



# **Delivering effective CBT for carers of people with dementia: Group work and online approaches**

**Jane Fossey, Jo-Ann Fowler, Amanda Robinson,  
Tania Thorn, Nicola Dimitrijevic, Sonia Morton,**

# Aims

- Delivering CBT for carers of PWD in the NHS
- What can CBT groups offer?
- How our action research project has influenced
  - The development of a large scale RCT of computerised CBT & educational support specifically for carers of PWD

# What is the scale of the issue?

- 850,000 people with dementia (PWD) in UK; 40,000 <65
- Increasing to 1 million by 2025 & 2 million by 2051
- Dementia is a main cause of disability in later life, ahead of cancer, cardiovascular disease and stroke.
- Symptoms include:
  - memory loss,
  - confusion
  - problems with speech and understanding
  - signs of distress such as agitation,
  - difficulties with daily living activities.

**(E.g. Alzheimer Disease Society, 2017)**

# What do carers provide?

- Emotional support (88%)
- Help with paperwork/financial matters (83%)
- Practical help (74%)
- Attending medical appointments 74%
- Arranging care & support services/ appointments (73%)
- Managing medication (60%)
- Supporting leisure activities (49%)
- Providing personal care (39%)
- Physical help with walking/stairs (38%)

# How much care is provided?

- 36% 1-9 hrs/week
- 26% 10-19 hrs/week
- 24% 35 hrs/week

# Who provides care?

- 75% caring at a distance
- Carers > 65 fastest growing group, typically caring for partner or parent in 80s+.
- ↑ people of working age caring for parent with dementia, or YOD partner
- Often caring for parent with dementia AND supporting primary carer parent, who may have their own health and support needs.

# Potential impact on Carers

- Emotional, practical & financial challenges
- ↓ paid work/volunteering, ↑ isolation,
- adverse impact on the mental health of 92% of carers (Carers UK, 2013)
- 50% of carers require medication to treat depression.
- Wide range of emotions in relation to own and person cared for.

# Typical Carer support

## Carers reported receiving:

- 20% - advice, info & training from health professionals
- 13% - specialist advice & support from dementia group
- 11% - advice & information on dementia-related medication



# Information interventions:

- **Systems approaches**
  - Provision of information about support organisations, respite, transport, financial assistance alone
- **Education and training packages**
  - Aim to enhance skills, improve knowledge and attitudes
  - Found to improve understanding and sense of coping (Milne 2014) but
  - Caution regarding education alone. Some studies indicate that greater knowledge of dementia increased distress/ anxiety in carers  
(Aakhus et al, 2009; Graham, Ballard & Sham, 1997)

# Therapeutic interventions

## **S**TrAtegies for RelaTives (**START**) carers PWD group:

- Manualised 8 session format: coping strategies, psychoeducation, relaxation, thought challenging
- RCT (Livingston et al., 2014):
  - ↑ mood and anxiety maintained at 2 yr follow
  - also found to be cost-effective

# Therapeutic interventions II

## **Cognitive behaviour therapy (CBT) for carers of PWD:**

- RCTs have demonstrated reductions in anxiety, depression, anger and psychiatric caseness in family carers and cost effectiveness

(Akkerman & Ostwald, 2004; Marriot et al, 2000; Buchanan, 2004, Knapp, 2014)

# Context to development of CBT for Carers groups

- Groups developed\* in specialist Older Adult Services based on Marriot (2001)
- Aim:
  - support carers of people with dementia
  - develop effective ways of addressing difficulties
  - enhance their coping and reduce symptoms of distress
- Outcomes showed benefit on measures of mood and coping
- Majority of carers were below commissioned service criteria for secondary care services.

\*with thanks to Harriet Barlow, Candy Stone, Lisa Beevers & Linda Piper

# Joint Step 4/IAPT Delivery

## The benefits of working with IAPT:

- Experienced in CBT for Anxiety and Depression
- Enables a lower threshold for access
- Allows for self referral
- Skills up IAPT staff in dementia issues

## Implementing the groups with IAPT

- No training in working with PWD and their carers
- Staff had 2 day training focussing dementia – acknowledging expertise in CBT
- 12 people trained initially
- Feedback: “Very practical and useful course. Informative and useful. I feel confident in the skills I have learnt”

# Group structure

12 sessions – 1 ½ hour each

Based on individualised CBT for Carers manual

- **Session 1** – Education about dementia
- **Session 2** – Stress and the person with dementia
- **Session 3** – Stress and the carer
- **Session 4** – Cognitive model of emotions
- **Session 5** – Relaxation training
- **Session 6** – Behavioural responses to stress
- **Session 7** – Reintroducing pleasurable activities
- **Session 8** – Identifying challenging behaviour and carer response
- **Session 9** – Behavioural analysis
- **Session 10** – Behavioural interventions
- **Session 11** – Thought challenging
- **Session 12** – Review; good-bye

