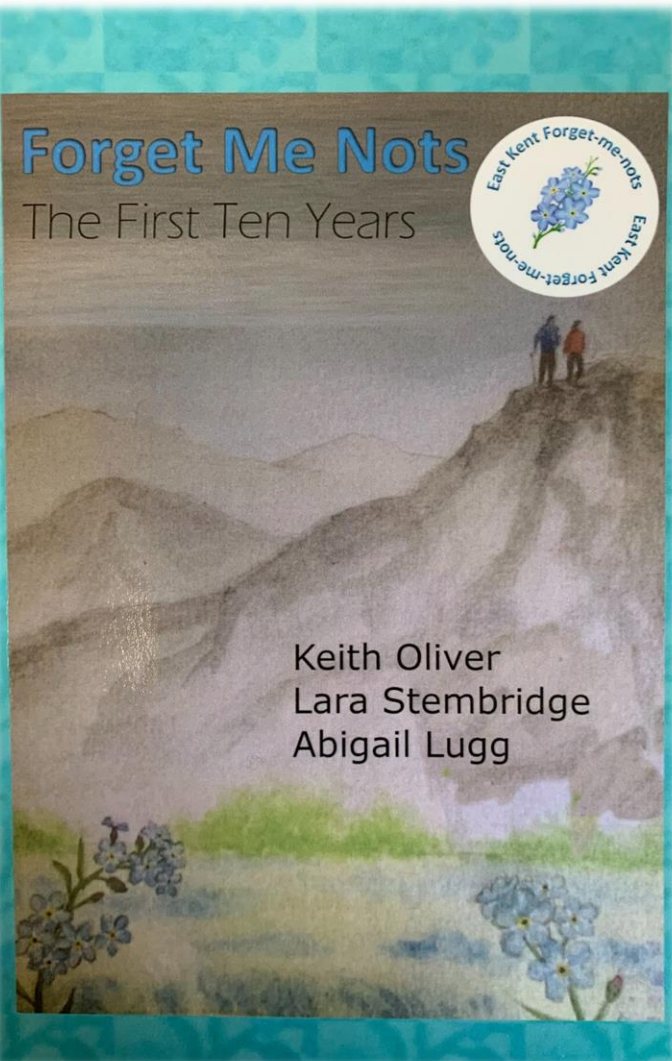


Forget Me Nots

The First Ten Years



Keith Oliver
Lara Stembridge
Abigail Lugg



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Written by Keith Oliver, KMPT Dementia Envoy & Alzheimer's Society Ambassador, Lara Stembridge and Abigail Lugg, University of Kent Psychology students on placement with KMPT 2021-22

Cover image by Abigail Lugg

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Introduction

WELCOME to this story of the East Kent Forget Me Not group which has been written by the three of us to mark the tenth birthday of this quite extraordinary group of ordinary people with dementia. It was written between April – September 2022 against a backdrop of the “new normal” in a world dominated by the Covid pandemic, something which had an enormous impact upon our studies and placements, the Forget Me Not group and their lives, and the world in which we all live.

This book is dedicated to the 63 people with dementia who have been a part of the group and to the fifteen staff and forty-seven students/volunteers who have supported us in the past ten years, especially to those who have travelled longest with us since the first meeting, namely Melvyn, Celia, Keith and Elizabeth. But, to everyone who has contributed to the Forget Me Nots your contributions will certainly not be forgotten.

Special thanks also go to Rachael Litherland from DEEP who generously supported and sponsored this book project from the outset. Coincidentally whilst DEEP

and Forget Me Nots are not twins, they each share a tenth birthday in 2022!

We hope you enjoy reading the book.

Thank you,

Keith Oliver, Lara Stembridge, Abigail Lugg

Chapter 1

‘Welcome to the club no one wants to join.’

ORGANISATIONS with ambitious and passionate aims are rooted and founded in the relationships of individuals who share hopes and who dare to dream together to see those hopes become a reality. So it was that the Forget Me Nots’ roots first formed through human connections and the vision that grew as individuals began to talk, share and unite in the cause of transforming the valuing of and opportunities for people diagnosed with dementia.

Establishment of the Group

After three months of coming to terms with his diagnosis of Alzheimer’s, Keith Oliver was determined to try and remain active and engaged in society through doing something useful. He had recently attended a living well course for people with Young Onset dementia led by Elizabeth Field, at which he met six or seven other couples in a similar situation to himself and Rosemary, his wife. Elizabeth then introduced

Keith to her colleague, Clinical Psychologist Reinhard Guss. Through this connection a variety of opportunities were presented to Keith to speak and write about his diagnosis and the early days of his experience of Alzheimer's.

It quickly became obvious that there was potential for bringing other people into what was termed 'service user involvement'. After the living well course, EKIDS (East Kent Independent Dementia Support) set up a support group, which most of those from the living well course attended.

Elizabeth and Reinhard had also been talking and hearing from others about service user groups for people with dementia and so Reinhard and Keith spoke to the EKIDS group in September 2012 to encourage people to come forward in joining what was then called a 'dementia service user network group'. There was very little support for this idea, and in fact lots of 'it'll never work' and 'it'll be a waste of time'. It was a difficult meeting at times and

perhaps set the tone for some future meetings of the group.

Before the first meeting, Reinhard and Keith gave a lot of thought to the structure of the gathering. We wrote to Richard Taylor, author of *Alzheimer's from the Inside Out*, who lived in Houston, Texas, and whom Keith had met at Alzheimer's Disease International conference in London during March 2012. He advised Keith as to how the group may work, and coined the phrase, 'Welcome to the club no one wants to join.' Richard, alongside a UK equivalent, Peter Ashley, became good friends of Keith's as the years unfolded. Subsequently, Keith investigated a base for the group and was able to secure Friday afternoons once a month at the Thanington Resources Centre. Four people from the EKIDS group came to the initial meeting held on 16th November 2012. These adventurers were added to by two enthusiastic recruits from another living well course, plus one other person who was recruited by Reinhard.

The first meeting set the tone for the group. It was business like, with an agenda, two

placement students taking minutes, a presentation by Keith and one by Reinhard, and Nick, a visitor from Kent and Medway NHS Partnership Trust (KMPT). KMPT were backing the group financially by paying for the room hire and supporting Reinhard and Elizabeth's attendance. We also gave the group an evaluation sheet, which the students helped participants to complete in the meeting. To express plainly to Nick – representing KMPT at that first meeting – how he saw the relationship developing with the Trust, Keith stated, 'We don't want biscuits or cake, not even cream cakes. We want a share of the keys to the bakery!' This was later quoted in a report written by DEEP in February 2019.

From the first meeting, the direction of the group was determined and its key aims written. These were: assisting in creating dementia friendly communities; to raise public awareness; to reduce stigma and negative stereotypes of dementia; to assist with staff recruitment and training; to evaluate the memory assessment service; to comment on new plans or service development; to link with other groups

nationally; and to support Keith, as Kent's dementia envoy.

The placement students spoke with members of the group to get their feedback, and whilst many comments were, 'happy to help with everything' and members thought that everything was good about the meeting, some specific and useful points were: wanting to help with training; more groups for people with dementia; opportunities to talk about our own experience; informing doctors, who in one person's view, knew nothing about dementia; helping with interviews; meeting other people with dementia; and hearing interesting information.

