

# DEMENTIA & IMAGINATION

Research Informed Approaches  
to Visual Arts Programmes

# About this handbook

## What it is, and what it is not

This handbook is not a tool-kit of prescription exercises to deliver visual arts projects, and it's not an evaluation guide. What it is, is a result of a research project and is intended to be used by artists and other people who plan to deliver arts-based activities with people who are living with dementia. It is a set of **useful ideas and recommendations** that come from a robust research project setting out some **foundations** for developing visual arts projects with and for, people affected by dementia. It is designed to be as accessible as possible. In it you will find information about the Dementia & Imagination project; some **key ingredients** for delivering research-informed visual arts projects; case studies, a set of guiding principles, reflections of people involved in the programme, and some recommendations. If you want to read about the research in detail, or find other sources of support, this handbook will direct you there.

This is the second edition of this handbook, and as we deliver training across the UK over 2018/19 we recognise that we will continue to refine this book. We would welcome any comments, reflections and suggestions you may have for the next update. Please forward these to us. You can find our contact details at the back of this handbook.

Section One - Setting the Scene

Section Two - Foundations for Excellent Practice

Section Three - Supporting Materials





People living with dementia and artists take inspiration from an exhibition in the North East.



# SECTION ONE

## Setting the Scene

### Introduction

In 2013 and with funding from the Arts and Humanities Research Council and the Economic and Social Research Council, the Dementia & Imagination team established a clear set of principles to underpin its visual arts research programme with people experiencing dementia in three geographical areas of the UK: North Wales, Derbyshire and Newcastle. These are what we call our research sites. Our team is a mixture of researchers and artists who are affiliated to Nottingham Contemporary for Derbyshire, Equal Arts for Newcastle and Denbighshire Arts Service, Denbighshire County Council for North Wales. We collaborated with people affected by dementia, families and professional carers to develop all aspects of our work. You can read more detail about the research and how it was undertaken in Section Three of this handbook.

Through large-scale events in Manchester and Nottingham, we developed our research questions. Through small-scale events with artists involved in providing the visual arts programmes, we delivered workshops to explore how they would facilitate this work. By 'programmes', we mean the consistent, high quality arts workshops with people living with dementia that we as a research team would try to understand.

We reviewed all the existing research and reports around claims that the arts impact on the health and wellbeing of people with dementia, and alongside all our overarching research questions



to explore how the visual arts can contribute to the creation of dementia friendly communities, we developed some founding principles based on two questions:

**What are the ingredients of an effective arts intervention?  
How do these arts interventions influence wellbeing?**

What we wanted to achieve through our research

#### **For the people living with dementia**

1. Improved wellbeing, observed as:
  - Pleasure/happiness
  - Interest and engagement
  - Attention and focus
  - Self esteem
  - Feeling 'normal'
2. Improve people's social connectedness
3. Reduce loneliness
4. Increase quality of life
5. Increase engagement with arts and cultural activities
6. Reduced distress and negative emotions

#### **For the staff and carers**

1. A deeper understanding of living with dementia
2. Improve social connectedness
3. New learning
4. Increase engagement with arts and cultural activities
5. Address wider perceptions of people dementia

#### **Our broad study aim**

To understand and demonstrate how art can contribute to the creation of dementia friendly communities. Dementia Friendly Community initiatives are springing up across the UK.



They aim to help people with dementia reconnect with their communities instead of becoming increasingly isolated. They also aim to challenge the stereotypes which limit the potential of people with dementia to enjoy and contribute to life in the community. That is one reason why there has been a strong community dimension to our project. We have been exploring how and why art seems to help people with dementia, and at the same time investigating the wider social and community implications.

#### **First Things First**

For artists of any discipline working with people living with dementia in community, clinical or domestic settings, an understating of dementia is critical. While interpersonal skills and sensitivity to individuals who experience memory loss might not be something that can be taught, dementia awareness training is available from a wide range of organisations, as is the support of Dementia Friends who provide critical insight into the real experiences of people experiencing dementia. Try to spend time with someone living with dementia. Organisations like Alzheimer's Society and Age UK offer important signposting. Details of Dementia Friends are in the Useful Connections section of this handbook. Here you'll find one or two simple and

informative resources like "Promoting psychological wellbeing for people with dementia and their carers": An enhanced practice resource which was developed for NHS Scotland.

### **Understanding Dementia**

Dementia is a neurodegenerative disorder which results in a range of symptoms experienced by the individual, and this is a key point, because every individual will have a different experience of different types of dementias. This means thinking, feelings and behaviour are affected as well as attention, memory, planning and inhibition.

Alzheimer's Disease International suggest that 46.8 million people have dementia worldwide. This is to estimated increase to 131.5 million in 2050. Dementia is poorly understood by the general public. People living with dementia, their families and carers, report high levels of stigma, social isolation or exclusion. Consequently there is a need to increase public awareness and challenge negative stereotypes about dementia.

There is currently no cure for dementia and the effectiveness of medication is limited, meaning dementia represents a challenge for healthcare. However, there is growing evidence from psychosocial approaches to dementia care, which aim to improve peoples' health, wellbeing and quality of life, enabling people to live as well as possible with the condition. The availability of innovative and effective arts activities that demonstrate impact on wellbeing and promote knowledge, potential and dialogue are timely and important.

### **Understanding the Arts in the context of Dementia**

The arts embody human expression – physical evidence of the impulse to create – influencing culture, changing culture and sharing stories with a wider world. Article 27 of the 1948 UN Declaration of Human Rights, states that: "Everyone has the right to freely participate in the cultural life of the community and to enjoy the arts", yet when people become disabled

or marginalised because of ill health, life opportunities can decrease significantly.

The Dementia & Imagination project recruited artists to facilitate group sessions focusing on connecting people; wellbeing; self-expression and pleasure – and the quality of our lives as we age, with (or without) a diagnosis of dementia.

Our work is not described as art therapy, although it may feel therapeutic to participants. Art therapy is a form of psychotherapy that uses visual art media as its primary mode of communication. It is a statutorily regulated profession and in the United Kingdom, only those persons who are appropriately qualified and registered by the Health and Care Professions Council can practice Arts Therapy. Therefore, the Dementia & Imagination project was not art therapy and it was not about reminiscence, but rather imagination, and living in the moment.

In a report to the government in 2008 The Foresight Project considered how to achieve the best possible mental development and mental wellbeing for everyone in the UK in the future. In response to this report, the New Economics Foundation set out what are now regarded as the five key actions we can all undertake to improve personal wellbeing: connect, be active, take notice, keep learning and give. The Dementia & Imagination visual arts activity encompassed each of these five actions to ensure an impact of the activity on wellbeing.

Currently the National Institute of Health and Clinical Excellence (NICE) recommend cognitive stimulation groups as a psychosocial treatment for people living with mild to moderate dementia. Cognitive stimulation may be a key aspect of the art programme described here, as there is congruence between the 'guiding principles' of cognitive stimulation, as described by Aguirre and colleagues, (2011) and aspects of the arts programme. If an arts programme reflects the 'foundations of excellent practice' identified in this booklet, services could consider provision as a follow-on or even perhaps an alternative to a conventional cognitive stimulation group.



# Dementia & Imagination – Developing the Research and Arts Programme – a summary

The design of our visual arts programme was informed through a survey of stakeholders and workshops with artists, exploring how and why such arts programmes may bring about positive changes. This was further underpinned by a rigorous exploration of what previous research tells us about arts and dementia research, this is described as a realist synthesis. This theoretical basis is recognised as important to inform an appropriate research design, and reflects the ‘Foundations for Excellent Practice’ we describe in this booklet.

Building on recognised examples of good practice, our arts programme extends the principles of creative ageing in older adults (Cohen et al., 2006) to those living with dementia. It comprises two underpinning factors:

1. **Dynamic and responsive artistic practice**
2. **A provocative and stimulating aesthetic experience**

We developed participatory art activities that offered stimulating, high quality experiences for the participants and which required no prior knowledge, experience or artistic skills. These interventions aimed to encourage creativity without overwhelming people with complex instructions, be interesting and challenging, and promote learning where possible.

