

Report

Working as an artist with people with dementia

John Killick

This report distils the learning from two roundtables held by NAWE (National Association of Writers in Education) exploring the skills, knowledge and understanding needed to work as a writer and artist with people with dementia, focusing in particular on the commonalities and differences between art forms and the implications for training, qualifications and standards.

The roundtables were held on 10/11 October and 6/7 November 2012 at the Campus for Ageing and Vitality at Newcastle University as part of NAWE's work with 'ArtWorks: Developing Practice in Participatory Settings', a Paul Hamlyn Foundation Special Initiative.

Participants: Writers' Roundtable: Moyra Donaldson, Karen Hayes, Susanna Howard, Rebecca Jenkins, Romi Jones, Jacqui Rowe, Lucy Whitman, and Paul Munden (Director, NAWE). Artists' Roundtable: Richard Coaten, Claire Craig, Lowri Evans, Claire Garabedian, Mona McCarthy, Maria Oller, Alison Mercer, Rebecca Pedlow, Jayne Wallace, and Sarah Zoutewelle-Morris. Written submissions were also received from David Clegg (writer) and Bisakha Sarker (artist). John Killick (Chair), Philippa Johnston (Co-ordinator).

Both Roundtables were sent a briefing paper prepared by John Killick, based on a short survey of arts and dementia activity and research in the UK, (see Appendix One) and shared the same agenda. In the following account, participants' names have been omitted, with the abbreviation WR being used for the Writers' Roundtable and AR for the Artists' Roundtable.

'ArtWorks: Developing Practice in Participatory Settings' is a Paul Hamlyn Foundation Special Initiative to support the continuing professional development of artists working in participatory settings. It has support and funding from the Arts and Humanities Research Council, Creativity Culture & Education (supported by Arts Council England) and the Cultural Leadership Programme. www.artworksphf.org.uk

About the author

John Killick has worked for twenty years as a writer with people with dementia. For six of these he was Research Fellow in Communication Through the Arts at Dementia Services Development Centre, the University of Stirling. Currently, as well as working at the Courtyard Centre for the Arts in Hereford, he is Writer in Residence for Alzheimer Scotland.

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About NAWE

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1: Similarities and Differences

In considering whether working with people with dementia was different from working with other groups in the community, both Roundtables expressed common views, namely that the differences acknowledged between the two modes of working far outweighed the similarities.

Amongst the similarities identified were: 1) Person-centredness is a given; 2) Stigma is in common; 3) so is being subject to extreme marginalisation.

Amongst the differences identified were: 1) Prejudices are much greater and more resistant to being addressed; 2) Health professionals and family carers have their respective inflexible attitudes – they constantly question the validity of the work; 3) Left-brain approaches are inappropriate - intuition and flexibility work best; 4) The idea of progression towards an end product may have to be set aside and the value of process be embraced; 5) Uncertainty and confusion may need to be accommodated; 6) Emotional expression has to be promoted in settings where this is often discouraged as disruptive.

Despite these differences, it was accepted that a skilled facilitator, with extensive experience of working in community settings, would be able to make a successful transition to working in the dementia field.

2: Personal Experience

There was a clear division between the two Roundtables as to whether personal experience of dementia was necessary or desirable for working in this field.

Amongst the members of the WR, there were more individuals with family experience and this led to a more forceful endorsement of prior knowledge. The view was expressed that this was highly motivating and gave insight into the range of challenges to be faced, as well as a depth of understanding which is hard to replicate in training. However, one participant found personal experience upsetting and inhibiting.

The contrary view – that a facilitator could be freer and share the moment with people with dementia if they had no personal experience – was predominant in the AR.

There was general agreement in both Roundtables that a certain level of training was essential, whatever one's previous history.

3: Values

A consensus was reached across the two Roundtables on the values that should be applied in this work.

The following were identified as essential for undertaking the work: 1) Promoting the person as their own advocate; 2) Accessing creativity as a sense-making tool; 3) Encouraging creativity as a trust-builder and a leveller; 4) Facilitating a re-engagement with wonder.

It was recognised that these often ran counter to the ethos of establishments and were not easily subject to evaluation.

Other points raised were: 1) Staff often had low morale which could sometimes be raised by offering opportunities to them to explore their own creativity; 2) There is currently a lack of assertion of the humane values of the work to counter the medicalised view of the person.

The need for guidelines for commissioners of projects, and for an advocacy leaflet for the work, was acknowledged.

4: Intents and Purposes

On the matter of the ways in which aims and objects affect ways of working and skillsets, here there was another clear distinction between the Roundtables.

The AR contained some therapists, and the WR did not, primarily because the profession of writing therapy hardly exists in the UK. The therapists had a growing research base, and clinical supervision and practice as part of their brief. Both groups needed to understand about dementia, and had respective training and development needs. They both had links to professional support, but in the case of the therapists, this was much more highly developed, and both had to adapt to respective care environments. Common ground between the two groups was referred to in the use of the terms 'reciprocity of process', 'engagement' and 'relationship'.

5: Different Settings

Looking at how working in different settings affects performance and ways of working, here again there was a contrast between the two Roundtables. There was a greater preponderance of hospital work in the AR group, and the severity of the limitations imposed by environments was stressed by them.