Much discussion at this first meeting, and indeed at the next four or five monthly meetings, revolved around a name for the group, as 'dementia service user network group' was certainly a mouthful. There was a mixed response to including dementia in the title of the group, although nobody liked the phrase service user. Keith approached the DEEP (Dementia Engagement and Empowerment Project) network for inspiration from their existing groups' names,

which he brought to a meeting. Everyone really liked the name 'Forget Me Nots', which was already owned by a group in Swindon, so we became the 'East Kent Forget Me Nots'. One member suggested Myosotis, which is the Latin name for Forget Me Nots, but this was overruled. Since this first meeting, we have maintained both the ethos of the group and the name.

To set the context for the group Keith explained at the first meeting that the diagnosis rate at that time nationally was only 42%, with Kent and Medway performing slightly worse at 38%, through the efforts of many including the Forget Me Nots this had risen to over 62% by January 2020.

The agenda was structured like a writing frame to give members space to scribble notes. Agendas have grown and sometimes too much has been placed on them, with as many as twenty-two items on some occasions. On the other hand, some meetings focused on two or three items only which were discussed in more depth. In recent years, agendas have been printed on coloured paper to enable them to be more easily filed and

accessed. For the first two years of the group, the three chairs (i.e.

Reinhard, Elizabeth and Keith) wrote the agendas, with some input from the group. We then moved to members of the group constructing the agenda, and currently the agenda is set by the group members with input from the professionals. At each meeting the group say what they want to discuss in the next meeting. Professionals add in any requests that come in during the month.

Development of the group

In order to grow the membership, our first leaflet was published in April 2013. It set out the aims of the group and had a welcome message from Keith as a dementia envoy, plus a photograph of some forget-me-not flowers. The leaflet, like the group, has evolved and was updated in February 2016, again in March 2022, and is currently at the time of writing (September 2022) being looked at again. Firstly we wanted to reflect the group logo which we identify with (which has been turned into a badge along with name cards for the

meeting) and quotes from members of the group were included in the leaflet. These leaflets were handed out at the memory clinic and were promoted at the living well courses, which has drawn new members over the years to the Forget Me Nots.

Some members of the group found speaking in the meeting more difficult. To address this, from the beginning until the group got too large, we had an opening item, such as speaking about a former job, a favourite book, reading a favourite poem, favourite foods, Autumn/Spring memories. We called this 'Around The Table'. Every meeting had a break for socialising and refreshment, which helped form friendship bonds. Some of the meetings were whole group discussions, whilst others have had speaking in pairs or small groups facilitated by professionals or a placement student/volunteer. Whilst our original aim was to support Keith as the sole dementia envoy, in 2016, Chris Norris also took on this role so the Forget Me Nots were to support him also. In turn, the envoys were supporting the advocacy skills of members,

enabling even the quietest members to have a voice and to participate in meetings and other activities for KMPT, such as interviewing. These meetings also gave members of the Forget Me Nots the opportunity to share their experience of living with dementia.

When the group was established, we gave thought to the role of family carers and it was decided by the group, and those leading the group that the Forget Me Nots would be solely for the person with the diagnosis; but that family carers would come to the meeting that celebrated each birthday of the group, and would support new members at their first meeting or any members who needed the support of their loved one at the meeting. This then gave great opportunity for the person with dementia to speak at the meetings. In June 2019 prior to Covid, a Friends and Family group was established by Clare Streeter, Dementia Empowerment Coordinator and two volunteers whose late husbands had had dementia. This ran at the same time and place, but in a separate room to the Forget Me Nots. This was initially funded by a grant achieved by Clare.

Whilst the business nature of the group has been successful and brought achievements to the group and individual members, in early 2015 there was some tension around some members requiring a more social focus for the group. So, on the 16th February 2015 at the Abode Hotel, Canterbury, a social group was formed. This met on and off monthly for four years, and since Covid (and post-Covid) the social group has run virtually as an online community, supported by placement students.

Members of the Forget Me Nots have always, right since the first meeting, recognised and advocated for the importance of peer support. Alongside a clinical psychologist, six members worked to develop a 'Dementia Allies' or 'Buddy' scheme which launched at St Martins hospital on 25th February 2019 with a celebration. Allies, accompanied by the Alzheimer's Society Support Worker, visited the homes of people newly diagnosed to offer support and signposting to whatever services we hoped would prove useful.

Where these meetings took place they were on the whole successful and were evaluated by an assistant psychologist and a placement student. However, referrals were problematic as some professionals at the Memory Clinic and GPs' surgeries were slow to refer. Staff changes both in KMPT and the Alzheimer's Society largely contributed along with Covid to its suspension in March 2020.

Thanks to volunteers phoning people up to teach video-conferencing skills we were able to meet virtually in May 2020, only missing one meeting in April.

The group continued to meet on this virtual platform until the July 2021 meeting, which was a hybrid meeting with half of the group happy to meet in our old venue and half joining with student/volunteer support via Lifesize, our online platform. Members were supported to attend by placement students. Amazingly after initial issues, by the January 2021 Lifesize virtual meeting, twelve Forget Me Nots were supported to attend. Alongside which, between 2nd April 2020 and 1st January 2021,

Jonah - a former placement student acting as a volunteer - led the production of seven periodical newsletters called "Keeping in Touch" which was a lovely way of keeping the group connected during this awful period. Led by Jonah a range of members and professionals/students contributed to the first and subsequent issues of the newsletter. Normal face to face meetings with Covid precautions in place recommenced from September 2021 - much to the relief of everyone who attended.

Membership of the group has been affected by Covid and the progression of people's dementia. The initial group of 5 - 7 members did grow to a peak of 22 by April 2016 and this was sustained until February 2017 when 20 members were still attending, although at the time of writing 9 or 10 remain as regular or more than occasional attendees. The group recruits from Canterbury and the surrounding towns and villages, and we are blessed to live in such an interesting part of the country. Many of the members have a rich and deep knowledge of the area. An example of this was shared by Martin

Taylor, who took the group plus some of our family carers for a historic walk around the city in 2015.

Chapter 2

Support

RIGHT FROM THE START of the Forget Me Nots it has been set up on a triad model, this being people with dementia, one or two professionals (psychologist, assistant psychologist, occupational therapists and dementia empowerment coordinator), and two or three placement students, this then being supplemented by volunteers when available.

The role of the professionals initially was to co-chair firstly with Keith, and then secondly with Chris, and then with a rota of group members. As less people have felt able to chair, we have moved to members hosting by starting off with the welcome, then handing over to Elizabeth or Clare to chair, but supplementing and supporting the chair on occasions. The agenda for the next month is decided at each meeting, with the students and professionals

supporting by sending out written agendas, writing minutes, booking venues, and generally reminding and supporting Forget Me Not members.

Fundamental to the success of the group has been the role of the placement students, who provide much administrative support as well as supporting members during the meeting to enable them to participate fully. Outside of the meetings, they also provide substantial support to individual members by way of support with technology, attending events and conferences, walking and talking and with providing help with writing.

For the year 2014-15 it was trialled that the Forget Me Nots and students were allied as buddies so that each of the seven students that year would support two or three Forget Me Nots. For some this worked well where personalities, commitment and interests were well matched, but for some Forget Me Nots and students the system was unsatisfactory and the experiment was not repeated. In the case of Chris and Keith as envoys, more one-to-one support from

students was provided with the envoys drawing from the whole group trying to keep it as fair as possible. Polly who was on placement in 2016-17 even ran the London marathon to raise money for Young Dementia UK while on placement.

