Time for Dementia

What is Time for Dementia?

Time for Dementia is an educational programme which is built on a teaching approach for understanding long-term conditions, in this case, dementia, which aims to improve the knowledge, understanding, attitude and behaviour towards dementia in health care professionals in training.

Medical students from Brighton and Sussex Medical School and nursing and paramedic students from the University of Surrey are currently undertaking a series of visits as part of a mandatory component of their curricula. Pairs of students are required to visit a person with dementia and their carer in their own home 3-4 times a year over a two-year period. Students are encouraged to use these visits to gain a greater understanding of the family’s experience of dementia and their journey. 800 medical, nursing and paramedic students and 400 families affected by dementia are currently taking part in the programme over a two year period.

How are we evaluating Time for Dementia?

There is a related research study, which is formally evaluating Time for Dementia. We are seeking to assess the impact of the programme on student learning, and to understand whether there is any impact on the wellbeing of the families involved. We also wish to understand the experience of the students taking part in the programme, so that we can improve the programme. A comprehensive dissemination manual will be developed to advise other Higher Education Institutions (HEIs) on how to deliver a similar programme successfully including optimum cost-effectiveness.

How will we find this out?

Students, people with dementia and their carers have been asked to complete questionnaires, interviews and/or focus groups on a yearly basis to assess the impact of the programme. Comparison groups of nursing, paramedic and medical students who are not taking part in the Time for Dementia programme. A comprehensive dissemination manual will be developed to advise other Higher Education Institutions (HEIs) on how to deliver a similar programme successfully including optimum cost-effectiveness.

What have we done so far?

The programme is now one year on and we have four cohorts of students undertaking the programme: two groups of nursing and paramedic students at the University of Surrey and two groups of medical students at the Brighton and Sussex Medical School.

Qualitative interviews and focus groups with students and families have been asked to complete questionnaires, interviews and/or focus groups on a yearly basis to assess the impact of the programme. Comparison groups of nursing, paramedic and medical students who are not taking part in the Time for Dementia programme. A comprehensive dissemination manual will be developed to advise other Higher Education Institutions (HEIs) on how to deliver a similar programme successfully including optimum cost-effectiveness.

What has Time for Dementia identified?

The families (person with dementia and their carers) also reported several positive aspects from taking part in the programme:

- Feeling listened to
- Feeling valued
- Increased positivity
- Making a difference
- Enjoyment of the social interaction
- Continuity – having the same student learners
- Shared learning
- Student professionalism
- Good organisation

Time for Dementia – What Next?

We intend to roll out the programme to the next two cohorts of student groups at both the Brighton and Sussex Medical School and the University of Surrey in September 2016. The hope is to establish the programme as a sustainable element of the two university courses. The programme is also looking to extend elsewhere in the region.

Based on the feedback from students and families involved in the programme, amendments will include more guidance to both students and families as well as involving a student and family representative in the future planning and development of the programme.

The first Time for Dementia conference was held in June 2016 which bought together both students and families involved in the project and reviewed progress so far. A second conference is scheduled to take place in the summer 2017.

The next steps for the study will involve comparing the quantitative outcomes of students with those in the control groups as well as looking at longer-term outcomes for all of the student cohorts and families.

Mary and Eddie, Time for Dementia participants.

‘Removal of “fear” – knowledge has made me more confident. I used to worry about how I would communicate or help people with dementia as I know little about it, but now I know more, I feel better equipped.’ (student)

‘Before the visits I had the perception that people with dementia cannot enjoy a good quality of life and that deterioration occurs rather rapidly, the visits however revealed that with sufficient social support it is possible to have a good quality of life.’ (student)

‘I would be a lot more patient because people with dementia can ask the same questions a lot and (previously) I wouldn’t always explain many times, but now following this experience I think I would take as much time as possible to explain and to re-explain… I’d just be very calm and patient and understanding.’ (student)

‘The students enlighten me… they listen to me. It bought me to life.’ (person with dementia)

‘They don’t talk down to people, they talk to us like equals.’ (carer)

‘I feel like we are sharing our experiences and they are learning for the future. Makes me feel more positive about things rather than being negative.’ (carer)

‘If we can help the students have a better understanding of how to approach and speak to people with dementia… if we can help them and they can put it into practice, that will help people that they see in the future.’ (person with dementia)

‘Having had some of the experiences we’ve had in hospitals… it was a good opportunity to give voice to those… if people can be caught early in their careers those problems shouldn’t keep repeating.’ (carer)

Time for Dementia Conference June 2016

‘Feeling newborns’ . (carer)

‘They listen to me. It bought me to life.’ (person with dementia)