The great variety of settings in which people worked was emphasised: day centres, arts centres, care homes, hospitals, doctors' surgeries and people's own homes. Performance and ways of working were very much affected by these. Even within one category – hospitals – there was a big adjustment to be made in moving between an assessment and a long-stay ward. Amongst the variables, apart from ethos (perhaps the most significant of all) were physical facilities, availability of clients, and staff involvement. The opportunity to work in people's own homes was commended, because it 'equalises power and normalises the situation'; these are also the places where most clients are living. The importance of involving staff and/or relatives was reiterated.

6: Assessment

Both Roundtables agreed that evaluation was essential and had a number of purposes. It should be seen as part of a continual process, not as an add-on. The more objective aspects of an evaluation, however, were perhaps better accomplished by an external assessor. Although quantitative methods had their uses, the various qualitative approaches were more appropriate for arts projects and should be further developed; they are gradually becoming more accepted. The wellbeing scales from occupational therapy could be explored, and Newcastle University was developing a tool which combined monitoring and evaluation. One participant recommended the contributions of Peter Graf and Dalia Gottlieb Tanaka. Video evidence was advocated, but it was proving increasingly difficult to persuade ethics committees to accept such proposals. Reports should be framed in a more accessible manner, and be more wide-ranging both in scope and distribution. It was recommended that assessment should be factored into project budgets.

7: Support

There was common ground between the two Roundtables as to the kinds of support needed, although the AR put more emphasis on emotional support than the WR. Two kinds of support were identified: the contextual and the personal. The former included: good project management; knowledge and training; and appreciation of the contexts in which work took place. The latter included: supervision and reflective practice; professional networks; artistic support; and resources, including remuneration that reflected the time and effort put in, materials and resources, and events and conferences.

There was widespread agreement that there should be an organization specifically responsible for the arts and dementia, which could provide administrative support and offer its members tangible benefits such as quality assurance, guidelines on practice, networks offering opportunities for sharing, and with the possibility for such adjuncts as public liability insurance. NAWA already offered some of these services to its members, and was prepared to offer further support to members of the WR and their colleagues, but it was agreed that this should not preclude their joining a body devoted to a wider spectrum of the arts and dementia community. It was proposed that the Association for Dementia Studies at the University of Worcester would be best placed to provide this service.

8: Training

Both Roundtables accepted that there was an overwhelming need for training in this area, delivered by a variety of methods – through a long course, short courses, on-line and through mentoring. They both agreed that the main provision should be a one-year diploma, shared with artists of all art forms, which could consist of core elements supplemented by units for specific art forms. There should also be short courses, day or weekend or on-line, which would not be certificated. The courses should be delivered by practitioners, people with dementia and carers. Bursaries should be available for all strands.

An extensive list of possible components of training courses was drawn up, including: shadowing; mentoring; reflections on practice; skills, methods and approaches; information about dementia; details of academic research and papers; placements and follow-ups; listening skills and empathy; and exploring and signing up to core values, such as respect for the person, confidentiality and being non-judgemental. There could be a core module of: finance/budgeting/fundraising; relevant legislation; understanding how institutions work; group dynamics/facilitation; and ethics.

There was general resistance to the inclusion of an element of counselling/therapeutic training. Two of the artists recommended an 'instant ageing' workshop. Meeting other artists for 'cross fertilisation' was supported. Regular gatherings like the Roundtables were unanimously endorsed.

Again NAWA could offer some of the above, and Worcester University was the favoured institution to provide comprehensive training.

9: Standards

The need for clarifying standards was agreed; this would be of particular use to those new to the work. The general view was that provision of the various forms of support outlined under 7 would result in the raising of the status of the work, and the meeting of the training needs outlined under 8 would result in greater consistency; taken together these would achieve the aim of establishing standards. One participant summed up the overall aim of the work as 'creating value in terms of what we do and the impact on those we work with.'

Some Quotations from the Roundtables

'I'm not coming in to entertain the troops or be a baby-sitter.'

*

'The world is a symphony not a spreadsheet.'

*

'You need to turn off your own ego.'

*

'We are trying to demonstrate flow: what creativity is really like.'

*

'It can be dangerous if we are aligned too closely with the work of occupational therapists - they bring in rabbits one week, clowns the next!'

*

'In working with people with dementia we must try to inhabit their internal landscape.'

*

'How do you create a network around yourself?'

*

'How do you measure a smile, and why would you want to?'

Recommendations

It was the general view of the Roundtables that there was common ground in terms of attitude, experience and need. This would enable a single approach to be made to the devising of a document outlining standards, and the establishment of a training course with attendant qualification. Any divergencies could be accommodated by means of supplementary provision.

1) Networking

That regular meetings of writers and artists working in the field should take place to combat isolation and promote innovative practices. Other forms of peer support would contribute to this end (see 5).

2) Support

That a body for support should be established, which would raise the profile of the work, set standards, and provide training opportunities. NAWÉ can do some of this for writers; the Association of Dementia Studies at the University of Worcester could be approached to do this for all concerned.

