

# THE LANCET Psychiatry

## Supplementary appendix

This appendix formed part of the original submission and has been peer reviewed. We post it as supplied by the authors.

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## **RESEARCH PROTOCOL**

START (STrAtegies for RelaTives) study: A pragmatic randomized controlled trial to determine the effectiveness of a manual based coping strategy programme in promoting the mental health of carers of people with dementia (Short study title: START Study)

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## **Background**

The frequency of dementia will rise dramatically over the next twenty years due to increased longevity. In the UK, 700,000 people currently have dementia (>1% of the entire UK population) and this is projected to reach over a million by 2020 and double again in the subsequent 20 years (3;4). Dementia affects the person with the illness, their family and society through increasing dependence and challenging behaviour. In the UK, dementia care is currently estimated to cost £17 billion pounds per year, and this is projected to treble to £50 billion in the next 30 years as the number of older people increases (4;5); for comparison, the entire NHS budget is currently £96 billion a year. Families and individuals bear the biggest financial burden; two-thirds of people with dementia live at home, receiving most of their care from family carers, who save the public purse more than £6 billion per year. The recent Alzheimer's Society *Dementia UK* report found that current levels of services and support for people with dementia and families are inadequate (4). This impacts on the NHS, as well as patients and families, as carer psychological morbidity predicts care breakdown and therefore institutionalisation (6). There is evidence from the USA that providing specialist, individually tailored psychological support to people with dementia and their family carers can reduce rates of institutionalisation (7;8). Nationally, a reduction of this magnitude in care home placements would have huge benefits for society, because most older people want to continue living at home, and report higher quality of life when they do so, compared with those placed in care homes. There are also economic benefits; the National Audit Office recently emphasised the need to "spend to save" on dementia care. The government's 10 year plans to increase the detection of dementia (currently only 30% of cases are ever diagnosed) and improve the quality of care for people with dementia and their carers, are outlined in the National Dementia Strategy consultation document. It is projected that this huge increase in service provision will be offset by a decrease in institutionalisation rates of between 6 and 20% in ten years (5).

### Evidence for a coping-based psychological therapy for carers

Our systematic review of the prevalence of mental ill-health in family carers of people with dementia has established that about 40% have psychological disorders while others have significant psychological symptoms (9;10). The coping strategies family carers use are more important than all other factors, including the cognitive and psychiatric morbidity of the person they are caring for and the hours of care they provide, in predicting their mental health. Carers who used more emotion-focussed coping strategies and fewer dysfunctional coping strategies were less anxious a year later in our recent longitudinal study (11). Such coping styles are also associated with reduced depression (12;13). These epidemiological findings accord with those from our systematic review of treatments for carer anxiety, that promoting emotion-focussed coping was one of the only interventions for which there was evidence of effect in reducing carer anxiety (14).

Coping-based therapies can also reduce carer's depression. The Coping with Caregiving programme (15;16) was developed in the USA as a group intervention, and systematic review evidence finds it has a stronger evidence base for efficacy than any other reported therapy in the field (17). It is a manual based, psychological intervention delivered in weekly group sessions. It involves promoting problem-solving and emotion-focussed strategies, and avoidance of dysfunctional coping strategies, using cognitive-behavioural methods. This programme was comprehensively evaluated in the REACH (Resources for Enhancing Alzheimer's Caregiver Health) project, which recruited carers from a range of clinical and community sources in the USA; depression scores were significantly decreased in treatment groups compared with controls in all the studies (16;18-20) and self-efficacy scores were increased (21). While the impact of this therapy programme on

rates of institutionalisation has not been tested, a recent systematic review finds that there is some evidence that carer support can reduce institutionalisation, and that therapies such as the Coping with Caregiving programme which include problem-solving strategies and offer carers a choice of support strategies which can be tailored to their individual needs are most effective (22).

