

~~~~~  
A  
HANDBOOK  
FOR  
CULTURAL  
ENGAGEMENT  
WITH  
PEOPLE LIVING  
WITH  
DEMENTIA



the **Whitworth**

~~~~~  
A
HANDBOOK
FOR
CULTURAL
ENGAGEMENT
WITH
PEOPLE LIVING
WITH
DEMENTIA



the **Whitworth**



CONTENTS

- 6 FOREWORD**
Professor John Keady, University of Manchester
- 7 THE FORGOTTEN**
Ronnie Lomax
- 10 INTRODUCTION**
Wendy Gallagher, Arts and Health Partnership Manager,
The Whitworth & Manchester Museum,
University of Manchester
- 14 UNDERSTANDING DEMENTIA**
Dr Helen Pusey, Senior Lecturer, Division of Nursing,
Midwifery and Social Work, University of Manchester
- 16 TOP TIPS FROM THE FABULOUS
FORGETFUL FRIENDS**
A guide to working with people living with
dementia by people living with dementia
- 18 ARTS FOR DEMENTIA**
Professor Victoria Tischler, University of West London

24 **BEYOND DEMENTIA; LESSONS LEARNT**
Beyond Dementia project team and
exhibition organisers

Wendy Gallagher,
Arts and Health Partnership Manager,
The Whitworth, University of Manchester

Matt Retallick, Assistant Curator,
The Whitworth, University of Manchester

Lesley Perkins, Non-Executive Director,
Together Dementia Support

Holly Grange, Project Curator,
The Whitworth, University of Manchester

36 **LETTERS FROM THE GROUP**

42 **VISITOR FEEDBACK**

48 **MERCHANDISE**





CONTENTS

52 IMPACT

Dr Nuala Morse, Research Associate, Not So Grim up North, The Whitworth, University of Manchester
Honorary Research Associate, UCL Culture, University College London

58 AFTERWORD

Sally Ferris, Director of Together Dementia Support CIC

60 FURTHER READING

62 INFORMATION, ADVICE AND SUPPORT

64 ACKNOWLEDGEMENTS

Image: Artwork produced by the Fabulous Forgetful Friends.



FOREWORD

During my lifetime, people with dementia and their everyday lives have taught me so much. In the 1980s, and during my mental health nurse training [1983-1986], I bore witness to people [patients would be a more apt figurative description] with dementia existing in the confines of an asylum where opportunities for self-expression, growth and choice were denied. In the 1990s I saw at first-hand the power of the 'new culture' of dementia care promoted by Professor Tom Kitwood at the Bradford Dementia Group and listened attentively as the words 'personhood', 'person-centred care', 'dementia' and 'well-being' slipped seamlessly into the lexicon of dementia care. And during this millennium I have seen people with dementia organise themselves into activist and social citizenship groups to wrestle ownership of 'their dementia' away from policy-makers, academics and service providers.

Quite right too: we are all more than the sum total of our cognitive scores. This book moves the agenda on once again and celebrates human creativity, innovation, performance, achievement and belonging. On the turn of every page people with dementia are positioned as the expert citizens who want to share that celebration of a creative life with us, as readers.

It is a truly inspirational text. And I am still learning.

Professor John Keady, University of Manchester

THE FORGOTTEN

A Poem by Ronnie Lomax, Fabulous Forgetful Friend

*This passage of life you cannot control some days are
good, some days are bad*

This invisible illness is so sad

*So look at life and you will see,
how it can change both you and me*

Struggling to capture the present for my future

*Had a thought and then it's gone,
my mental camera will not stay on*

*The lights are on, but no one's at home,
the family all here, but you still feel, so alone*

*Woke up this morning and all that I could see
was a blue and grey mist in front of me.*

*Waiting, hoping pictures will stay,
to stop sands of time slowly trickling away*

So theft of thoughts and the right words to say

Many past and present memories have gone away

*So with your support in our lives
Let's educate our communities to understand*





“As a voice of people with dementia we need to challenge the stereotypes and attitudes, of people in our community and paint a different picture of dementia.

Challenging these attitudes and indeed challenging ourselves to find new and different strategies for coping with dementia is important.”

Ronnie's chosen artwork: Suzuki Harunobu, *Boys Wrestling*, c. 1760s
Woodblock print on paper



INTRODUCTION

Close encounters with the arts and museum collections offer an escape, a chance to join in, be creative, and learn about the world and ourselves, to be surprised, to reflect and to care. The Whitworth and Manchester Museum, part of the University of Manchester have developed strong and successful cross-sector partnerships with Manchester University Hospitals NHS Foundation Trust and its community health service providers. As a university museum and gallery we work closely with our colleagues and students across a number of faculties and research teams. Together we co-produce programmes, events and resources inspired by our collections for the benefit of our community. Through collaborative practice and research we aim to create a culture of cooperation and coordination between the arts, health, social care, public health, other local services and the third sector for wider social impact.

In 2008 the Whitworth appointed the first dedicated arts and health post, which is now shared across Manchester Museum. Health and wellbeing work across both organisations has grown and we now have 6 staff dedicated to health, social care and wellbeing programmes. These include our Cultural Park Keeper, funded by Esmée Fairbairn, who works with mental health organisations to develop horticultural wellbeing programmes in our Art Garden and explores the park as a site of wellbeing.