3) Research

That there should be more research in this area, especially of a qualitative nature; this would establish tools for evaluation for both writers and artists to use.

4) Resources

That there should be guidelines issued for writers and artists, and also for commissioners, and there should also be an advocacy leaflet for the work. (NAWE is already offering a whole issue of its journal 'Writing in Education' to be devoted to writing and dementia).

5) Training

That courses should be instituted - a one year across-the-arts course leading to a diploma, with short courses covering specific art-forms or aspects of the work, which would be non-certificated, in order to raise standards and confer status on the sector. Bursaries should be available for these.

In addition, opportunities should be created for writers and artists in the field to collaborate with, and shadow and mentor each other.

John Killick
21 December 2012

Appendix One

Briefing Paper

Working as an artist with people with dementia

John Killick

This briefing paper is based on a short survey of arts and dementia activity and research in the UK undertaken by leading arts and dementia writer John Killick. It has been commissioned by NAWE (National Association of Writers in Education) which has received funding to run an Artists Laboratory exploring the knowledge and skills needed by artists in the UK to work with people with dementia. This forms part of NAWE's work with a larger project ArtWorks, a three-year Special Initiative being delivered by the Paul Hamlyn Foundation to support the continuing professional development of artists working in participatory settings.

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Part One: Introduction

We know a great deal about the generic skills, knowledge and understanding needed for working as an artist in participatory settings, as well as the values to be applied, and the learning pathways for such artists, but there are still gaps in our knowledge concerning practice differences.

In the NAWÉ lab we shall look at two areas of activity concerned with the arts and people with dementia: those involving writers, and those involving artists in other media, and the broad range of settings in which those activities take place. We will investigate the range of skills necessary for the successful completion of work in these areas, and the different purposes of the work.

The outcome of this lab will be learning around working as an artist with people with dementia, focusing in particular on the commonalities and differences between art forms, resulting in recommendations for training, qualifications and standards.

Methodology: Two roundtables have been convened to fulfil this brief, one made up of writers, and the other of artists in other media; this briefing paper is going to both. Participants will be invited to make provocations (brief presentations) on selected topics. The discussions will be recorded, and a summary of the key discussion points will be sent to all participants. A report making recommendations for training, qualifications and standards will be available at the end of the year and will be circulated widely. John Killick has been commissioned to write the briefing paper and report, as well as chair the roundtables.

Part Two: Snapshot of the current state of the arts and dementia in the UK

a) Activity

(i) General

Over the last fifteen years there has been a steady increase in the number and variety of projects involving people with dementia in artistic activities, and this trend is continuing. The vast majority of these have been concerned with art and/or crafts, or music, but there are also significant initiatives involving dance, drama and creative writing. An example of the former would be Music for Life, which has been bringing interactive music to groups in communal settings for most of this period. An example of the latter would be Chaturangan which is currently offering the experience of South Indian Dance to groups in Merseyside. There are also some combined arts projects, and intergenerational ones. The scene, after a tentative start, is looking increasingly healthy. (Details of these and other initiatives can be found in Appendix 1).

The geographical spread is uneven, with the larger conurbations (such as the London area and Tyneside) claiming the most, and there are still areas of the UK such as Northern Ireland where little seems to be happening. The Alzheimer's Society's successful programme 'Singing for the Brain' has swiftly spread throughout the UK.

Otherwise, most initiatives are small-scale and local, and there is little connection between them.

One publication *The Journal of Dementia Care* has worked tirelessly to highlight successful work and give practical advice over the period, and two organizations (Creative Dementia Arts Network and Arts 4 Dementia) have been founded in the past year with the aim of bringing practitioners together, but there are still far too few opportunities for sharing insights.

As many as eighteen books on creative approaches have become available in this country in the last five years. Some of these are the product of projects, some cover specific art forms, and two (those by Lee and Adams, and Killick and Craig) attempt to be comprehensive. (Details can be found in Appendix 3 along with articles which have appeared in the JDC over the last five years).

(ii) Aims

Projects can have a number of purposes: (i) artistic (ii) social (iii) clinical (iv) therapeutic. For example, a visual art project where the outcome would be an exhibition would be (i). A project which aimed at integration with the local community would be (ii). A project where the aim was to reduce drug use would be (iii). A project whose purpose was to assist with diagnosis would be (iv). Many projects would, of course, fall into more than one of these categories.

(iii) Artists

As far as we know, artists working in the field come from a variety of backgrounds, with a similar disparity in levels of experience and training. The team of professional performers that deliver Hearts and Minds' 'Elderflowers' programme with elderly people with dementia in Scotland, for example, come from backgrounds in acting, clowning, physical theatre and classical mime as well as directing, teaching and facilitating. They receive specific training to work in healthcare environments with vulnerable people. (You can meet the team at <http://www.heartsandminds.org.uk/elderflowers-meet.html>). Artists involved in the majority of action research projects with older people with dementia run by engage Cymru received awareness training from the Alzheimer's Society and Bangor University Dementia Research Department. We know that arts therapists will have had a high level of training. Some artists who have an extensive nursing background will have medical knowledge beyond the average, but they may also have absorbed attitudes and practices which could set them aside from other creative people. We have no idea of the number of artists involved.