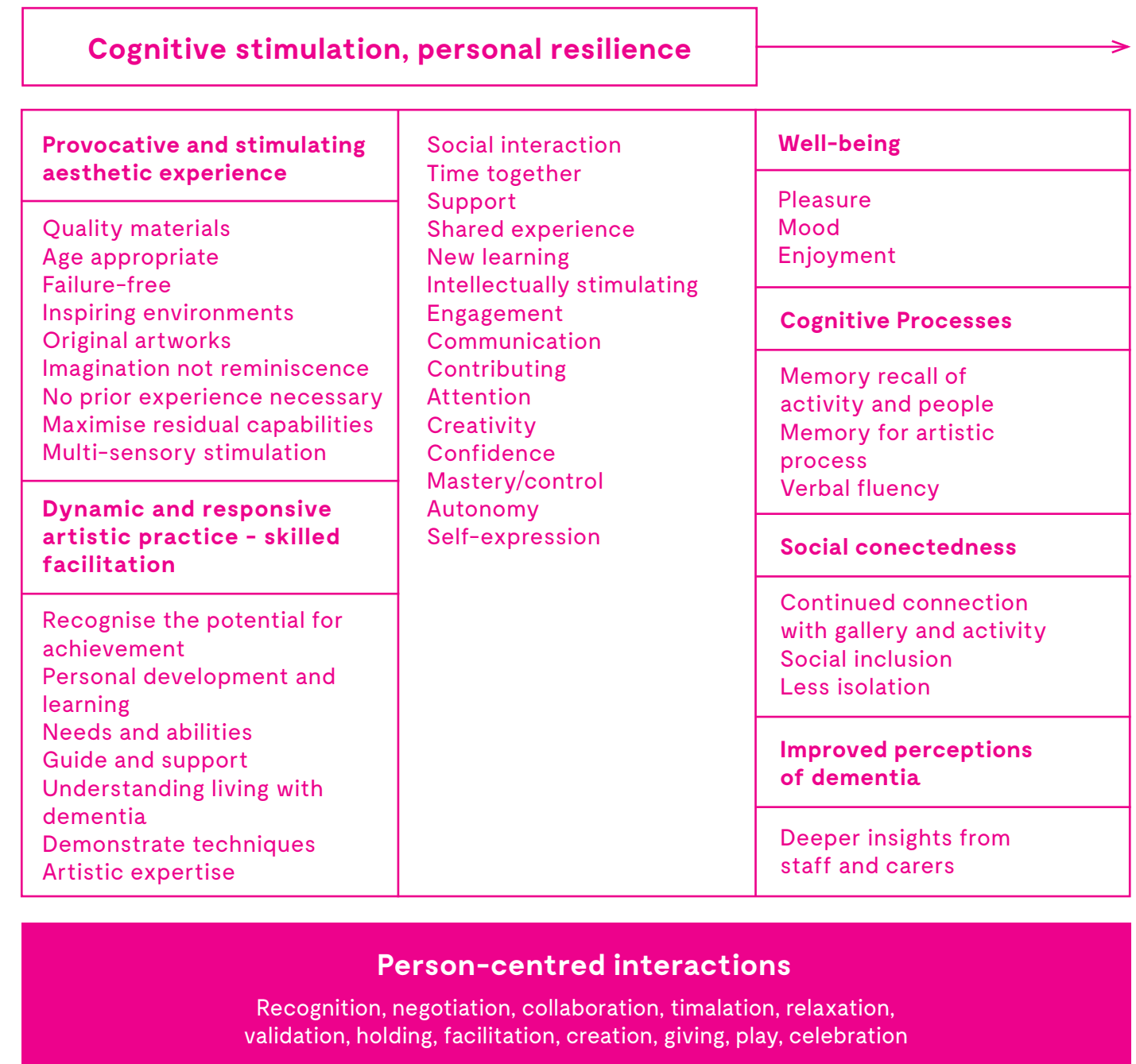
We wanted our arts activities to offer meaningful engagement, stimulating imagination and discussion. We did not want to lecture participants or focus on factual discussions, which are dependent on memory, names and dates. We wanted to provide structure, alongside the opportunity for individual expression, fun and celebrations of achievements in a failure-free environment, with art as the catalyst.

Artists had to adapt to the needs of the participants and their level of impairment, adjusting practice activities for those with advanced dementia week by week, and within the session.

## Visual Arts Programmes - the aesthetic encounter

### Mechanisms

### Outcomes







Facilitated group discussion with artists in North Wales.



## Delivering the Dementia & Imagination Arts Programme – a summary

The following is a simple summary of what we did. Section two expands on this, describing what we feel are the underpinning foundations for excellent practice.

The arts programmes consisted of small groups with a maximum of fifteen participants. Each research site in Derbyshire, Newcastle and North Wales was expected to deliver four waves of activity, with each wave structured as a once a week, two-hour activity over twelve weeks.

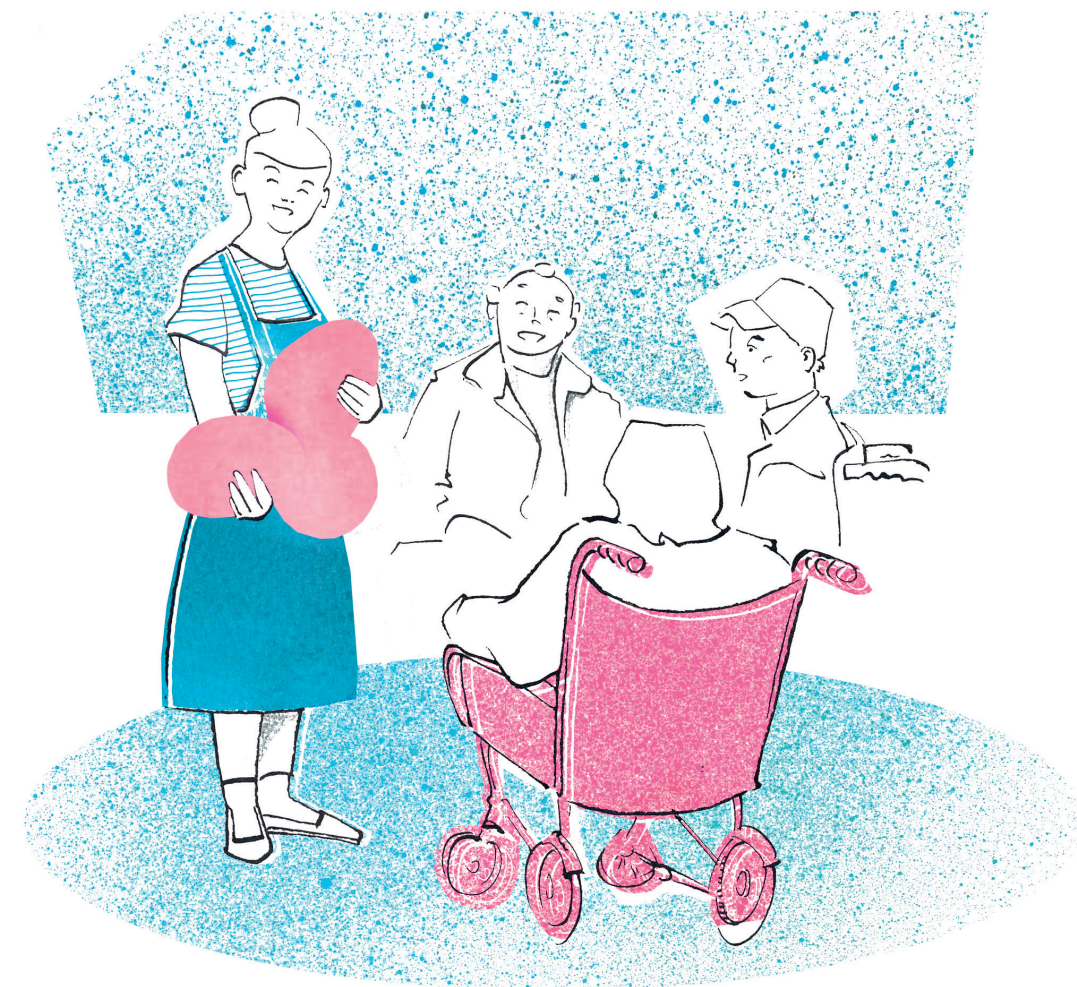
Our programme was delivered to people with varying degrees of impairment, ranging from those in milder stages of the condition still living at home (mainly in North Wales) through to those with more advanced dementia living in care facilities (mainly in Newcastle). However, distinctions in impairment are not hard and fast, with some people in advanced stages being supported at home. One hundred and twenty-five people living with dementia, and one hundred and forty six professional and family carers took part across the three research sites. The delivery of the programme was led by our community arts partners. Nottingham Contemporary worked in the Derbyshire site, Equal Arts in the Newcastle site and Denbigh County Council Community Arts for the North Wales site.