An Age Friendly Culture Coordinator, largely funded by public health, develops work by, with and for older people, with a focus on those who are socially isolated across the city. Our work with early years, engages babies, new parents and health visitors from the earliest moments. We believe that early intervention work reaches those who need it most, they are our most diverse visitors and it makes a significant difference to the health and wellbeing of the whole family. Like the wider health sector, we are considering our impact across the duration of a person's life.

Of course, sited opposite one of the largest hospitals in the UK (with over 12,000 staff), it makes sense for the Whitworth and Manchester Museum to do this work. We are also responding to need. Greater Manchester has some of the poorest health in the country (higher rates of mental ill health, significantly higher than average rates for suicide and the second lowest male life expectancy in the UK for a start). Therefore, it is imperative that the cultural organisations of Manchester provide inclusive spaces and activities that improve quality of life and mental well-being for all its citizens.

Museums and galleries are crammed full of objects and artworks of historical, social and personal significance. Across the Whitworth and Manchester Museum, we have reflected on how we can use these museum sites and the collection to open up conversations and focus on in-the-moment creative activity. A perfect example of such a programme is Beyond Dementia, which was designed both with and for people living with dementia and those who care for them.





Image: Lesley Perkins (carer) with her mother Eunice Perkins (Fabulous Forgetful Friend) in the Whitworth study centre, June 2017

Our core aims for Beyond Dementia were to stimulate imagination, encourage conversation and develop creative capacity whilst supporting active citizenship for those living with dementia. In partnership with Together Dementia Support and their activity group the Fabulous Forgetful Friends, we co-developed a programme of gallery visits culminating in an exhibition in the Whitworth's Collection Centre. Museum professionals and creative practitioners led the workshops and were supported by trained volunteers. The artists we selected to work with us are experienced in working with people who have a loss of cognitive function. They also possess excellent communication skills, understanding and empathy toward the issues faced by those living with dementia. Our creative practitioners are highly talented artists, accessible and inclusive.

Programmes such as Beyond Dementia support meaningful connection with others, encourage people to remain active, provide new learning opportunities, and focus on the here and now. Beyond Dementia seeks to tackle some of the myths and discrimination associated with dementia. Exploring artworks and engaging in practical art making provides a creative outlet for the expression of self. Creativity connects us to emotional memories, and it allows enthrallment and wonder.

Wendy Gallagher, Arts and Health Partnership Manager,

The Whitworth and Manchester Museum,
University of Manchester.



UNDERSTANDING DEMENTIA

The way we think about dementia will have a profound impact on the experience of those who are living with the condition. Thankfully we have come a long way from the perception of dementia as a 'living death' where there was no expectation of a 'quality of life.' Although medical advances have resulted in better diagnosis and for some people with certain types of dementia medications that can be of some benefit, the most exciting developments have been around the social and psychological models of dementia.

From a biological perspective dementia results from damage to the brain from illnesses such as Alzheimer's or an event such as a stroke. We are beginning to understand some of the risk factors for developing dementia. We know that people who have dementia may experience difficulties with memory, their thinking and problem solving skills or perhaps language. However, no two people will experience these effects of dementia in the same way as it will be determined by the part of the brain affected. Memory problems might mean that people have trouble recalling recent events. Difficulties with thinking may mean someone struggles to make a decision or carry out a sequence of events such as getting dressed.

Language problems may mean difficulty with following a conversation or perhaps finding the right word for a familiar object. Some people may have trouble judging distances making things such as stepping through doorways or upstairs challenging. Dementia can sometimes lead people to become confused about the date or time or perhaps where they are.

However all these difficulties and the overall experience of living with dementia can be influenced by how others perceive the illness. Tom Kitwood's model of Person Centred Care helps us to see that the experience of dementia results from biology, yes, but also from the person's biography and life story, from their physical health and probably most importantly from the social environment. When people with dementia take control, have fun, take risks and have the same opportunities to be creative, quality of life can be enhanced.

Dr Helen Pusey

Senior Lecturer

Division of Nursing, Midwifery and Social Work

University of Manchester



TOP TIPS FROM THE FABULOUS FORGETFUL FRIENDS

The Fabulous Forgetful Friends are a group of people who actively speak out about dementia and their experiences of living with the disease. Some of the group write speeches and present in public and by doing so help to bring about change. Beyond Dementia has provided a platform to break down some of the stigma and myths that surround the disease. It has enabled the group to advocate for themselves and others who are living with dementia.

- Don't say, 'remember when...'
- Don't say we are 'demented', 'losing the plot', 'not all there', 'on another planet', or call us 'victims' or 'sufferers'
- Do not talk to us as if we were children
- Do not under estimate what we are capable of
- Do not remind us of the death of loved ones
- Only give the help that people ask for NOT what you think they need
- Be patient with us, it may take us longer to do things

- Allow us to answer for ourselves
- Don't talk about me to other people, in front of me
- Don't tell me that I don't look or sound like I have dementia
- If I struggle finding the correct words or can't speak don't assume I can't communicate
- Don't remind me that I've already asked you or told you something
- Don't tell me I'm wrong, correct me or argue with me, particularly over trivial things
- Treat me the way you would like to be treated
- Communicate clearly with us, one point at a time please
- It's a good idea to wear name badges if we are doing group work
- Acknowledge and respect what we are saying and doing
- Keep things quiet if possible, reducing conflicting noises and crowds helps us concentrate



ARTS FOR DEMENTIA

A pink paper butterfly fluttered towards an elderly woman in a wheelchair. Sounds of birdsong filled the room as a drum softly beat, and whirring scenes from a projector covered the audience in a golden glow, feeling like the warm sun. The woman in the wheelchair reached out for the butterfly and held it momentarily, then moved it with her hands to simulate the beating of its wings. Time stood still and a hush filled the room.

