PPI NEWSLETTER

ISSUE 5
DECEMBER 2023

This newsletter contains the latest updates for the TIMES project. TIMES is a series of research packages exploring sleep disturbance for people living with dementia or mild cognitive impairment, and ways to improve its assessment, treatment, and management in the community.

TIMES would like to thank everyone who has been involved this year, and we wish you all the best over the Christmas period.

Please contact Jess (pictured) on **jessica.a.blake@uea.ac.uk** with any feedback or questions.

TIMES NEWS

REALIST REVIEW (WORK PACKAGE 1A)

The TIMES literature review entitled *'Sleep disturbance in dementia or mild cognitive impairment: a realist review of general practice'* has now been published in the British Journal of General Practitioners. To read it click here.

FIELD RESEARCH UPDATE (WORK PACKAGE 1B)

TIMES researchers have been observing consultations with patients in GP surgeries and care homes. They have analysed this data and are now drafting an article about their findings.

A survey of healthcare professionals' views and experiences of tailored care has just closed. The analysis of the 300+ responses will commence in the new year.

TIMES FEASIBILITY STUDY (WORK PACKAGE 3)

The research team have collated evidence from previous work packages and PPI to develop a novel tailored intervention for testing. A protocol to support this has been drafted and is currently under review. The study will include eight GP surgeries and 64 patient-carer pairs. We hope to begin the feasibility study in the new year.

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LIVED EXPERIENCE ADFVISORY FORUM SLEEP (LEAFS)

LEAFS had their quarterly meeting in November as well as drop-in sessions in September and October. In these meetings, the feasibility trial was discussed and the group reviewed the study's Participant Information Sheet.
The drop-in LEAFS sessions are currently under review. Please let us know your thoughts on how and when these sessions should be run.

SHARED EXPERIENCES

In the article below, George Rook (pictured), who is a TIMES co-applicant and co-chair of the LEAFS group, shares his experiences of PPI and research.

About our PPI work
Our lived experience group of people living with dementia or mild cognitive impairment and family carers meets every month. We have more formal meetings every quarter, but it is important to stay connected and involved as the study develops, and as time passes.

The disease causing dementia often affects memory (as well as other functions) and it can take us a lot of effort to remind ourselves before each meeting what TIMES is all about, and what has happened previously.

We find that clear, well-presented information, using non-technical language helps us enormously.

Frequent, timely reminders of meetings (including virtual links), including the day before and the morning of a meeting, help ensure we don't miss a meeting.

We need meetings to be relaxed and informal, so that we do not become stressed about keeping up, or working out what things mean. So we make sure we chat and go back and forth as necessary to keep everyone included and involved. This approach is probably new to many researchers, but with good chairing we can cover the agenda items.

As Eric Morecambe once said to Andre Previn, we 'play all the right notes, but not necessarily in the right order'.

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Dementia does not prevent most of us from taking part in research and PPI work, but we do need the research team to work with us in ways that work for us. That is probably just as challenging for them, as it can be for us.

In the following short articles, two members of LEAFS and carers for people living dementia describe their experiences of sleep disturbance.

Lisa and Doreen*

The difference in my mother's cognitive awareness was noticeable when she had slept well. It was a rare occurrence, especially later in her dementia journey. She would be more focused and interacted with me far better. There was less agitation, as well as noticeable improvement in distressed behaviour.

The knock-on effect was that this lifted my morale and let me relax, but the best outcome was that I could have a positive interaction with mum, even if this was for only that day, or part of it.

Michael and Jean*

My mother's sleep was very patchy. I don't believe she ever really had a good sleep. Because of this, she would be confused as to what time of day it was. This led to myself, as her carer, losing sleep, which presented another problem as I had to be the best version of myself that I could be.

I was tired most of the time, I also had to think of my mother's welfare, her appointments, her health etc. I would be thinking and planning at least 2 weeks ahead while being tired. It does take its toll on your overall wellbeing and stress.

It was never a case of, 'oh, mum's having a sleep so I'll just take a little nap', as there was always too much to do.

This was my experience, I wish I could give a positive feedback, but there wasn't any except the privilege of being by her side and doing all that I could. The truth is I would do it all again as she was my mam and I love her.

*all names have been changed