A lead artist with prior experience and training in art and dementia, supported by a second artist, facilitated each session. Regular contact was maintained between the research team and arts partners. It was not a requirement that carers and staff were engaged alongside the participants, although some chose to take part.

This was a multi-sensory experience. Sessions were generally structured so that the first half was an art viewing activity, focusing on a small number of artworks and the second half was art-making, inspired by the viewing activity.

Where practical, visits to local galleries and community libraries were made, providing cultural settings for the arts programme to take place. Where gallery visits were not possible, because of the increased risk, the artists brought a small selection of artworks to the participants to facilitate discussions. In care settings, the environments were transformed.

With participants' permission, artworks were professionally curated and exhibited in public spaces, at the end of each overall wave of activity. In North Wales an exhibition was held after each wave of activity.



# SECTION TWO

## Foundations for Excellent Practice

In this section we share what we describe as the key ingredients, or foundations of excellent practice. They are not exhaustive by any means, but form the bedrock of research-informed visual arts practice within dementia contexts.

1. Artists Understanding Dementia
2. Developing a safe and supportive physical and psychological environment for an inspirational visual arts viewing and making programme
3. Creating a structure for the viewing and making sessions
4. Delivering sessions that enable inspiration, imagination, creativity, enjoyment and celebration
5. Using the sessions to develop social connections with the groups
6. Artists Development and Training
7. Values, Ethics and Communication: Some Guiding Principles

### **1. Artists Understanding Dementia**

We began this booklet highlighting that it is critical that artists working with people with dementia, have an understanding of living with the condition, and a sensitivity to the experiences of people affected by it. This doesn't mean that artists are expected to be clinical specialists - on the contrary - it simply means that if you are equipped with some basic understanding and concepts, and are working safely and in a supportive environment where those you meet and work with have an understanding of what you're trying to achieve - and how - you will be more likely to be able to deliver your best work.



The professional and informed knowledge and support available should be used to improve the experience for everybody, and before any arts project happens, artists should always attempt to develop a meaningful relationship with people living with dementia.

One of the major influences in dementia care is the 'person-centred approach', developed by Professor Tom Kitwood (1997). This recognises that people with dementia have five main psychological requirements to support their quality of life: comfort, attachment, inclusion, occupation, and identity. Consequently, wellbeing and a life with quality are a direct result of the quality of the relationships between people with dementia and those around them. Highly relevant to arts practice delivery are the suggestions of twelve positive interactions that are theorised to underpin good dementia care.

**The best outcomes will be achieved by artists who have a good understanding of dementia and embed person-centered approaches into their own practice, and who see dementia not just as a health issue, but a social one too. Being dynamic, inspirational and responsive is crucial. The abilities and needs of the participants will vary within and between sessions, with best outcomes achieved when artists are able to adopt responsive practice and through this, observe and listen, acknowledge emotional expression, empathise, take note and adjust the pace and content of their work accordingly.**

It is easy to assume that we would all be appropriately responsive to the changing dynamics of an arts session, but bear in mind that dynamics change quickly. People may become angry, they may destroy their work - they may simply fall asleep - so have in mind contingencies for the unexpected. Often these changes may be positive and involve singing, or individuals with strong personalities dominating sessions. It is important then, to create the right kind of physical and psychological environment for your activities to take place in.

For useful sources of training and support around dementia awareness, see the Useful Connections at the rear of this handbook.

It's quite something really. It's very soothing to take part in something. You feel you are achieving something. It's not completely gone - your mind's not completely gone. It relaxes you, for the whole day. I feel I'm not going as daft as I thought I was going! There are still some things I can still do and still take part. What a difference! I'm kind of on a high. I enjoyed it...it's far better to be going and doing something, and doing it with other people.

(Female participant living with dementia)

Participants engaging in group activities.



Psychological needs of the person living with dementia	Explanation
Comfort	Carrying 'meanings of tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety, the feeling of security which comes from being close to another' (p.81).
Attachment	The need to be bonded to others and to know that, despite losses of primary relationships, there still is a group of persons that accepts one. This need flows into the need for inclusion, the need to be accepted into a group and to be part of the social life of that group.
The need for occupation	This is met when the person with dementia is engaged in activity that is meaningful, significant and personally appropriate. This type of activity may be work-like or may take the form of participation in intellectual activity, media or the arts. Knowing the individual's past and what has been meaningful to them helps in the planning of appropriate occupation.
Maintain identity	When a person with dementia cannot remember who they are or who they were, staff and carers, by knowing the individual's history, can help them to remember and help maintain continuity in their identity.
Inclusion	Human beings are social creatures. The social life of the person with dementia should be actively nurtured, regardless of the level of impairment.

Positive interactions for person-centred arts approaches	Explanation
Recognition	The person with dementia is acknowledged as a unique and individual person, known by name and respected for who they are.
Negotiation	The person with dementia is consulted about their preferences, desires and needs rather than having the carer make assumptions. Negotiation goes at the pace of the person.
Collaboration	Working together to accomplish a shared task; person is not passive; a process in which their own abilities and initiatives are involved.
Play	The kind of spontaneous activity that has no other particular goal than self-expression and enjoyment. This can be nurtured in the right environment.
Timalation	An interaction involving the senses, not requiring cognitive abilities, providing contact, reassurance and pleasure without demands
Celebration	Involves acknowledging and holding up moments that are intrinsically joyful and participating in them to the fullest capacity. The interaction is an equal experience between the person and the carer.
Relaxation	Involves a letting go of bodily tension and a sense of comfort in sharing that tension-free slow pace with others in the common group.



Positive interactions for person-centred arts approaches	Explanation
Validation	To support the person's experience by acknowledging their feelings and emotions, and respond based on feelings and empathy, nurturing rather than confronting 'reality' enabling them to feel connected.
Holding	Means providing a safe psychological space into which the person with dementia can bring any feeling or emotion and know that all will be accepted.
Facilitation	Enables a person to 'do what otherwise he or she would not be able to do, by providing those parts of the action – and only those – that are missing' (Kitwood, 1997, p.91).
Creation	The person with dementia takes the lead and spontaneously offers the social setting, something from his or her own ability and/or social skill and invites them to join (e.g. reading a favourite poem to the group).
Giving	The person with dementia, because of their own sensitivity, expresses concern, affection, a desire to help or a sense of gratitude.

## 2. Developing a safe and supportive physical and psychological environment for an inspirational visual arts viewing and making programme

**Best results will be achieved in an inspirational setting that is adapted where necessary to support and stimulate people living with dementia. Artists should be enabled to visit the space and meet workers well in advance of the sessions and consider practical aspects in advance, so participant safety and risks are managed accordingly.**

A phone call to the participants/carers/staff the day before the session will be a useful reminder. If working in the community, you may have to help with arranging transport. This could be a useful reminder to ensure people have their glasses, hearing aids and other agreed resources for the session with them. Galleries can be a source of inspiration and stimulation. If practical, aim to work in a gallery or museum setting, or try and incorporate a trip to one. If taking people from care settings, ensure you consider the amount of time required to get people ready to leave. Galleries and museums offer a connection to the wider community and build people's confidence to be in wider, social and cultural spaces.

Cultural venue cafes are often positive spaces for meeting, relaxing and conversation. The walk to the Gallery from the workroom provides another element in the rhythm of the sessions and an opportunity for participants to form their own groups for chatting as they walk to the gallery and around the exhibition.

Finding a time that is suitable for care staff and gallery staff will require some negotiation. If this is not possible, because not everyone will be able to get out to a gallery, look to recreate that experience in the environment you are working in.