Transcendence

I reflect on a performance of *The Garden* by Spare Tyre Theatre Company at a recent *Dementia, Arts and Wellbeing Network* meeting. It is difficult to convey in words the power of arts for dementia because art transcends verbal language. It is this power that is transformative for people living with dementia, and indeed for us all. The elderly woman in the wheelchair was living with dementia. Yet, during that immersive performance, she became an actor, and the audience; carers, people with dementia, academics, clinicians, artists and students, shared the stage as an embodied whole. This sense of community and connection, parity, the aesthetic experience, and potential for transformation, underpins the utility of arts for dementia.

Magic

Arts move beyond the everyday and ordinary. They introduce the magical, the mystical and the 'what if', that enable us to shift from reality to another place, one where rationality and sensibility

assume less importance, critical for those with dementia who may experience confusion, memory loss, and disorientation. Like stepping into a gallery, a theatre or a museum, we enter another world, we are physically and psychically transported elsewhere. Cultural venues belong to the community and by opening them up to people with dementia we extend an invitation to pleasure and inclusion. Accessible and welcoming cultural spaces remove obstacles to creativity, and promote reaching one's potential regardless of age or ability.

Communication

Dementia aims at the heart of identity and what we become. Who are we if we cannot remember our past and our loved ones? This question is philosophical more than biomedical. Hence it provides rich creative material to explore, unconstrained by health and social care structures. Even in advanced dementia, gesture and glance convey important information that emphasise the non-verbal as that which communicates the most. The arts provide methods for harnessing this in creating, communicating and questioning, even where there may be no answers. With art there is often no need to speak at all, instead marks, sounds, and colours become connective tissue, transcending speech and logic. There are no absolutes in art, few rights or wrongs, and flexible boundaries mean we cannot fail. This is deeply therapeutic as well as creative and is in stark contrast to contemporary health and social care that operates on assessment, evaluation, reason and solution.



Creation

Much about dementia focuses on loss whereas art focuses on what we have in the present, hence the emphasis on process and creation as well as outcome. And often the outcomes are extraordinary, witness for example the series of self-portraits made by William Utermohlen after his diagnosis with Alzheimer's Disease. There are countless other examples of creatives inspired by dementia.

I was so inspired by artwork made by people with dementia as part of the research project *Dementia and Imagination* that I created an installation around it - a pop-up space called 'The Imagination Café' that celebrated the creativity of those with dementia, sharing information and artistic resources, and giving the public hope that a life can be lived well with dementia. Here art, science and public engagement intersect to create what Lynn Froggett refers to as the 'third space', pushing knowledge and practice to a new transdisciplinary domain. This demonstrates another important function of the arts, to connect with the public and to provide information and learning in a variety of interesting formats.

Research

I am privileged to work in the exciting, rewarding and fast developing international field of arts and dementia research. Pragmatically and critically, we are building evidence for the use of arts in dementia care. A range of art forms including music, singing, visual art, theatre and dance are demonstrating important benefits including increased attentiveness, improved mood and enhancement of meaningful conversation. Many talented artists and practitioners now seek to work with people who have dementia and a growing body of researchers is being funded to undertake nuanced and large-scale studies. This means that more people should experience the benefits I have described.

A recent conference hosted by the Royal Society for Public Health in 2017 showcased the latest global research and a dynamic network of PhD students including the Alzheimer's Society's Art and Dementia Doctoral Training Centre will provide future breakthroughs and leadership.

Our time is now.

Professor Victoria Tischler,
University of West London



the Whitworth

MANCHESTER
1824
The University of Manchester
The Whitworth



BEYOND DEMENTIA

An exhibition exploring how to live well after a diagnosis of dementia. Curated by the Fabulous Forgetful Friends

EXTENDED UNTIL
JANUARY 2018



“The exhibition and accompanying public programme has been a resounding success. The Fabulous Forgetful Friends and their carers have offered a different, powerful and moving narrative of their experiences of dementia. It is a narrative that provides understanding and aims to raise people’s awareness of the condition whilst providing meaningful ways to engage with the arts.”

Wendy Gallagher

Arts and Health Partnership Manager

Image: The poster for the exhibition Beyond Dementia (July 2017-2018). The exhibition was extended due to popular demand.



BEYOND DEMENTIA – LESSONS LEARNT

This is a collective summary from the diverse perspectives of the collective project team. The purpose of the partnership between the Whitworth and Together Dementia Support is to support active citizenship for people living with dementia, and to raise awareness and understanding around the many issues that people living with dementia have to face on a daily basis. In order to achieve this together it is important to have shared goals and values, openness and clarity, trust and regular communication.

The partnership between the Whitworth and Together Dementia Support has provided a plethora of learning for each organisation. Our facilitators have highlighted some of the useful learning and key considerations for those who maybe considering embarking on similar programmes and partnerships.