# Developing knowledge & skills

- Two co-facilitators in each session, from:
  - Older Adult Clinical Psychologist from Step 4
  - Step 3 Clinician from IAPT
  - Step 2 Clinician from IAPT

# Group evaluation

| Measures                                       | Rationale for use   |
|--|---|
| GAD 7  | These scales are used as outcome measures by IAPT and Psychological Services in Oxford Health NHS Foundation Trust. They allow comparison of level of anxiety and depression experienced by carers being referred and those entering the wider services.  |
| PHQ 9  |   |
| CORE 10  |   |
| GHQ 12   | This is a widely used research tool and which was part of the original Marriott (2000) study of CBT for Carers to enable comparison of our groups with those originally receiving the programme and check relative effectiveness.                         |
| Relatives Stress Scale (RSS)                   | These are specific measures of carer stress and coping that provide useful information particularly where carers score in the non- clinical range on other measures. They are reliable and valid and enable comparison of outcomes with other treatments. |
| Short Sense of Competence Questionnaire (SSCQ) |   |



# Feedback from Carers

*“I am extremely likely to recommend family/friends if they needed similar care or treatment because of the treatment I have received.”*

*“I have really enjoyed this course, especially hearing other people’s experiences and understanding the problems of dementia.; The manual is very good too”*

*“It makes you become empowered to deal with the situations you are dealt with and to approach your thoughts differently which has a knock on effect”.*

*“Turned my life around in 12 weeks”*

# Roll out & evaluation in another service

- Groups were rolled out to another NHS service.
- Data was analysed from 2 groups with 22 participants
- The groups were found to be effective with significant reduction on GHQ-12, PHQ-9, GAD-7 and CORE-10.
- Cost-effectiveness analysis also completed (Allen, 2015).

# Can we increase access still further?

- Evidence shows that carers don't consistently get support and our experience highlight difficulties with access to psychological therapies for some carers due to
  - Venue or transport issues
  - Time of groups/ attending for 12 sessions/ work
  - Difficulties finding replacement care even when funding available
- Another cause for unmet needs is that people are not willing to use services, because they consider them not attuned to their wishes (Van der Roest *et al.*, 2009).



# Caring For Me And You

- create an on line CBT package for carers of people with dementia **in consultation with carers**
- create an on line psychoeducational package
- conduct a 3 arm RCT to evaluate effectiveness

Oxford Health NHS Foundation Trust

Alzheimer's Society

Leading the fight against dementia

Do you care for someone with dementia?



We understand that caring for someone with dementia can be stressful and that sometimes carers can experience anxiety and depression. To help carers with coping strategies, Oxford Health NHS Foundation Trust and the Alzheimer's Society have developed and are evaluating a new therapy to be delivered online called "Caring for Me and You".

If you're a carer and sometimes find things difficult, and are comfortable using a computer, you might be eligible to help trial this new therapy to test how effective it is.

If you'd like to find out more information about this research, please visit:

[www.caringformeandyou.org.uk](http://www.caringformeandyou.org.uk)

lapt  
Leading Access to Psychological Therapies

nomineertrust

social care institute for excellence

Alzheimer's Society

Caring for Me and You is a research project led by Oxford Health NHS Foundation Trust, funded by Alzheimer's Society. Alzheimer's Society is grateful for the support of National Trials, Science Research Foundation and Improving Access to Psychological Therapies (IAPT) National Programme, and the contribution of IAPT to the research.  
Alzheimer's Society operates in England, Wales and Northern Ireland, registered charity no. 274645.      Caring for Me and You 01/12/13



**Team:**

Susie Hales - OHNHSFT

Jo-Ann Fowler - OHNHSFT

John Pimm - OHNHSFT

June Dent - OHNHSFT

Clive Ballard - KCL

Georgina Charlesworth-UCL

James Picket – Alzheimer's Society

Clare Walton and Louise Walker – Alzheimer's Society

Amanda Robinson and Alison Griffiths- OHNHSFT

Eleni Frangou and Sharon Love- Oxford University Centre for Statistics in Medicine.

Bob Khan – lay advisor

Martin Knapp - LSE

Alzheimer's Society QRD members

OHNHSFT service users

# Development of package

- Phase 1: data-gathering phase
- Phase 2: Co-production and refinement
- Phase 3: Pilot testing

Hales and Fossey (2017) Aging and Mental Health 1-8 Jul 10.