In January 2019 Lucy, who was on placement was joined by Elizabeth, and Jen a former placement student, plus a number of student volunteers along with eight Forget Me Nots for a DEEP workshop led by Rachael Litherland entitled “Capturing the Story.” This recognised the important relationships alongside highs and lows over the years between students and people with dementia in the group. Many of the placement students really do become part of the family that is established within the group and understandably often wish to continue this relationship after placement, initially as volunteers, sometimes as friends, or in some cases as assistant psychologists.

Lara Stembridge and Abigail Lugg, providing support with the writing of this book, are well placed to speak about the experience of spending time with on placement the group.

‘We as placement students have really valued being involved with the Forget Me Nots; although it is sometimes challenging, the highs really outweigh any difficulties and we have felt as though we have been welcomed and supported by the group. This connection is primarily why we have decided to continue to be involved with the Forget Me Nots beyond our placement and they continue to challenge stereotypes and inspire us in our lives.’

The problem with the student placement model is the period between July and September, when term is over. If volunteers are not available, the group do struggle when having meetings and events during that time, and there is also the need to recruit new volunteers and to manage them. To address this as a short term measure, DEEP generously gave us a grant of £2,100 to cover paying the students to help during July – September 2014. In 2016, Keith, Chris, Reinhard and Elizabeth wrote a bid to DEEP for funding for a Dementia Empowerment Co-ordinator to source and support volunteers to work with the Forget Me Nots. This was secured

and achieved and we were delighted when Clare took up the post which is now funded by KMPT within voluntary services.

One of Clare's many achievements within the group was alongside Julia, setting up a parallel Friends and Family group, which meets at the same venue at the same time as the Forget Me Nots in a separate room.

In the background, KMPT have right from the start of the group been extremely supportive, recognising the value to the trust that the group can bring. They fund the venue and staff, celebrate our achievements and have made use of the groups' expertise. The Friends for Mental Health (East Kent) and Patient and Liaison Service (PALS) have also given additional support when required for projects that the group have undertaken as individuals or collectively.

Often visitors will come to the Forget Me Nots with good intentions of remaining a supporter of the group but seldom is this materialised. The exception being Liz Jennings, who first visited the group in 2014 to embark upon what became the 'Welcome to our World'

writing project. Liz remains without doubt the closest friend supporting the group, as was witnessed at our 9th birthday party in November 2021 when she curated this group poem, gathering phrases from the group and arranging them altogether to form one cohesive piece during a group session. The poem featured in the DEEP Newsletter. The members wanted to capture their group in a poem and were asked to write down words or phrases about what the Forget Me Nots means to them.

Poem by and for Forget Me Nots

This is much more than a meeting,
It's connecting with others to share,
As we learn and grow with a purpose,
We come here because we all care;
This is much more than a meeting,
I feel energised; I feel alive,
Through the kindness of likeminded friends
here,
I feel hope as I see I can thrive,

This is much more than a meeting,
And although this is only a poem,
We may have dementia,
But it doesn't have us,
This is knowing that I'm not alone.

Chapter 3

Projects

ONE THING WHICH makes the Forget Me Not group quite unique is the rich history of projects that the group has undertaken since its formation. These projects have gone a long way to exceed the expectations of what people with dementia can achieve with good support.

Forget Me Not Library

Looking at this chronologically, the first project suggested by the group in 2013 was to establish a Forget Me Not library of books relating to dementia, which members could access to improve their knowledge of the condition alongside learning ways of living with whatever challenges dementia presented to them. This idea

was put on ice until some funding became available.

In the meantime, in 2017 and 2019 a number of Forget Me Nots volunteered to read new books by Wendy Mitchell and Christine Bryden and, through Keith, to provide reviews for the Alzheimer's Society's *Dementia Together* magazine. As a thank you, members were given free copies of the books to keep.

A library was established in 2019 by Clare Streeter and supported by a volunteer with skills as a library worker featuring fiction and non-fiction books, DVD's and informative literature all pertaining to dementia. This facility allowed members of the Forget Me Nots to access books and information for themselves and friends and family to raise awareness and understanding about lived experience of dementia. Covid has halted the library but it will resume in the near future.

Welcome To Our World

In March 2014, local author and writing tutor, Liz Jennings, visited the group to encourage

members to join a life writing class being formed after Keith secured funding from the Alzheimer's Society. Eight Forget Me Nots joined the writing group, supported by five placement students, and we met at the Canterbury library for six fortnightly sessions concluding on the 26th June 2014.

Liz encouraged us to write about our pasts, in both poetry and prose, and the resulting writing was so amazingly rich that we decided to publish it as a book and to launch the book at Waterstones in November 2014. Each writer was supported by a student buddy and the collaboration was genuine and rewarding. The Alzheimer's Society secured funding for the book, as well as a fabulous foreword by Jo Brand.

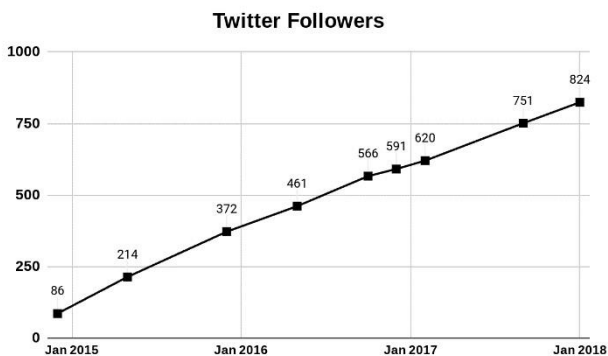
The book was then sold on behalf of the Alzheimer's Society, selling over 1,000 copies in its first year, and has since raised over £6,000. Sadly, at the time of writing, it is out of print. The book has since been quoted and referenced as a ground-breaking publication in a number of other publications such as *The D Word* *Rethinking Dementia* by Jordan & Collins.

Forget Me Nots on Social Media

Whilst most Forget Me Not members are not confident using social media, the students supporting us are, and in November 2014 one student supported the set up of a Forget Me Not *Twitter* account as the basis for her University of Kent student placement project. During the life of the Twitter account, the profile was visited by people from the following countries: UK, US, France, Italy, Australia, Luxemburg, Lebanon, Costa Rica, Austria, Cyprus. The graph overleaf demonstrates how the account grew, with the number of ‘followers’ of the account.

- By December 2014: 86 followers
- May 2015: 214 followers
- December 2015: 372 followers
- From October to December 2015: profile visited 585 times from all around the UK, US, France, Italy, Australia, Luxemburg, Lebanon, Costa Rica, Austria, Cyprus. Subsequently during 2016 followers joined from Nigeria, Canada, Netherlands, Russia, Denmark, Spain and Australia.
- May 2016: 461 followers

- October 2016: 566 followers
- December 2016: 591 followers
- February 2017: 620 followers
- September 2017: 751 followers
- January 2018: 824 followers



At the time of writing the twitter account remains dormant but might be re-energised if a placement student next year is interested in taking this on.