(iv) Client Groups

These can include family carers, staff, other professionals, as well as people with dementia. A project may include training the staff to carry on the work, for example. Another one may include family carers alongside people with dementia.

(v) Settings

These can include day centres, residential and nursing homes, doctors' surgeries, hospital wards, arts centres and individuals' own homes. Some art forms may not be appropriate for certain settings. Some clients may not be able to move out of the setting

in which they are accommodated. In some settings or projects it may be appropriate to work one-to-one; in others in groups; and in some, both approaches may be possible.

(vi) Employers

These can include, as well as the places of work, universities, charities, theatre companies and arts councils.

(vii) Funders

These can be arts councils, social services, and especially charitable foundations such as Baring, Esme Fairbairn and Paul Hamlyn.

b) Training

Artists working in participatory settings can access training from various organizations such as NAWA, organized according to specific art forms. There are national occupational standards (NOS) in dance leadership and one in participatory arts leadership is under development (NOS describe what a competent person working in the field needs to know and understand, and what they need to be able to do) and codes of practice in music education, community dance and the visual arts (a code of practice sets out how a practitioner should behave). None of these specifically refer to dementia work.

In the dementia field, some training is offered in certain locations by individual organizations. There are no agreed standards and there is no coordination. Here are some examples:

* Alzheimer's Society offers a one-day workshop in dementia awareness. Participants who have completed this can go on to sit the Alzheimer's Society Foundation Certificate in Dementia Awareness.

- Arts 4 Dementia, in collaboration with Dementia UK, offers half-day courses for artists and volunteers.

- Bangor University, North Wales, in collaboration with Ty Newydd (the Welsh Writers Centre) and Dementia Services Development Centre, Wales, is setting up a training programme for writers this year which will be followed by similar programmes for artists in other art forms.

- Courtyard Arts Centre, Hereford is training writers to work in the community through an ongoing mentoring scheme.

- Cornerhouse and Library Theatre Company, Manchester, with funds from Paul Hamlyn Foundation and in collaboration with the Alzheimer's Society, will be offering training to artists for its storytelling through drama project. (They also hope to develop an evaluation framework with Manchester University.)

- Equal Arts in Gateshead offers training to artists and volunteers who work in its schemes.

- European Reminiscence Network has a 2-day training scheme for facilitators and a pilot apprenticeship scheme in Reminiscence Arts in Dementia Care in October 2012 in partnership with the University of Greenwich and the University of Bradford.

- Jabadao offer a bespoke one-day staff training course entitled 'Meeting Beyond Words'.

c) Research

There is a dearth of research in Arts and Dementia. This may reflect the difficulty in carrying it out. It may also be the result of the predominance of the medical in this funding area. Here are some examples of what has been attempted and what is ongoing:

- Music for Life (in collaboration with Dementia UK) has completed a research project on reflective practice, creative music-making, learning and dementia awareness. The researchers were Dr Rineke Smilde, Leader of the Lifelong Learning in Music in the Arts Research Group, Hanze University, Groningen and Professor Peter Alheit, University of Grottingen. Take a look at www.wigmore-hall.org.uk
- Paul Camic at Canterbury University has completed a pilot study on 'Does a 'Singing Together Group' improve the quality of life of people with dementia and their carers?' *Dementia* October 2011. Find out through www.sagepub.com
- Hearthstone Care (USA) in collaboration with Chris Gage of Ladder to the Moon is running a major study in the States called 'Whose Shoes?' It is just entering its second phase and involves 450 participants over 18 sites. See www.laddertothemoon.co.uk
- Kate Allan has begun a PHD on Flow and Dementia, and is particularly interested in how the arts can give people with dementia peak experiences. More information on www.dementiapositive.co.uk
- Bangor University (Gill Windle); Manchester Met University Arts for Health (Clive Parkinson) and Newcastle University New Dynamics of Ageing (Andrew Newman and Anna Goulding) have submitted a bid to AHRC for a 36-month project (decision due end of this year).
- The Newcastle Initiative on Changing Age at Newcastle University is undertaking the study 'Ageing Creatively' exploring the relation of creative arts interventions to wellbeing in later life. Find out more at http://www.ncl.ac.uk/changing_age/research/projects/ageingcreatively.htm

Part Three: Areas for Discussion

1) Knowledge

What kinds of knowledge do we need as writers/artists in order to work with people with dementia?

How best can we gain this knowledge?

Is working with people with dementia different from working with other groups in the community, and if so, in what ways?

Do we need to have a background of working in the community or in health and social care?

Do we need to have a personal experience of dementia?

What facts do we need to know about dementia?

What are the key gaps in our knowledge in this field?

Do writers experience this kind of work differently from other artists?

2) Values

What values should we be applying in this work?

Should the values be specific to this field or shared with other fields?

Need they be the same as those which apply in the settings where we work?

How are we to apply these values in assessing our work?

3) Skills and Settings

What skills do we need as writers/artists for working in these settings?

To what extent are these skills specific to the field of arts and dementia?

How best can we gain/develop these skills?

How does working in different settings affect our performance and/or ways of working?

