

Time for Dementia

A Message from Time for Dementia

Time for Dementia is just one of the many things that have been affected by Covid-19 in 2020. When the pandemic hit in March 2020, it was with a heavy heart that the Time for Dementia team called a halt to all face-to-face visits. Since then, however, the team have been very busy coming up with a new and exciting ways for students and families to continue with meaningful learning opportunities.

Students and families who were already part-way through the programme and had met each other before lockdown have continued to keep in touch through telephone calls, with some embracing video calls! These calls are providing students an opportunity to continue to learn about the impact dementia has on the lives of both the person with dementia and the carer, as well as the complexities that Covid-19 and national lockdowns have had.



New students who have started Time for Dementia this academic year have been taking part in online virtual visits with a family living with dementia and up to 12 students. A 90 minute video call, each term, with the same family, gives students the opportunity to ask families questions about what it is like to live with dementia. The virtual visits, facilitated by a member of the Time for Dementia team, are already proving to be a huge success with both students and families.

The Time for Dementia team are incredibly indebted to, and would like to say a huge thank you, to the families who have embraced the new opportunities to share their experiences with students either by phone or by video calls. We couldn't have continued with the programme without their support.

We are also very grateful to those families who are keen to stay with the programme until we are able to resume face-to-face visits, hopefully later in 2021, We do recognise that technology has its challenges, and isn't for everyone

From all of us at Time for Dementia, we wish you all the very best for 2021

An Annual Update from Time for Dementia

Alzheimer's Society

The team at Alzheimer's Society have been working from home since March, supporting around 700 Time for Dementia families remotely during the first lockdown, offering information and signposting to available support. Later in the summer we updated everyone on the plans for the new academic year and offered all families an opportunity to get involved in Virtual Visits, 90 families are now helping! The team have had a lot to adapt to this year, but the highlight has been the extra contact we've been able to have with all the families, we'd like to thank each family for their time and support!

Brighton and Sussex Medical School

We are now working with our seventh cohort of students on Time for Dementia and are very proud of the way our students have adapted to the new virtual format. We are delighted with the way the new virtual visits have been going and are pleased that our students continuing from last year have been able to stay in touch with their allocated families during lockdown and into this academic year via phone or video calls. We are hugely grateful to the families who have made Time for Dementia possible this year by agreeing to take part in this new and innovative format.

University of Surrey

In October our sixth cohort of nursing and paramedic students started their virtual Time for Dementia visits and feedback from the students has been very positive. Students have said how much they enjoy the experience of being in a larger group to share stories and questions because they can reflect on the visit together. One student fed back how much they enjoyed being able to talk openly about dementia and ask questions in a safe space. Our seventh cohort of students will start their visits next Spring.

An article of the findings from Dr Wendy Grosvenor PhD on adult nursing students experiences of their Time for Dementia visits over 3 years was recently published in the International Journal of Geriatric Psychiatry: 'Reframing dementia: Nursing students' relational learning with rather than about people with dementia. A constructivist grounded theory study' <https://onlinelibrary.wiley.com/doi/10.1002/gps.5452>

University of Brighton

The School of Health Sciences continues to

be actively engaged in Time for Dementia. We value this interprofessional collaboration and currently have BSc Physiotherapy, BSc Adult and Mental Health Nursing and BSc Paramedic Sciences participating in the programme. Students recently completing the programme have given very positive feedback about how it has increased their understanding of dementia, how people can live well and they identified it as is an insightful and valuable learning experience.

This year some of our new student groups have completed their first virtual visits as a group. They have highlighted how inspirational the families taking part are, and how they have enjoyed interacting with their family.

Finally, we are really pleased to welcome Anna Castagnetti to the team as our new Time for Dementia administrator.

