

SHIELD Carer Supporter Programme for family carers of people with dementia

Submission date 15/06/2009	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered
Registration date 27/08/2009	Overall study status Completed	<input checked="" type="checkbox"/> Protocol
Last Edited 22/08/2016	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Statistical analysis plan
		<input checked="" type="checkbox"/> Results
		<input type="checkbox"/> Individual participant data

Plain English summary of protocol
Not provided at time of registration

Contact information

Type(s)
Scientific

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Additional identifiers

Protocol serial number
RP-PG-0606-1083

Study information

Scientific Title
SHIELD Carer Supporter Programme: a peer support intervention for newer family carers of people with dementia

Acronym

SHIELD CSP

Study objectives

SHIELD Carer Supporter Programme (CSP) alone or in combination with reminiscence group work will be more effective in improving quality of life, effect, and self-efficacy of family carers than treatment as usual.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Outer North East London Research Ethics Committee (REC), 11/06/2009, ref: 09/H0701/54

Study design

Multicentre single-blind randomised controlled trial

Primary study design

Interventional

Study type(s)

Quality of life

Health condition(s) or problem(s) studied

Dementia

Interventions

Three intervention conditions and one control condition are evaluated. These are:

1. SHIELD Carer Supporter Programme (CSP)
2. Remembering Yesterday, Caring Today (RYCT) group reminiscence work
3. Combined SHIELD CSP/Ryct
4. Treatment as Usual (TAU)

SHIELD CSP:

The aim of the SHIELD CSP intervention is to improve a sense of self-efficacy/competence in the early stage carer through encouragement and positive reinforcement of carer skills development and carer network building activities. The Carer Supporters will be recruited through the voluntary sector by the Carer Supporter Manager based at Age Concern Havering, and will be supported by local Carer Supporter Coordinators based in voluntary organisations at each research site. Once recruited and trained, Carer Supporters will be matched with newer family carers through the voluntary sector. The SHIELD CSP intervention will involve weekly contact between a research participant and a more experienced carer (Carer Supporter) over a 3-month period. In this time, Carer Supporters may meet with the carers alone or jointly with the carer and relative with dementia. They may also attend support groups, educational meeting or social gatherings with the matched newer carer. The Carer Supporter will not meet with the PwD in the absence of the carer. Ongoing contact between the Carer Supporter and early stage carer will be encouraged with a target of a fortnightly meeting, supported and monitored for a further 7 months.

RYCT:

The aim of the RYCT intervention is to improve the relationship and communication between the

carer and PwD. This is achieved through the carer and PwD attending a weekly Remembering Yesterday Caring Today (RYCT) Reminiscence group over a 3-month period. The RYCT uses memory triggers (photographs, recordings, artefacts, etc.) to promote personal and shared memories. Groups of approximately 12 pairs are facilitated by a worker with experience in reminiscence work and running active or arts groups, and are supported by a team of paid staff and volunteers drawn from health, social services and the voluntary sector. After the initial 3 months of the RYCT intervention, participants are encouraged to take part in 'reunion' meetings at monthly intervals.

Combined SHIELD CSP/RyCT:

The aim of the SHIELD CSP/RyCT intervention is to combine the essential elements of the SHIELD CSP and RyCT interventions, and to extend the benefits of RyCT through bringing knowledge of the care dyad to the group, and taking knowledge of reminiscence into the carer's home. As such, it will involve both attendance at the RyCT group intervention and contact with a more experienced carer (Carer Supporter). The newer carer will have weekly contact with the Carer Supporter for at least 1 month prior to attending a 12-week RyCT group. During the RyCT group programme, Carer Supporters will be encouraged to attend as a part of the reminiscence team in place of other health, social care or voluntary sector personnel. After the RyCT group programme is complete, carers will be in contact with the Carer Supporters on a fortnightly basis, including attendance at the monthly RyCT 'reunions'.

NB. All participants, including those in the intervention groups, will continue to receive treatment as usual from statutory and voluntary services in their locality.

Treatment as Usual:

Participants randomised to the control group will continue to receive treatment as usual.

Baseline assessments will be carried out pre-randomisation. After this, two follow up assessments will be carried out at 5 months and 12 months after baseline. It is anticipated that participants will be involved in the intervention for a total of 12 months.

Intervention Type

Other

Phase

Not Applicable

Primary outcome(s)

1. Quality of life
2. Self-efficacy

Measured at baseline pre-randomisation, then at 2 follow ups: + 5 months from randomisation and +12 months randomisation.

Key secondary outcome(s)

1. Relationship quality
2. Anxiety and depression
3. Social Support
4. Hospitalisation/institutionalisation

Measured at baseline pre-randomisation, then at 2 follow ups: + 5 months from randomisation and +12 months randomisation.

Completion date

30/09/2012

Eligibility**Key inclusion criteria**

1. English-speaking family caregivers aged 18 years or over, either sex
2. Identified by themselves as a carer for person with a primary progressive cognitive impairment /dementia as defined by Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) criteria for dementia including Alzheimer's, vascular dementia, dementia of Lewy Body type, and mixed dementias
3. Both the family carers and the person with dementia live within the areas covered by the research

Participant type(s)

Patient

Healthy volunteers allowed

No

Age group

Adult

Lower age limit

18 years

Sex

All

Key exclusion criteria

1. Carers of people who are living in Residential, Nursing or long-stay hospital accommodation on a permanent basis
2. Carers of people with: congenital cognitive impairments (e.g. Down's syndrome); acquired non-progressive brain injury; cognitive impairments in the context of longstanding psychiatric illness e.g. schizophrenia
3. 'Carers' with significant congenital or acquired cognitive impairment, or where cognitive deficits are suspected in the carer
4. Family members with whom the suspected diagnosis of dementia has not been disclosed /discussed
5. Seriously ill carers, e.g. those receiving hospice or hospital treatment for terminal illness
6. Carers unable to take part in an intervention of 10 months duration
7. Carer unwilling for their person they care for to be approached
8. Non-family, paid carers
9. Either party already taking part in a psychosocial research study

Date of first enrolment

01/07/2009

Date of final enrolment

30/09/2012

Locations

Countries of recruitment

United Kingdom

England

Study participating centre

University College London

London

United Kingdom

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Sponsor information

Organisation

North East London NHS Foundation Trust (UK)

ROR

<https://ror.org/023e5m798>

Funder(s)

Funder type

Government

Funder Name

National Institute for Health Research (NIHR) (UK) - Programme Grant for Applied Research (PGfAR) (ref: RP-PG-0606-1083)

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Not provided at time of registration

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article	results	01/11/2016		Yes	No
Protocol article	protocol	15/09/2011		Yes	No