What kinds of support do we need?

What would help us work more effectively in this field?

How are we to evaluate our contributions?

4) Conclusions

What are our recommendations for writers/artists working in this field in terms of:

a) Training

b) Qualifications

c) Standards

Appendix 1: Arts and Dementia Activity in the UK

Multi Arts

Artlink Central

Cowane Centre, Cowane, Stirling FK8 1JP

Arts and disability, health and prisons in Central Scotland. Dementia Training Handbook available to download.

Contact: Kevin Harrison Tel: 01786 450971 Email: info@artlinkcentral.org

Website: www.artlinkcentral.org

Artlink West Yorkshire

191 Belle Vue Road, Leeds LS3 1HG

The Living Story --- two projects with male and female patients in dementia wards. Book available to buy.

Contact: Dianne Darby Tel: 0113 2431005 Email: info@artlinkwestyorks.org

Website: www.artlinkwestyorks.org

Arts 4 Dementia

20 Charlwood Road, London SW15 1PE

Various arts initiatives in the London area and some training.

Contact: Veronica Franklin Gould Tel: 020 8780 5217 Email: info@arts4dementia.org.uk

Website: www.arts4dementia.org.uk

Collective Encounters

Liverpool Hope University, 17 Shaw Street, Everton, Liverpool L6 1HP

'Live and Learn' dementia programme based in North Liverpool. Audio material online.

Contact: Sarah Thornton Tel: 0151 291 3887 Email: info@collective-encounters.org.uk

Website: www.collective-encounters.org.uk

Entelechy Arts

The Albany, Douglas Way, London SE8 4AG

Pioneering multi-arts based company working nationally and internationally

Contact: David Slater or Lou Errington: Email: lou.errington@entelechyarts.org

Website: www.entelechyarts.org

Equal Arts

Swinburne House, Swinburne Street, Gateshead NE8 1AX

Offers a wide variety of art forms in a range of social and health settings in the North East of England. Regular newsletter.

Contact: Alice Thwaite Tel: 0191 477 5775 Email: information@equalarts.org.uk

Website: www.equalarts.org.uk

Innovations in Dementia

PO Box 616, Exeter EX1 9JB

DVDs made with people with dementia. Guide on filmmaking to download. DVDs to view online.

Contact: Steve Milton Tel: 01392 420076 Email: steve@innovationsindementia.org.uk

Website: www.innovationsindementia.org.uk

Magic Me

18 Victoria Park Square, London E2 9PF

Intergenerational projects. Newsletter available.

Contact: Susan Langford Tel: 020 32222 6064 Email: info@magicme.co.uk

Website: www.magicme.co.uk

Pictures to Share

Century House, High Street, Tattenhall, Chester CH3 9PX

Books specially designed for people with dementia. Catalogue available. Short DVDs can be viewed online. A user guide can also be downloaded.

Contact: Helen Bate Tel: 01829 770 024 Email: helen@picturestoshare.co.uk

Website: www.picturestoshare.co.uk

Sandwell Third Age Arts

9th Floor West Plaza, 144 High Street, West Bromwich, West Midlands B70 6JJ

Variety of art-forms offered to individuals and groups.

DVD of a project 'Fountain's Jolly Inn' can be viewed on line. DVD 'Art for the Person's Sake' available on request.

Contact: Sharon Baker Tel: 0121 500 1259 Email: info@staa.org.uk

Website: home.btconnect.com/sandwellcct/staa/

Pontio Project

Main Arts Building, Bangor University, College Road, Bangor LL57 2DG

New arts centre currently developing participatory programme with a focus on dementia.

Contact: Jerry Hunter Tel: 01248 351151 Email: wescO2@bangor.ac.uk

Website: www.pontio.co.uk

Creative Writing/Reading

Courtyard Centre for the Arts

Edgar Street, Hereford HR4 9JR

Poetry in dementia project in partnership with Ledbury Poetry Festival, funded by Esmee Fairbairn Foundation and Hereford Council.

Contact: Alice Saunders Email: alice.saunders@courtyard.org.uk

Website: www.courtyard.org.uk

New Writing North

Holy Jesus Hospital, City Road, Newcastle Upon Tyne NE1 2AS

'What about me' dementia and creative writing project to better understand the science and experience of living with dementia. Run in partnership with the Changing Age team at Newcastle University, Alzheimer's Society and Age UK Newcastle. Currently exploring scope for further work around this.

Contact: Anna Disley Tel: 0191 233 3850 Email: anna@newwritingnorth.com
Website: <http://www.newwritingnorth.com/communities-writers-in-communities-th-dementia-project-page-2134.html>
<http://nwncommunities.wordpress.com/>

The Reader Organisation

The Friary Centre, Bute Street, Liverpool L5 3LA

Get Into Reading groups in care homes for the elderly and those living with dementia across the UK. Open and commissioned training.

Contact: Katie Clark, Older People's Project Manager (on maternity leave, back December 2012 – locum, Emma Gibbons) Tel: 0151 2077207 Email: info@thereader.org.uk

Website: <http://thereader.org.uk>

Dance

Chaturangan

10 Awelon Close, West Derby, Liverpool L12 5JY

South Asian Dance – health and wellbeing initiatives with particular focus on older people.