University of Greenwich

We are delighted to be able to continue Time for Dementia this term, albeit in a different way. We were disappointed when Time for Dementia had to stop last March and our first group of students were unable to complete their visits. Our second group of students are keen to catch up with their families again, and some are looking forward to meeting new ones either by video link or by telephone. Our students are keen to continue to learn more about what is like to live with dementia, together with the impact Covid-19 restrictions have had on people with dementia and their families both personally and in relation to accessing care and support services.

Canterbury Christchurch University

We are delighted that our Time for Dementia families have been able to continue to support our students learning this year.

It has been a major exercise to change the way students and families communicate due to Covid-19. Our three student training programmes participating in the programme (Adult Nursing, Radiography and Occupational Therapy) have continued to develop knowledge around the experiences of people living with dementia and on top of this the challenges faced by "living in lockdown".

We have run some interprofessional learning with students to identify how team working can improve people's experience when living with dementia and the University continues to develop its research work in dementia.

Research Update

During this year, our research team has been continuing to look at the impact Time for Dementia visits have had upon the students taking part, specifically looking at changes in dementia knowledge and attitudes. We have conducted research with over 600 students starting their studies in 2020, including our new dietetics students at the University of Surrey, and are intrigued to find out what the impact of the virtual visits may be. We were also really excited to conduct research with comparison groups of students studying Medicine, Nursing and Radiography at the University of Exeter and University of Plymouth, before the universities embark on the programme next year.

The team has also been working on the related Covid-19 study, which aims to understand the quality of life and care implications of the Covid-19 restrictions on people living with dementia and their family carers. Both our normal Time for Dementia study and our new Covid-19 study have continued throughout the pandemic as our team have adapted to working from home,

meeting and engaging with students virtually, and talking to carers via telephone.

This year we have welcomed Georgia Towson, our new Time for Dementia research assistant. We've also been joined by Beth Fine, and colleagues at the Dementia Research Unit in Crowborough to help assist us with the Covid-19 study.

We are looking forward to meeting more students and carers over the upcoming year, and we are looking forward to being able to conduct research in person again in the future.



Georgia Towson



Joanna Pooley

A changing year as a Service User Involvement Officer at Alzheimer's Society

By Philippa Charlton

Reflecting over the last nine months, I can now appreciate how much the Time for Dementia team has adjusted to the challenges of Covid-19 in order to take the programme online. These changes have been made with breath-taking speed and I feel privileged to have been part of the continuing journey.

Due to these changes, my role as a Service User Involvement Officer has changed quite significantly. On reflection, I believe I took some aspects of my role for granted. For example, my favourite part of the week was to meet a family in their own homes to discuss their interest in the time for dementia programme. During these meetings, I felt privileged listening to such inspirational life stories and learning about their personal

experiences of living and caring for someone with dementia.

I can't tell you how much I am looking forward to a time where I can do this again... but in the meantime, I would like to share how much I have enjoyed the virtual visits. Each virtual visit has been a pleasure to facilitate and I continue to feel inspired by our families who have embraced new technology and have been so open and honest in sharing their experiences with the students. I also feel inspired by the students who have shown such resilience to the current situation and have made my job of facilitating virtual visits a real joy. They have been incredibly supportive and considerate of our families and asked thoughtful and considered questions, gaining a real insight into how it really feels to live or care for someone with dementia.

Impact of Covid-19 Study

The Time for Dementia research team has been working on the Covid-19 study, which aims to understand the quality of life and care implications of the Covid-19 pandemic on people living with dementia and their family carers.

In order to achieve this, the team contacted 248 Time for Dementia carers who answered questionnaires during the first national lockdown, and again in October and November.

We also contacted a small group of 12 carers who have completed interviews about day to day life during the pandemic.

This information will be analysed further and reported early in the new year.

The questionnaires aimed to discover the quality of life of people caring for someone with dementia, the quality of life of people with dementia, levels of social functioning of people with dementia and the cognitive, functional ability of people with dementia. The interviews aimed to understand the experience of carers and those with dementia during the Covid-19 lockdown, and identify any factors that have sustained, improved or compromised quality of life in this period.