# Development of package

- Review of literature
- Review of a number of packages being used within services we run and one developed by colleagues in Oxford University
- Discussion with 8 experts running CBT for dementia carers groups
- Discussions with IAPT staff delivering on line therapy packages about perceptions of what worked well and where difficulties lay

# Carer involvement in design

- Interview with service user who had used BtB – to inform development of functions in online package
- Discussion with group attending the face-to-face CBT for carers groups – to inform priorities and content
- Development of case studies from carers own stories – to increase relevance and engagement



A background image showing several hands of different skin tones cupping a heart shape in the center. The hands are positioned around the heart, with fingers pointing outwards, creating a sense of care and support. The heart is a light pink color, and the hands are in various shades of brown, tan, and beige. The overall image is soft and focused on the central heart.

## **Pilot testing:**

# **Carer/PPI involvement and beta testing**

- Sessions tested by carers from Alzheimer's Society QRD network who hadn't previously received CBT
- Sessions also tested by a group of carers who had attended the CBT for carers face-to-face group
- Research team tested eta system - 100 test users created

# Outcome: Content

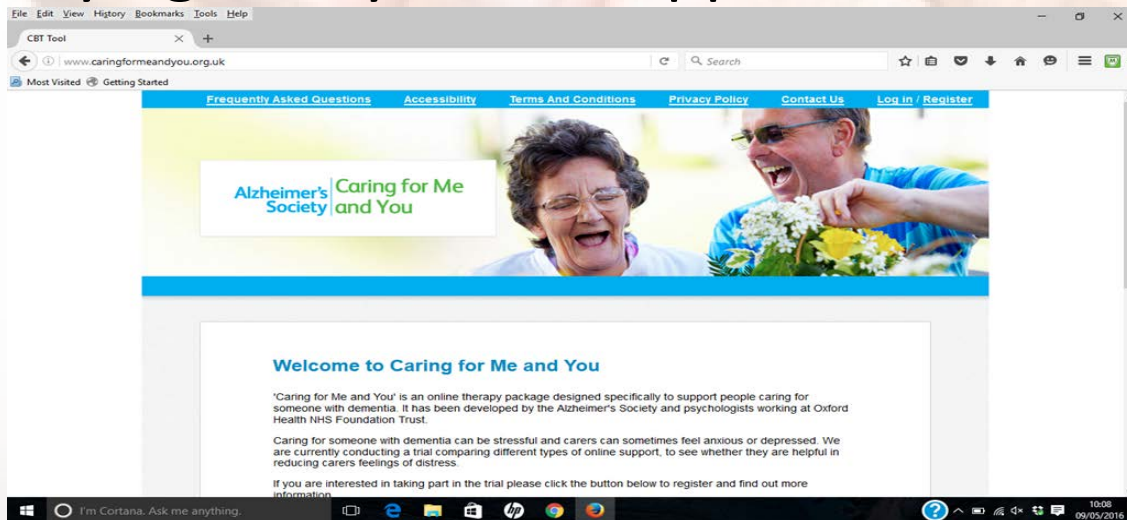
- Transdiagnostic approach
- 4 commonly experienced emotions: Anxiety , Depression, Guilt, Anger and Resentment
- CFMAY package includes:
  - dementia education
  - CBT skills to reduce, stress, distress and depression
  - CBT skills to improve sense of competency and emotional self care

# Outcome: Design features

- Short sessions: 20 modules x 20 mins
- Content linear ie. participants will complete modules in same order BUT personalised sections to enable prioritisation order of emotions addressed
- A therapist 'presence' communicated through either audio or video commentary
- Considerations for sensory impairments – text size, visual acuity on screen, audio options
- Video case studies illustrate content
- 'Personalised' formulations and emails sent to participant between sessions to increase retention

# CBT package

- Understanding dementia and how people respond to stress
- Recognising and coping with common emotions, stress management, relaxation and problem solving
- Identifying unhelpful thoughts and reactions and learning new skills
- Identifying lifestyle and support factors.



Screen 5 - Audio off

In the previous session, you began to learn that there are simple techniques you can use to help you change the way you view or think about situations, which in turn can change the way you feel.

Now that you know that change is possible, we'd like you to begin today by setting some personal goals for change that you can work towards in the rest of the sessions.

Then, in the rest of the session today, we'll keep working on the emotion that you rated as occurring most often.

We'll review the thought challenging techniques that you learned in the previous session, before moving on to learning about how you can challenge your thinking too.