Delivery of therapy

The NICE/SCIE dementia care clinical guidelines recommend that “Carers of people with dementia who experience psychological distress and negative psychological impact should be offered psychological therapy, including cognitive behavioural therapy, conducted by a specialist practitioner”. In reality, resources are not available. One of the main research recommendations made by these guidelines was that there was an urgent need for a study to answer the question “For carers of people with dementia, is a psychological intervention cost effective when compared with usual care?”. The National Dementia Strategy states there is a need “to develop practical materials for frontline staff” and to provide high quality support to carers of people with dementia. The Department of Health vision for world class commissioning is that services will be evidence-based and of the best quality (23). Although the efficacy trials discussed above have shown promising reductions in family carer morbidity, there are no manual based therapies currently available for dementia carers in the NHS, nor is there an evidence base to demonstrate whether such standardised psychological interventions can be realistically, effectively and economically delivered to family carers within NHS services. A therapy which is needed by many NHS consumers that can only be effectively implemented by clinical psychologists is unlikely to be economically viable. At the other end of the spectrum in terms of amount of professional training, Charlesworth et al (24) in the Befriending and Costs of Caring trial (an existing HTA programme) recently found that an unstructured, non-manual based befriending programme delivered by ex-carers was ineffective in reducing anxiety or depression. In 2008 the UK Department of Health unveiled plans for £170 million investment in the *Improving Access to Psychological Therapies programme* (25). This funding will be used to train an extra 3,600 psychological therapists, who will treat depression and anxiety in primary care, with training and supervision from clinical psychologists. This strategy is based on the premise that if, as anticipated, less highly trained therapists, under the supervision of clinical psychologists, can deliver manual based training that decreases morbidity, enabling people to return to work, this programme will be cost-effective and highly beneficial for society (26;27).

In our proposed study, we would use similar delivery infrastructure; we anticipate that a psychological therapy specifically tailored to the emotional, practical and information needs of carers could have significant population benefits, including greater carer and care recipient wellbeing and decreased statutory care costs. Our therapy will be delivered by Graduate Mental Health Workers (GMHW), trained and supervised by the co-applicant experts in psychology, carer involvement, nursing and psychiatry, who all work in the NHS. The therapy will be manual based and our system of training and regular supervision will aim to ensure a high degree of fidelity to the programme manual. Plans to restructure community mental health teams, outlined in *New Ways of Working*<sup>1</sup>, include the development of GMHW posts within teams in future

The need for an effective individual manual based therapy

Through our clinical and personal involvement in caring for people with dementia, we are aware of the difficulties carers face in attending a group intervention, as it can be very difficult to make alternative care arrangements and to be available at a pre-specified time. Individual therapy also has the advantage that it can be tailored to the specific problems faced by the carer. There is evidence from systematic reviews that therapies individualised to the carer receiving them were most effective in delaying institutionalisation (29), and that individual behavioural therapies are more effective

than group interventions in reducing carer morbidity (30). We have adapted the above programme, *Coping with Caregiving*, with the authors' agreement, for NHS use, as an individual therapy. As individual therapies are quicker to deliver, because in groups time is needed for all group members' problems to be discussed, this has decreased the number of weekly sessions required. During piloting of the therapy, we found that our therapy took eight sessions to deliver.

#### Summary

Family carers of people with dementia are a group at high risk of mental health problems. As they provide most of the care received by people with dementia in this country, and the number of people with dementia is projected to increase substantially, there is an urgent need within society to develop ways to decrease their distress. The UK government has recognised that family dementia carers need dedicated psychological therapies, and that this should be a key component of high quality dementia care, but in practice resources are not available. The only randomised controlled trials that have demonstrated efficacy of a manual based psychological therapy in this group were carried out in the USA and the therapy was conducted by clinical psychologists. Clinical psychologists are a highly trained and finite resource within the NHS. Programmes of stepped care, in which mental health workers deliver therapy supervised by clinical psychologists, have been devised to widen availability of psychological therapies. We plan to test the feasibility, efficacy and cost-effectiveness of an individual psychological manual based intervention for family carers, delivered by GMHW as part of NHS care. This would be the first study to test a manual based therapy for dementia carers in an Randomised Controlled Trial (RCT) in the UK, and the first study worldwide to test the effectiveness of GMHWs delivering therapy to this group.

#### **Aims and objectives**

Primary objective: To determine (1) the clinical and (2) the cost-effectiveness of eight sessions of manual based coping strategy therapy, delivered over 8-14 weeks by supervised graduate mental health workers to family carers, compared to usual service provision. We will determine these from the perspective of family carers of people with dementia living at home, and from a societal and National Health Service (NHS) perspective. Our primary outcomes will be measured at 4, 8, 12 and 24 months, and analysed using repeated measures.

Secondary objectives:

(1) To determine the effect of the intervention on time to institutionalisation of the person with dementia, strategy use (coping and abusive behaviour) and the quality of life of the carer and person with dementia.