The sample was mainly composed of older adults, in both the person with dementia (who had an average age of 77 years and the carer (who had an average age of 70 years. Participants were overwhelmingly White British. 68.1% of carers were female. The carer was most frequently a spousal/partner (79.4%) of the person with dementia, followed by a son/daughter (19.8%), and the remaining were either a friend or other family member. 68.5% of the families were living together at the time of the follow-up interview.

Our preliminary findings from the questionnaires has showed:

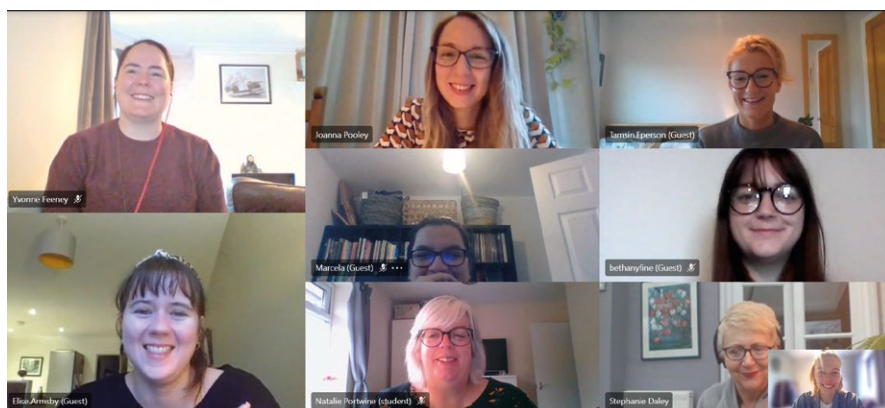
- Living with the person with dementia had a negative association with carer quality of life.
- Female carers reported lower quality of life of the person with dementia during lockdown

- Female carers reported reduced social functioning in the person with dementia.

Results from the interviews conducted during June and July showed that life 'pre-Covid' for carers was generally positive, with carers having some support and freedom. The person with dementia was able to have social connections with others, as well as opportunities for being occupied and stimulated. Families were still able to maintain a 'full life' with routine and joint activities, including dementia support services. Regardless of the Covid-19 pandemic, carers reported noticing a progression of dementia and there was a general impact of caring for someone with dementia on carers.

When asked about the impact of the Covid-19 restrictions, carers reported having a lack of freedom, and a loss of control. Carers also stated that they were not able to have a break, and were unable to meet their own needs, as well as the needs of the person with dementia. Changes in emotional wellbeing, such as anger, sadness and exhaustion were also discussed. Carers reported Covid-19 having an impact on the person with dementia, mainly a lack of understanding of the current pandemic or need for restrictions and a lack of stimulation. There has been a reduction in dementia support services available, and a noticeable acceleration in cognitive decline of the person with dementia was noted by some.

However, it is clear that the Covid-19 pandemic has had an impact on both carers, and the person with dementia. We hope to be able to share the findings from our final round of data collection for the Covid-19 study soon, and we are really thankful to all those that have taken part.



A Family Experience – Time for Dementia

Family from Kent, taking part in Virtual Visits

Why did you decide to take part in time for dementia?

We both see the value in young people learning about dementia - particularly the rarer forms - so that they can bring this to their practice in various NHS professions. I also worked in research for a while, and although I no longer work, it makes me feel connected to and engaged with the working world, which I like.

How did you find the visits before lockdown when they were in person?

We mostly enjoyed having a nice chat with people who are not much younger than our daughter. It's nice meeting and interacting with young people, and we want to help if we can. But after the initial meeting, it was hard to know what to say next time, as my husband's dementia had deteriorated so slowly. Also, because we're together all the time, we have both gradually adapted to changes day by day, so it's hard to say exactly what might have happened since the previous visit. When the first lockdown happened, I was asked to email my thoughts to the 2 students we were seeing. I found this easier - I can articulate myself better in writing I think, although this will be different for other people.

What kind of things have you discussed with the students?

