

Autumn 2024

Time for Dementia

brighton and sussex
medical school

Alzheimer's Society
**Time for
Dementia**

Annual Message from Time for Dementia

What a year it's been for Time for Dementia as we've celebrated a decade of the programme. You'll read more about our celebrations later in the newsletter - but for now, we want to say a huge thank you to everyone who has made it possible for Time for Dementia to continue over the past ten years. Especially to everyone who has helped us grow from strength to strength, and to all the families that have taken part.

However, we have a huge task ahead of us as we build upon previous successes and look towards our ambitions for the future. One day, we want Time for Dementia to be an essential part of the training for every health and social care professional in this country. So, as we embark upon this journey, we've been working on our five-year strategy and are outlining our vision and mission for the future of the programme.

We are really pleased to announce that we have launched our Family Engagement Forum where those with lived experience of dementia will be involved in key decision-making and future planning across all our work. We have increased our engagement amongst diverse

communities and will soon see families from different backgrounds joining the programme. We've reviewed and revamped our governance structure, meaning that we are better equipped to evaluate our work and we've firmed up our model and delivery so that we are in a better position to achieve our mission.

We are also strengthening partnerships with healthcare providers and community organisations across all our regions, with the aim of broadening our impact. We are pleased to announce that we are expanding into Northern Ireland in the coming year and are also having discussions with universities in Wales and many other parts of England. University leaders are telling us that Time for Dementia is innovation in education and will help deliver a better healthcare workforce for the future.



Messages from Participating Universities

Alzheimer's Society

This year we've welcomed new team members Nicky and Wendy as we further expand the programme and develop the team here at Alzheimer's Society - we are now a team of 16! Bik-Kay has also been promoted to Senior Co-Ordinator in recognition of her work to support the virtual delivery of the programme. We are excited by the recognition and interest in Time for Dementia across the country and are looking forward to what this next year will bring.

Brighton and Sussex Medical School

This year we have been marking our 10-year Time for Dementia anniversary. To celebrate this great achievement, we held a webinar in March which helped spread the word about how we are driving forward the future of dementia education. We also produced a film which followed up on some of our original families and former medical students who are now working as doctors. Our annual symposium in June brought together students and families in a chance to reflect back on taking part in the programme.

University of Brighton

We have now had over 750 mental health and adult nursing students participate in Time for Dementia since we started the programme in 2018. Students recently completing their visits described it as a unique and innovative learning experience and an inspiring, empowering and insightful component of practice.

In the BSc Hons Physiotherapy programme, the 7th cohort completed three visits this year and our 6th cohort completed their final visits for the programme. Students highlighted they have increased understanding of the condition and the presentation of different types of dementia, and commented that it is really helpful preparation for practice, and a great introduction to working with service users. Other students have found it to be an 'invaluable' and 'wonderful' learning experience.

University of Chichester

Following a positive launch of the Time for Dementia programme at the University of Chichester, the September 2023 BSc Adult Nursing cohort and the January 2024 PgDip Adult Nursing cohort have both completed their first visits and are booking second visits. Student and family feedback has been positive and planning is taking place to expand the project to include Physiotherapy students in September 24.

One family said "we had a lovely visit, the students were super and (we) spent a very happy couple of hours together. The students were very interested in (us) and were very interesting to talk to."

A student said "In the short time that we were at the house we.... got a good insight into their life experiences. I am looking forward to the next visit to get to know them more."

University of Exeter

After careful consideration we have moved our visits to be fully virtual from this year. Our first year Nursing and Medical Imaging students have been attending visits with families in small groups. The students have provided informal feedback of these being enjoyable and several identified them as one of the highlights of their learning in Term 1 and 2. Formal evaluation and research will continue and the next cohort will join in the autumn.

Our final group of students who have completed the face-to-face visits have just attended a celebration event to mark the end of their learning. We were joined by colleagues from Brighton and Sussex Medical School and Alzheimer's Society who led seminars with the students. Two families also joined us for a reflection of our learning session. The students really appreciated their contribution and many of them left with some key ideas of how to ensure their practice is compassionate, caring and understanding.

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Kent and Medway Medical School

We are delighted to have run Time for Dementia for a second year now with our next cohort of 3rd year medical students at Kent and Medway Medical School. The opportunity to hear personal stories makes a huge impact on their training and practice as person-centred doctors of the future. We would like to thank each family across Kent and Medway who have welcomed our students into their homes to share about their lives and experiences with dementia.

University of Southampton

This year over 250 medical students have taken part in a very successful first year of the programme. First year students engaged in a virtual visit and two in-person visits with families across Hampshire. Overall, the feedback has been positive with students particularly valuing the opportunity to meet families outside the traditional clinical environment. A small cohort of year 3 international transfer students newly arrived from overseas also completed two visits with families, with one saying: "It was a really interesting and different learning experience. I liked that I was able to learn a lot about dementia from someone's personal perspective."