Dementia Friendly Film Club

Buoyed by the success of Welcome to our World, Liz and Keith moved onto another project with the Forget Me Nots in 2016. This was again funded by the Alzheimer's Society, and aimed to encourage people with dementia and family carers to watch and enjoy modern films (we

decided upon films no more than six years old). Having watched the film in a group, we then broke into smaller groups and, with the assistance of Liz's PowerPoint prompts reminding us of actors and key scenes, we would then discuss the film we had watched, considering themes and symbolism, actor's performances and the story's emotional impact and message.

Liz took a list of 20 films to a Forget Me Not meeting for the group to vote on which six they wanted to watch over a six-week period. This was then advertised through Age UK and other couples came along who weren't involved in the Forget Me Nots, though the bulk of attendees were a Forget Me Not or family carer.

The first film, *The King's Speech*, proved to be the most popular, and the least popular film was *The Monuments' Men*. As a venue, at first we used a room at a local church and then latterly the last two films were shown where the Forget Me Nots meet.

To conclude the project, Keith got extra funding from the Alzheimer's Society (who were

again sponsoring this project as part of their campaign to promote dementia friendly cinema), for the group to have a special private viewing at Canterbury's ODEON cinema of a new film being shown at the time, 'Eddie the Eagle'. The cinema manager worked closely with Liz and Keith and used it as a basis for making the Canterbury cinema more dementia friendly. The project was supported not by placement students, but by volunteer students from the University of Kent.

Dreams and Visions

Having watched films, Liz, supported by Keith, applied to the National Lottery for an 'Awards for all' grant to run a ten-week course which would result in people with dementia writing a script for a short film.

This project ran from September to December 2017 and recruited from the Forget Me Nots and SUNshiners (another dementia service user group from Kent). The ten sessions were held at Canterbury library and taught by Liz, drama practitioner Rhiannon Lane and film maker Al Reffel, supported by a mixture of

placement and volunteer students from the University of Kent. Again, this project was unique and, to the best of our knowledge, had not been undertaken anywhere else at that time.

Six participants with dementia completed their scripts, which in June 2018 were performed by professional actors on stage at the Kit Marlowe theatre in Canterbury, with each performance co-directed by its writer. This performance was funded by The Friends for Mental Health (East Kent) and DEEP and was a fabulous conclusion to another unique, groundbreaking project.

Every Picture Tells a Story

In 2018, after some discussions, former placement student Jen Holland (who previously supported Welcome to our World when on her university placement with the group) planned and delivered a fantastic six-session photography project for five Forget Me Nots.

This was based at Canterbury Christ Church University and sponsored by DEEP. Jen skilfully and patiently taught the group how to make better use of their own camera or tablet.

At the end of the project, each participant was given a book showcasing many of their individual photographs.

Time and Place Poetry Project

Prior to Covid, Jess Shaw (who had supported the Dreams and Visions project as a student volunteer) achieved a grant from the University of Kent to run a community project. Initially, she met with Keith to talk through ideas which might appeal to the Forget Me Not group. We decided upon something involving poetry and the next move was to bring in Liz Jennings again to help lead the project. We planned a theme of the here and now, and where we live (Canterbury), and called the project Time and Place.

Jess, Keith and Liz spoke to the Forget Me Nots and quickly recruited at the group's December 2019 meeting eleven keen participants.

After initially securing the Waterstones café as a venue to meet we decided this was unsuitable due to noise levels, so we spoke again with Canterbury's library who were extremely keen to give us a base for free where we could

meet and write, and Liz set about preparing a programme which we would deliver during 2020.

Jess recruited a large number of student volunteers because we had only one placement student available.

Then Covid struck.

The project could have ended there, however it did not because Liz remodelled the place to be our own home where we were locked down into at the time, and Keith, through DEEP, spoke to a number of groups nationally via Zoom and recruited participants from England, Scotland and Wales. Some Forget Me Nots and SUNshiners stayed with us, but others felt doing a project virtually at this challenging time was beyond them. Five out of the initial twenty student volunteers who'd expressed interest remained committed.

Liz used her website to place tutorials encouraging the people with dementia to write poetry in a number of different genres, each week placing a different tutorial taking us around our own home, the first one being the kitchen, then to

the lounge, and subsequently around the rest of our home.

These video-led sessions with visual prompts and inspiration remain available at <https://www.lizjenningswriter.com/2020/05/26/time-and-place-poetry-group-welcome-and-session-1/> and are free for anyone to use to explore and enjoy poetry.

We were overwhelmed by the quality of writing which came from everyone, and this resulted - with thanks to further DEEP funding - in Elsa Lewis from Canterbury-based publishers, Lioness Books, producing a book entitled *Time and Place*, which was launched in April 2021. The book showed the many different forms of poetry the group tackled, from Tankas to Daisy Chains, and gave clear instructions to encourage readers to have a go themselves.

Writers discovered the power and the practical value of poetry as an everyday tool to express how they feel about life and to connect with others.

Here are three examples of poems written by the Forget Me Nots for the book, which convey

something of the variety of tone and topic, from whimsical humour to poignant reflection and a hopeful looking forward.

Biscuit Tin a Tanka poem by

David Jones

Ginger Nut biscuits
Why don't they have much to say?
Are they just stupid?
Or thinking of other things...
That's why they stay in their tin!

I Cannot Tell

A Sensory Poem by Melvyn Brooks

I can hear the dripping tap
I wish I could smell the flowers in the vase
And I cannot tell you how I feel
As every time I walk into the kitchen I see the
clutter
And also taste the times gone by.

Friendship Matters a *Haiku*

poem by Keith Oliver

Friends pass through our lives
Filling our hearts with their love
Stays with us forever

Wanting to build upon this, Liz secured funding from the Arts Council to run poetry workshops based across East Kent and within the Forget Me Not's monthly meetings. These have been supported by placement and volunteer students and are continuing for a second year at time of writing.

In this way, the Forget Me Nots' lived experience that reading and writing poetry can improve daily life is rippling out to affect others living with a diagnosis of dementia. One PhD student from the University of Hull, Sherry Anpomsen, has already referenced the project and used it to inspire more poetry for her own PhD study, and at the time of writing, it is being referenced by and inspiring others working in the academic community to further investigate the

very real benefits that engagement with poetry brings.

Chapter 4

Partnerships

Working with KMPT

FROM THE ONSET of the group there's been a close alliance with the Kent and Medway NHS and Social Care Partnership Trust (KMPT), who support professionals in facilitating the group and pay for the hire of the venue. The group have taken on an important role as a service user forum and to act as a critical friend to the Trust, giving feedback on literature, strategic planning – including work on the dementia care pathways during 2013/2014, staff and student interviews, and providing insightful talks for staff and newly diagnosed people – the latter through Living Well groups which ran prior to Covid and have started again this year.

On a number of occasions, the group have welcomed the chief executive and senior directors of the Trust to our meetings, who have

either come with an open mind to listen to the views and experiences of the group on our personal pathway or have brought some strategic planning to the group which they sought feedback on. One significant occasion was in December 2016, when Helen Greatorex, KMPT's Chief Executive at time of writing, visited the group and made ten pledges in dementia care which she promised would be followed up, as indeed they were in a subsequent correspondence from her. All of this is designed to help improve dementia services within Kent and Medway and sits consistently with the key aims of the Forget Me Nots as outlined in our first meeting, back in 2012, and maintained since.