The venue must be accessible and easy to find. Parking needs to be close. If taxis are used, try to find a taxi company that has had dementia awareness training, or at least, establish good practice with them, for example, taking their passenger

to the door and walking them to the taxi afterwards. If possible, try to get the same driver each time. A ground floor venue is preferable. If this is not practical, lifts must be available. The simple things like lighting, access to toilets and ease with which drinks and refreshments can be served are important. Some of our artists found it easier to arrive early and prepare hot drinks in advance from a pre-planned drinks list. Always have a safe place to store coats and bags for participants. These points may seem superficial, but are critical to the smooth flow of an arts programme and the comfort of the people you are working with.

It is also important that the group will not be disturbed. In advance, try to communicate the importance of staff, carers and family members not walking into the session when it is part way through. The room should be private and not a through route where anyone can pass through, as this disrupts the safe space and group cohesion you are trying to create. However, we acknowledge that this might not always be possible, for example if you are working on an inpatient ward.

Try and choose an environment that is large and bright, comfortable, convenient and accessible. In health and care facilities, try to use alternative space if possible, not a typical dayroom and minimise distractions. Where practical, change the dynamics of the space that make it unique for the sessions you will be working there, and remember, the hearing and vision of participants might be impaired, so be aware of noises and obstacles.

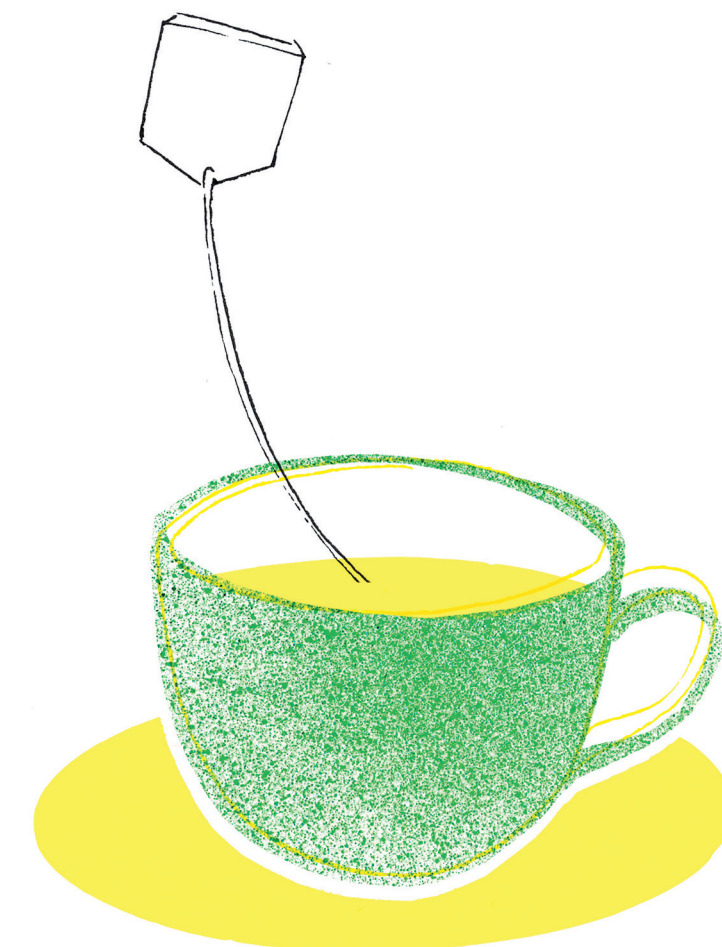
To ensure continuity, aim to create a familiar setting each week. This could incorporate the same distinctive table covers, the way the room is presented, the type of food used. Try and display work from previous week. Artists might consider consistency in clothes worn, for example, the same colour apron each week, and many of our artists recommended clear black and white name badges for everybody involved. This familiarity can be further supported by music or song that marks the beginning of a session and helps orientate people. Shaking hands with people as they arrive is a strong symbol that almost everyone recognises.

Routine can help provide rhythm and confidence. Use lots of signage and arrows in large print to help direct people to the space where the arts programme is taking place, and where possible, try and have someone available who can meet and greet the participants as they arrive. An absolute necessity is tea, coffee, cake, biscuits and fruit!

If working in a gallery setting, try and display reproductions of any collections viewed as part of the programme, or perhaps objects that might relate to the artwork. Key points to consider when planning your sessions are your own values, the ethical implications of your work and communication. We will explore these issues briefly later.

Tea Time is a very important part of the sessions – 20 mins minimum – We have tea at the beginning, as a social opportunity for the group to chat, share news and jokes, both individually with neighbours and round the table. Artists sit and move amongst the group and then draw everything together outlining the session ahead before setting off for the Gallery visit.

(Sian Hughes - Artist)





### 3. Creating a structure for the viewing and making sessions

The best outcomes will be achieved through a structured, stimulating and engaging visual arts viewing and making session. The artists that Dementia & Imagination worked with are all experienced and highly skilled in arts and dementia contexts and represent strong practice in the field. One of the key factors in the success of arts activities is forward planning including reflecting and building on the previous weeks failures and successes. Without exception the artists we worked with were completely immersed in their subject prior to meeting any project participants. They were familiar with the art and artists that they would be using, the gallery, materials and possible contingency plans in their activities.

It has given my husband another regular activity to look forward to where he is independent of me. Although he has never been a particularly creative person and shown no interest in arts and crafts, he did enjoy the activity to a degree. He particularly enjoyed the company and seeing other people's achievements. He seemed quite proud of his work even though he kept telling me it was rubbish. It was nice to see his work on display at the exhibition. I feel that his view on dementia sufferers has changed, for the better, since attending the sessions. Finally, his attitude towards the future has improved in the way that he is more positive and no longer dwells on 'the prognosis'!  
(Spouse of participant living with dementia)

#### Arts Viewing

Sit participants in ways that mean they can all see one another, either in a circle or around a table and use name badges for everyone all the time: all staff, artists and participants. Welcome and introductions are important, as is keeping people connected and engaged if you are waiting for others to join, potentially through object handling to stimulate conversations.

Consider having simple titles on paper on the table to help orient people. Participants can refer to if they get lost or forget where they are, what they are doing, and it also gives people something to look at if they become anxious. This could look like a menu, with the venue at the top, the date and time, the title

of your activity, the artists names and work you are exploring today alongside images relating to the session. This all requires thorough preparation.

All sessions should begin with an exhibition or presentation of artworks as stimulus. This inspiration will be as a result of visiting galleries, or from the galleries recreating the experience in the health or social care setting. Inspiration should be chosen prior to the intervention and based on a particular artist, exhibition, or collection.

I revisited the exhibition last week and took photos. I realised each artwork was a continuation and could see the linkages and reused materials throughout. I can now explain to acquaintances using my photos. When I came home each week, I thought about what we did, what was said a lot. Before I went each week, I knew exactly what I wanted to do, things fell into place. I learnt quite a lot there.  
(Male participant living with dementia)

Begin with a brief introduction to the work. Object handling, where possible, adds a sensory dimension, provoking interest and discussion. It is important to use, where possible, 'failure free' techniques and questions with no wrong answer. Where possible, seek feelings and responses, not thoughts, but as ever, remember that all your participants are individuals with varied life experiences, and the more experienced you become in this work, you will be able to explore more difficult and nuanced conversations.

Initially, questions that avoid simple one-word responses should be avoided.

- ✗ "What is this?" "Who painted this?" "What does it make you feel?"
- ✓ "What might/could this be?" "How does this make you feel?" "Any thoughts about this?"

Just like the participants, artists are individuals too and will have different skills sets and areas of conversation that they feel more comfortable with. Open-ended questions vary and might not be about feelings, but about colour, form and materials.

This work took place in a gallery setting.

Reg began the group as a bit of a joker and would use humour to dismiss the content of the sessions. He took frequent cigarette breaks, and needed much encouragement to remain engaged with the art-based tasks offered.

During visits to the gallery, the artists encouraged participants to question the materials and to explore the methods used. Reg felt that L.S. Lowry's stick people were childish and lacking skill, and that he much preferred realist approaches to art. This feeling was echoed among the group, and was commonly observed in the interventions as our older participants in rural Wales and Derbyshire tended to hold traditional ideas of what 'art' is and should look like.