Contact: Bisakha Sarker Tel: 07850 127823 Email: bisakha@blueyonder.co.uk

Website: www.chaturangan.co.uk

Circle Dance in Dementia

DVDs to view online. Commissioned training.

Contact: Kath Kershaw or Cynthia Heymanson Email: kath.kershaw@hotmail.co.uk

Website: www.circledanceindementia.com

Green Candle Dance Company

Oxford House, Derbyshire Street, Bethnal Green, London E2 6HG

A community and education dance company

Contact: Fergus Early Tel: 0207 739 7722 Email: info@greencandle.com

Website: www.greencandle.com

Jabadao

Robin Lane Health Wellbeing and Medical Centre, Robin Lane, Pudsey, Leeds LS28 7DE

Movement play specialists promoting physical communication through playful interaction.

Bespoke training offered. DVD can be viewed online.

Contact: Penny Greenland Tel: 0113 236 3311 Email: info@jabadao.org

Website: www.jabadao.org

Drama/Film

Age Exchange

11 Blackheath Village, London SE3 9LA

Reminiscence theatre and creative activities. Training courses and publications.

Contact: Craig Muir Tel: 020 8318 9105 Email: administrator@age-exchange.org.uk

Website: www.age-exchange.org.uk

CIRCA Connect

School of Computing, University of Dundee, Dundee DD1 4HN

Exploring ways in which computer-based technologies can help support people living with dementia. 'Living in the Moment' touchscreen entertainment complex available to buy.

Contact: Norman Alm Tel: 01382 385596 Email: nalm@computing.dundee.ac.uk

Website: www.circaconnect.co.uk

Cornerhouse & Library Theatre Company

70 Oxford Street, Manchester M1 5NH

Storybox – three-year project using drama and storytelling to engage older people with dementia. Run in partnership with the Alzheimer's Society with funding from the Paul Hamlyn Foundation.

Contact: Lowri Evans, Storybox Project Coordinator Tel: 0161 200 1533

Email: lowri@librarytheatre.com

Website: <http://www.librarytheatre.com/project/storybox>

Hearts & Minds

The Canon Mill, Canon Street, Edinburgh EH3 5HE

Elderflowers Project – interactive humour in hospital settings with elderly people with dementia. DVD available for sale.

Contact: Magdalena Schamberger Tel: 0131 270 6051 Email: enquiries@heartsminds.org.uk

Website: www.heartsminds.org.uk

Ladder to the Moon

Branch Hill House, Branch Hill, Hampstead London NW3 7LS

Relationship theatre to improve the quality of care services. DVD material can be viewed online.

Contact: Chris Gage Tel: 020 7794 2593 Email: chris@laddertothemoon.co.uk

Website: www.laddertothemoon.co.uk

Salmagundi Films

The Studio, 44 Forest Lane, London E15 1HA

Using Stop Frame Animation to engage people living with people. DVD extracts can be viewed online.

Contact: Zoe Flynn or Bo Chapman Tel: 0208 519 0143 Email: studio@salmagundi.co.uk

Website: <http://www.salmagundifilms.co.uk/#Working-with-Dementia>

Music

Barchester Music Therapy

A healthcare company offers music therapy with 13 therapists working in 25 homes.

Contact: Stuart Wood Email: stuartwood@gmail.com

Website: www.barchester.com/media/news/2009/6/music-therapy-reveals-the-creativity-in-people-htm

Harmony

The Avenue, Drygrange, Melrose, Scottish Borders TD6 9DH
Gives concerts in 100 venues once a month. Video on YouTube.
Contact: Violet Baillie or Jim Smith Tel: 01896 849778
Email: harmonyharmony@btinternet.com
Website: www.bowden.bordernet.co.uk

Lost Chord

The Wesley Centre, Blyth Rd, Maltby, Rotherham S66 8JD
Concerts in care homes in South Yorkshire. DVD material available online.
Contact: Helena Muller Tel: 01709 811160 Email: helena@lostchord.fsnet.co.uk
Website: www.lost-chord.org.uk

Music For Life

Wigmore Hall, 36 Wigmore Street, London W1U 2BP
A collaboration between Dementia UK and the Wigmore Hall offering live music in residential homes, hospitals and day centres.
Contact: Elizabeth McCall, Head of Learning Tel: 020 7258 8241
Email: emccall@wigmore-hall.org.uk
Website: <http://www.dementiauk.org/what-we-do/learning-partnerships-and-training/learning-partnerships/music-for-life/>

Singing for the Brain

Service provided by the Alzheimer's Society in locations across England, Wales and Northern Ireland which uses singing to bring people together in a friendly and stimulating social environment.
Website: <http://alzheimers.org.uk/singingforthebrain>

Sing for your Life

Shepway Business Centre, Shearway Business Park, Folkestone, CT19 4RH
Improving the health and wellbeing of older people through music. Runs Silver Song Clubs across England. There is a DVD online.
Contact: Adrian Bawtree Tel: 01303 298546 Email: adrian@singforyourlife.org.uk
Website: www.singforyourlife.org.uk

Turtle Key Arts

Ladbroke Hall, 79 Barlby Road, London W10 6AZ
Mounts performance arts projects with emphasis on disabled, disadvantaged or socially excluded people. 'Turtle Song' is a collaboration with English Touring Opera and the Royal College of Music in the making of a song cycle.
Contact: Charlotte Cunningham Tel: 020 8964 4080 Email: charlotte@turtlekeyarts.org.uk
Website: www.turtlekeyarts.org.uk

Visual/Applied Arts

Art in Hospitals

Blawarthill Hospital, 129 Holehouse Drive, Glasgow G13 3TG

Provides an extensive programme of visual arts in a variety of healthcare settings in the city of Glasgow and Scotland-wide, working especially in long-term care for older people.