University of Surrey

Nursing and Paramedic students tell us how much they value their interactions with the families, and how it has increased their understanding and confidence in supporting

people with dementia. A recent evaluation of the impact of visits on students identified enhanced knowledge and understanding of dementia, empowering students to improve the quality of care provided by challenging misconceptions (own and others), sustaining person centred practice approaches focusing on the person rather than their dementia. Student feedback: "The better we understand it, the better care we can give."

Our Dietetic students continue to enjoy talking to their families during visits. This year they particularly enjoyed meeting two different families in the preparatory sessions and felt this helped them make the most of their first visit. Students reflected "before the first visit, there was some nervousness and apprehension but after the visit, this became excitement and curiosity and left us wanting to know more". In July we are celebrating the graduation of our first cohort of dietetic students who completed the programme, I know they will continue to share their learning in their careers.

Thank you to all the families who continue to make Time for Dementia possible.

University of West of England

University of the West of England have just celebrated their first year of Time for Dementia. In September 2023, the programme was introduced to occupational therapy, and mental health nursing students. Learning outcomes have been very positive and student engagement was excellent. This autumn the programme will be extended further to include paramedic and physiotherapy students.

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I have learnt so much about how dementia affects families - care professionals can be ignorant about the illness - families shouldn't have to struggle to find answers. Accessibility could so easily be improved.

University of Surrey Student

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Being able to talk to people who actually have the chronic conditions we learn about and able to see how it affects them is an invaluable experience.

Brighton and Sussex Medical School Student

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New universities join Time for Dementia

We are thrilled to welcome two new universities, University of Portsmouth and Bournemouth University to Time for Dementia. Their enthusiasm for improving dementia education and care is a great match for our mission and we've been working with them since the beginning of the year to implement the programme into their curriculum with students starting in the autumn. This addition shows how much we're growing and how dedicated we are to transforming the landscape of dementia education.

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We are excited to be adding Time for Dementia to the curriculum here at Bournemouth University. Our Masters and Apprentice Nursing courses will gain a great deal from learning directly from those with lived experience of dementia.

Bournemouth University

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We are delighted to be offering the Time for Dementia experience to our Paramedic students for the first time here at the University of Portsmouth. We recognise that those with a diagnosis of dementia can potentially face both discrimination and sub-optimal treatment by health care professionals and if by exposing our undergraduate students to those with dementia we manage to improve their treatment in the future then our involvement with the project has been more than worthwhile.

University of Portsmouth

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Celebrating ten years at Brighton and Sussex Medical School

In 2024 the Time for Dementia team are celebrating their 10-year anniversary. The programme started at Brighton and Sussex Medical School back in 2014 and is still going strong with the 11th cohort of students due to start in October 2024. The medical school is incredibly proud of Time for Dementia and of having set up this ground-breaking dementia education programme. 1,669 of our medical students have undertaken Time for Dementia, an element of their medical training which we cannot teach in the classroom. Of these students, 700 are now doctors in practice.

It is important to add that none of this could be achieved without our fantastic family volunteers who give up their time and invite our future workforce, who are essentially strangers,

to their homes to improve the care for the next generation of people living with dementia.

Brighton and Sussex Medical School have also used the Time for Dementia model to develop a new programme, Time for Autism, where students visit a family with an autistic child. This programme has also been very successful and has just finished its third cohort of students.

View our celebrating 10 years of Time for Dementia at BSMS film here:

https://bit.ly/TFD_ten_years

or scan the QR code



Introducing the Family Engagement Forum: Shaping the Future Together

The Family Engagement Forum aims to bring the voices of those with lived experience of dementia into key decision-making and future planning for the Time for Dementia programme. This initiative ensures that our strategies are informed by the real-world experiences and insights of those directly affected by dementia.

We've had a couple of meetings already and are planning an in-person session for early autumn to bring everyone together as a group.

We will focus on three of our strategic areas to start with. Forum members will choose one area to collaborate with an assigned manager, working together to achieve specific goals. Progress on each aim will be shared with the entire group during our wider forum meetings, fostering transparency and collective growth.

We are excited to see the positive impact this collaboration will bring and look forward

to the valuable contributions from our forum members.

Zohra says:

“

We are grateful to be involved with the Family Forum. It is beneficial to hear other families' situations and to talk about ours. We find the suggestions and advice put forward by the team lead to interesting discussions how best to help the students from various disciplines learn how to recognise and support people, both diagnosed and undiagnosed, with dementia.

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Poem

Tender Loving Care

By Phillip, for Vivienne

I can mend leaking taps
I can put up cupboards too,
The list is almost endless,
Of things I could do for you.

There isn't any job too big or too small,
That I won't tackle in whole or in part.
I'll even have a go,
Though I could be rather slow,
At running repairs to your heart.

Your particular situation -
More common than you suppose;
You're keeping your act together for now,
But the strain really shows.

Nails or glue, no matter what you spend,
Are simply useless in a case such as this is.
The choice is yours, but I recommend,
Regular hugs with plenty of kisses.

Such a course of treatment,
Should start without delay.
The ingredients of course are priceless,
But you won't have to pay.