The artists noted after running several groups that "something seems to happen" around Week 5 when "a little shift" takes place. Participants begin to appreciate that abstract does not have to refer to anything, but is open to interpretation, and might be metaphor rather than an actual thing. As the participants became more relaxed with the format of the group and each other, we found that singing would sometimes occur in the session and references to other arts forms they were familiar with, such as films and music artists.

Through a discussion of 15th Century art, one participant offered a piece of history. "Amazing what's in your head" said Reg - on conversation and remembering things. By Week 8, Reg was taking significantly fewer cigarette breaks and was observed to be very engaged with the piece he was creating. When prompted, Reg became used to making choices through selecting colours and additional shapes to add to his work. Eventually another participant asked if a work was that of the artist being studied. They had not realised this had been made in the room and by Reg.

By this time, the artists noted he made no jokes, as he had at the outset. Eventually Reg stated that he had really enjoyed the sessions. Moreover, he called his fellow participants by name, which had not been observed before.

**Principles in action: Open questions; offering choice; using alternative media to engage; gentle pacing; making the activity social; respectful.**





If viewing art in a gallery – arrange chairs in front of each artwork before the start of the session. Try and have someone to assist with moving people. If practical, encourage people to look at the exhibition on their own. This might mean an independent visit, or could be for the period immediately before they begin their session, which gives the artists opportunities to mingle with the group and see where group and individual interest lies. Introduce a regular routine in the organisation of the sessions, around opening and closing the sessions and about moving between sections for example - the transition from appreciation and discussion, to making. Aim to have a structured running order, e.g. tea, exposure/handling, viewing and discussions, making and discussions. Where possible, enhance the sensory experience by using smells, a distinctive tablecloth and sounds to indicate beginnings/ends/a shift of focus

### **Art Making**

It is normal for people participating in practical arts interventions to be hesitant in taking part in activity that they may not have engaged in since childhood. The standard response for most adults is, 'I can't do art'. Over one-third of the Dementia & Imagination participants said they had not previously engaged with art. It is natural that different materials and techniques will provoke different responses in participants dependent on a variety of factors ranging from their adult experiences of the arts, to feeling they are 'no good at art'. Whilst taking part in arts activities won't be for everyone, it is often people who are unsure about taking part that gain pleasure from the creative group experience. Your aim is to stimulate creativity and imagination. Be mindful of peoples' phobias that you might not expect, like balloons, polystyrene or unexpected noises. Strange sounds may disorientate and distress participants.

The Dementia & Imagination arts programme used a broad range of techniques and materials ranging from mono-printing to sculpting and painting. This guidance is not about materials and techniques, as this is the individual artists expertise and skill set, this guidance is about the basic principles of the delivery of your practice in a safe and informed way. Quite often artists

and participants are exploring new territory together. Break down the process of creating work by simple demonstrations of procedures. Be prepared to help, by re-tasking, but without taking over, and try to go with the flow where possible, modelling the activity.

Where family and carers are involved in the sessions, you'll need to be mindful that people often take over the task, in a well-intentioned attempt to make sure something is produced. This can create patterns of behaviour that contribute to the person with dementia feeling disempowered and perhaps, being more disabled than they might be. Try to encourage the carers to be participants in their own right and as the sessions progress, it may be possible to provide separate space, but giving carers an understanding of the creative process is important.

Often someone who appears to need a lot of support can surprise you when they have space to think and work on their own, so it is always worth moving away after giving support. People generally find a way of exploring the materials, especially if they are to hand, which may not be what you thought or had planned. If someone is stuck, another way is to sit with someone and ruminate together... 'tell me about this...'  
(Sian Hughes - Artist)

Artists should not be afraid to choose appropriate tools and materials for the task, offering explanation and guidance and safety measures where needed. Participants often have latent manual skills that surface within the sessions. Managing risk and safety is essential, for example using non-toxic materials, but at the same time they should be of good quality and age appropriate. The artists should manage risks realistically and through clear communication with the participants and those who care for them.

### **It will be important to:**

- Recognise fears and where possible, acknowledge them, or help people label them
- Offer continual reassurance, especially at the outset of the session
- Assure all participants that they can withdraw at any time

- Recognise that some people may already be quite proficient and need challenging more than others
- Realise that perception of colour can change with the progression of dementia, and primary colours remain stronger in later stages

**Try to remain vigilant for the range of difficulties people with dementia may experience which might include:**

- Word finding difficulties
- Struggling to get started
- Visual impairments
- Hearing impairments
- Confusion
- Perseveration, (or getting stuck on one track)
- Motor difficulties
- Arthritis

**Try to adjust approach and activities to specific abilities, for example, in terms of memory loss it may be better to:**

- Keep instructions simple
- Model the tasks for participants to follow
- Break tasks down into manageable chunks
- Present and repeat frequently
- Provide print outs of the artists/theme/task instruction/images of products if appropriate
- Quick visual stimulations are essential
- Change the task where necessary
- Finish the activity in the session and don't run over two sessions

It's been really nice meeting everybody involved. I've loved the fact that a lot of the members started quietly, then opened up more, talking at ease in each other's company. The work we produced has surprised me regarding producing high quality work in a short time. The freedom and encouragement to express ourselves was very good. I felt the older members had expectations that they should be being taught the right/wrong way of doing things. It's lovely to see it's ok, no right/wrong - see freedom and enjoyment. I don't want detailed instructions. Given clear instructions on methods and skills.

Demonstration by the artist at the start was invaluable and sharing experience. I'm surprised what I achieved - learn new techniques. Exhibition was the icing on the cake - thrilled with it - I've posted this (on facebook) with my friends and have had posts back from friends. I'm proud to be associated with this. We need this as core provision as a preventative tool, we shouldn't wait until problem arises to give people this opportunity.

(Female participant living with dementia)

**Length of session** - up to two hours, with a mid-way break, but sessions will need to be adjusted accordingly to the needs of the participants on the day.

**Time of day** - this will be largely dependent on the setting you are working in. From our experience, for people living in the community, the early afternoon allowed participants and their carers plenty of time to prepare. In care settings, sessions should be designed to fit around the daily routines and activities.

**How many artists/facilitators?** - The evidence is variable, depending on the activity. We propose that two artists are required for each group, providing mutual support and opportunity for reflexive practice. Ideally one would lead the session, the other would support people who might need more support. Professional and family carers may also be present to take part and support activities, although their presence will need to be carefully managed, to avoid the well-intentioned over supporting of the person with dementia, which can instill excess disability, which we talk more about below in section 5.

**Themes** - Choosing a theme will depend on where the sessions take place. If in a gallery setting, the theme will be inspired by the collections viewed. If not, the theme will be one inspired from the stimulus taken into the venue by the artists. The themes explored will depend on the art selected as a catalyst. Again different artists bring different skills and approaches, exploring the connections with processes, art forms and materiality rather than the subject matter of a work.





Re-imagining and transforming the care home environment.



People in the later stages of dementia responded well to themes such as colour/shapes/specific and specific themes such as 'Forests' – themes such as 'landscapes' would have been too broad and difficult to connect to. These themes also have an automatic connection to the five senses, which help the connection. (i.e. For the forest theme: the feel of bark/the smell of cut grass etc.) The theme was created first and then we linked in the artwork – not the other way round. We felt this was more responsive to the groups we were working with as we knew which themes they would best connect to.

(Claire Ford – Artist)

There is a natural tendency to keep the stimulus and conversation simple, and in group situations the need to pitch at an appropriate level is critical. However, participants will be from diverse backgrounds, with diverse experiences – this may well include a cultural and artistic history. Always have contingency plans to accommodate people with higher levels of nuance and ability, as well as people who are under confident.

Themes should be age appropriate. Researchers have argued that people's psychological and spiritual needs should be addressed towards end of life. It is important to remain aware that we might feel uncomfortable about some topics, for example, grief, loss, and death, but we must take care to ensure that we are not avoiding certain topics due to our own discomfort and not that of our participants. Existential discussions can take some getting used to but we must be aware that these may be agreeable to some people and they might need 'permission' to broach them. This is often related to culture and how death is visible or otherwise.