(2) To consider the effect of the following possible modulators on outcome: carer's ethnicity, age, psychiatric history, coping style, baseline psychological symptoms and burden; type of relationship (spouse, child), carer level of education and whether the carer is living with the patient; the severity and type of the patient's dementia and associated neuropsychiatric symptoms; and centre and access to Admiral Nursing.

This study would enable the translation of our epidemiological and systematic review research findings about carers' anxiety and depression and its management into clinical practice. We want to determine whether our evidence based psychological treatment package would deliver significant clinical benefits if offered to all family members providing regular care to people with dementia referred to specialist care. If such benefits are demonstrated this package could be implemented throughout NHS dementia services as the initial part of a stepped care programme. There would also be scope for considering the adaptation of the programme for other chronic illnesses.

#### **Methods**

## **Study design**

This is a pragmatic multi-centred randomised controlled trial.

## **Recruitment**

### Setting and infrastructure

As most people identified in primary care with possible dementia are now referred to a specialist service for diagnosis we intend to recruit through: three mental health trusts (North Essex Foundation Partnership Trust, Camden and Islington Foundation Trust and Barnet, Haringey and Enfield Mental Health Trust); and the Dementia Research Centre- National Hospital for Neurology and Neurosurgery (DRC-NHNN), a tertiary service whose referrals include a high rate of people with young onset dementia. Consultants from all these recruiting centres are co-applicants. We will also recruit from the North East London and Essex Admiral Nurse service, covering Barking, Dagenham, Redbridge, Havering and Waltham Forest, to include those who use this growing resource. This service is led by Juanita Hoe (nurse practitioner and co-applicant). Our sampling frame encompasses urban, suburban and rural areas and ethnic and social class diversity, ensuring results will be generalisable to the UK. Our recruitment will be assisted through adoption of the project by North Thames DeNDRoN. Neurology (CM) and psychiatry (GL) leads for North Thames DeNDRoN, and the national lead for neurology (MR) are co-applicants.

### Recruitment plans

We will use the recruitment process streamlined during previous and current large studies in this population. The Admiral Nursing service, Camden and Islington Foundation Trust and Dementia Research Centre-NHNN all have anonymised databases of existing clients who have agreed to be approached for research and these will be searched. The DRC-NHNN is a national referral centre, so we will approach all London and Essex carers who meet criteria. When potential participants are identified on these databases their current suitability will be checked with clinicians currently seeing them.

Research Assistants who will all have contracts with the participating trusts, with the additional help of DeNDRoN clinical research officers (CROs), will identify potential participants from the mental health trusts through discussion with clinicians when attending weekly team community mental health or memory clinic meetings. They will have their suitability confirmed by a clinician and initially will be approached by the clinician and only if they agree to the research will notes be read. Appropriate patients will be notified of opportunities to join in, and will be free to choose whether they wish to do so, after a full explanation. We would expect, extrapolating from previous figures, that from the three mental health trusts we would approach at least 20 carers of people with young onset dementia.

Family carers who provide emotional or practical support at least weekly and identify themselves as the primary carer of someone with dementia living at home, will be sent a standard letter from the treating clinician together with an information sheet inviting them to participate. The content of this letter will be agreed with the clinician at the start of the project, then, as participants are identified, we will seek the clinician's agreement to send out the letter. The research assistants and manager will complete this for them. Clinicians may also invite people to participate and directly give them the information sheet. The standard letter will explain that a research assistant will call the carer in about a week to answer questions and, if the carer agrees, arrange an interview to obtain informed consent. The carer will also be given a contact telephone number for the clinician, and invited to ring them if they do not wish to be contacted by the researchers. Research assistants will have logistic support (mobile phone, availability of one of the coapplicants) to enable some of the interviews to take place in the evening, to be inclusive of all carers, including those who are in paid employment.

### The assessment

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The interview will take between between forty minutes and one and a half hours. The longer time will be when the carer is unable to read (eyesight or literacy), or wishes to widen the discussion.

At baseline, carers will be asked about sociodemographic details for the carer and the person with dementia (including age, gender, ethnicity, relationship (e.g. spouse, child), level of education, last occupation and their living situation. At baseline, 4, 8, 12 and 24 months, the carers will be asked about their psychiatric history and psychotropic medication.