For they are freely given,
With tender loving care;
One lonely soul to another,
With so much love to share.

A Decade of Commitment – A Voice for Change

By Sam Swanson, Time for Dementia Officer

Susan has been involved in education for most of her life. It seemed natural therefore that she would use her diagnosis to help others.

Susan and her husband Chris joined the Time for Dementia programme when it started – 10 years ago.

Over those ten years they have shared their story with over 60 medical, nursing and paramedic students, giving them an insight into what it is like living with Posterior Cortical Atrophy (PCA) – a form of Alzheimer’s disease. They have also been heavily involved with family engagement activities, helping to shape the development of the programme.

Susan’s symptoms started around 2010 but it was a long and difficult road to get a diagnosis.

As Chris says:

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One minute we were a fairly normal couple enjoying our retirement. The next minute we were a person with PCA and a carer.

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Chris and Susan have enjoyed having the students from Brighton and Sussex Medical School in their home and Chris makes sure they know all about PCA by the time they have had two or three visits.

Chris is hopeful that PCA diagnosis and support will be better in the future:

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I think the students will always remember my mini lectures on Posterior Cortical Atrophy and our experiences with diagnosis, doctors and care providers!

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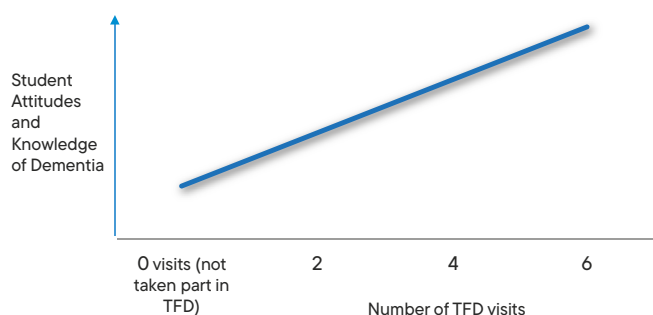


Ten years of Time for Dementia Research - an update

Since Time for Dementia started in 2014, a research project has been conducted to evaluate the programme. The research aims to understand the impact of Time for Dementia on students, families, and staff using questionnaires and interviews. Thank you to everyone who has been involved in this research!

As we mark Time for Dementia's 10th year, here are 10 key findings reflecting on 10 years of research across 10 published papers from students and families taking part in the programme!

1. Students taking part in Time for Dementia had significant improvements in attitudes and knowledge about dementia compared to students not taking part.
2. Increased visits are associated with greater improvements in student knowledge and attitudes towards dementia.



(illustrative diagram only. For data see <https://doi.org/10.1002/gps.5922>)

3. Students feel that the impact of the programme lies in real-life learning and relationships with families.
4. The programme promotes a person-centred approach to dementia care, enhancing social comfort in interactions. 78% of students surveyed agreed that the Time for Dementia programme had increased their knowledge of psychosocial issues.

5. A key motivation for families to take part is altruism and wanting to improve the healthcare workforce.
6. Families express high satisfaction and value their participation. 95% of people with dementia surveyed agreed they would recommend others to take part in the Time for Dementia programme.
7. Families appreciate the beneficial social interactions facilitated by the programme.
8. The programme's value is greater for its mutual benefits for families and students.
9. Early recommendations for improvement included adding structure and enhancing organisation of visits
10. The programme's model could be applied to training for other long-term conditions, benefiting broader healthcare education.

Research Impact

Initially, research findings helped shape the programme's direction; for example, students now receive more guidance, and a student handbook has been developed with their feedback in mind. Since then, the research has helped build an evidence base facilitating ongoing programme support. It has also influenced other educational interventions, such as the creation of the 'Time for Autism' programme.

What's next from research on Time for Dementia

We hope to shortly release our findings on student and family views on virtual visits compared to face-to-face visits.

Keeping up to date with the research on Time for Dementia

Research findings are regularly published on our website: http://bit.ly/Time_for_dementia

Key contacts and getting in touch

Alzheimer's Society Contacts:

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

You can contact us by E-mail on **timefordementia@alzheimers.org.uk**

Bik-Kay Talbot, Senior Time for Dementia Co-ordinator **T: 07562 430 204**

Rohan Charles, Project Manager **T: 07484 089 562**

Lauren Wonnacott, Project Manager **T: 07713 779 582**

Thabrez Khan, Manager **T: 07355 021 307**

New enquiries:

If you would like further information about implementing Time for Dementia within your training course please contact:

Thabrez Khan, Manager **E: timefordementia@alzheimers.org.uk**

Research:

Our research findings are regularly published on our website:

http://bit.ly/Time_for_dementia

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

Dr Stephanie Daley **E: s.daley@bsms.ac.uk**

You can keep up to date with the Time for Dementia Team Follow us on X:

 **@Time4Dementia**

If you require this booklet in larger text, if you no longer wish to receive this annual newsletter, or would like to change your preferences of receiving by email or post, please let us know by contacting Senior Time for Dementia Co-ordinator Bik-Kay Talbot

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