As we discussed earlier, the underlying philosophy of our work has not been 'art therapy' and our arts programmes aimed to be socially engaging, giving opportunities for shared explorations, personal development and be outward looking offering a mixture of challenge and pleasure.





#### 4. Delivering sessions that enable inspiration, imagination, creativity, enjoyment and celebration

The best experiences will be achieved through the use of high quality multi-sensory stimuli; the visual through viewing, creating and touch, auditory through sound, music and through discussions and creating opportunities for conversation; even through smell and the materials used.

Make sure that opportunities to make decisions are maximised throughout the creative process. A person might have motor limitations but can select colours, or they might have lost some visual ability but like to feel the movement of a brushstroke or some clay in their hands.

Try to focus on working 'in the moment' to stimulate imagination especially with people who have more severe levels of dementia. Make the most of the moment, by ending the sessions on a high. Use the last 10-20 minutes to curate a mini-exhibition and discussion. Groups often comment on each other's work and offer praise for each other. All this helps people to see value in what they have done. This offers a positive end point, that you can refer to at the start of the following session. Use of praise should be explicitly encouraged, whilst avoiding patronising language or tone. Where possible, use constructively critical feedback.

Make use of playful approaches. The fact that this tends to maximise creativity can be shared with participants, relatives and staff so that they do not feel infantilised as a result of being invited to be playful, but remember it often takes people time to get into the activity, if they have not been involved in creating artwork for a long time. During the process of making, try to keep these ideas in mind and try to to maximise them:

- Art can encourage people to realise their potential
- This is an opportunity for sharing and admiration
- This might be a pleasurable experience
- This is an opportunity for self and group expression
- It is good to get lost in the moment of deep engagement

I couldn't understand it all initially. I thought, why am I here, why are we doing this? Then I got to know people when you go to a strange environment like that as time goes by you can relax and you get to know people. I expected art would be art. I could do drawing before, a long time ago, this was different, people floating bits of paper, but obviously, it was for a reason. I thought it was strange, it surprised me it got better, the company and I wasn't standing back, keeping back from things. I was looking again at the people.  
(Female participant living with dementia.)

It is important to acknowledge that the arts can allow people to encounter a range of emotions. Art is often cited as connecting thought and feeling, and connecting to our inner selves. It may facilitate expression in the absence of language. We should be explicit about acknowledging people's emotional expression.

Acknowledgement can be a powerful tool in de-escalating a problem, whereas ignoring such expressions can exacerbate them. For example, if a participant expresses frustration with the task at hand - an act such as throwing down a paintbrush - this is better acknowledged: "It seems to me that you are frustrated." By acknowledging, being empathic, recognising and naming an emotion, you show acceptance. Simply re-tasking people, without acknowledging, can be experienced as being ignored, or worse still, as invalidating or infantilising. If expressed emotion does not relate to the creative tasks, or if situations arise that you are not comfortable with, it may be better to seek support from clinical staff or family members present.

This may be particularly important in people who firstly, are likely to be experiencing emotional upheaval and distress due to their condition, and secondly, may lack the ability to adequately express and process this.

The arts are well placed to encourage:

- An outlet for emotions
- Self-communication
- Shape and give meaning to complex feelings
- Outward communication
- Social connections
- Fun and playfulness
- A sense of identity





Above: Image by Penny Klepuszewska.  
Right: Finished participant's work exhibited  
in Derbyshire.





This work took place in the activity area of a care home.

Mary had no prior experience of making art but was very sociable, enthusiastic and strongly motivated to take part. The artists note that she “holds and spreads the energy and really got into the session and drew a fantastic image using charcoal.”

One week the group responded to Jackson Pollock through various multi-sensory painting processes. In another session participants created shadow puppets and acted out a story they had produced. The production of the story and the associated puppetry was a complex process involving the use of remaining individual and collective memory of the industrial and manufacturing culture of the city within which they lived and shared with each other, which has now largely gone because of economic decline. As part of the session they also sang a local song unprompted, which again reflects that culture they shared.

The impact of the visual arts enrichment activity is given by a carer who states: “She grew closer to other residents who were doing the art as well. She liked being involved. She does like artwork so it helped her a lot. She was very sociable during activities, and enjoys socialising with others and has become very interested in art.”

Mary herself says; “Your team really is splendid. Wow you always have the tools and are so professional. Look at that – we did that together.”

The environment gave Mary the freedom to respond as she wanted and to use her imagination in ways that were otherwise not possible. Her family arrived once, and it was evident that she became embarrassed. It seems that during the art sessions she was released from assumptions about appropriate behaviour.

**Principles in action: Using different media as a way in (accessibility); use of multi-sensory media; making use of preferred roles; making the activity social; attention to personhood and meaning; use of personalised knowledge (local song); respectful; responsive; playful.**



## 5. Using the sessions to develop social connections with the groups

I enjoyed their company because they are all as daft as me. I thought it was good, I've never considered myself artistic but it was good to have something to do.

(Male participant living with dementia)

**The best outcomes will be achieved through artists who understand and are responsive to the communities and people they work with. This will stimulate connections between the art viewed and the participants' creations, connections with others present in the group, and more broadly connections between the creative process, the output generated and wider society.**

Aim to facilitate communication, build relationships and feelings of belonging, and cohesion as much as possible. Make links, highlight commonalities and look for similarities, point them out to help people feel included. Encourage teamwork and mutual support.

A round of applause at the end of each session, gives a real sense of pride and connectedness for everyone in the group, and more often than not, will happen spontaneously when sharing work. To keep the sense of positive connection between group members, it is always good to conclude the sessions with a positive group activity around the circle.

### Getting to know participants

It is recommended that there is some incorporation of participants' biographies, likes and dislikes, and use of their personal information to re-engage people, and capture their attention. If the artists are aware that a participant used to have a specific job or hobby, such snippets of information can be useful to address disengagement and tailor the intervention sensitively.

Realistically this will be at a very basic level, but most care facilities produce a simple document e.g. "Getting to know your loved one" including a few pertinent details. If your work

is part of a research study, you will need to obtain ethical approval. To explore this further follow the link to the Health Research Authority on page 62.

All care facilities should be approached before the arts programme starts for any information related to risk. For example, where someone might display frustration by lashing out, this should be conveyed to the artists.

### A Note on Excess Disability

Excess disability is where a much greater level of impairment is assumed than is actually there. It occurs when people do not allow the person living with dementia sufficient opportunity to draw on their own residual abilities, or make mistakes. It will be necessary to find the right balance if carers are present. Carers need to feel valued and included, but the participant needs as much independence as possible. This might be achieved through considering for example:

- The position of seating and changing group dynamics
- Asking people living with dementia to explain and share their work to their relatives and wider group
- Making sure people living with dementia have choice and control
- If carers are present, and you know the group well enough, try and mix up the participants (e.g. the usual carer is not necessarily with their usual partner)
- Remember too, that carers are often wives, husbands, partners, children and friends. It can be easy to forget family relationships and see everyone in blanket terms.

Participants may be 'recruited' to support one another e.g. pairing a person with difficulties initiating activity with someone able to begin independently; nominating those with specific needs to care for others to support those who may need more reassurance. If you can mix-up the pairings, you may achieve some unexpected results.





This work took place in an NHS hospital setting.

Harry had been a very active member of his community and by his own admission “interested in everything.” However, we found that what he really meant was heavy topics such as politics and history. Harry was a sophisticated man used to having influence in his community. He had assumed that an art class would be childish and suggested he bring his grandson to them.

He became engaged only once the artists’ intentions were explored and themes ‘of substance’ were discussed. For example, an early session studied the themes linking a visual piece (which Harry was not interested in) and the work of a composer (which he was).

It became clear that as a curious man, Harry was interested in the questions and concepts even though he was not interested in the physical art. Following debriefs between artists and researchers at the end of each session, and through experimentation, it was found that Harry could be effectively engaged by being invited to document the session using photography.

In this way, Harry was supported to fulfil his preferred role as facilitator of the group and maintained a safe distance (for him) away from the more practical elements, which he deemed as of little interest to him. He was further engaged by being invited to play an accordion one session, following a previous session where music had been discussed.