The role of the dementia envoy arose in part from service user groups developed after the Forget Me Nots started. We currently have five dementia envoys, and it is fair to say that their individual advocacy skills and confidence were developed through their involvement in one of the groups such as the Forget Me Nots. Within a year or two of the formation of Forget Me Nots, a second group called Memorabilia was established

in Maidstone, run by a partnership of KMPT and the Alzheimer's Society. This group later spread and drew from the Medway towns and that area. Later, more groups were formed: The SUNshiners in Folkestone and Dover, Phoenix in Ashford, Pathfinders in Swale, and the Seasiders in Thanet.

Whilst each of these groups work independently, there have been times when collaborations and partnerships have taken place between the groups. Notable examples of joint projects have been two amazing conference events, one held in Chatham and one in Canterbury, the latter led by the Forget Me Nots. Another highlight for those who were involved was a Tree of Life workshop held in May 2017, which brought together eight members of Forget Me Nots and SUNshiners in exploring the potential benefits of a Narrative therapy approach. This workshop was led by Elizabeth Field, supported by two Assistant Psychologists, and was a great learning experience for professionals and service users alike.

Subsequently, three members of the Forget Me Nots who attended the workshop helped deliver training alongside Elizabeth Field to KMPT staff and placement students, as well as nationally and internationally through a 3 Nations Dementia Working Group webinar.

Working with DEEP

Another important partnership for the Forget Me Nots has involved working with the Dementia Engagement and Empowerment Project (DEEP). The group's first meeting with DEEP was with Nada Savitch on 19th April 2013, after which she - along with Rachael Litherland, Steve Milton, Rachel Niblock and Philly Hare - became great allies of the group, and in turn the group did an enormous amount to help DEEP.

Early in the Forget Me Not story we were keen to become part of this national network in order to influence more widely than Kent, but also to learn from other groups similar to ourselves. One of the first examples of this partnership was the production of a guide to

psychosocial interventions, also in collaboration with the British Psychological Society.

Another early important piece of work in October 2013 involved a group of Forget Me Nots meeting in St Peter's church hall, Canterbury with DEEP to discuss a plan to improve the mental capacity act with two representatives from the House of Lords. Discussions focused upon our capacity for decision making and having decisions made for us. We were the only group in the country with dementia to comment on this legislation. Comments from the Forget Me Nots who attended were included in the House of Lords report presented to Government in March 2014.

In December 2015, eight Forget Me Not members attended a training workshop and were given recording equipment to take part in a national DEEP sponsored project called the Dementia Diaries. This project continues to this day, with one Forget Me Not being particularly prolific, and three other Forget Me Not members still making regular contributions, some of which were taken by Rose Vincent as part of her PhD project at the University of Edinburgh.

In February 2016 Philly Hare worked with ten Forget Me Nots and two placement students to produce an impact report to record successes the group have had with showing how society portrays and perceives dementia. The document went on to outline how the group were influencing policy and decision making through collective action and peer support. Chris, Caroline and a placement student then went on to represent the group at a national DEEP event where this work was showcased.

Along with the launch of this book at the Canterbury Festival on 22nd October 2022, the occasion will also mark the Canterbury public unveiling of the Kent DEEP banner (it will officially be launched at the SUNshiners DEEP Kent wide event in Folkestone in September 2022 having been postponed in May 2020 due to covid.) This was created by Ian Beesley sponsored by DEEP and incorporated ideas which emerged over 3 meetings, the final one being on 18th November 2019. The banner features suggestions made about our county taken from members of

four dementia groups – the Forget Me Nots, SUNshiners, Seasideers and Memorabilia.

Over the years, Forget Me Nots have forged various links with our two local universities, the University of Kent at Canterbury (UKC), and Canterbury Christ Church University (CCCU). These partnerships, largely formed through student placements, have been an exceptionally important part of the story and this has extended to the work of the other service user groups. Rachael Litherland from DEEP recognised this and held a workshop with present and former students alongside the Forget Me Nots in 2018, after which this intergenerational model was written up by DEEP as an example of good practice.

Another highlight of our partnership with DEEP since 2013 included a visit with Philly Hare to a local theatre in February 2017 to comment upon its provision for people with disabilities, especially those living with dementia. Sadly in the case of the latter piece of work nothing noticeable was actioned by the theatre, which remains largely not dementia- friendly as a venue,

primarily regarding poor signage both into and within the building.

Research

Most Forget Me Not meetings have on the agenda an opportunity to hear about research projects, this is usually delivered by Keith. Alongside this, a number of universities e.g. Kent, Exeter, Essex and LSE have brought their research projects to the group for comment or involvement. Part of Keith's reporting to the group will make reference to research sponsored by the Alzheimer's Society.

Canterbury City Council

As the group is based in Canterbury, we have supported projects run by the City Council which have been based in the Beaney House of Art and Knowledge, the first of which was an interesting short project where members were invited in to handle historical artefacts and comment on the experience.

Soon after this, we used the Beaney as the base for our project Welcome to our World and then bringing this partnership up to date, we are currently working with the City Council in planning an exciting event for the Canterbury Festival 2022.

Royal College of Psychiatrists -National Memory Services Forum – MSNAP

From 2014 a small number of Forget Me Nots have been closely involved in the work of the Royal College: Keith served on their Older Adults National Executive Committee and Chris Norris did sterling work linked to MSNAP in visiting memory clinics around the country to help with assessments as a person with dementia.

Chapter 5

Campaigns

SEEING THE FORGET ME NOTS as a campaigning group was a central key aim of the group when it was established and has remained a big driving force over the last ten years. Individually and collectively, group members have taken part in many campaigns, some following invitations from one of our partnerships but some self-driven by members.

Picking out examples from the last ten years, these are the ones that immediately come to mind. During 2017, an enormous amount of anxiety was caused for people living with dementia around the introduction of personal independent payments (PIP). One result of this was that Chris, a Forget Me Not member supported by Nicki (a volunteer aligned with the group) campaigned vigorously, including writing to the then-Prime Minister, David Cameron, and to the Alzheimer's Society and DEEP. His efforts contributed positively to successful outcomes for people living with dementia. Also during 2017,

the Alzheimer's Society and the National Dementia Action Alliance improved and updated what were called the dementia statements, which should focus any national or local planning of dementia care. The Forget Me Nots played a part in constructing these statements, which have since been known as the 'We Statements':

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.
- We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

- We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and to be supported to take part.

These statements formed part of a campaign which Keith, his wife, Rosemary, and Philly Hare took to the United Nations Commission Representing Persons with Disabilities (CRPD) in Geneva in August 2017, when Keith addressed the UN on behalf of people in the UK living with dementia about their rights. What he later said to the UN, he read to the Forget Me Nots at their meeting prior to his trip, in order to bring them into the picture and seek their views. Alongside the statements, he also presented to the UN a book called 'Our Lived Experience', which had a number of contributions from Forget Me Not members. The UK government was then

examined by the UN, partly on the basis of Keith's talk and the written information he presented alongside Philly and Rosemary.

Alongside DEEP the Forget Me Nots organised a Language and Media day in January 2015 when the group were supported in discussing and making recommendations for the use of appropriate, clear, concise language which is accessible for people with dementia, and indeed we used the adage that what is good for people with dementia is good for everyone!