Set goals for change

Keep working on your main feeling

Review thought challenging techniques

Challenge your thinking by testing things out

Plan an experiment to test your thinking

Screen 5 of 28

Click on the next button

back next

**Narrator**  
**Audio/ non audio version**  
**Ability to prioritise**  
**Video case examples**  
**Worked examples**  
**Own examples**  
**Progress feedback \***

Caring for Me and You (A)

Well-being Progress

Your well-being progress

The graph shows your mood over the weeks. You can view the changes in your mood anytime you want.

| Week | Mood Level |
|------|------------|
| 1    | 4          |
| 2    | 4          |
| 3    | 4          |
| 4    | 2          |
| 5    | 1          |
| 6    | 3          |

Course progress

You have completed 8% of the programme.

21 weeks remaining

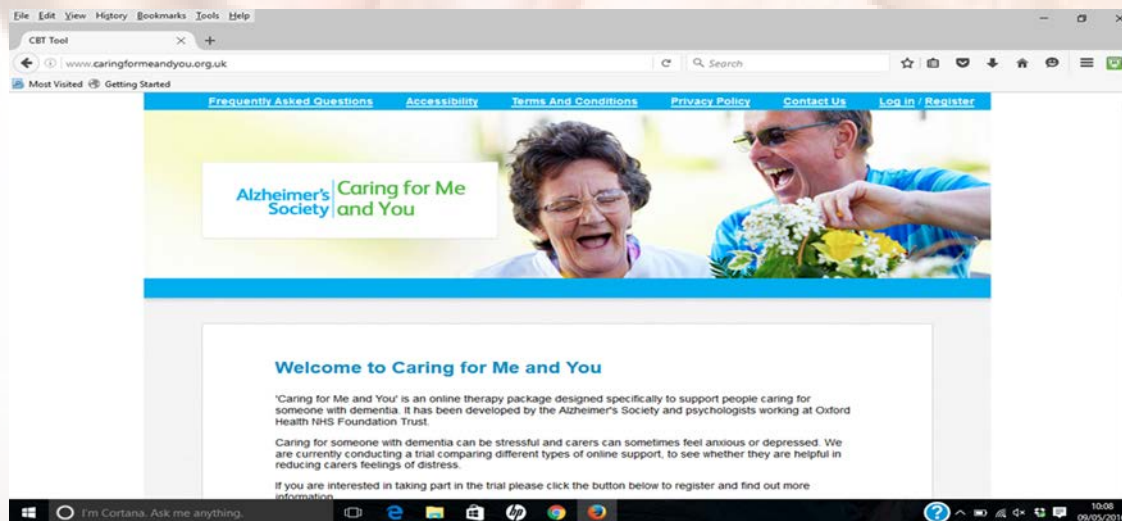
You currently have 10 modules remaining

Need help?