They will also complete: the Hospital Anxiety and Depression Scale (HADS) (31): this is validated for all ages and settings (32), and in one Asian and one African ethnic group. It generates scores and caseness for clinically significant anxiety and depression. Our pilot data shows that carers' psychological symptoms worsen over 6 months even in those initially reporting no symptoms and those who were "cases" did not improve over time. In addition, emotion-focussed coping strategy use prevented future carer psychological morbidity as well as treating it . We have therefore not specified a minimum HADS score for carer inclusion.

Carers will also complete the Brief Coping Orientation to Problems Experienced scale (COPE) to measure coping strategy use (33); the Zarit Burden Interview (34) a 22-item self-report questionnaire, the most consistently used measure of carer burden and the Modified Conflict Tactics Scale (35). We will use the Minimal State Examination (36), the most widely used measure of cognitive impairment, to give the level of cognitive impairment in carers aged >60 to ensure they themselves do not have dementia. If they score <24 the carer will be discussed with a supervising clinicians applicants to see whether this is related to cognition or education; The Health Status Questionnaire (HSQ) (37) and the Euroqol EQ5D (38), both quality of life measures, will also be completed by the carers. The EQ5D is a generic measure to generate QALYs (quality of life adjusted health years); societal weights will be applied.

Regarding the patient, the carer will complete the Neuropsychiatric Inventory (NPI) (39): a validated instrument with 12 domains, included as neuropsychiatric symptoms are associated with carer psychological morbidity and the Quality of Life for patients with Alzheimer's Disease (QoL-AD(40)). The QoL-AD has proven reliability and validity when completed by the carer. The Client Service Receipt Inventory (CSRI; (41)) will be used to collect service use information about the carer and the patient (including institutionalisation, extra patient care during therapy), unpaid carer support and other aspects relevant to health economics. We will measure the use of institutional care by collecting information from carers at each interview and making sure we use the CSRI (Client Service Receipt Inventory) to collect accurate and sufficiently disaggregated data to capture the growing variety of placement types. We will define "institutional or 24-hr care" to mean residential, nursing and continuing care placements. We will use the CSRI to give us measures of number of days living in each of a number of different settings over the course of the research period. When we consider date of entry to 24 hour care settings, we will include any time people were in hospital awaiting placement to 24 hour care.

We will also use the CDR (Clinical Dementia Rating) as an informant instrument to grade the level of impairment of the individual with dementia(40a)

We will keep anonymised data on the age and gender of those carers invited to participate who did not respond, to assess the generalisability of our findings. The study recruitment criteria are very inclusive to ensure generalisability within the UK.

### Feasibility of recruitment

In our recent (2007-8) non-intervention study, we completed recruitment and interview of family carers of people with dementia living at home without inducement (CC, GL, SN, ZW, RB), ahead of schedule. We achieved a recruitment rate of 18

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carers per centre per quarter, and recruited from North Essex Partnership, and Camden and Islington Foundation Trusts, recruiting only carers of newly referred patients with dementia. In the proposed study, we will also be approaching all carers who have been referred in the last year to these trusts, so will be recruiting from a larger pool and have also added more services (BEH and DRC). We think that more carers may be interested, as we are offering the possibility of an additional service. However, as the amount of time we are asking carers to dedicate to this study is greater, we have predicted a modest total recruitment rate of 9 carers per centre per quarter (over 6 quarters). As we are aware that recruitment is labour intensive, we have projected that each research assistant will be required to recruit and complete the baseline interview on 2 carers a week. This estimate is based on previous experience of employing Research Assistants of the same grade for similar work.

### Allocation to trial groups

Randomisation to group allocation, and to therapist, will be undertaken by PRIMENT (CTU), by means of a computergenerated code. Use of an automated telephone randomisation system will ensure concealment of allocation.

### Blinding

We cannot blind participants to treatment group, but outcome assessors will be blinded. Assessors will ask participants at the beginning of each rating session not to disclose their allocation group; we will ask the rater to guess the allocation group for each participant at the end of each assessment to detect whether unblinding occurs. Six FTE GMHWs will work as therapists and assessors, but they will not fulfil these roles at the same centre, to ensure they remain blinded to allocation. The therapists will work in two teams of three, housed in separate offices. PRIMENT will allocate each carer to a group, and allocate one of the two groups to complete baseline and follow-up assessments for each carer, and allocate the other group as therapist for those in the intervention arm. This will ensure that, in the intervention arm, the assessor is not the therapist, or working in the same team as the therapist. The database will be set up, with assistance from the PRIMENT, with web-based data entry to ensure that assessors will not have access to the other information in the database. We have used self-report measures for our main outcome measures as another means of reducing the potential for bias.