During 2019, five Forget Me Nots with an assistant psychologist and a volunteer formed a Dementia Care Working Group chaired by Edward Mundy (clinical psychologist trainee) which resulted in the group communicating their views to the Alzheimer's Society in London who at the time were preparing a response to Government policy on social care.

Chapter 6

Awards and Achievements

THE BIGGEST ACHIEVEMENT that the Forget Me Nots have accomplished has been their longevity

and stamina. That the group is thriving ten years after its foundation and still making a positive difference to the lives of members and beyond is a source of great pride and much joy for the Forget Me Nots. Researching this chapter through the records, we were amazed to see just how many awards the group and those connected to the group had achieved over the ten years.

Building upon our early chapter on partnerships, the Forget Me Nots were given an award recognising the partnership with Kent County Council (KCC). Still on the theme of partnerships, KCC also awarded the group a dementia friendly award in its partnership section. Here is a list of some of the main awards and achievements of the group, collectively and individually:

- Alzheimer's Society: Realising Potential Award – given to Keith Oliver for his contribution to the 'Welcome to Our World' project.
- The Faculty of Psychology for Older People (FPOP) Annual Conference: Best Academic Presentation –given to Chris

Ryan and Lewis Slade (a Forget Me Not's Placement Student).

- FPOP Annual Conference: Best Poster Award – given to Elizabeth Field and Lucy Elias (Assistant Psychologist) for their work with Forget Me Nots and SUNshiners on Tree of Life.
- KMPT: Rising Star award –given to Lewis Slade and Alex Bone (Placement Students) for their work with the Forget Me Nots.
- KMPT: Digital Innovation Award (highly commended) –the Forget Me Nots for the DEEP digital inclusion project conducted during Covid.
- KMPT: Volunteer of the Year (highly commended) – Theo Chan for her work with the Forget Me Nots, especially on the digital inclusion DEEP project.
- KMPT: Volunteer of the Year (highly commended) – Jess Shaw for her work with 'Time and Place' and the Forget Me Nots.

- KMPT: Peak of the Week – given to Chris Norris and Reinhard Guss.
- KMPT: Inspiring Volunteer – given to Keith Oliver 2013, Chris Norris 2016.
- Emma Kent Award – given to Liz Jennings for her outstanding contribution and leadership of the ‘Dreams and Visions’ project.
- Traiblazer of the Year 2019 – awarded by the Alzheimer’s Society at a glamorous event in London – the award was accepted by Anne-Marie, David, Elizabeth and Clare with Chris and Keith in attendance as Ambassadors of the Society.

Some of these achievements of the group have been recognised, acknowledged, and recorded, along with the other achievements of each year on a birthday certificate given to all members once a year at each November meeting.

Alongside receiving these awards, and having our achievements acknowledged, a number of Forget Me Nots have served on judging

panels for awards, especially with the Alzheimer's Society in regard to their annual national poetry awards and Chris had the privilege of announcing a winner of an award at the national UK Dementia Congress in 2014.

During the time of writing this book, three of the placement students, Michael, Lara and Celine organised an inter-group quiz, the Big Kent Quiz which was run through Lifesize, pitting five service user groups from Kent against each other in a pub-style quiz involving questions on areas such as history, sport and entertainment. Chris quite rightly placed his allegiance with the Phoenix group since he is chair of this group, and the Forget Me Not's team was made up of Melvyn, Nigel, Jim and Keith, kept in line by Tricia and Lydia, two assistant psychologists.

It was a lovely event, extremely well organised and run, and we were, of course, thrilled when the Forget Me Nots won!

Chapter 7
Contribution to Knowledge of
Living with Dementia

THROUGHOUT THE TEN YEARS since the group was formed, we have been keen to participate and support research projects. A number of universities including one of our local ones, University of Kent, have visited the group and sought our advice on their work relating to care and wellbeing of those affected by dementia.

A small number from the Forget Me Nots have also volunteered to be participants in testing for new drugs which is based at Queens Square, London or have been contributors to projects such as IDEAL, which focuses on living well with dementia and is based at the University of Exeter. During Covid, Chris and Keith were key members of an advisory group working with the University of Exeter to formulate an outstanding dementia toolkit which can be easily accessed at www.livingwithdementiatoolkit.org.uk

As well as being participants in research or advisors on steering groups, in 2020/21 the

Forget Me Nots, supported by our placement students Theo and Adam alongside Clare and some volunteers, devised and completed a DEEP Dementia Enquirers' research project.

The subject for the project was what impact has Covid had on a person's connections with others, especially other Forget Me Nots. It involved three members of the group as lead researchers, supported by the amazing students and volunteers alongside Clare in conducting interviews with eleven participants from the full Forget Me Not group. All Participants contributed to creating the interview questions and the interviews were led by the person with dementia with the student setting up the virtual Lifesize link and supporting from the background. In addition to showing what people with dementia can achieve with support, we aimed the enquiry to help reduce feelings of loneliness during this difficult time and to empower people with dementia alongside inspiring future research in this area. We developed six themes during the project, and these were expanded upon during monthly Lifesize meetings. The themes were:

- Use of technology
- Relationships with others
- Coping strategies
- Challenges presented from social restrictions
- Impact on physical and mental health
- Any positives we can draw from the experience

The placement students were fundamental in the gaining of ethics and the analysis and production of the results which was shared with, and discussed with the full Forget Me Not group. An amazing report publication was produced and given to the group at the September 2021 meeting when we celebrated our combined achievement. Subsequently Theo, one of the students involved in the project supported by Keith alongside some from the following year's group spoke about the project to undergraduates and academic staff at a Cafe Psychology event at the University of Kent.

Since 2011/12, placement students supporting the group have needed to complete a placement project and this has often involved members of the Forget Me Nots, examples being evaluating online and face-to-

face meetings within Kent involvement groups, establishment and growth of a Forget Me Nots Twitter account and working with the Dementia Envoys.

Between June 2013 and June 2016 the group were often joined at our meetings by clinical trainee Jocelyne who was completing her doctorate at the University of London, and she used the Forget Me Not group as a part of her final research project which was focusing upon how service user groups such as the Forget Me Nots can help people with dementia to live as well as possible.

Research comes alive when shared through conferences as well as written documents, and some Forget Me Nots have been privileged to speak at conferences both in Kent, in the UK and in the US. Our part in these presentations has been widely acknowledged and often helps bring the research alive.

Supporting Dementia Friendly Communities and Action Alliances has always been an aim of the Forget Me Nots, and in April 2014 a number of Forget Me Nots, placement

students and psychologists attended and ran a stall at a Dementia Friends' Market Place at Canterbury Christ Church University which showcased the work of the group both locally and potentially nationally.

Not only have Forget Me Nots attended and spoken at conferences about research, but more often have been invited to share with audiences their unique individual lived experiences of life with dementia. One example of this was in November 2014 at the National Dementia Conference – UK Dementia Congress, held in Brighton. When five Forget Me Nots supported by five current and former placement students attended and either spoke at the event or presented a poster. Our involvement and occupation of a hotel together was organised by Reinhard, who was at the time co-leading the Forget Me Nots.