Click here if you are looking for urgent emotional support

# Psychoeducation package

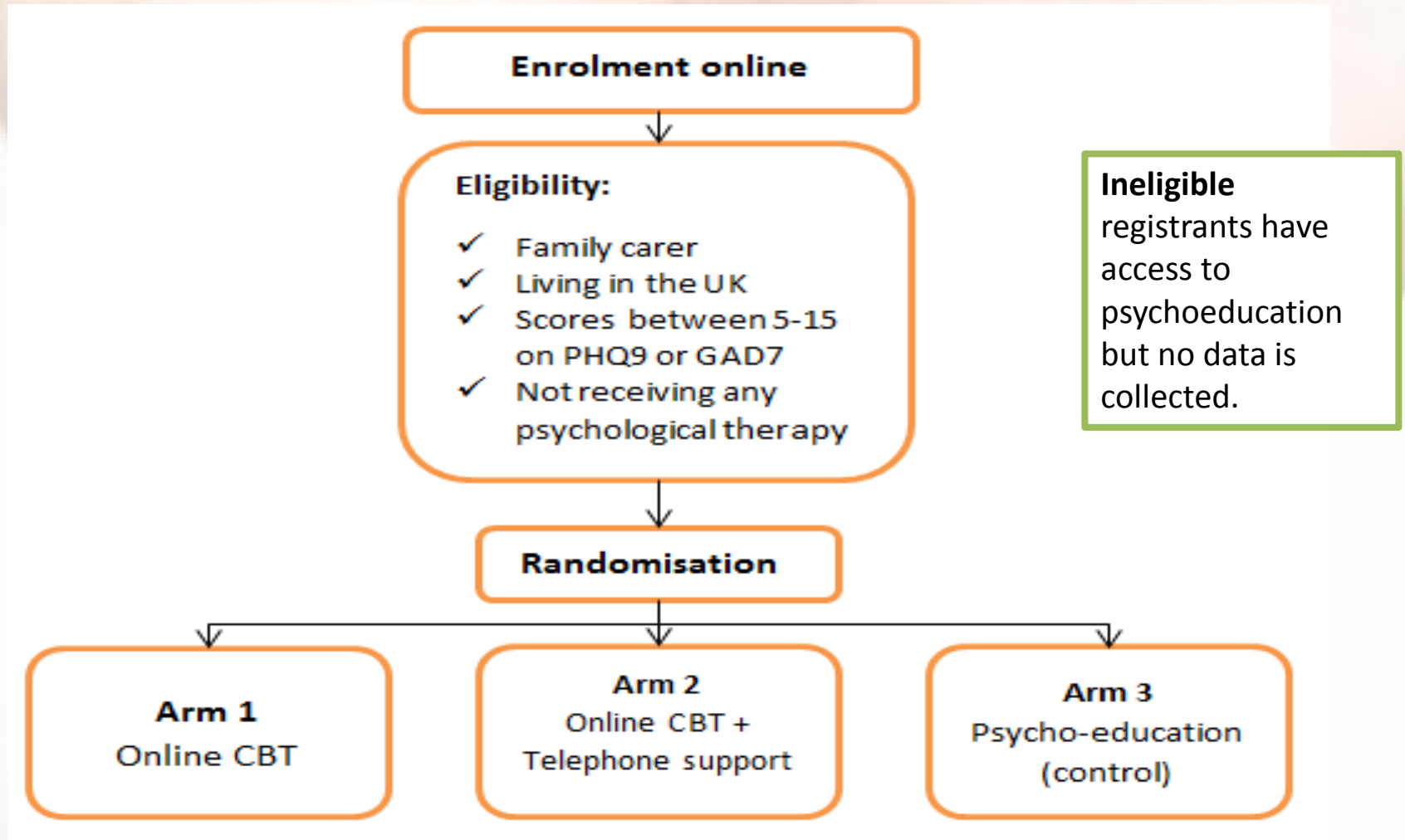
- Matched for session length and delivery style
- Based on well regarded currently available materials
- SCIE modules and Alzheimer's Society fact sheets designed into a deliverable course
- Mirroring the engagement principles and progress feedback identified as useful in the CBT package development



# Alzheimer's Society funded 3 arm randomised controlled trial

- Evaluating online CBT with and without telephone support and psychoeducation
- Primary hypothesis : supported and unsupported online CBT will confer significantly greater improvement than psychoeducation over 26 weeks in carers with significant depression or anxiety at baseline

Wide recruitment policy to enhance inclusion  
[www.caringformeandyou.org.uk](http://www.caringformeandyou.org.uk)





# Measures

- Outcome measures are recorded at baseline, week 12 and week 26
- General Health Questionnaire (GHQ)- Primary Outcome Measure
- Short Sense of Competency Questionnaire (SSCQ)
- SF6D as a measure of general health
- Relative Stress Scale (RSS)
- Care Older People's Evaluation (COPE)
- Hospital Anxiety and Depression Scale (HADS)
- Short form Client Service Receipt Inventory (CSRI)

# Delivery of support work (SW) through 2 IAPT services

- SWs have specific training for this package (reduced remit, not PWP)
- Receive supervision in line with the IAPT service PWP model in which they are hosted, from band 8a clinical supervisors
- Complete the sessional IAPT measures – enables us to benchmark and understand feasibility of delivery within a national service model
- Following service protocols as closely as possible for calls and risk

# Management of risk

- Session by session monitoring on PHQ9 of all study participants
- SW calls to those with an identified risk
- GP contact if required.

# Learning so far (nearing end of trial)

- Recruitment >1200 people registered an interest in participating
- Over 50% of those expressing interest are eligible to participate
- Importance of having the bespoke materials
- Accessible for those living away from person they care for - but can be a hard to reach group who aren't always focused on their own needs or directly in contact with services
- Value of association with IAPT services for supported arm
- Unsolicited feedback from individual participants across all arms has been helpful
- Anticipated results: summer 2018

# Opportunities for wider implementation are being explored

1. If we were to roll this out in IAPT services what training do you think staff would need and how could it be best delivered?
2. Given that CFMAY is a transdiagnostic package, do you anticipate any difficulties for implementing in IAPT setting, and any suggestions for resolving them?
3. Are there features of other online packages you use which you and/or service users find particularly helpful, which we should consider including if we update CFMAY materials ?



# Thank you

[jane.fossey@oxfordhealth.nhs.uk](mailto:jane.fossey@oxfordhealth.nhs.uk)

[Jo-Ann.Fowler@oxfordhealth.nhs.uk](mailto:Jo-Ann.Fowler@oxfordhealth.nhs.uk)