PPI NEWSLETTER

ISSUE 3
MAY 2023

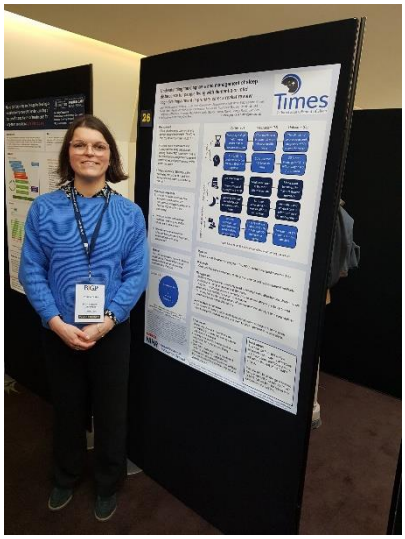
Thank you for your interest in the TIMES research project, which is exploring approaches to sleep disturbances for people living with dementia or mild cognitive impairment and ways to improve its assessment, treatment, and management in the community. This newsletter contains the latest project updates.

Please contact Jess on **jessica.a.blake@uea.ac.uk** for any feedback, comments or questions.

TIMES NEWS

REALIST REVIEW UPDATE (WORK PACKAGE 1A)

The first part of the TIMES project is now complete! We reviewed 60 papers looking at how sleep disturbance is currently assessed and managed in primary care, and what the experiences of service users and informal caregivers are.



In March, Jess Blake (pictured) presented our findings at the British Journal of General Practitioners Research Conference in London.

We have submitted a research article to the British Journal of General Practitioners and await their feedback.

FIELD RESEARCH UPDATE (WORK PACKAGE 1B)

Observations and interviews have taken place at a range of primary care sites, including care homes and GP surgeries. This data is now in the process of being transcribed and analysed.

CO-DESIGN WORKSHOPS

The first of six co-design workshops took place on 3rd May 2023. This workshop comprised people who worked in primary care and carers of people living with dementia and mild cognitive impairment. The findings from the previous two work packages were discussed alongside participants' personal experiences. Four key themes that need to be addressed in the intervention were identified and discussed: Early Assessment; Continuity of Care; Holistic Approach; Care in Context.

Our second workshop was on 10th May 2023 and discussed what intervention elements to include in each of the four main themes. Subsequent workshops will further explore how we can implement these intervention elements in general practice.

CARER STORIES

We are fortunate to work with an enthusiastic group of current and former unpaid carers. Their lived experience is invaluable and their ongoing support has played an important role in helping to inform and develop the TIMES intervention.

In this newsletter we want to share some of their stories, where they share their experiences of sleep disturbance when caring for someone with dementia or mild cognitive impairment. All identifiable information has been changed.

If you wish to read more of these stories, please go to our website. We would like to extend our thanks to all those involved in this project.

Mark (pseudonym)
Former carer for his mother, who had mixed dementia.
In order to carry out my caring role it was crucial for me to try and keep up with my sleep. You had to be the best you could possibly be for the person being cared for. Giving medication, any hygiene issues, getting appointments in order, shopping and the list goes on, and quite often you find yourself thinking ahead of yourself. To carry all of this and to expect a good night's sleep is easier said than done. Each night I would go to sleep trying to play it all out in my mind... Have I made a mistake? Was there something I could have done better? My caring role came to an end several years ago, and it's only in recent months that I have stopped waking up at 3:30am, which was the time I would check on my mother nightly. Even though she has passed away, I still did this…

Joanne (pseudonym),
Former carer for her mother, who had vascular dementia.
We suffered from sleep deprivation throughout my mother's 5-year dementia journey. Prior to moving in with her, I would get calls at all hours of the night to ask where I was, or to come and fix or find the remote control. I luckily stayed across the road, but broken sleep whilst working full time and caring for her in the evenings was taking its toll.

I had to give up my career and home life, and moved in with her to be 24/7 carer, daughter, and best friend. I don't regret a moment, I loved her, but the exhaustion due to sleep deprivation was debilitating. It lowered my mood and I couldn't think straight. It stopped me being able to enjoy the time we shared together as mum and daughter. We slept in the same room in single beds, but I only ever cat napped. Mum was awake a lot due to her heart failure and fluid in her lungs which meant she couldn't lie flat. She was always restless, distressed

and continually woke me to ask when she was going home, or to tell me she was scared.

I had to hide the door key on myself or she would go out alone. It came to a crisis one day a year before she passed, when she developed severe delirium. I was beyond tired, coping with living grief and no change on the horizon. I decided to call the community psychiatric nurse for assistance and respite to be told, “What do you expect us to do?” I didn't want to stop caring, or loving her, but I needed sleep, I needed help. However, I carried on caring. After mum passed I was left very broken, and am still unable, 6 years later, to sleep through a night without disturbance and ‘what ifs‘ in the small hours of the morning.

Sleep deprivation almost made me unable to carry on caring. With better sleep for both of us, the journey would have been more manageable and pleasant, with less bad memories to look back upon.