at the Laban Centre focused on DMT with Parkinson's patients. Jill lectures in universities in the UK and abroad, linking the theory and practice of neuroscience with psychoanalysis, child development and learning difficulties. She was made an honorary member of the neurological department of Staffordshire General Infirmary, and is now establishing research work into palliative care in the arts therapies, particularly in the area of degenerative illness, dementia and care of the dying. Her current practice is with people with multiple sclerosis, Parkinson's disease and children with autism, learning difficulties and disabilities.

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Barry Falk is an artist and art therapist. While training at Goldsmiths College he was awarded the Corinne Burton Scholarship, enabling him to specialise in work with cancer patients or those with terminal illnesses. He currently runs an art therapy group on the Oncology Ward of the Royal Sussex Hospital, at the Towner Club, Martlets Hospice and at two of the centres featured in the Apollo Art Therapy Research Project in Brighton and Newhaven.

Dorothy Jerrome spent nearly 25 years in higher education as a social gerontologist at the universities of Sussex and Southampton before moving on to Age Concern in Brighton, Hove and Portslade. She currently works as a training and development officer in older people's services in local government. Her chapter draws together her knowledge of the ageing person and the existential world of dementia, her love of dance and belief in its transformative capacity.

Neil McArthur was academic registrar at King's College, London before moving into work with the Alzheimer's Society in Brighton. He is now the manager of the Brighton and Hove branch, developing an extensive network of volunteers who give respite to relatives of people with dementia and providing training. Neil was instrumental in setting up the research project on the needs of people with early onset dementia and their carers, and in bringing the Towner Club into existence.

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John Tyler came to art therapy with a background of art teaching in primary through to secondary level. While training as an art therapist at Goldsmiths he did a placement with older adults and later went on to develop his work with older people with dementia, using both group and individual approaches. John recently completed a psychotherapy training and is now exploring the hypothesis that art therapy can assist people experiencing memory loss to resolve significant conflicts during the final stages of their lives. He is Head Art Therapist in an NHS Trust hospital in Surrey.

Diane Waller founded the Art Psychotherapy Unit at Goldsmiths College, London. She is Professor of Art Therapy there, and Visiting Professor in the School of Psychology at Queen's University, Belfast and at Brighton University. Her research has included the history and development of the profession of art therapy in the UK and abroad, action research on art therapy training, art therapy with eating disorders, groups, drug addiction, and currently with older people with dementia. Her background in art, ethnography, dance and the process model of sociology has led her to question many of the assumptions prevalent in the 'caring' professions. This was heightened by her experience of being 'carer' for her husband with Parkinson's related dementia.

Foreword

Robin Higgins

By a number of measures, this is an important and wide-ranging book. Ostensibly about dementia and the contribution that arts therapists can make to relieving the 'nameless dread' that lies behind dementia's implacable tread, a cursory reading will quickly reveal that topics broached extend far beyond these limits.

In the first place, the population of those suffering from dementia must be a key issue in any society that has to cope with increasing longevity. Whom now do we class as elderly? Several case studies in this book describe people who are in their forties and fifties, with the prospect of many more years ahead of them, depending on a set of interrelated issues: physical health; a sense of identity, place, and purpose; the retained capacity for enjoyment.

An equally glaring point, dementia is not confined to those who suffer from it themselves. There are those designated officially and somehow inadequately as the carers, both among the relatives, spouses, and friends, and among the care homes and hospital staff, all of whom are drawn into this engulfing circle of need. Several chapters in the book are given over to poignant descriptions of what is entailed in becoming entangled in the web of dementia: from bearing witness to the slow dissolution of a loved one (as John Bayley bore for Iris Murdoch) to disentangling the confusions of projective identifications. Other chapters outline some of the management problems that give rise to institutional paradoxes. Among many examples cited, two situations stand out: one where personal care and concern, the lifelines for someone in the throes of dementia, and the very purpose for which the institution was set up, become threatened or destroyed by rigid routines; the other where sustained atmospheres of 'hysterical merriment' are imposed to jolly carers and patients alike out of their all too understandable moments of authentic and healing sadness.

So in the second place, the book faces us with some stark questions. What are we expecting of carers, whether family, friends, or staff? And what sort of support are we providing them with in their acutely difficult task of fulfilling these expectations? In a cultural ethic where great emphasis is placed on market values, and winning (from league tables to the most up-to-date

weaponry), where to advance up a career ladder we appear to need increasing specialisation and segmentation (witness the medical and sociological networks spelt out in Ken Evans's chapters), what time can we really spare for those whom dementia and related progressive debilities have sidelined?