### Co-carers

Occasionally, two family members share caring responsibilities equally, so there are two primary carers. Where this has occurred in previous studies, we have found that families select one person to take part. For one of the intervention sessions in which information about care and legal planning is imparted, the participating carer is invited to bring another family member along if they share caring responsibility, but the research outcome is measured only with the pre-agreed main participant.

## **Planned intervention**

### ***Therapy intervention***

The Coping with Caregiving programme <sup>2,3</sup> was developed as a group intervention programme for USA carers, and systematic review evidence finds it has a stronger evidence base for efficacy than any other reported therapy in the field <sup>4</sup>. It uses the stress appraisal and coping response model, and principles from cognitive behavioural therapy <sup>5</sup>. With the author's permission, we have developed and piloted an individual therapy programme based closely on this original therapy, adapted for NHS use. The therapist has a manual and the carer is also given written information and guidance. The intervention is designed to be delivered in eight sessions over 8-14 weeks. The therapy will take place where the carers prefers, we anticipate this will usually be at their home. The therapy will be carried out with an interpreter if the carer does not speak English fluently.

The sessions cover 1: Introduction: learning about dementia, carer stress and understanding behaviours of the person cared for; 2-6: Discussion of problems that

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the carer finds difficult, incorporating behavioural management techniques; skills to take better care of themselves, including changing unhelpful thoughts, assertive communication, relaxation and planning pleasant activities; increasing communication; promoting acceptance; where to get emotional support and positive reframing. 7: Future needs of the patient, with psychoeducation about care and legal planning, specifically adapted to the UK 8: Maintaining the skills learned over time. Carers are given homework tasks to complete between sessions, including identifying triggers and reactions to challenging behaviours, and identifying and challenging negative thoughts.

### Training and delivery

Graduate Mental Health Workers (GMHW) will be employed to deliver the intervention. We envisage recruiting psychology assistants, who have a degree in psychology but without clinical psychology training. Job descriptions will specify evidence of listening skills, empathy and clinical experience. This level of expertise will ensure breadth of skills (to impart information, knowledge of dementia, mental health & knowing when more support is needed). During recent recruitment, we advertised a research assistant post at the same level, received 86 applications despite advertising for less than a week, and identified seven out of eight shortlisted applicants at interview with this level of experience who would be appropriate to appoint to such a post. A short training programme will be delivered by the psychologist, medical, and nursing co-applicants. There will be a strong practical focus on how to deliver the therapy, empathic listening skills, effective use of supervision and when to ask for help. They will also have teaching sessions dedicated to working with interpreters and cultural sensitivity. As the manual will be delivered by English speaking researchers with an interpreter it will not be translated but the interpreters will be asked to translate the homework material as the sessions progress. Training will emphasise the need to operate from an inclusive values base and to respect diversity. Knowledge will be acquired through a combination of seminars, discussion groups, reflective learning and guided reading. Skills-based competencies will be learnt through clinical simulation in small groups. In devising our training programme, we will draw on the curriculum for psychological therapists devised by the Department of Health for their improving access to psychological therapies programme <sup>6</sup>.

All therapists will be trained to adhere to the manual. They will be required to demonstrate, by role-play, competence in delivering the intervention before recruitment commences; this will be assessed by our clinical psychologist (Dr Penny Rapaport). Dr Rapaport will meet with each of the teams (two teams of three therapists) on alternate weeks for 1.5 hours for group supervision. She will also have available an hour of dedicated time for individual consultation as needed by the therapists. These individual meetings will be initiated either by the therapists or by the research team as needed. Therapists will, with the carer's permission, record one therapy session per participant. They will use this in supervision, and they will submit a random sample of recordings for monitoring by two researchers not involved in the therapy, who will independently rate fidelity to the manual using a standard checklist. This will score adherence to the manual text and leader instructions for each of the subsections of the session recorded. Any discrepancies will be discussed with a third rater, and results fed back to the therapist and Trial Steering Committee. Supervision will be in a group format to enable effective learning from the experiences of others and to facilitate a professional network for the workers of peer support. All participants will have been seen by clinicians before the trial and most will have been seen at home and risks will have been assessed as part of clinical work. The trial manager will have a diary detailing where the workers are. All workers will carry mobile phones and will have

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telephone access to a named co-applicant involved in the training and supervision during working hours and in the evening if they are delivering therapy then.