One of the most simple but effective things you can do is sign up to become a Dementia Friend. A Dementia Friend learns a little bit more about what it's like to live with dementia and then turns that understanding into action – any one of any age can be a Dementia Friend.

Visit www.dementiafriends.org.uk

Get the Welcome Right

Entering a gallery can be an intimidating experience regardless of who you are, your background or abilities. If you don't consider yourself to be a culture-vulture it can often be perplexing, it's a big step. Do I need to understand these artworks in a certain way? Do I need to behave in a certain manner? How long should I look at this artwork for?

When we first met the Fabulous Forgetful Friends for our introductory session, we saw this as an opportunity to gauge levels of comfort in the gallery environment, after all, for some of the group this was their first visit to a gallery. We gave a short tour of the Whitworth's exhibition spaces asking for thoughts along the way. The group were at first cautious, perhaps a little daunted by the unfamiliar and some of our large open gallery spaces. The Whitworth continually aspires to be accessible and inclusive with our visitors, and it is important to remember both of these intentions as programme facilitators. We realised the importance of having the regular use of the studio, so that the space became familiar to them and close to amenities such as the toilets and lifts. It is often the small things that make a difference to feeling welcome, comfortable and safe, such as chairs with arms to help those with mobility issues, coat racks to hang personal belongings, name badges for everyone participating in the session, and introductions to new members of the group.



We found that the best way to engage a group with a diagnosis of dementia in arts and culture, is to allow them to get hands-on and to experiment with different artistic techniques. After all, there is no better way to understand art than trying it yourself. We employed five practitioners that would allow a wide-range of skills that echoed the exhibitions on display at The Whitworth. Screen-printing, linocut, assemblage and collage, working with clay, marbling, badge making, drawing and horticultural workshops inspired by our Art Garden. We quickly realised the importance of allowing the group to create on their own terms and in their own time, never forgetting the influence and value of the social element. Deliberately, we did not create step-by-step instructions, we abandoned the didactic and prescriptive approach in favour of a gentler steer. These sessions were a chance to unearth the untapped creativity of each individual, allowing their creativity to flourish through a gentle and fun exposure to making and creation.

Through observation, conversation and collaboration, we moved beyond dementia to discover the rich lives and personalities of the group. From this we were able to build-up a profile of each individual, their likes and dislikes, their interests and hobbies, which assisted us in selecting long list of artworks from the Whitworth's collection relevant to the tastes of each group member. We found this was much less daunting than presenting the group with our database of 55,000 artworks and asking them to choose. We then introduced the basic methodologies of curatorial practice to the group, giving them the confidence to make decisions about the display. Sitting down together over coffee and cake (an important

and always welcome fuel) the group noticed common themes emerging from their chosen works, they recognised particular artists or styles, and although they didn't realise it at first, they were slowly piecing an exhibition together, offering opinions and making clear and informed decisions in exhibition making. The flood gates were opened, and ideas for the exhibition hang, the promotional materials and supporting public programme were developed in further discussions.

Practical Considerations

There were several key considerations in making the group happy and comfortable during their weekly sessions. We used the Whitworth's Clore Learning Studio as a base as much as possible, keeping a familiar environment week on week; this also meant we could make a mess and get hands-on as much as we wanted to. The Learning Studio was also selected due to its proximity, an easy and flat route on ground level from our park side entrance. It is also adjacent to accessible toilets, and if it was required the quiet and contemplative space of the Art Garden was always available.

Although some members of the core group could not be in attendance every week, we were keen that nobody missed out, and that they were introduced to the full range of artistic techniques on offer.



When participants could not attend, members of Together Dementia Support would take back learning to encourage creative expression outside of our weekly workshops. This meant that some group members were inspired to create their own artworks in their own time, and some of these creations are included in the exhibition as testament to the power of culture to inspire.

Travel was another practical consideration, as some group members were unable to use public transport, so we booked taxis for them with a trusted local firm, and with booking were explicit about the needs of the passenger. This door-to-door service removed any potential stress at either end and ensured the passenger got to the gallery and back home safely.

Each week we ended the session with tea and cake in the Whitworth's Café in the Trees. We learnt quickly that it can take time to move the group from one room to the next, and therefore allowed extra time for this transition. We also made sure we kept an eye on the personal possessions of group members to be sure nothing was misplaced or left behind.

Active Citizenship

Together Dementia Support is dedicated to making the lives of those living with Dementia and their families as happy, meaningful and fulfilling as possible. Together Dementia Support values the contributions of its members; their unique personalities and experiences shape the support we offer.

When the chance to work collaboratively with the Whitworth was discussed, we realised we had found a project that would not only fit with our values, but also explore dementia and beyond through creative activity, collaboration and celebration.

The Beyond Dementia project has creativity at its heart. The Whitworth have designed a programme that has also allowed Together Dementia Support members to explore the Whitworth's collections, as well as acquire skills in pottery, assemblage, lino cut, screen printing and art appreciation workshops.

Using learning techniques to assemble personal histories and create objects of importance that connect to emotional memories, the group has forged a real and lasting bond. Members have gone on to create art for themselves, involve their families and find wonder in the process. They have now formed a community based creativity group.



Working In Partnership

Good partnerships depend on mutual respect and a give and take balance.