The issue takes us far beyond the sphere of politicians and economic planners, where we have often been only too happy to dump it. It devolves on the question of understanding the other-in-the-margin, and that is one of the questions on which the whole future of our species depends.

The third reason why this book is important are the glimpses it offers of a landscape with some exciting possibilities. These go along with a number of sea-changes which are occurring in the scientific and humanities background and of which arts therapists are well placed to take advantage.

Neurological and biochemical studies, for example, are opening up our understanding of how physical forces link with psychological and social ones in psyche-soma networks that ramify (as Freud and others intuited) well below the 5 per cent of mental activity we call 'conscious'. We're moving to a position where a state like dementia can no longer be dismissed as 'just organic', since we know now that organic is not only linked through field forces to the inorganic but also through emotive channels to the realm of ideational expression.

One doesn't have to be a dancer or a singer (though it sometimes helps) to appreciate the subtleties implicit in the physical postures we assume every moment of our lives and of which we are usually quite unaware. The ideas they convey to us and to others – the body language – may lead to our walking on air, or falling in the ditch in a knot. In her chapter on Parkinson's, Jill Bunce singles out posture as just one body-mind-spirit expression which has infinite potential and with which an arts therapist can hold a non-verbal dialogue with the patient. Dorothy Jerrome elaborates similar possibilities inherent in the touch and rhythms of circular dance.

The confluence of the neurosciences and psychoanalysis, and of trance, hypnosis, and visualisation must be grist to the arts therapists' mill, since so much of their work occurs at a non-verbal or pre-verbal level, and they do not feel compelled to move prematurely from a procedural (the drawing, the improvisation, the gesture) to a declarative symbol, verbalising what it's all about. Of course, this move from procedural to declarative may happen, but when it does, as John Tyler observes, something is laid to rest in a different way than if words only were used.

Another complementary polarity addressed in the book is that between narrative-based and evidence-based approaches. Two detailed control group studies (Diane Waller's and Dorothy Jerrome's) offer a valuable counterweight to the many lively narratives of dramatic events that bring a scene and a person to life. This balance of science and humanity informs and illustrates the book's endeavour: creative understanding to improve the quality of life.

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The book is dedicated to the late Daniel Lumley and Ilya Sabev, to Maria Sabev, and to all the known and unknown sufferers from progressive illness and their carers.

Arts therapies, progressive illness, dementia

The difficulty of being

Diane Waller

Art therapists have traditionally worked with patients excluded from verbal psychotherapy services, beginning in the 1940s and 1950s with so-called 'chronically mentally ill' or 'burnt out' patients, later in the 1970s with the 'severely mentally handicapped' and in the past two decades with elderly dementing patients. As early as the 1860s, asylums housing chronically ill, psychotic patients and those suffering from 'senile dementia' were providing arts activities, but not all had access to the 'entertainment' they provided and the preferred option for such patients was work (Skailes, 1997: 199).

The results of encouraging patients with virtually no verbal communication, who were severely depressed and isolated, and for whom hope had been lost, to engage in visual, musical or bodily expression were often startlingly positive (Wood, 1997: 144–175; Henzell, 1997: 176–197). Although access to the arts was on a very *ad hoc* basis, the beneficial effects of 'arts therapy' on these extremely withdrawn people led some prominent medical practitioners to support the development of the arts therapies as effective interventions.¹ Despite the growing number of reputable arts therapy publications focusing on specialised client groups, many of the positive effects of these therapies with people suffering from progressive or degenerative illnesses remain undocumented, known only to recipients, carers and the immediate health care team. Systematic research, from detailed case work to control group studies, is urgently needed to remedy this situation.

Although not all progressive illnesses lead to dementia, there are many that do, including stroke, Parkinson's (and its variants), Alzheimer's and Huntington's disease. Dementia is described as a condition which involves a severe decline in an individual's mental abilities, most markedly in language, judgement, reasoning and memory (Terry and Katzman, 1992). One of the major effects of a dementing illness is the concomitant emergence of depression, one of the effects of which is a reduced cognitive capability. The impact of a diagnosis of dementia on the sufferer and their family and friends is often underestimated. It is a sentence of 'no hope', condemning all concerned to a never-ending series of losses and humiliations. The terms 'progressive illness' and 'organic brain disorder' bring with them suggestions of rapid, unrelieved

deterioration, and it is not surprising to find that the sufferer and their relatives get very depressed, very quickly.