### Treatment as Usual (TAU)

As several teaching trusts are involved we expect the TAU to be similar to good "TAU" throughout the UK. We will adjust for centre in analyses, as TAU may differ between them. We will record services received and consider them as confounders. Most existing services are based around the person with dementia. Treatment is medical, psychological and social. Thus it will consist of assessment, diagnosis and information; practical support; treatment of neuropsychiatric and cognitive symptoms and carer support. There will be no restrictions on treatment options for carers as this would be unethical, and we are proposing a pragmatic trial to assess the benefits of this treatment package in addition to usual care. Few carers were receiving psychology input (<1%) in our previous carer study, so we do not expect this to influence the outcome.

### **Planned inclusion/ exclusion criteria**

#### Inclusion criteria

- Family carers who provide emotional or practical support at least weekly and identify themselves as the primary carer of someone with dementia not living in 24 hour care.
- We will only recruit carers of patients referred in the last year, as early mental health interventions work best, and this is the intended point of delivery within the NHS.
- We will use interpreters to ensure our recruitment strategy is inclusive.

#### Exclusion criteria

- Carers who are unable to give informed consent to the trial, for example because they have dementia themselves.
- Carers who are currently taking part in a randomised clinical trial in their capacity as a family carer.
- Carers who live more than 1.5 hours from the researchers' base.

### **Proposed sample size**

Our cross-sectional pilot study found the mean anxiety score for family carers in a representative sample from secondary care was 7.2 (Standard Deviation (SD) 4) on the HADS. We consider a decrease of 2 points in mean and 0.5 change in SD to be a clinically significant improvement.

This potential size of reduction was previously demonstrated by using an emotion focussed coping strategy intervention. In order to achieve the mentioned reduction with 90% power at the 5% level of significance, 75 participants per group need to be recruited.

In order to take the therapist effect (cluster on GMHW) into account, a design effect of 1.87 was used for those in the intervention group, based on a projected cluster size of 30 and an Intra-Class Correlation (ICC) of 0.03 (37).

We therefore need to recruit 75 participants in the usual care group (no clustering) and 140 in the intervention group (clustering). Thus we aim to recruit 215 participants overall (providing 90% power at the 5% level of significance).

Assuming 20% attrition, we are going to recruit 90 participants in the usual care group and 168 participants in the intervention group or 258 in total. These figures will also be sufficient for the repeated measurement analysis.

We therefore plan to recruit 43 carers a quarter, or an average of nine per quarter from each of the five centres. This is a conservative estimate given that we have attained a recruitment rate of 18 family carers a quarter per centre for a non-intervention study in the same population. This sample size will also be sufficient to

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examine the outcome of depression with similar power and using repeated measures analysis.

### **Statistical analysis**

We have a statistician as a co-applicant in our research team and additional support from the PRIMENT statisticians.

Our health economic analysis will be led by our health economist PI Prof Knapp who will supervise Dr Romeo's work on the project. Our analytic strategy is based around the two primary main study objectives.

Carer health component: We will test our main hypotheses that HADS anxiety score will be significantly lower in the intervention compared with usual care group, using a repeated measures analysis and a multilevel mixed model to take account of the clustered design. We will also test the secondary hypotheses in the same way. In addition, we will calculate estimated mean times to care home entry for the groups using Kaplan – Meier survival analysis.

We are comparing the trial intervention to treatment as usual (TAU). Some NHS centres have Admiral Nurses (AN) as part of the TAU. Their contribution to the TAU arm will be addressed:-

- As a potential confounder, it will be entered as a covariate in the analysis to assess the clinical benefit of AN.
- We will also conduct a sensitivity analysis excluding centres that have ANs.
- Any additional costs arising from the use of AN will be incorporated in the TAU costs in the normal way.

Health economic component: Cost comparisons will be made between the groups, adjusted for baseline differences, and any non-normality of data (transformation or non-parametric test). Cost-effectiveness analyses combine costs generated from the CSRI with (a) HADS anxiety and depression score and with secondary outcomes at the same time points as outcome analyses. (b) QALY measures generated from the EQ-5D, allowing comparison with other health care interventions. Cost-effectiveness acceptability curves will be plotted using bootstrap analyses to locate the findings of the economic evaluation in their wider decision-making context. Sensitivity analyses will examine the consequences of key assumptions. Study perspectives will be (1) health and social care system; (2) societal.