Initially, we can be uncertain about a partnership as we fall into set ways of doing things and aren't sure that we want to compromise.

Together Dementia Support, however, quickly realised that the Whitworth had much to offer us and our members and we were reassured that they recognised and valued our contribution and expertise too.

Being able to access professional artists and high quality activities in a lovely, prestigious setting with plentiful volunteer support is not something we would otherwise have been able to provide. The opportunity for the participants to exhibit their work and have distinguished and family guests celebrate it, is also a rare treat and does so much to reduce stigma and give people with dementia the self respect they deserve.

It is also important that large, well-funded institutions commit to supporting the smaller voluntary sector organisations with whom they work. The Whitworth has done this through assisting Together Dementia Support with grant applications in the hope that we can provide an art project into the future. They have also invited the group to keep visiting the gallery to attend workshops and view the collections.

Recruitment

"It's not my thing" is a phrase often heard by practitioners and family members when trying to persuade a person living with dementia to participate in a new activity.

This is sometimes due to brain-damage-induced apathy; the person has lost their *joie de vivre* and get-up-and go. It could also be due to anxiety: who will be there; will I be able to do the activity; will I get lost again? Or, again, it could just be a fear of the unknown. Art, in particular, is an activity that some will believe they simply cannot do and were never good at.

So we have to be very smart, skilful and persistent in persuading people to give it a go. Appealing to and emphasising their previous skills, asking for their help in testing a new project, or persuading them with the promise of refreshments and time with friends might work. It will usually help if they already know some of the participants so that they can "give it a go" together.

The person living with dementia either needs to trust their relative who will participate too or the practitioner whose recommendation they trust.

We also need to give informative, easy to read and appealing literature about the project to lessen the sense of the unknown. A photo of a diverse group of people enjoying the activity can help the person to identify with it.



It is so important that people's first impressions are positive because, once they feel insecure, uncomfortable or unsuccessful, they are likely to refuse to go again. Having enough helpers to sit alongside new recruits can help them to feel safe and secure.

As with any group, it's really helpful to have an 'energiser', someone whose positivity lifts the mood but it's also important that the staff and volunteers set the mood of the group by complimenting, encouraging and celebrating everyone's artistic efforts – whilst not taking themselves too seriously! Laughing together is often the glue that builds group cohesion and identity.

Access

A rigorous risk register was produced and shared with all staff and volunteers.

Access to facilities was a consideration at all times as several members had limited walking ability. They also found the modern design of the toilets confusing and the toilet doors were camouflaged rather than highlighted.

Signage inside the building was a constant factor and members and volunteers were often disorientated, taking up valuable time in getting from one place to another.

Transporting members to and from the gallery was time consuming and labour intensive as few of the participants had family members who could bring them. This is a programme overhead that needs careful consideration.

Parking places, drop off and pick up points, escorts and helpers also need consideration to ensure participants' safety and to minimise any anxiety.

Quality of Experience

Members have committed to the programme and have fully engaged. Attendance has been high and feedback very positive

"I have felt very included and supported. I enjoy talking to others and experimenting with different art activities. I have used the sessions to advance my own artwork when I get home" (Ronnie) .

Members and their families have spoken publicly about individual as well as collective contributions to the programme and how their experiences have improved mood, increased circles of friends and offered opportunities to socialise.

Carers have welcomed the break that the programme has afforded. Other carers have stayed to enjoy the workshops and discussions.

Carers and families have fully supported the programme by preparing members in advance, prompting and encouraging them to select personal objects of interest and importance as memory aids for use in the Assemblage workshop. Those objects, stories and conversations have provided insights into members' past and present sense of identity.





“This painting reminds me of a Picasso painting. Whenever I look at it I remember my time spent in Malaga visiting the Picasso museum. Malaga is a place that me and my wife visited a lot. The couple in the photo are drinking coffee – one of my life’s passions!”

Phil's chosen artwork: Christian Rohlf, *Two Figures at a Café Table*, circa 1912. Watercolour and charcoal on paper. The Whitworth, University of Manchester



LETTERS FROM THE GROUP

Hi Exhibition Visitors

My name is Lilian, I have recently been diagnosed with the early stages of dementia. My children tell me that I repeat myself on a regular basis. I do not think I have any behaviour problems, which are out of character, such as making tactless and inappropriate comments. My daughter has told me I must think about the way I speak to people because they can be offended. I sometimes have problems finding the right words when having conversations. My daughter has told me to spend up to half an hour, twice a day completing the word search book, which will help to activate my memory. I really think it is helping me to remember things.

My medication is dispensed from a dispensing machine, which is on a timer. It releases the correct amount of medication I need during the day and at night. I cannot forget to take my medication with the device. I have a healthy balanced diet. I do not exercise as much as I would like to. I know that if I do eat unhealthy food, I can be susceptible to other illnesses. If and when I deteriorate, I know that there is help out there for my family and myself.

Yours Sincerely

Lilian

LETTERS FROM THE GROUP

Dear Dementia

F*** YOU! That's how I felt about you when I first got the diagnosis. I was angry then – that's after I got over the shock of it.

I'd been having some problems at work but, because I was the team leader, I could get other people to do the jobs that I couldn't manage. Before that I was able to multi task, guiding the aeroplanes out onto the runway whilst eating my sandwich, but it all got too much for me. Now I just feel that you're not going to get the better of me. I'm managing YOU right now, I'm doing alright. So f*** you!