The arts therapies are 'person centred' and, importantly, build on the positive attributes of patients, assuming that all can be creative at some level. The materials and methods of the arts therapist are flexible, and a skilled therapist assesses the patient's capabilities, gently encouraging and supporting even the smallest mark, sound or movement. For people with dementia who have lost their identity, feel frightened in a confusing and controlling world and who can no longer express themselves through speech, writing or even perhaps touch, having access to the safe, quiet spaces of the art therapy studio, with the full attention of the therapist, can give a purpose, containment and means of being in control. This last point is very important as it may be that the person has lost control of their bodily functions as well as their emotional life and relationships. This brings a strong sense of shame and constant anxiety.

Depression, loneliness and terrible fear are features of progressive illnesses, especially of dementia. The term 'nameless dread' was chosen for the book because the person is frightened but does not know why. Bion (1957: 105) used this term in reference to the effects on a baby who constantly cries but is not answered, thus it gets terrified because obviously it is totally dependent on the adult for its survival. When the mother (or carer) does not respond to the baby's frantic crying then the baby's sense of abandonment is not dealt with. The baby's experience is that its terror cannot be managed, it cannot be comforted, and there is no safety. The fear is all-pervasive, particularly during the night (darkness, alone). A person with severe dementia, I would say, is often in a similar position to the baby, feeling abandoned in a state of terror, and it is essential that a way is found for such torment to be expressed and acknowledged.

Valerie Sinason (1992), although writing about 'mental handicap', discusses with great sensitivity many issues very relevant to people with progressive illness and dementia. Her work is very important in demonstrating that persons traditionally excluded from psychodynamic therapies, such as those with mental handicap, psychosis, dementia, may, in fact, benefit greatly from sensitive interventions. Sinason is a psychoanalytic psychotherapist working at the Tavistock Clinic and she is also a poet. Her papers and case studies are accompanied by the poems she writes to help her to manage the often painful and puzzling material of her clients. She pays great attention to the subtleties of communication, verbal and non-verbal, describing, for example, an incident when a profoundly handicapped man pours his breakfast cereal all over the table but manages to miss the cereal bowl. The residential worker confesses to feeling angry, then guilty, preferring to see this as an accident rather than a meaningful communication. The task has, however, been mismanaged with great accuracy. We may refer to such an action as 'being stupid', but Sinason points out that 'To be stupid is to be numbed with grief and those who bear the burden of a mental handicap carry an enormous amount of

grief' (1992: 31). We could say the same about the persons who are the focus of this book, who by losing their memories, their faculties and their relationships, often appear 'stupid' to themselves and others.

Sinason points out that the emotional experience of the individual with late-onset physical illness or handicap is very similar to that of the mentally handicapped individual. In 'The man who was losing his brain' (1992: 87–110) Sinason writes:

The difference between someone at the start of Alzheimer's disease and someone near the end is as large as the difference between someone who is normal and someone who is profoundly handicapped. The total continuum is experienced in the mind and heart of a single being.

(1992: 89)

She describes her work with a 56-year-old man, a university lecturer when he developed Alzheimer's. She arranged to see him in his own home and continued for a year. The story is deeply moving. At one point the session was so painful that Sinason tried to encompass her experience in a poem before writing up her notes. One day she arrived at his house:

I stood on the doorstep feeling equally lost. 'I am Mrs Sinason', I finally managed to say: 'Have you forgotten my face?' It was somehow easier to say that than to ask 'Have you forgotten me?' In feeling the experience of being lost to memory, wiped out, even momentarily, I was experiencing just a tiny moment of what Edward Johnson had to live with.

(1992: 109)

Eventually Mr Johnson found the sessions too difficult: 'He found thinking harder and preferred gardening.' One year later he died. Sinason concludes:

He had held onto thinking, as represented by my presence, as long as he could. According to his sons, therapy allowed him to come to terms with his degeneration, with the unpicking of the fine embroidery that had been his brain. However, once it got to the point of the last unravelling, when he knew mindlessness and death lay ahead, he felt better equipped to go with nature (the tree) and his mother (the scarf) and his father (the book).