We've spoken about both our backgrounds, and also a lot about when my husband was diagnosed and the process to getting the diagnosis. We've shared what's changed in his life since his diagnosis.

How did you find the virtual visit with the group of students over Teams?

We both enjoyed it. It felt like you got more bang for your buck, meeting with multiple students together, and it felt as if we were giving greater value somehow.

How have you found them in comparison?

To be honest, I preferred the virtual approach. It's easier for us to accommodate.

What do you hope the students will learn from the Time for Dementia programme?

That someone with dementia is a fully rounded person initially and can still talk and take part in things and have a sense of humour. The importance of showing respect and compassion to someone with dementia and their carers. When our consultant went through a series of tests with my husband and he was looking tired and a bit stressed, he said "I know it's hard isn't it. Thank you for doing that." It made an impression on us - we felt valued and heard. The need to consider whether an appointment at 9am in the morning is appropriate given how long it takes to get up and go anywhere with someone with dementia. The need to ask about someone's needs when they need a stay in hospital - so they understand for example if someone can't see and will need to be shown food etc. That the process of negotiating the diagnosis, benefits, and long-term care systems is really hard and stressful for carers, so anything these professionals can do to help would be great. e.g. Our Cognitive Neurology consultant wrote a supporting letter when we went through an appeal to get the Personal Independence Payment; we also had a local voluntary agency present at the clinics, so we could find out what services there were locally - as my husband has early onset this was extremely useful as there isn't much.

What advice would you give to students before they go on their first family visit?

Be themselves; go with an open mind; know that a social visit is valuable in itself to some people with dementia because it can be isolating, but don't outstay your welcome. We found an hour was quite a lot - we'd run out of things to say. This will vary from person to person, so just read body language and check in with them.

What would you say to other families who were thinking about taking part in Time for Dementia?

Do it, it's fun, and it'll help to improve understanding of this set of diseases, and improve services over time.

Virtual Studying: A Student Perspective

Cohort feedback collated by Ajibola Sanni and Remi Adelaja (Student Representatives) and John Krohne (Time for Dementia Lead for Nursing) at the University of Brighton.

The February 2020 cohort of BSc Nursing students at the University of Brighton recently undertook their first 'Virtual visit' in small groups online as part of the Time for Dementia programme.

The students have been studying remotely via online learning over recent months. This cohort had a few weeks of face-to-face teaching before the lockdown, giving them time to get to know each other. Students have been keeping in touch with each other via phone and social media, but find that working remotely is harder without direct peer support. Finding a peaceful place to concentrate at home can be a challenge, although saving time and money on commuting is seen as a positive impact of working remotely.

Students fed back feeling 'enriched' by the positive experiences gained from their first Time for Dementia Virtual visit, accessing personal accounts of living with dementia that cannot be gained through a text book or website. Students found hearing families life stories rewarding, including being played songs on the piano, and found the personal experiences of the families' dementia diagnosis extremely insightful.

Students appreciated the way that the families had embraced this new technology so they could continue to teach and educate the students. Some students felt this 'Virtual

visit' was a less invasive way of allowing them to gain an insight in the families' lives, while others hoped face to face visits could be introduced in the future when possible.

The Virtual visits were well organised and the material provided prior to the session was helpful in preparing questions in advance. The facilitator from the Alzheimer's Society provided structure for the session and considered the needs of the family, for example, rephrasing questions when needed.

The learning from this first Virtual visit included;

- Greater insight into the effects of a dementia diagnosis
- Realising how important it is for the carer to also receive support
- The importance of continually stimulating the mind through activities to delay the progression of dementia
- How those with dementia and their partners continue to have active lives, despite the challenges of living with dementia
- Recognising how nurses can support those diagnosed with dementia and provide person centred care
- The need for additional support packages from services

Students are hoping that the next two Virtual visits can be used to gain more insight and practical knowledge into supporting people with dementia in their future nursing career.