I'm planning on living a lot longer. I've got a lot of things I still want to do. I'm not at all scared of you. I just get on with my life. The others I meet with, they feel the same. We have a laugh and we get on with it. I'm still frustrated by all that you have stopped me from doing. I'm not so good at sorting all my computer problems out. Luckily I've found a class at the Tree of Life and they can do those things for me. I also can't do simple things like cooking or even putting my seatbelt on. And I can't do all the woodwork that I used to be good at.

I have bad days now and again – but only now and again. My music makes me feel good – especially my record player and vinyl collection that Amanda's brought over to me. Some days I feel like normal. Perhaps other people can see you in me.... but I don't know.... Some of my family and friends don't bother with me any more but I don't care. That's up to them.....

Despite you, I'm doing alright.

Phil



LETTERS FROM THE GROUP

Hello, my name is Lesley.

I am my mother's daughter and Carer. I am also a Non-Executive Director of Together Dementia Support (TDS), a long serving public servant and artist.

Dementia entered our lives many years ago. I have no siblings, and an ever-decreasing family network.

I have been amazed by the changing and complex nature of the condition. It is very easy to become isolated from your community as social skills fade. My Mum is a very private person and would not let anyone other than me help her.

This was an overwhelming position to be in. My Mum was neglecting herself and for the first time in her life her health was beginning to fail.

I couldn't see this happen, so I gave up my job and managed my Mum's care plan. This was life changing and for a time we both became rather isolated and experienced perhaps the most frightening time of our lives.

Everything changed. Mum was losing her memory very quickly and all practical tasks became impossible, frustrated or needed reworking to simplify them or eliminate them altogether.

No more cooking, going out alone, her personal care needed constant supervision, all financial and legal matters became my responsibility too.

LETTERS FROM THE GROUP

Whilst everything was changing for me professionally and personally, what was consistent was our determination to be positive, productive and well. For us **being** well means, thinking well, eating well and living well. But this takes time, patience and a lot of learning about how **Dementia** is affecting the person who has it. It also entails re-thinking your own coping strategies, dealing with the loss of my professional self and status, loss of the relationship I had with my Mum and personal relationships that broke under the stress as a consequence.

We struggled together for perhaps too long. Frustration boiling over due to the lack of understanding and the sheer volume of responsibility in addition to the above.

The book *Contented Dementia* was our lifeline and changed everything for us. A philosophy, as well as a book; we continue to use this approach in everything we do.

The support of TDS has helped us find our feet and become citizens again. We have much to thank them for.

Beyond Dementia has added a creative dimension to our lives also. We have had fun, met others, grown friendships, learnt new things and produced tangible and bright objects of beauty and remembrance.





tangles

A Journey into Dementia

Beyond Dementia is rich in content with thanks to the Fabulous Forgetful Friends and their Carers. Not only have they shared personal selections from the Whitworth's collections but also private memorabilia, letters and sketchbooks that have provided visitors with very personal insights to the different experiences of living with the disease and caring for those with a diagnosis of dementia.

"My dad's journey into Dementia started a few years ago when he decided to visit the doctors because he was losing his memory. He was a very strong and opinionated character and didn't welcome old age!

At the time that I started spending more time with him, I had started a textile course at a local college. This project began as a general sketchbook of images and scribbles combined with poetry and words that I dreamed up! This journey of my drawings evolved while I was keeping my dad company and it was about half way through this process, that I had the revelation that the sketchbook was all about my relationship with him!

When I started to really look and evaluate my images I saw my dad. It took about 2 years to complete and I decided to dedicate it to my dad's journey into Dementia."

Theresa Fox-Bryne

To see more of Theresa's sketchbook visit www.healthandculture.org.uk/publications/a-journey-into-dementia-sketchbook/

Image: A page from the sketchbook, A Journey into Dementia by Theresa Fox-Byrne.



VISITOR FEEDBACK

“Wonderful exhibition! Would love to do something similar with people living with dementia I am working with. Anything that challenges how society views people with dementia - so they see past the diagnosis and see the person is the way forward.”

“Beyond Dementia - so encouraging to see work and read the testimonies by those affected. An eye-opening and perception changing exhibition. Thanks for putting this on.”

“Fantastic exhibition - I will take this idea way with me. I work in the NHS and I know how important it is that we are aware of dementia and how it affects not just the person but their families too. This isn't going away we need to embrace it and work together.”

VISITOR FEEDBACK

"You cannot fathom the ripples dementia creates when it affects a family. I miss you Mama."

"The exhibition has made me feel sad - I wish I had know some of these ideas 5 years ago. I could have helped with my mother's dementia so much better. I need to talk to my sons in case my turn arrives soon."

"Like a thief in the night, dementia steals memory. But I am still here."

"I don't know how I feel, but I am scared I will get it."

"Today I met someone who's wife has recently been diagnosed with dementia. I'm sure this exhibition was so helpful. It gave him hope. He said it gave him ideas on how to cope and who to contact for help"



THE CHRISTMAS CHORUS, CONCERT,
BY THE COMRADES OF THE ADULT STAFF,
OF THE COVENANT CHAPEL, AT
WESTERN CAROLINA CENTER.