Taking this much further. As a part of her initial job description Clare was tasked with coordinating a Canterbury based, Kent wide event which took place on 20th June 2019. The event was entitled “A celebration – The Forget Me Nots

managing life with Dementia”. After months of planning by a Forget Me Not working group led by Clare and supported by Lucy, a placement student and volunteers, the day was a great success. Almost all of the presentations were led either solely by a person with dementia or jointly with a professional. Topics covered ranged from The Power of Mindfulness, the photography project, the Allies, Dreams and Visions project, Neuroscience and different types of dementia. The efforts of the group and Clare were recognised both by DEEP and with a celebration afternoon tea at Howfield Manor on 30th September 2019 for all the group and close family members.

It has long been recognised that GPs have a vital role to play in dementia care and in February /March 2015 nine Forget Me Nots volunteered to help with dementia awareness training for GP’s receptionists. We had hoped that GPs would also access these sessions, largely they didn’t attend in person, but we were pleased that a large number of receptionist and administrative

staff attended sessions we supported at Canterbury, Margate, Folkestone and Ashford.

April 2015 continued to show how busy the Forget Me Nots were becoming with two major contributions by the group to national projects – nine members of the group, Reinhard, Elizabeth and Jess a placement student met with DEEP connected to a nature project they were funded to undertake, two weeks later six Forget Me Nots met with the Mental Health Foundation to give personal thoughts on Truth Telling from professionals with people who have dementia. This was then recorded in the Truth Inquiry report.

Another contribution to the knowledge base is through film and in December 2015, six Forget Me Nots were filmed by KMPT for the Live It Library, the aim being to share with the audience our top tips about living with dementia and to confront stigma and misinformation thus giving people hope by sharing our experiences.

The films are available at www.liveitwell.org.uk/live-it-library and are regularly shown in post-diagnostic courses run by

KMPT. Readers of this book can discover more about our contribution to knowledge in Chapter three when we outline some of the projects the group have completed, and in Chapter two, where we talk about the support given from and to students.

Chapter 8

Overcoming Obstacles

THE FORGET ME NOTS all agree being a member of the group feels like being a member of a family, and there are few families where there are not a large number of highs but also some lows, and in many ways, the last 10 years for the Forget Me Nots has been a rollercoaster ride. Whilst there have been low points and challenges there have been as recorded in this book far more high points on this ten year Forget Me Not roller coaster ride.

The phrase 'If you meet one person with dementia, you've met one person with dementia' - because everyone is so different and unique - is so true, and in the case of the Forget Me Nots, this statement really resonates. Each member comes with their own expectations, hopes, frustrations, beliefs and attitudes, which often are common with others in the group but on occasions, are different.

Many people with dementia say a key element of having the condition is an element of frustration and this at times is brought out in the

meetings. People want to express themselves and to bring to the group issues that perhaps have been bubbling in their mind for days before the meeting. Some people are more tolerant than others, but occasionally this tolerance can be tested.

There are members in the group who come to each meeting, listen carefully and say very little. There are others in the meeting who when approached to speak will do so willingly, but others will decline. Having an agenda helps keep people to time but pacing the meetings is often difficult – for some discussions become laboured and protracted and slow, for others not enough time is devoted to issues. The gender balance in the group right from the beginning has been more men than women and there have been times when discreetly, female members of the group have expressed frustration that the men were dominating.

Alongside establishing terms of reference, we had two review meetings with Forget Me Nots and students, firstly in September 2014 and secondly March 2015 at

which in small groups and collecting together in a whole group, we sought the views of members and students as to how the group could successfully proceed. This was then followed up in July 2016 with the Forget Met Nots' opinion questionnaire where we asked all members what they liked most about the group, why they came, what improvements they would wish to see and how might things be done differently. One challenge that always comes up and did in each of these reviews, revolves around transport to get members to the meetings. A small loyal committed group of volunteer drivers help with this but there is never enough.

Chairing the meetings has been both a delight and also a challenge. Elizabeth has been the constant co-chair since day one and thankfully still holds that position today. Alongside her initially, Reinhard took on the role with Keith fulfilling it from 2012-2015 before Chris took over 2015-2016; since then there has been a rota of four members of the group taking a turn.

During June and July 2016, there was some discussion about how democratic the group was for some people. Two or three members felt sidelined in the creation of the agenda. It was then agreed that to be part of the agenda creation, one needed to have access to an email. Some felt that a Forget Me Not elected chair person was the right way forward, but no one was prepared to take on the role. The situation now is that the placement students contact members seeking suggestions for the agenda, which are then followed up at the monthly meetings where the group are also invited to suggest items for the next meeting. Life is about compromise and Forget Me Nots is no exception. One may not get exactly what one really wants, but we recognise the need to be satisfied and comfortable – and, indeed, encouraged – with achieving something.

In an effort to address some of the dips in the rollercoaster, in 2015, the group formulated some terms of reference, which were designed to enable all members whether outspoken or quiet to be given the opportunity to be heard. This was helped in 2017, when the group received a supply

of the DEEP 'I want to speak' cards, which have been diligently used since and have helped with the smooth running of the meetings.

Tensions within what was at the time a very large group (regularly twenty-plus members would attend during June and July 2016). The professionals, supported by Jocelyne and six placement students led the group in a whole meeting devoted to small groups talking about the future of the group, what people liked or found difficult. The meeting then came together to share the thoughts of the four groups and a general consensus (with some disagreement) was achieved around people feeling valued, the meetings being on balance the right length, the benefit of the student support, the benefit of hearing information about dementia and discussing this, the need to rotate the chair, value of the DEEP 'I would like to speak' cards, sticking to the terms of reference to address rudeness of any member, looking at a buddy system within the group, encouragement for those who want the social meetings whilst maintaining the business nature of the main meeting and the need for

professionals to recruit new members who can add to the work of the group.

Building upon this and needing to revisit the issue, in May 2018, eight members of the group led by the KMPT staff and students revisited the Terms of Reference alongside a document about the emotional challenges people with dementia often face. These in-depth discussions were recorded in writing by the placement students and then shared with everyone in the full group including those unable to attend the meeting.

Whilst the group is apolitical and members generally keep their political allegiances to themselves, we have twice invited our local MPs to our meeting. The first occasion was in June 2015 when Julian Brazier, Conservative MP for Canterbury visited; unfortunately his answers to our pre-prepared questions left the group dissatisfied. Most of the questions focused upon funding of dementia care and research nationally but also closer to home questions were asked about his understanding of

dementia and the future of our local hospitals and health and social care provision.

After Brazier was defeated in the 2017 General election, the new MP, Rosie Duffield, was contacted to come to one of our meetings. She came to the September 2018 meeting amidst a great level of expectation and hope, and as a Labour opposition MP answered questions about the rights of people with dementia alongside our concerns relating to local issues connected to hospitals and social care. She listened, took notes and tried to answer – she did also promise to follow up back in Westminster any questions she was unable to answer fully.

Chapter 9

Impact of Covid-19 Pandemic

LITTLE DID THE WORLD or indeed the Forget Me Nots know what lay around the corner when the group met on March 13th 2020. This was to be the last face to face meeting due to the pandemic for some time. The April meeting was cancelled whilst students, volunteers and staff worked out

how to move meetings online. Clare recruited volunteers to be IT buddies to train people in using videoconferencing and with their support we were able to meet online from May 2020 using Lifesize as a platform.

Sadly, not all members could connect using this method, despite the support of staff, students and volunteers. Jonah became a volunteer as his placement ended prematurely and, with Clare, helped keep people connected with a newsletter. Both he and the next students, Adam and Theo, kept in touch with all members through phone calls as well as email. Numbers attending these meetings varied but on average six or seven Forget Me Nots were regularly able to attend.