“My husband, who has dementia, said he felt as though the whole interview went well and that the students seemed really engaged and that he really did feel it was worthwhile, especially if it helps other people in a similar situation. More knowledge of this awful condition can only help others in the future.”

Time for Dementia Family, Kent

“Enlightening about the condition affecting home lifestyle especially with carer.”

University of Brighton
Physio Therapy Student

Family Engagement Feedback

We'd like to say a big thank you to the families who volunteered their time to take part in our Family Engagement Groups in September. We held two virtual focus groups where families provided us with valuable insights, feedback and tips ahead of running Time for Dementia in a whole new way this year. While we haven't had long to prepare for a virtual Time for Dementia delivery, the feedback from speaking with families has really helped to shape how we have set up virtual visits and phone calls with students.

Time for Dementia Virtual Visits

By Laura Pack-Hagan

Having had the pleasure of facilitating a number of Time for Dementia Virtual Visits, I have seen first-hand the value and importance of this interaction between families affected by dementia and students training to be our next generation of healthcare professionals. Each visit has been unique with so many highlights.

In one particular virtual visit I saw how the students built rapport and engaged with both the person living with dementia and their partner who is also their carer. After a round of introductions we heard from the family and got to learn about their day to day life and some of the challenges of living with a dementia diagnosis. We also got to hear a bit about them as individuals, with one of the students relating to the person living with dementia's love of music.

The student really picked up on the person living with dementia's passion for music, and by discussing this further it included him in the session and resulted in him offering to play a piece on the piano for the students. Listening to a rendition of Edelweiss being performed to the group live over the video call and observing the student's reactions and appreciation of that person and their musical skills was a very moving experience.

The family said *"It was overwhelming how much my husband engaged, he very much enjoyed the social interaction...just communicating. In these times I have noticed how much people with dementia and older people have missed out on social interaction and been really deprived of it. Please thank the students the visit made a big difference to my husband's day-loved it!, I enjoyed it too- it was lovely to speak to the students!"*

The students left the session with a greater understanding of that person and I hope that the person living with dementia has taken away a sense of recognition, having emphasised to us all that there is so much more to the person than a diagnosis.

"This has been very beneficial. I have never had any direct experience with someone with dementia so it has given me a new understanding of the condition and how it can be managed."

University of Brighton Physio
Therapy Student

"Thank you for doing such a good job mediating the meeting, we are looking forward to the next."

Time for Dementia Family
Carer, Sussex

"It was a really lovely couple of hours spent with the paramedic students. What a brilliant bunch of caring individuals. I don't think the interactions would have been half as good if it wasn't for the fact that they really did seem genuinely interested. I really got the impression that they have chosen their niche in life and I wish them lots of luck in their studies."

Time for Dementia Family, Kent

Key contacts and getting in touch

For family questions about the Time for Dementia programme, your involvement or if you need advice and support contact Alzheimer's Society team

If you know anyone who might like to be involved in the programme, please share our details with them as we would love to hear from more families in Kent, Surrey, and Sussex who would like to take part. You can contact us on:

T: 077 13 779 582

E: timefordementia@alzheimers.org.uk

For questions about the research or how your data is used and stored, contact The Research Team.

T: 07393 761947

E: s.daley@bsms.ac.uk

To get in touch with your students, or for any student visit related query contact the Programme Administrator at your University

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If you do not have access to email please do call Denise Roden on 07787 272 308 and she will make sure that your message reaches the appropriate administrator.

If you require this booklet in larger text, if you no longer wish to receive this annual newsletter, or would prefer to receive it by email, please let us know by contacting programme officer Denise Roden

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You can keep up to date with the Time for Dementia Team Follow us on Twitter:
[@Time4Dementia](https://twitter.com/Time4Dementia)

“It was great to have the time to explore the person and relationships in a very human way, and not solely see the condition from a clinical perspective.”

University of Surrey 2nd year Paramedic Student

“Time for Dementia has exceeded my expectations”

University of Brighton Physio Therapy Student