Exhibitions and publications available.

Contact: Barbara Gulliver Tel: 0141 211 9031 Email: info@artinhospital.org

Website: www.artinhospital.org

engage Cymru

34 Dewing Avenue, Manorbier, Pembrokeshire, SA70 7TS

The UK's leading membership organisation for gallery education. Has run a number of Wales-wide action research projects focusing on older people with dementia in care homes, assessment units in hospitals, and galleries. Evaluation report 'Quality of Silence' available at www.engage.org/downloads/OP_Research_Report_English.pdf.

Contact: Angela Rogers Tel: 01834 870121 Email: cymru@engage.org

Website: www.engage.org

Appendix 2: Umbrella Organizations

Arts 4 Dementia

Forum for arts and dementia in London area

Contact: Veronica Franklin Gould, 20 Charwood Road, London SW15 1PE

Tel: 020 8780 5217 Email: info@arts4dementia.org.uk

Website: www.arts4dementia.org.uk

Arts and Dementia Network

Forum for arts and dementia in the North East of England

Contact: Ruth Abbott, Equal Arts, Swinburne House, Swinburne Street, Gateshead NE8 1AX

Tel: 0191 477 5775 Email: ruth@equalarts.org.uk

Website: www.equalarts.org.uk

Centre of Excellence in Movement, Dance and Dementia

Aims to equip health professionals and others working in dementia care with the knowledge and skills necessary to explore and develop the use of movement and dance

Contact: Richard Coaten Tel: 01422 385775 Email: richard.coaten@swyt.nhs.uk

Website: www.dancedementiahub.co.uk (under construction)

Creative Dementia Arts Network

Works to promote participation in the arts for people with dementia in care homes and community through providing information, training, consultancy and research services for both commissioners and arts providers

Contact: Maria Parsons Tel: 07801 509993 Email: info@creativedementia.org

Website: www.creativedementia.org

European Reminiscence Network

15 Camden Row, Blackheath, London SE3 OQA

Creative approaches to reminiscence. Offers training in reminiscence arts in dementia care.

Contact: Pam Schweitzer Tel: 020 8852 9293 Email: pam@pamschweitzer.com

Website: www.europeanreminiscencenetwork.org

Society for the Arts in Dementia Care, Canada

Contact: Dalia Gottlieb-Tanaka, Chair Email: info@cecd-society.org

Website: www.cecd-society.org

UK contact: Association for Dementia Studies, Institute of Health and Society, University of Worcester, St John's Campus, Henwick Grove, Worcester WR2 6AJ

Aims to become the centre for excellence for arts work in the UK.

Contact: Karan Jutlla Tel: 01905 855250 Email: k.jutlla@worc.ac.uk

Website: www.worc.ac.uk/discover/association-for-dementia-studies

Websites

Age of Creativity

A platform for anything and everything that can inspire, inform and support art projects for older people

Website: www.ageofcreativity.co.uk

Dementia Positive

Encouraging communication, consultation and creativity in work with people who have dementia

Contact: John Killick or Kate Allan Tel: 07971 041844 or 07971 170243

Email: johnkillick@dementiapositive.co.uk or kateallan@dementiapositive.co.uk

Website: www.dementiapositive.co.uk

Appendix 3: Bibliography

Books published since 2007

Clegg D. (2007) *Ancient Mysteries* (prose) Trebus

Killick J. (2007) *Dementia Diary* (poems) Hawker

Hayes K. (2007) *The Edges of Everywhere* (Poems) City Chameleon

Heathcote J. (2008) *Memories are made of this: reminiscence activities for person-centred care* Alzheimer's Society

Hayes K., Aylwin R. (2008) *Only Just Orchid* (poems) Margent

Schweitzer P. Bruce E. (2008) *Remembering Yesterday, Caring Today* Jessica Kingsley Publishers

Basting A.D. (2009) *Forget Memory: Creating better lives for people with dementia* John Hopkins University

Killick J. (2009) *The Elephant in the Room* (poems) Cambridgeshire County Council

Whitman L. (2009) *Telling Tales about dementia: experiences of caring* Jessica Kingsley Publishers