(1992: 110)

How to hold on to one's faculties as long as possible becomes a real challenge in organic, progressive illness and it is here that we may see some chance for the arts therapies. Visual image-making activates a part of the brain still intact, as we can observe throughout detailed analyses of art therapy case studies. Dance, music and movement provide valuable expressive

and socialising possibilities and may help to reorientate the sufferer in the world. The drama of dementia is always present and although dramatherapy is not specifically addressed in this book, we may find that important elements of dramatherapy emerge in the art therapy or dance and dance movement therapy groups.

Unfortunately, very few patients with progressive illness currently have access either to psychodynamic therapy or to the arts or arts therapies. This is mainly due to the fact that many hospitals and centres catering for the elderly, who form the largest group of sufferers, do not employ an arts therapist; partly, though, it is because few doctors, and indeed few sufferers themselves, would think that it might help. Nursing homes, which house more severely dementing residents, are ill-equipped to provide spaces where creative activity can take place. There are many negative attitudes to be overcome about making a mess, fear of things getting out of control, anxiety about the use of art materials both among residents and staff. Moreover, the all-pervasive sense that 'it is no use, it is too late' has to be overcome.

The following quotes (referring to chronic psychotic patients) which I have borrowed from Salomon Resnik seem to express this well:

Space and 'madness' are two aspects of being with which I have been concerned for a long time. What does it mean to be an individual? What does it mean to be in the world and what about the world itself? A being is not a thing, not merely an object, but mainly a subject. Being a subject, to be one's self, to be a person means to have a 'living body', a moving body, a thinking body. To be means to have a place of one's own, to experience one's body and mind as a living element in space and time. To live means to experience time ('temps vecu' in Bergson's view) and the passing of time (becoming) as part of existence . . .

(1992: 221)

and he continues:

Bion used to speak of 'wandering thoughts' searching for a thinker (or wild thoughts in search of somebody able to tame them, of someone able to contain them, to stand and understand them). The main problem in counter-transference with psychotic patients is to tolerate madness and at the same time to protect one's self from being seduced or possessed by these very thoughts . . .

(1992: 222)

These images are powerful and in my experience, as well as bearing in mind Sinason's comparisons with mentally handicapped persons, we could substitute the 'person with dementia' for 'the person with a psychosis' – not in a manner designed to negate the difference in these conditions but because

when one's senses, one's perceptions, one's relationships are jumbled, confused and undifferentiated this is indeed a state of madness into which those closest to the sufferer may also be drawn. It becomes urgent to find a way to reinforce a sense of self. Schaverien puts it well:

It is through actions and symbolic forms, such as art and language, that a sense of self, and of agency, develops . . . Belonging to a group involves shared rituals and a common language: it is through these that membership of a community is confirmed. The psychotic patient suffers because he/she does not experience him/herself as a member of a community. The use of symbolic forms fails and there is no communal understanding. The spoken word cannot be relied upon to mediate. At this point pictures may form a bridge between unmediated experiences and the Other . . .

(1997: 17)

Even if dementia is not present, or not yet present, there are few who can tolerate a relentless progressive loss of their faculties, an inability to feel part of the world, such an assault on their person, without feeling, at least some of the time, that they are going mad.

Thanks to the work of pioneers like Tom Kitwood between 1987 and his untimely recent death, and especially to his (1997) *Dementia Reconsidered: The Person Comes First*, and of Bère M.L. Miesen's work between 1992 and 1999, more attention is gradually being given to the possibility that people with dementia may be able to live a more fulfilling life than had hitherto seemed possible. At the time of writing this book, the English government's medicines-rationing body NICE has announced that the new and still controversial drug Aricept, and its equivalents Exelon and Reminyl, is to be made available nationwide to people with mild to moderate Alzheimer's, at an apparent cost of £45 million annually. This drug may slow the progress of deterioration for a period. Another potentially helpful vaccine, AN 1792, is currently being tested on mice, but although human trials are underway it is likely to be 3–5 years before a treatment emerges. As Neil McArthur mentions in his interview (see Chapter 8, p. 94), for the first time the possibility exists for alleviating the disease. There are many developments in the treatment of Parkinson's: in terms of dopamine (L-Dopa), which works on the neuroreceptors in the brain, and, from January 2001, in embryo research – a very controversial step but one which may produce benefits for this client group.