VISITOR FEEDBACK

"A very moving, enlightening and inspiring exhibition. Just shows creativity reaches through boundaries and can be a real healing process. Thank you to all those 'fabulous forgetful friends' who shared their experiences. A real insight into the condition."

"A fantastic exhibition to remind us each person with dementia is an individual and has their own story. Something society often forgets."

Charlie's chosen artwork: *Brooks Yeomans Christmas Choir, Concert, at the Comma, of the Adult Staff, of the Covenant Chapel, at Western Carolina Center 1997. Felt-tip pen on paper.*
The Whitworth, University of Manchester



JOYFUL MEMORIES



VISITOR FEEDBACK

"I'm training to be a speech and language therapist at University and have been on clinical placements working with people who have dementia. It's really wonderful to be able to hear the voices of people living with dementia, their experiences and attitudes and makes me feel so positive about work I could be doing to help people living with dementia. Great to see so many voices through the medium of art and will be recommending to my peers! These kinds of exhibitions inspire me and make me appreciate and understand how best to work with people in future."

"As a registered nurse, the patients I love looking after are patients who suffer with dementia. Each one of them are unique and beautiful with amazing minds."



MERCHANDISE

The T shirts, Tote Bags and Badges have been especially designed and made by the Fabulous Forgetful Friends, in collaboration with printmaker Sally Gilford. They can be purchased from the Whitworth's shop. All proceeds from these items got towards the charity, Together Dementia Support.



MERCHANDISE



- T Shirts **£15**
- Tote Bags **£10**
- Badges **£2**





"I chose this painting because it feels complete and balanced. The colours are dramatic and yet soft. The painting has warmth and depth but is also quite bleak. Through this artwork I can consider my own role caring for someone with dementia. The lived experience of dementia is not a fixed state but subject to change and complexity. I see this reflected in this artwork."

Lesley's chosen artwork: Wilhelmina Barns-Graham, *Godrevy*, 1959. Gouache on paper. The Whitworth, University of Manchester



IMPACT

Approaches to ageing that are organised around illness have contributed to a dominant view of dementia as loss: the loss of memory, the decline in physical functioning, and the progressive loss of self. This view can lead to a further and more problematic loss, the loss of voice, as the stories of people living with dementia are too often ignored. Beyond Dementia is a ground-breaking exhibition that brings together the words and stories of people living with dementia.

The programme has had a significant impact on all who have been involved, from participants, carers, support workers and museum staff. A process approach to evaluation was taken, with feedback gathered throughout the project.

At the centre of this project is the Fabulous Forgetful Friends, a group of activists living with dementia brought together by Together Dementia Support. The motivation for participants to take part in the exhibition project was the opportunity to talk about living with dementia from their own experiences.

The group gave participants an opportunity to socialise with others with shared experiences. Over time, a much clearer sense of the group emerged, as a team of creators and curators working collaboratively towards an exhibition. In particular, participants described how much they valued the professional input of all the different museum staff involved in the project, from curators and

IMPACT

artists to session facilitators. That professionalism supported the group to achieve their vision and to design an exhibition to the highest standards.

We can never truly express our appreciation and respect for your outstanding professional contributions in supporting us on our journey.

Over the course of the programme, the group produced a number of art works, including 2D and ceramics. Each piece holds a certain vitality and energy that often filled the activity sessions in which they were produced. Participants also selected artworks from the collection that represented an aspect of their individual personalities. The main impact of the project was the opportunity for participants to make their voice heard: as a group, and as individuals with varied lived experiences of dementia. In turn, the group hopes that visitors to the exhibition will gain new insights into dementia that challenges some of their assumptions and enables them to see the person beyond the diagnosis and to hear their voice, loudly and clearly.



IMPACT

'I hope that our display will play a part in changing our communities' views of dementia and let us live for the moments we're in. Please remember even within the illness we remain very much individuals'

The project has also had a direct impact on staff at the Whitworth and their working practices. It has added a further dimension to their inclusive and accessible approaches to engaging diverse groups. Staff highlighted the importance of recognising different needs within a group living with dementia: as each individual brings their unique creativity, imagination and personal stories, they may also require different levels of support or may work at a different pace. This needs to be more than simply accommodated but built into the programme, for example by differentiating or sequencing activities to suit a range of abilities and cognitive functioning. Staff also described the importance of carefully thinking through issues of transport and access when inside the art gallery, particularly the need to collect, escort and support participants due to difficulties with navigation, memory and spatial awareness.

The project has also further cemented the Whitworth's commitment to offering training opportunities for all staff in dementia awareness to ensure that the gallery is a safe and welcoming environment.

IMPACT

The impact of the programme is clearly demonstrated by its legacy and the continued partnership between the Together Dementia Support and The Whitworth, University of Manchester. As for the Fabulous Forgetful Friends, they continue to meet and collaborate as active citizens.

Dr Nuala Morse, Research Associate, *Not So Grim up North*,
The Whitworth, University of Manchester
Honorary Research Associate, UCL Culture, University





“I selected some works depicting mothers and children for the exhibition. I like the nurturing nature of these images that show the close bond between mother and child. When my son was born it was a difficult birth and it was touch and go whether he’d pull through. I was worried sick but overjoyed when he gained in strength – he’s a healthy young man now.”

