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Effective home support dementia care

Submission date
25/07/2016

Recruitment status
No longer recruiting

Registration date
29/07/2016

Overall study status
Completed

Last Edited
30/08/2023

Condition category
Mental and Behavioural Disorders

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
Dementia is a common condition in the aging population. People with dementia have difficulties with mental processes such as memory, language, reasoning and identifying people and objects, which become progressively worst over time. People are now living longer, meaning that dementia represents a significant public health and care challenge. About 60% of people with dementia live in their own homes but finding the best ways of helping them to live well at home and supporting their carers is a challenge. Although more innovative home support services, from the NHS, social care and voluntary organisations exist in some areas, they are often underdeveloped. The study will be for those in early stage dementia, receiving care through memory clinics. The aim of this study is to evaluate the effectiveness of memory aids (a tool used to trigger memory), delivered by Dementia Support Practitioners (DSPs).

Who can participate?
Adults aged 50 years and over with early stage dementia who are under the care of a participating memory clinic or equivalent.

What does the study involve?
Practices are randomly allocated to one of two groups. Those in the first group receive specialist advice, information and memory aids from DSPs, as well as usual care from the memory clinic or equivalent that they attend. The memory aids pack includes a calendar or clock, whiteboard with electric time, and 'post-it' note dispenser. Those in the second group receive usual care from memory clinics with a general guide to dementia for patients and carers. Participants and their carers are visited at the start of the study and then three and 12 months later to be interviewed about their opinions, quality of life and use of services in order to establish the effectiveness of the DSP program.

What are the possible benefits and risks of participating?
Participants may or may not benefit from participating in the treatment from the DSP. If participants are not chosen to take part in the treatment, there may be no direct benefits from taking part in the study. However, the information participants provide will help to strengthen the evidence for developing more appropriate support at home for those in early stage dementia. There are no notable risks involved with participating in this study.

Where is the study run from?
Nine Memory clinics or Older Adult Services in England (UK)

When is the study starting and how long is it expected to run for?
July 2015 to September 2018

Who is funding the study?
National Institute for Health Research (UK)

Who is the main contact?
Dr Paul Clarkson
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Contact information

Type(s)
Scientific

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers
31288

Study information

Scientific Title
Effective home support in dementia care: Project 2.1 dementia early stage cognitive aids new trial

Acronym
DESCANT

Study objectives
The aim of this study is to evaluate whether memory aids, delivered by Dementia Support Practitioners (DSPs), are effective and cost-effective.

Ethics approval required
Old ethics approval format

Ethics approval(s)
North West - Haydock Research Ethics Committee, 20/06/2016, ref: 16/NW/0389

Study design
Randomised; Interventional; Design type: Treatment, Process of Care, Device, Rehabilitation

Primary study design
Interventional

Secondary study design
Randomised controlled trial

Study setting(s)
Hospital

Study type(s)
Treatment

Participant information sheet
Not available in web format, please use the contact details below to request a patient information sheet

Health condition(s) or problem(s) studied
Dementia

Interventions
Randomisation will take place after baseline interviews with consented participants but before data entry in MACRO4, the data entry database used in the study. On receiving completed screening forms and baseline interview schedules, the Trial Manager will complete a randomisation request form and email this to the Trials Unit (Swansea Trials Unit - STU). The participant will then be randomised by the Assistant Trial Manager at STU who will email the Trial Manager with a PDF with details of the allocation. Participants will be allocated on a 1:1 basis into Intervention: Dementia Support Practitioner – DSP or Comparator: Treatment As Usual – TAU without DSP.

Comparator: Participants will receive a general guide to dementia for patients and carers as well as treatment as usual (TAU) in the form of support from their carers with or without help from memory clinic staff, post-diagnostic counselling and advice, and specialist follow-up.

Intervention: Dementia Support Practitioners (DSPs) will augment TAU with specialist advice, information and memory aids. They will dispense appropriate aids; and provide training in using

these aids and general advice about improving memory. Their standard pack of memory aids will include: calendar or clock, whiteboard with electric time, and 'post-it' note dispenser, with a budget of £150 per participant. Support and follow-up will seek to ensure correct use of the aids. DSPs will work alongside any existing support and offer the memory aids in addition. The total duration of treatment will be 4 weeks.

For participants in both groups, follow up will be at 3 and 12 months after baseline (referral from memory clinic).

Intervention Type
Other

Primary outcome measure
Activities of Daily Living (ADLs) are measured using the Bristol Activities of Daily Living Scale (BADLS) at baseline, 3, and 12 months.