After six sessions Harry was losing his hesitancy to engage with the arts materials. He began to talk more intuitively, commenting on the unexpected use of materials and becoming inventive and abstract in his comments. One week he built a large, ambitious three-dimensional piece unaided, and named it “Stickasaurus”. Other participants similarly became willing to experiment without having directional purpose, being experimental then refining their work and being critical and reflective.

**Principles in action:** Using different media as a way in (accessibility); use of preferred roles; attention to person-hood and meaning; age-appropriate; respectful; responsive.



When you are young it's easier to connect with other people. Although I have my family here, they are very busy so I am alone, but don't feel lonely. Especially when you are old, you became invisible, if you look at, and start to talk to people, they want to rush off. Some will talk, but they are busy. I looked forward to going to the group, enjoyed it very much. The girls who run it were lovely, 100% brilliant, and the participants too were all very nice. I couldn't fault it - 10/10.  
(Male participant living with dementia)

### **Public celebration of activities**

As yet, arts activities are not part of mainstream care delivery. Consequently, many artists will inevitably be delivering short-term projects, and closing short-term projects demands careful thought.

Common aims of dementia strategies around the world include increasing visibility and awareness, and reducing stigma and isolation. If we have access to visual artworks and peoples' stories (and the permission to use them), it makes sense to think about how we can challenge negative stereotypes with this material. One way is to work towards developing a community event, where some of the outputs are curated and exhibited in a public space.

Your clients and those who care for them can be invited to a preliminary private viewing, to formally launch the exhibition. This celebration can be an immense source of pride in achievements. It can also challenge others to consider the capabilities and strengths of the person living with dementia.

By way of example the Dementia & Imagination team held several public events to encourage conversations and understanding around living with dementia.

### **Science and Arts Fairs**

At the popular Green Man festival in Wales, artist Carol Hanson created an interactive, playful cartoon installation suitable for all ages, where people could learn about the research and dementia more generally, and share their own experiences of family members with dementia. Over 1600 people engaged in

this installation over two weekends and the team collected a large number of moving personal stories.

### **Exhibitions**

Each of the three sites curated exhibitions of the artwork created by our participants with dementia. These exhibitions were intended to be based in the community, celebratory, and educational. For example, in Derbyshire the pieces were displayed in a public space attached to a popular town centre church, and were viewed by over 100 people.

We found that the people living with dementia could not always remember creating the work when we presented it through an exhibition. The work itself then became a new space for creativity. The exhibition worked well to promote what people living with dementia can achieve and enjoy, but didn't necessarily connect to them personally. The process of the workshops were much more integral to their wellbeing than the final celebration events.  
(Claire Ford - Artist)

## **6. Artist Development and Training**

A key part of Dementia & Imagination has been to understand the experiences of the programme artists and arts organisations involved in the project. This is a comparatively under researched area, as many evaluations tend to concentrate on the participants or wider social and community groups. The artists and arts organisations that we have worked with have rich experiences around a range of health, social and educational issues and have been a key part of our research project, in both its development, delivery, and where we go from here.

Over 2018/19 we are delivering a series of masterclasses and further developing accredited training for emerging socially engaged artists who want to work with people affected by dementia, and this will build on the unfolding research findings, and some of the principles shared in this handbook.



At the end of this handbook you'll find details of how to contact us, so you can tell us a little about your training needs, your responses to this handbook and share other reflections on artists development and training.

## 7. Values, Ethics and Communication & Guiding Principles

I suppose I'd underestimated how capable people with dementia are and had assumed they would find this difficult. The sessions allowed people to achieve their full potential, as there were no assumptions that they may not be able to do things. The final celebration was great - we all enjoyed dancing and singing (rock and roll). It just felt like any social occasion/party - friends enjoying themselves, no distinction between those who were experiencing dementia/carers/family/friends.  
(Care home manager)

There are certain qualities for an artist working within a health or social care context that are central to success, some of which are about who you are as a person, what your values are, and why you want to work in this context. Perhaps you have been affected by dementia in your personal life or perhaps you want to test your own creative practice. A handbook like this cannot teach interpersonal skills, but offers research informed guidance and perhaps sets down some overarching principles.

**Personal Values** - understand why you are doing, what you are doing.

**Respect** - the person with dementia comes first and foremost.

**Consent** - understand how you might help the person living with dementia make choices in all the activities that you undertake.

**Personal Governance** - embarking on arts based projects with people who are living with dementia means artists need to work within the ethos of the environment they are invited in to and adhere to the protocols in place. Your personal governance will impact on your own safety and ability to work productively within the setting.

**Ethics** - you are working with vulnerable people, whose wellbeing is paramount. Share any concerns with those with responsibility for the welfare of the individuals you are working with in a timely manner. If your project is in any way a piece of research, you will need ethical approval. Details can be found on the signposting page. Evaluation of your practice is a different matter and artists should always encourage honest feedback from participants and others involved in their work.

**Communication** - family members, health professionals and artists often have conflicting priorities. Listening to each other and respecting each others roles will be central to supporting the individual at the centre of your focus. Most conflicts arise through misunderstanding and miscommunication. Making an effort to ask questions and sharing your practice will help alleviate a range of issues. Sometimes the rigidity of routines can seem obstructive to artists, sometimes the ambiguity and uncertainty of arts practice can seem challenging to health and care professionals - timely communication can generate mutual understanding.

**Challenge Prejudice and Stigma** - first challenge your own - then others.

**Affecting Cultural Change** - let us all aspire to change the ways in which people living with dementia are perceived, and how the arts might contribute to peoples' quality of life. The arts allow us to focus on potential and possibility - our work will be central to an asserts-based future and not one defined by deficit. The arts allow us to focus on potential and possibility - our work will be central to an assets-based future and not one defined by deficit.



In Derbyshire, the artworks created by research participants were showcased in a public exhibition, “Dementia & Imagination: Making Connections Through Contemporary Art.” Professionally curated by artists from Nottingham Contemporary and the Dementia & Imagination team, the images were selected to display a range of materials and techniques used in the arts intervention, and to offer insight into living with dementia. Each image was accompanied by a quote from either the artist with dementia, a family member, or a member of staff observing the sessions.

One of the hopes for the exhibition was that it would be educational, as evidenced this viewer: “It has been a genuine eye opener. Some incredible pieces of art. The stories behind them is very touching. I have been surprised at what I have learned.”

The exhibition was held in association with a prominent cultural site, the Crooked Spire Church in Chesterfield. Their Parish Coffee shop hosted the artworks and this location was chosen for its accessibility to the public. People who viewed the exhibition were invited to feedback their comments. One viewer offered that the exhibition “Emphasises positive aspects of dementia, for example the capacity to both appreciate and create artworks, and the advantages of art as a medium to communicate what may not be easy to put into words.”

Another suggested that the artworks “prove what people can do when you think they can’t do anything.”

**Principles in action: Education and awareness; challenging stigma; located in public view (accessible); art as education.**



## Some Suggested Ingredients of a Successful Visual Arts Programme

- Surprise
- Unexpected adventures
- Genuine interest
- Respect
- Gestures
- Choice
- Attention
- Need to be free
- Having fun
- Taking risks
- Play
- Mirroring
- Stories into song
- Improvise
- Always looking for the entrance to stories
- Finding sounds that are meaningful
- The joy of small presents
- Positive and meaningful connection and relationship

(Ideas contributed by Claire Ford and Kate Sweeney at Equal Arts)



## Closing Thoughts

This handbook is a snap-shot of ideas built on the experience of a research-informed arts programme. It starts a bigger conversation that began with an exploration of theory, and of practice, around how a visual arts programme might impact on the lives of people living with dementia. We will extend this thinking and practice through a series of journal articles and publications over the next few years, alongside developing training, which stems from the rich experience of the artists and researchers.

None of this work could have been undertaken without the support and enthusiasm of the people living with dementia who took part in all the elements of this work, and who continue to illuminate our thinking. Thank you.

The goodwill and support of health and social care professionals, educators and artists, family members, carers and friends has enabled us to deliver a robust and deeply considered research programme. Their input has contributed to all our learning and will inform the policy recommendations that will emerge from our research.

