The Centre for Dementia Studies (CDS) is a joint venture between Brighton and Sussex Medical School and Sussex Partnership NHS Foundation Trust. Its programme of work in applied health research, education, and policy in dementia is designed to improve the quality of life of people with dementia.

Good quality dementia care requires multi-disciplinary and interagency working, with patients and carers at the core. The Centre for Dementia Studies works in collaboration with a number of partners, including: the Universities of Brighton and Sussex, patient and carer groups, primary care, Health Education England, Health Education Kent, Surrey and Sussex, Clinical Commissioning Groups (CCGs), acute NHS Trusts, local authority Social Service departments, private care providers, and wider regional and national universities.

**Centre for Dementia Studies**

**The Cognitive Treatment and Research Unit (CTRU)**

The Cognitive Treatment and Research Unit (CTRU) offers patients the opportunity to participate in clinical trials. Most studies examine the effect and impact of new medications on the symptoms of Alzheimer’s disease, or look at the way in which current medications can be repurposed to help people with the disease. Most dementia clinical trials explore ways to reduce the damage that harmful proteins cause in the brain as the disease progresses, with a view to slowing down and reducing the impact that dementia has on patients’ lives.

Patients are usually randomised into one of two groups and may receive a new treatment or a placebo. As part of the data collection process, we use questionnaires to ask patients about the impact that the disease has on everyday life, assess their memory and cognition, and also gather information from their carer. Although lots of safety data has already been gathered about new medications before they are used with research participants, most of our clinical studies are designed to include people in the early stages of their illness with quite mild symptoms, who are generally in good physical health. This is both to ensure patient safety and means that data collected is as unbiased as possible. Although some study visits can be conducted at home, most of our research requires patients to come to the clinic in Crowborough or Brighton on several occasions. Travel costs are usually reimbursed or we can book a taxi if this is more convenient.

Dementia affects just over 800,000 people in the UK and it is hoped that research will help us improve the lives of people with the condition. Some patients who volunteer say they are doing so to help improve treatments for future generations, as well as the potentially experiencing the benefits of new medications themselves. In addition, all of our study participants receive close physical health monitoring throughout the trials they take part in which usually includes regular blood tests, ECGs and sometimes tests such as MRI or PET scans.

The CTRU Research Nurses coordinate a range of research studies addressing Alzheimer’s Disease. They work closely with patients and their caregivers to provide information about studies and, once consented into a study, coordinate their journey through it. They undertake clinical assessments, deliver research interventions and collate study data.

**Involvement in dementia research is more than participation in a study**

Jean Southey is Co-ordinator for service user and carer involvement in dementia research at Sussex Partnership. Her job is to develop and support a group of patients and carers who are willing to share their lived experience of dementia, becoming expert advisors and subjects working alongside researchers in each stage of dementia research, from the study design to the reporting of findings.

The Dementia Consultation Group, which Jean has established, meets regularly and advises researchers on: whether the research is important; on the clarity of information given to participants and on the researchers’ interpretation of results. These views help to inform researchers’ priorities and decision making throughout their research. The group makes sure the findings are widely reported in easily accessible language.

Our lived experience experts can also collaborate in research, for example as peer researchers who might interview participants. The aim of involvement is to increase the likelihood of dementia research being of high quality, of being respectful and relevant to the needs of participants, and being translated into practice which is beneficial to people living with dementia.

Laura Hughes, PhD student, Brighton and Sussex Medical School, Centre for Dementia Studies.

**Development and evaluation of a methodology for the routine measurement of quality of life in care homes.**

Quality of life (QoL) is important to understand in a dementia population because of the impact the illness has on people’s lives. Understanding QoL in care homes is especially important because there is an ever growing population of people with dementia living in a care home setting. At present, there are many measures of QoL in dementia, however it is not routinely measured in care homes.

The aim of the study is to develop and evaluate a measure of dementia related QoL so that care homes can incorporate it into their practice routinely and systematically. It is hoped that by doing so it will better allow care home staff to target and improve QoL of their residents.

The CTRU Research Nurses will use the DEMQOL-Proxy, a well validated measure of dementia related QoL to routinely assess their residents’ QoL. Researchers will work with staff to develop the best method for incorporating this into normal care practice so that it can be used independently by the staff in a helpful way to understand overall QoL of the care home. This will be accomplished by assessing who is the best person to rate residents’ QoL and how often this could feasibly be accomplished.

**MODEM: Comprehensive approach to modelling outcome and cost impacts of interventions for dementia**

Researchers from Brighton and Sussex Medical School, London School of Economics, Southampton University, Newcastle University, and the International Longevity Centre-UK are carrying out a 4-year study that will project needs, supports and costs to help plan good, affordable dementia care up to 2040. MODEM, funded by the NIHR and ESRC “Improving Dementia Care” funding initiative, aims to generate new evidence to inform policy and practice to better meet needs, promote health and wellbeing of people with affected by dementia and their carers, and achieve efficiency in the use of society’s resources.

We have begun recruiting 300 people with dementia and their carers for the project. Data collected in the study will feed into developing a comprehensive, integrative, quantitative set of models to estimate current and future needs, and the outcomes and costs of interventions aimed at meeting them.

If you are interested in taking part in a clinical trial, please contact us at: CTRU@sussexpartnership.nhs.uk or 01892 603107

**Time for Dementia**

Time for Dementia is an educational programme which explores the use of a unique educational model to improve the knowledge, understanding, attitudes and behaviour towards dementia in health care professionals in training.

Medical students from Brighton and Sussex Medical School and Nursing and Midwifery students from the University of Sussex will complete the Time for Dementia programme as a mandatory component of their training.

Pairs of students will visit a person with dementia and their carer in their own home over a three to six month period. Students will be expected to use these visits to gain a greater understanding of the family’s experience of dementia and their journey.

Students, people with dementia and their carers will be asked to complete questionnaires, interviews and or focus groups on a yearly basis to assess the impact of the programme.

People with dementia and their carers have been actively involved in the planning of the research, giving their feedback about the student visits in order to improve the programme and in supporting the delivery of educational workshops for students as part of two larger Time for Dementia conferences which are planned for 2016 and 2017.

Laura Hughes, PhD student, Brighton and Sussex Medical School, Centre for Dementia Studies.

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