Rio R. (2009) *Connecting through music with people with dementia: a guide for caregivers* Jessica Kingsley Publishers
 Zeisel J. (2010) *I'm Still Here: A breakthrough approach to understanding someone living with Alzheimer's* Piatkus
 Zoutewelle-Morris S. (2011) *Chocolate Rain: 100 ideas for a creative approach to activities in dementia care* Hawker
 Killick J. (2011) *In the Pink* (poems) Courtyard Centre for the Arts, Hereford
 Clegg D. (2011) *Tell Mrs Mill her husband is still dead* Rebus
 Killick J, Craig C. (2011) *Creativity and Communication in Persons with Dementia* Jessica Kingsley Publishers
 Hayes J., Povey S. (2011) *The Creative Arts in Dementia Care, Practical Person-Centred Approaches & Ideas* Jessica Kingsley Publishers
 Lee H., Adams T. (2011) *Creative Approaches in dementia care* Palgrave Macmillan
 Killick J. (2012) *Singing Under Our Breath* (poems) Courtyard Centre for the Arts, Hereford

Practice articles from the *Journal of Dementia Care* since 2007

(The *Journal of Dementia Care* is the leading journal for professionals working with people with dementia. Details of how to subscribe and buy individual articles at: <http://www.careinfo.org/journal-of-dementia-care/uk-jdc-subscriptions/>)

Wood S. (2007) *Chalfont Lodge Choir: heart of a home and community* 15(1)
 Clegg D. (2007) *The Trebus Archive: piercing the fragments together* 15(3)
 Hayes K. (2007) *Devising the Poetry of Dementia* 15(4)
 Rose L. et al (2008) *Music for Life: a model for reflective process* 16(3)
 Killick J. (2008) *'It moves you, it hits you inside': Reading Poems at Redholme* 16(6)
 Killick J. (2008) *Museums, the Arts, responsive care and supportive design* 16(4)
 Greenland P. (2009) *Dance: five minute love affairs* 17(1)
 Gilfoy K., Knocker S. (2009) *Magic Across the Generations* 17(3)
 Benson S. (2009) *Ladder to the Moon: interactive theatre in care homes* 17(4)
 Whyte S. (2010) *Life Enhancing Dance for elders with dementia* 18(2)
 Powell H., O'Keefe A. (2010) *Weaving the threads together: music therapy in care homes* 18(4)
 Wynn-Jones F. et al (2010) *A whole month of pleasure making music on the South Downs* 18(4)
 Newman-Bluestein D., Hill H. (2010) *Movement as the medium for connection, empathy, playfulness* 18(5)
 Killick J. (2010) *The Funshops: improvised drama and humour* 18(6)
 Sherratt C. (2010) *Lighting Up: lessons learned in establishing an arts project* 18(6)
 Killick J. (2010) *The Power of Laughter* 19(1)
 Rodger R. (2011) *Dance for all* 19(2)
 Hendron J. et al (2011) *Yes, we can together (quilting)* 19(2)
 Crockett S. (2011) *Music in the air* 19(2)
 Dennis E. (2011) *It's a good thing to have, to keep you happy (music)* 19(2)
 Salisbury K. et al (2011) *Arts programmes and quality of life for people with dementia – a review* 19(3)
 Nairn H. (2011) *'Thank you very much for that' (music therapy)* 19(4)
 Craig C., Killick J. (2011) *Why creativity and dementia go together* 19(6)
 Flynn Z., Chapman B. (2011) *Making animated films with people with dementia* 19(6)
 Hayes K. et al (2012) *Poetry in Dementia Care: one project, four voices* 20(1)

Hayes K. et al (2012) *Poetry in Dementia Care: overcoming the challenges* 20(2)
Dowson B. (2012) *Meeting Through Music* 20(2)

Because people with advanced dementia can no longer communicate clearly, they cannot share their concerns. Is Uncle Bert refusing food because he's not hungry or because he's confused? Why does Grandma Sakura seem agitated? Caring for people with Alzheimer's or other dementias at home can be demanding and stressful for the family caregiver. Depression is a problem for some family caregivers, as is fatigue, because many feel they are always on call. Family caregivers may have to cut back on work hours or leave work altogether because of their caregiving responsibilities. Many family members taking care of a person with advanced dementia at home feel relief when death happens for themselves and for the person who died. Max, 81, now suffers from advanced dementia. Nine people with 'direct knowledge of his condition' told the New York Times he hasn't seriously painted in four years. This would surprise many who have spent tens of thousands of dollars on Max's art at cruise auctions, purchasing work from the studio that, up until recently, was run by his son Adam. A shocking new expose has claimed that the estranged son of Pop Art sensation Peter Max (pictured in 2012) hired 'ghost painters' to mimic his father's work and continue making a profit even as Max himself fell deep. Dementia affects everyone differently so it's important to communicate in a way that is right for the person. Listen carefully and think about what you're going to say and how you'll say it. You can also communicate meaningfully without using spoken words. Communicating and dementia. Dementia and language. You are here: Tips for communicating with a person with dementia. Non-verbal communication and dementia. Dementia and sensory impairment: communicating. As populations age, caring for people with dementia has become more common. Elderly caregiving may consist of formal care and informal care. Formal care involves the services of community and medical partners, while informal care involves the support of family, friends, and local communities, but more often from spouses, adult children and other relatives. In most mild to medium cases of dementia, the caregiver is a family member, usually a spouse or adult child. Over time more professional care in