PPI NEWSLETTER

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This newsletter contains the latest project updates for the TIMES project. TIMES 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.

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

TIMES NEWS

REALIST REVIEW UPDATE (WORK PACKAGE 1A)

In July, Aidin (pictured) presented the findings of the literature review at the Society for Academic Primary Care (SAPC) Annual Scientific Meeting in Brighton. You can read the abstract here.

The abstract for the review has been published in the British Journal of General Practitioners (BJGP) and can be read here .

The full research article has also been submitted to the BJGP for consideration.

FIELD RESEARCH UPDATE (WORK PACKAGE 1B)

In this work package we are looking at how primary care services such as GP surgeries currently tailor their care. We have nearly finished our observations and the data analysis is well underway.

Once the analysis has concluded, we will share the results and draft a research paper for publication.

CO-DESIGN WORKSHOPS

All the co-design workshops are now complete. In these workshops, people living with dementia or mild cognitive impairment, unpaid/family carers, health and social care professionals, and researchers met to discuss the following elements of the new TIMES intervention:

1. How a TIMES assessment tool will capture holistic information about the person with dementia in their individual context.

2. How TIMES will facilitate the co-creation of a tailored health plan between GPs, patients and carers, and other healthcare professionals to address sleep disturbance.

3. How tailored health plans will be reviewed and revised.

The TIMES team are continuing to work together with stakeholders to co-design and test the intervention as part of a feasibility trial.

LIVED EXPERIENCE ADFVISORY FORUM SLEEP (LEAFS)

LEAFS, a group comprising researchers, people living with dementia or mild cognitive impairment and carers, meet monthly. We discussed outcome measures to assess the effectiveness of the intervention. Some of the important measures identified included sleep, functional performance and quality of life. This will be explored further in future meetings.

SHARED EXPERIENCES

In the article below, George Rook (TIMES co-applicant and co-chair of the LEAFS group) shares his lived experience of sleep disturbance:

Sleeping with dementia

I really don't know whether the brain disease underlying dementia itself causes sleep loss or irregularity. But I know that I and many others do not sleep well. And we have dementia.

Having Alzheimer's I am prescribed Donepezil. It woke my brain up, within 48 hours. But it also gives me really vivid, often distressing, dreams. This is quite common. I don't want to stop taking the medication, as I know that when I forget to take it just once I have terrible brain fog for a day .I may take several hours to lift out of my dream story, to realise that it is not reality. Until then I live in an alternative dream reality. Whatever happened in sleep is all too real.

In recent years I have also developed regular wake ups, almost by the hour. I turn over and see 12.35. Next time it's 1.33. Then 2.30. Then 3.35. Ridiculously regular, though my clock does not tick.

Because of restless legs and diabetic neuropathy my legs and feet keep me awake for up to two hours, so I often take painkillers just to get over that first painful waiting. So I may sleep till 1 or 2.

I don't get much good quality deep sleep, which is good for brain health, and think I didn't have good regular sleep for much of my working life. There is some evidence that this can lead to disease that may cause dementia, or at least mild cognitive impairment.

I know I sleep better if I have had a good walk or gardening session, and have not spent too much time in virtual (or face to face) meetings.

Sleep is somehow hard to pin down. I am rarely asked about it, and I suspect there are a lot more poor sleepers than most care to acknowledge. Many of my friends with dementia find good sleep hard to come by. So I hope the TIMES

research project will lead to more effective approaches to solving sleep problems.

In the following short articles, two members of LEAFS and carers for people living dementia describe the benefits of sleeping well:

Nancy and Grace (pseudonym)
I feel that the overall temperament and cognitive engagement is hugely improved (temporarily) after a good number of hours sleep of a person living with dementia, whether that is in a conventional night-time sleep, or daytime, if this is the only time that they can settle and rest. Sleep is vital, so I would go with what she was able to have, and when she wanted to sleep, I'd sleep at the same time too.

If mum had a minimum of 5 hours undisturbed sleep, the next day I could see that she was less confused, happier to interact in activities, and her memory would be much improved (temporarily).

This also had an impact on her co morbidities, if she had a decent sleep, she would feel healthier from her heart condition, and be more active, and less anxious the following day.

Tony & Yvonne (pseudonym)
On the nights that Yvonne sleeps through the night without many interruptions, she is less angry and more compliant with accepting her personal care from her morning carers. This has a knock on effect to her overall mood as she's more awake, is clean, dry, and has eaten her breakfast. Having a good start to her day after a sleep will affect her underlying mood.