The other frustration during this time was that the post-diagnostic living well course was suspended with few people taking up online courses, and so only one new person tried out the meetings and no new Forget Me Not members were recruited. Another substantial piece of work during this time was the DEEP enquiry.

DEEP Enquiry

From February 2021-October 2021, the group led by Theo and Adam (placement students), Laura and Linda (volunteers), Melvyn, Nigel and Keith (members) all with the support of Clare, undertook a significant piece of research funded by DEEP and called a DEEP enquiry, the title of which was ‘What Impact has Covid-19 had on my connections with others, especially the Forget-Me-Nots?’

We recruited all of the Forget Me Nots who were attending the virtual meetings, plus one or two who found it difficult and Theo and the team constructed a questionnaire, which ended up focusing primarily on each individual’s use of technology before and during the pandemic, taking this further by exploring their views on this.

To showcase the project, DEEP funded a 33-page book as the report and Theo and Keith gave a presentation about the project at the University of Kent Psychology department for students and staff. This project, given the

immense challenges that we all faced in that time, ranks highly in the achievements of the group over the last ten years.

Chapter 10
Looking Back and Looking Forward:
Ten Years On

AS WE COME TO THE CLOSE of this short but hopefully interesting story of the first ten years of the Forget Me Nots group, we are reminded that sometimes good things come in little packages. If Alan Bennett can produce a 49-page book called House Arrest Pandemic Diaries, then the three of us are in good company.

The group is back together after a summer break. Covid has left its mark, with some members still not able to attend due to health vulnerabilities. Indeed, the impact of Covid on people living with a diagnosis of dementia has been significant; some have returned to the group experiencing greater cognitive impairment and, in some cases, members have decided the time has come to retire from full and active membership. We have shortened our meetings from two-and-a-half to two hours and increased volunteer support to better enable people coming back from this tough time.

We carry on, in good faith that new members will be recruited now that the Living Well courses are resuming and old members will be supported by staff, students, volunteers and other members to hang on in there for as long as possible.

One highlight which the group is looking forward to being part of at the time of writing centres upon a creative day in Canterbury as part of the city's International Arts Festival in October 2022.

We hope to show through this event how members, students and staff can work together alongside the community in which we live to challenge stigma, stereotypes, misconceptions, fear and all of the other malignant social psychology that Tom Kitwood so eloquently described in his seminal work *Dementia Reconsidered* (Kitwood, 1997, Brooker et al 2019). The event will feature readings, music and singing, poetry, painting, papercraft and photography workshops, and an information stand where we hope people diagnosed with dementia during lockdown, who may not have

found it easy to connect to a supportive community will find encouragement, opportunities and places where new friendships and interests can blossom and grow. Excitingly, it will also be the occasion for the launch of this very book.

Although the three of us have told this story we're going to close with some thoughts and words of members of the group which Lara and Keith drew together in May 2022. We asked each member a series of questions and here are some of the questions and responses.

What have you found most interesting or enjoyable today or at a recent meeting?

'Camaraderie amongst fellow sufferers.'

'Somewhere we need a focus on enjoying the occasion.'

'Being part of something that is evolving, doing things for a cause I believe in.'

'Meeting professionals. The wish to do more and help the group.'

'Talking with likeminded people who are capable and interested in the group with a sense of humour.'

As a Forget Me Not, what things in the time you have been in the group have you most enjoyed?

'Learning new things every time.'

'Working with students on projects-especially the DEEP enquiry.'

'Being with other people.'

'Being creative-photography, writing, Time and Place, poetry, performing for the group on piano at birthday and Christmas.'

'Meeting other people with dementia.'

'Creative projects.'

'Interesting to get information.'

What do you think you get out of coming to Forget Me Nots and being a member of the group?

*‘Fellowship and progress, particularly of students-
they develop very nicely during their time here.
The lived experience between
Alzheimer’s sufferers and psychology students.’*

*‘A voice, chance to participate as a useful member
of society.’*

**Do you have any other comments you’d like to
share?**

*‘It’s nice to know that you are with people who
have similar diagnoses thus making it easier for
people to understand how you feel.’*

*‘Sharing our different takes - staff and people with
dementia. Not often get a chance to share
thoughts and feelings - bring out the best in each
other.’*

*‘Coming to Forget Me Nots makes me less
frightened about the disease.’*

'Tomorrow's another day.'

The questions we used were the same as those used at the end of the first meeting ten years previously. It is interesting to note that their answers were equally positive, that members of the group's answers certainly resulted in greater depth, knowledge and insight.

The Forget Me Nots' story began with relationships, and as we've seen, it is relationships that have guided us through these first amazing ten years.

Thank you for enabling the three of us to share this narrative with you, and here's to the next ten years!

Cast in order of appearance in this book Keith

Oliver - Forget Me Not, KMPT Dementia Envoy and poet

Abigail Lugg - University of Kent placement student with KMPT

Lara Stemberidge - University of Kent placement student with KMPT

Rachael Litherland- DEEP & Innovations in Dementia

Melvyn Brooks - Forget Me Not and poet

Elizabeth Field - clinical psychologist

Rosemary Oliver - Keith's wife
Reinhard Guss - clinical psychologist
Richard Taylor - international dementia advocate
Nick Dent - KMPT PALS
Chris Norris - Forget Me Not
Clare Streeter - Dementia Empowerment Coordinator
Martin Taylor - Forget Me Not
Polly McBride - Canterbury Christ Church University
placement student with KMPT
Lucy Jobbins - University of Kent placement student
with KMPT
Liz Jennings - author, writing tutor and co leader of
Forget Me Not projects
Wendy Mitchell- author and dementia advocate
Christine Bryden- author and dementia advocate
Rhiannon Lane - drama practitioner
Al Reffel - film maker
Jen Holland - University of Kent placement student
and photography tutor
Jess Shaw - student volunteer and co- leader of Time
and Place project
Elsa Lewis - publisher
David Jones - Forget Me Not and poet
Sherry Amponsem - University of Hull PhD student
Helen Greatorex- Chief Executive KMPT
Steve Milton - DEEP & Innovations in Dementia
Rachel Niblock - DEEP

Philly Hare - DEEP & Innovations in Dementia
Caroline - Forget Me Not
Nicki Griffiths - volunteer with Forget Me Not
Edward Mundy- clinical psychologist trainee
Chris Ryan - Forget Me Not
Lewis Slade - University of Kent placement student &
Assistant Psychologist KMPT
Lucy Elias - Assistant Psychologist KMPT
Alex Bone - University of Kent placement student &
Assistant Psychologist KMPT
Theo Chan - University of Kent placement student
Anne-Marie Norris - Forget Me Not
Michael - University of Kent placement student
Celine - University of Kent placement student
Nigel - Forget Me Not
Jim McNee - Forget Me Not
Lydia Smith - University of Kent placement student &
Assistant Psychologist KMPT
Tricia Enefer - Assistant Psychologist KMPT
Jocelyne Kenny - Trainee clinical psychologist
Julian Brazier - MP for Canterbury
Rosie Duffield - MP for Canterbury
Jonah Desalesa - University of Kent placement student
Adam Reid - Canterbury Christ Church University
placement student
Laura Smith - Volunteer
Linda Milton - Volunteer