Chris’s chosen artwork: Eric Gill, *Mother and Child*, 1924.
Wood engraving on paper in bound book. The Whitworth,
University of Manchester



AFTERWORD

We should never underestimate how much people living with dementia can teach us – about life in general and the impact of dementia specifically.

I have learned that this fast-paced world will often fail to support people living with dementia because time and care are essential if they are to participate fully in society. This cannot be done on the cheap.

I have also learned that living fully in the moment can be liberating and great fun. And I have learned the value of friends who are happy to simply be alongside us and with whom we can enjoy special moments and achievements, as well as our frustrations.

Art is a medium through which people can express their individuality. We have seen how therapeutic it is on many levels – to be present and focussed, to enjoy colour and texture, to be quietly working alongside others, to celebrate each other's achievements, and to be inspired by beautiful spaces, works of art and nature.

Life can be mundane or problem-filled. We live for the special times when we are taken out of ourselves by love, laughter, joy and beauty. All of these can be experienced when we meet as equals to explore and create together.

AFTERWORD

It is not enough that there is a wealth of artistic and cultural experiences out there in society. It is also necessary that disempowered and marginalised people are encouraged to believe that those experiences are there for them – and that we will support them to access the activities. Big institutions, small community groups and family carers need to truly respect each other's contributions and work together to enable the participation of people with dementia.

People who have a diagnosis of dementia are usually positioned negatively in society. This must stop! 'Beyond Dementia' has shown us that they can be storytellers, entertainers, poets, nurturers, artists and curators – if we only give them the opportunity.

Sally Ferris,

Director of Together Dementia Support CIC



FURTHER READING

These texts have been selected by our Arts and Health Partnership Manager, Wendy Gallagher, who co-curated the Beyond Dementia exhibition and is studying for an MSc in Dementia Care at the University of Manchester. They have been selected to provide support and advice for people living with dementia and their carers, and those organising creative programmes for people living with dementia.

Art Therapy and Creative Coping Techniques for Older Adults,
Susan I. Buchalter, 2011

Becoming a Dementia Friendly Arts Venue: A Practical Guide,
Alzheimer's Society, 2015

Contented Dementia: A Revolutionary New Way of Treating Dementia : 24-hour Wraparound Care for Lifelong Well-being,
Oliver James, 2009

Creating Moments of Joy Along the Alzheimer's Journey: A Guide for Families and Caregivers, Jolene Brackey, 2016

Creativity and Communication in Persons with Dementia: A Practical Guide, John Killick, 2011

Dear Dementia: The Laughter and the Tears, Ian Donaghy, 2014

FURTHER READING

Dementia Reconsidered: The Person Comes First,

Tom Kitwood, 2011 reprint (originally published 1997)

Dementia: The One-Stop Guide: Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease, June Andrews, 2015

Forget Memory: Creating Better Lives for People with Dementia, Ann Davis Basting, 2009

Health and Wellbeing Creative Health: The Arts for Health and Wellbeing Report, Association of Directors of Public Health and All-Party Parliamentary Group on Arts, July 2017

I'm Still Here: Creating a better life for a loved one living with Alzheimer's, John Zeisel, 2012

Lost in Space: Architecture and Dementia, Eckhard Feddersen and Insa Ludtke, 2014

The 36-Hour Day, 5th Edition: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss, Nancy Mace, 5th edition, 2012

**What the Hell Happened to My Brain?
Living Beyond Dementia,** Kate Swaffer, 2016



INFORMATION, ADVICE AND SUPPORT

Alzheimer's Society

Website www.alzheimers.org.uk

Email enquiries@alzheimers.org.uk

Telephone 0330 333 0804

Arts 4 Dementia

Website www.arts4dementia.org.uk

Email info@arts4dementia.org.uk

Telephone 020 7239 4954

Dementia UK

Website www.dementiauk.org

Email helpline@dementiauk.org

Telephone 0151 237 2669

Dementia@Manchester

Website www.dementia.manchester.ac.uk

Email dementia@manchester.ac.uk

Telephone 0161 306 0441

Dementia and Imagination

Website www.dementiaandimagination.org.uk

Email imagination@bangor.ac.uk

Telephone 01248 383050

INFORMATION, ADVICE AND SUPPORT

Manchester Dementia Action Alliance

Website www.dementiaaction.org.uk

Email DAANorthWest@Alzheimers.org.uk

Support For Carers Manchester

Website www.manchesteradvocacyhub.co.uk/support-for-carers/

Email advocacy@gaddum.co.uk

Telephone 0161 214 3934

Tide

Together in dementia everyday

Website www.tide.uk.net

Email carers@tide.uk.net

Telephone 0151 237 2669

Together Dementia Support

Website www.togetherdementiasupport.org

Email sally@togetherdementiasupport.org

Telephone 07854 335890

The Whitworth, University of Manchester

Website www.whitworth.manchester.ac.uk

Email wendy.gallagher@manchester.ac.uk

Telephone 07920 595772



ACKNOWLEDGEMENTS

With special thanks to

the Fabulous Forgetful Friends, Together Dementia Support, Professor John Keady, Ronnie Lomax, Dr Helen Pusey, Professor Victoria Tischler, Dr Nuala Morse and the Beyond Dementia Project Team.

This publication has been generously funded by



Supported using public funding by

**ARTS COUNCIL
ENGLAND**



The University of Manchester
The Whitworth

And supported by