We hope that this handbook will positively contribute to your practice, and that you might contribute to the next version of this work, by feeding back your constructive feedback to us. Our contact details can be found at the very back of the handbook. Here is the last word from one of the participants describing what they had got from the artists work.

Friendly, welcoming, hard to describe, I had surges of endorphin. My Dr is very happy with me. Another participant took care of me, and I lapped it up. The connection with other people - I loved being with them. I found I wasn't on my own with memory problems, that was good. The whole thing was very well done. There was no pressure, even when we made a mess of things. A thoroughly enjoyable time, and I came home full of ideas rather than memory problems. The group sucks you out of the abyss, and lifted me out of depression.  
(Female participant living with dementia)



Celebrating participants artwork through a curated final exhibition in North Wales.



# SECTION THREE

## Supporting Materials

### 1. References

**Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource**  
[www.dsdsc.bangor.ac.uk/documents/  
PromotingpsychologicalwellbeingforPWDandcarers\\_NHSScotland\\_000.pdf](http://www.dsdsc.bangor.ac.uk/documents/PromotingpsychologicalwellbeingforPWDandcarers_NHSScotland_000.pdf)

**1948 UN Declaration of Human Rights**  
[www.ohchr.org/EN/UDHR/Documents/UDHR\\_Translations/eng.pdf](http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf)

**Mental Capital and Wellbeing: Making the most of ourselves in the 21st century**  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/  
file/292450/mental-capital-wellbeing-report.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/292450/mental-capital-wellbeing-report.pdf)

**Five Ways to Wellbeing**  
[www.nef-consulting.co.uk/our-services/strategy-culture-change/five-  
ways-to-wellbeing](http://www.nef-consulting.co.uk/our-services/strategy-culture-change/five-ways-to-wellbeing)

**Making a Difference: An Evidence-based Group Programme to Offer Cognitive Stimulation Therapy (CST) to People with Dementia**  
Aguirre E, Spector A, Streater A, Hoe J, Woods B and Orrell M (2011).  
Making a Difference 2. Hawker Publications: UK.

**Realist Synthesis**  
(see supporting evidence below)

**Kitwood TM (1997) Dementia Reconsidered: the Person Comes First.**  
Buckingham: Open University Press

### 2. Useful Connections

**Dementia & Imagination**  
[www.dementiaandimagination.org.uk](http://www.dementiaandimagination.org.uk)

**Age UK**  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

**Alzheimer's Society**  
[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

**Ethical Approval**  
[www.hra-decisiontools.org.uk/ethics](http://www.hra-decisiontools.org.uk/ethics)

**Dementia Friends**  
[www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

**British Association of Arts Therapists**  
[www.baat.org](http://www.baat.org)

### 3. Supporting Evidence

In this section, we briefly summarise the programme of work that informed the development of our visual arts programme.

At the outset, we recognised the existence of considerable arts innovations in dementia care. Art viewing and making programmes for people with dementia have been delivered by some major art galleries (e.g. Museum of Modern Art, New York; the Royal Academy, London; Dulwich Picture Gallery, London; National Gallery of Australia, Canberra; and Nottingham Contemporary).

We explored the ways in which visual art programmes might lead to positive outcomes in people living with dementia at all stages of the condition. Creating effective services first requires a strong understanding of how they may influence changes in patient outcomes. If the underpinning theory is incorrect, then the desired changes will not occur.



Participant deeply engaged in the here and now.

We undertook:

- A review of primary research on visual art programmes. We used a methodology that aimed to uncover what works, for whom, how, why and in what circumstances.
- Two workshops with artists, exploring perceptions of their practice impact in dementia care.
- A qualitative exploration of stakeholder perspectives of art programmes.

We then synthesised these pieces of work to produce a conceptual framework for developing and testing our visual arts programme (see page 13), and inform the development of this handbook.

#### **Read the full publication**

The full article describing the development of the programme is published in a peer-reviewed journal and is freely available.

For further reading, see:

Windle, G., Howson-Griffiths, T., Gregory, S., O'Brien, D., Newman, A., Goulding, A.

**Exploring the theoretical foundations of visual art programmes for people living with dementia. (2017).**

*Dementia: the international journal of social research and practice.* First Published September 15, 2017.

Empathy is everything. Meet the person you are working with as a valuable individual, regardless of their ability or cognitive capacity.  
(Artist facilitator, male).



## What was the impact of our visual arts programme on quality of life, communication and well-being of people living with dementia?

### What did we do?

We delivered our visual arts programme and examined the impact on people living with dementia through a mixed-methods longitudinal investigation. We used four different methods to collect data, aiming to capture the impact 'in the moment' and 'over time'

### Who took part?

One hundred and twenty-five people living with mild to severe dementia were recruited across three research settings in England and Wales (residential care homes, a county hospital and community venues). This is one of the largest research investigations to test an arts programme in dementia care.

### What are the key findings?

- Taking part in a visual arts activity was better for well-being than just taking part in a social activity, highlighting the unique contribution of the arts.
- Quality of life scores were significantly higher at the end of the programme compared to the start.
- The programme was a stimulating experience, enabling personal resilience and social connectedness.
- Participants reported the programme as being interesting, friendly, and enjoyable. They reported a high sense of achievement and felt involved in the session.
- The benefits were evident regardless of the setting or stage of dementia.

The group sucks you out of the abyss, lifted me out of depression.  
(Male/female? participant living with dementia)



- 1 year
- 3 research centres
- 4 art groups per centre
- 12 weeks per group

### Read the full publication

The full article describing the results of the programme is published in a peer-reviewed journal and is freely available.

Windle, G., Joling, K., Howson-Griffiths, T., Woods, B., Jones, C. H., van de Ven, P., Newman, A., Parkinson, C. (2017). **The impact of a visual arts programme on quality of life, communication and well-being of people living with dementia: A mixed-methods longitudinal investigation.** *International Psychogeriatrics*, 1-15.

For more information about our research methods, you can freely download the research protocol, published by BMJ Open in 2016. Windle, G., Newman, A., Burholt, V., Woods, B., O'Brien, D., Hounscome, B., Parkinson, C. Tischler, V. (2016). **Dementia and Imagination: A mixed-methods protocol for arts and science research.** *BMJ Open*.

A further publication describes how the methodological approach for Dementia and Imagination was formulated and is freely available: Newman, A., Baber, M., O'Brien, D., Goulding, A., Hedd Jones, C., Howson, T., Jones, C., Parkinson, C., Taylor, K., Tischler, V., & Windle, G. (2016) **Carrying out research across the arts and humanities and social sciences: developing the methodology for Dementia and Imagination.** *Cultural Trends*, 25:4, 218-232, DOI: 10.1080/09548963.2016.1241338

## 4. Contacts

This Handbook has been written and edited by Clive Parkinson, Gill Windle and Katherine Taylor with the input of the research team, artists, participants and partners. Special thanks to the artists who delivered this work:

### **For Equal Arts:**

Led by Alice Thwaite; artists: Claire Ford and Kate Sweeney

### **For Nottingham Contemporary:**

Led by Kay Hardiman; artists: Gillian Brent, Chris Lewis-Jones, Joanna Dacombe, Sam Metz and Lauren Halford

### **For Denbighshire Arts Service, Denbighshire County Council:**

Led by Sian Fitzgerald; artists: Sian Hughes, Tara Dean, Lisa Carter and Rosey Paul



Sensate, visual and tactile pieces created by participants.

### **To feedback on this handbook please contact:**

Clive Parkinson [c.parkinson@mmu.ac.uk](mailto:c.parkinson@mmu.ac.uk)

Gill Windle [g.windle@bangor.ac.uk](mailto:g.windle@bangor.ac.uk)

### **Dementia & Imagination**

[www.dementiaandimagination.org.uk](http://www.dementiaandimagination.org.uk)

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Regional and national collaborating partners in Dementia and Imagination: Age Watch, Alzheimer's Society, the Arts Council of Wales, Denbighshire County Council, Engage Cymru, Derbyshire Community Health Service NHS, Equal Arts, the BALTIC Centre for Contemporary Art, Tyne & Wear Archives and Museums and Nottingham Contemporary Ltd.





Documentation of a visit to a stimulating gallery space.

This work is part of the Dementia and Imagination research programme.  
Thank you to everyone who has contributed to this series of activities.

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