Secondary outcome measures
1. Cognitive function measured using the Standardised Mini-Mental State Examination (S-MMSE) at baseline, 3, and 12 months
2. Quality of life measured using DEMQOL and DEMQOL-PROXY (carer rated) at baseline, 3, and 12 months
3. Health status measured using the EQ-5D-5L at baseline, 3, and 12 months
4. Service receipt measured using the Client Service Receipt Inventory and the Resource Utilisation in Dementia (RUD) at baseline, 3, and 12 months
5. Minor psychiatric morbidity in carers measured using the General Health Questionnaire (GHQ-12) at baseline, 3, and 12 months
6. Carer coping measured using the Short Sense of Competence Questionnaire (SSCQ) at baseline, 3, and 12 months
7. Carer rating of patients' performance of activities measured using the Revised Interview for Deterioration in Daily living activities in Dementia (R-IDDD) at baseline, 3, and 12 months
8. Patient quality of life measured using the ICECAP-O and CASP-19 at baseline, 3, and 12 months

Overall study start date
01/07/2015

Completion date
31/12/2019

Eligibility

Key inclusion criteria
Participants with dementia:
1. Aged 50 years or older
2. Under care of one of the trial memory clinics or equivalent
3. Within one year of their first attendance at that clinic
4. Dementia is of mild to moderate severity
5. Physically able to engage with the intervention, usually as judged by researcher
6. Clinically able to engage with the intervention, usually as judged by responsible clinician
7. Living in their own home, or sharing a home with relative (i.e. not in residential or nursing home at baseline)

Carers:
The primary person who feels responsible for, and supports, the person with dementia. They may be any age and may live with the person with dementia or independently.

Participant type(s)
Patient

Age group
Adult

Sex
Both

Target number of participants
Planned Sample Size: 360; UK Sample Size: 360

Total final enrolment
468

Key exclusion criteria
Participants with dementia:
1. Individuals who are under 50 years of age
2. Advanced dementia, e.g. in late stages
3. Resident outside local authority boundary served by the service
4. Those currently undergoing emergency treatment or care

Date of first enrolment
12/09/2016

Date of final enrolment
15/04/2019

Locations

Countries of recruitment
England

United Kingdom

Study participating centre
Stockport Memory Service
The Meadows
Owens Farm Drive
Offerton
United Kingdom
SK2 5EQ

Study participating centre
Tameside Memory Service
Etherow Building
Tameside Hospital
Fountain Street
Ashton under Lyne
United Kingdom
OL6 9RW

Study participating centre
Oldham Memory Service
Forrest House
Royal Oldham Hospital
Westhulme Avenue
Oldham
United Kingdom
OL1 2PN

Study participating centre
Rochdale Memory Service
Watergrove Day Hospital
Birch Hill Hospital
Union Road
Rochdale
United Kingdom
OL12 9QB

Study participating centre
Bury Memory Service
The Ribchester Centre
Bury
United Kingdom
BL9 0JT

Study participating centre
Havering Older Adults Services
Victoria Centre
Pettits Lane
Romford
United Kingdom
RM1 4HP

Study participating centre
Barking and Dagenham Older Adults Services
Broad Street Health Centre
Morland Road
Dagenham
United Kingdom
RM10 9HU

Study participating centre
Waltham Forest Memory Service
Red Oak Lodge
Leytonstone
London
United Kingdom
E11 4HU

Study participating centre
Redbridge Older Adults Services
Older Adult Mental Health Team
Goodmayes Hospital
Barley Lane
Goodmayes
United Kingdom
IG3 8XJ

Sponsor information

Organisation
The University of Manchester

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Sponsor type
Hospital/treatment centre

ROR
https://ror.org/027m9bs27

Funder(s)

Funder type
Government

Funder Name
National Institute for Health Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Publication and dissemination plan
The findings of this trial will inform the case for structured support to patients diagnosed with early-stage dementia and their carers. It is therefore planned to present findings to professionals who care for dementia; and to submit them for publication in high-impact medical journals and specialist mental health journals. If the trial is successful, the study team intends to develop a toolkit to inform commissioners, managers and practitioners in late 2018.

Intention to publish date
31/03/2020

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study are not expected to be made available

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article	protocol	10/10/2018	10/12/2020	Yes	No
Results article	results	19/10/2021	22/10/2021	Yes	No
HRA research summary			28/06/2023	No	No
Results article		30/06/2021	30/08/2023	Yes	No