Perhaps the most striking point, an obvious one but often overlooked, to be made by Kitwood and other 'radical' workers is that each person with dementia is an individual, and that each person's needs are going to be different. That this should be a radical suggestion is indeed astonishing and is indicative of a socio-cultural context which is completely hypocritical in emphasising the rights of the individual but not, apparently, those of the

person with dementia – especially those who are old (the majority), poor and do not have a supportive family.

This book does not pretend to provide solutions for the care and treatment of people with the grave and life-sapping illnesses discussed. It asks the question, why are things the way they are, and what might we try to do about them? It offers some positive possibilities in terms of art as therapy, and art psychotherapies. Living and working with someone who knows that the life they took for granted is gradually disappearing, that they may be physically and mentally declining but they do not know how long this will go on for, and that the outcome will be that they will be totally dependent on others, is hard in itself. Living in environments where they watch others deteriorate and disappear, and know that is probably going to be their fate, is hellish. The book will reflect the struggle of its authors (including its editor) in their efforts to come to terms with such a reality. For example, in Chapter 14 I give a personal account of my own extreme difficulty in reconciling myself to the awfulness of my late husband's condition, my own 'nameless dread', in the form of learned anxiety and panic, which even three years after his death is regularly present.

It is not only close relatives and carers of the person with progressive illness who are affected. The staff caring for the sufferer and the institutions in which they find themselves are subject to the unrelenting process of 'projective identification' (Segal 1975: 126), further confusing and distressing everyone concerned. For those unfamiliar with the term, it was coined by Melanie Klein and is defined as:

the result of the projection of parts of the self into an object. It may result in the object being perceived as having acquired the characteristics of the projected part of the self but it can also result in the self becoming identified with the object of its projection.

(Segal, 1975: 126)

In other words, such a process can lead to the other person taking on and 'acting out' the projections, which could lead to a carer getting overwhelmed by feelings of rage, hopelessness and incompetence, which are actually felt but cannot be dealt with by the person with dementia and thus projected out.

While emphasising the importance of the arts and arts therapies for patients, we also have to recognise their limitations and not assume that they are always a means of communication. Killick (1997: 40–41) usefully draws our attention to the need to recognise when a patient is making art (or mark-making) to defend themselves against unbearable anxiety and when they are trying to communicate. In the first instance Killick, drawing on Bion (1957), suggests that the art is: 'used by the patient experiencing catastrophic anxiety as a means of intrusive identification, i.e. as a way of forcibly evacuating unbearable anxieties into the art object, and that accordingly it holds

evacuated beta elements' (1997: 42). She considers that patients in this state benefit from the 'concreteness of the substances and objects available to and made by the patient in the art psychotherapy setting', allowing the 'violences of the intrusive identifications to be absorbed without damage to the patient or the therapist' (1997: 43). If the therapist can tolerate the period of intrusive identification, it may be that the patient will reach a stage where they can communicate, or may make a piece of art that has the potential for communication (1997: 44). To reach such a stage will require consistent, safe, bounded time and space and the regular presence of the therapist. As we shall see from the contributions to this book, the possibility of encountering such a desirable intervention is extremely rare for patients suffering from progressive illness and dementia.

Staff in institutions caring for people with the progressive illnesses featured in this book are, then, subject to massive projective identification which can be dangerous both for the staff and the patients, even leading to cases of abuse. Yet we find a noticeable absence of therapeutically trained employees, agency staff who come and go, minimal or no support and supervision. Surely this is one of the most difficult areas of work, being with people who have 'no hope'?

Kitwood discusses 'the nature of empathy and projective and empathetic identification' (1997: 128–130) and shows how it can happen that all kinds of difficulties may arise in a relationship with someone with dementia:

When we develop empathy with someone who has all their mental powers intact, we attend both to their words and to their non-verbal signals. Sometimes we notice discrepancies between the two kinds of message. A person might, for example, claim to be feeling 'perfectly OK', while showing clear signs of anxiety or inner turmoil. Gradually, keeping all the information in a kind of 'soft focus' we gain a sense of what they might be experiencing.

(1997: 128)

Consider, though, what happens when a caregiver gets caught up in a process of projective identification, when the caregiver will:

'see' aspects of his or her own self in the person who has dementia, and may even induce that person to act some of these aspects out; making them become more angry, more helpless, more confused etc.

(1997: 128–129)

So, if these processes operate between the person with dementia and their relative, they obviously can do so in formal care, and it is the opinion of Kitwood, and certainly of the authors in this book, that these processes may become (in Kitwood's words) 'noxious'. When we think of the thousands of

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