### **Proposed outcome measures**

Assessors will be blinded to randomisation group. Outcomes will be measured at 4, 8, 12 and 24 months. Our primary outcome measures are:

1. Carer HADS depression and anxiety scores (31).
2. Cost-effectiveness: Cost of care for each group will be measured using the Client Service Receipt Inventory (CSRI). The EQ5D is a generic measure to generate QALYs (quality of life adjusted health years); societal weights will be applied.

Our secondary outcome measures are:

1. Time to entry of the person with dementia to 24-hr care
2. Depression and anxiety caseness on the HADS
3. Carer (HSQ) and care recipient (QoL-AD) quality of life

We envisage that while the majority of the participants will be of white European ethnicity there will also be significant numbers from Black and minority ethnic groups. No measure of depression in older people is validated across all the ethnic groups from whom we plan to recruit. Screening measures for mental illness have been found to be valid in UK black older populations and attempts to construct a culturally specific instrument have not improved on their psychometric properties. Current expert consensus is that the cultural sensitivity of researchers is the most important

factor in cross-ethnic validity and that generic measures should be used (46). Our primary outcome measure, the Hospital Anxiety and Depression Scale (HADS) has been validated in one Asian and one African group but not all ethnic groups (47).

### **Ethical arrangements**

We will apply for multi-centre research ethics approval (MREC) and obtain local research governance approval for the study, as appropriate. The study personnel, co-investigators as the management group and independent Trial Steering Committee (TSC) will ensure that the study is conducted within appropriate NHS and professional ethical guidelines. All the information will be kept strictly confidential and held in accordance with the principles of the Data Protection Act (1998). Each participant will be assigned a research number and all data will be stored without subject name or address. Data will be held on a secure database on a password-protected computer at University College London. Access to data will be restricted to the research team, and research assistants' access will be limited as far as possible. In order to enable follow-up contacts, it will be necessary to identify the patients, but access to contact details (e.g. name and address) will be restricted to key members of the research team. Audio-tapes of interviews for training and fidelity monitoring (using a digital voice recorder) will be destroyed once the main study is complete. The people with dementia will not be interviewed nor will their medical notes be accessed.

Carers will be sent a standard letter from, or approached in person by the treating clinician, and provided with an information sheet with full study details including possible benefits and risks. They will then be contacted, unless they have declined, and offered the opportunity to ask questions and make a date for the interview. Their written informed consent will be obtained prior to commencing the baseline assessment for the trial and at least 24 hours after they have received the information sheet. When asking for consent, the researcher will explain that, as this is a clinical trial, they cannot choose which group they are allocated to, and that whilst we hope that the therapy will be beneficial this cannot be guaranteed. Patients and carers will continue to have usual care in both groups. Carers who do not have capacity to consent to take part in the trial will not be included.

The anticipated benefits for trial participants are significant improvement in carer mental health and quality of life. We do not anticipate any risks for trial participants. Although talking about the problems of coping with caring could be upsetting, in our experience carers do not find it distressing and usually find it helpful. Although the graduate mental health workers may not have worked previously in a clinical setting, evidence of listening skills will be a criterion for recruitment and they will be trained and well supervised. The potential benefits for society are the development of a cost-effective therapy that will reduce distress of carers of people with dementia that is widely deliverable within the NHS. As well as reducing distress at a population level, there is evidence that carer mental ill health predicts institutionalisation (45) and elder abuse (46), and that carer support can decrease care home placements (47). Thus there will be benefits to people with dementia and economic benefits.

If information disclosed by a carer leads us to believe that a patient or carer is at significant risk, the researcher will discuss this with their supervisor. If appropriate they will approach the participant and seek their consent for disclosure to the referring clinician. The information sheet will specify that "we respect confidentiality but cannot keep it a secret if anyone is being seriously harmed or is at high risk of serious harm". If there is reason to believe that harm is occurring or there is a high risk it is likely to occur, we will report this to the referring clinician without consent if this is refused. In our recent study of 220 carers of people with dementia, in which we specifically asked about abusive behaviour, we judged it necessary to ask the carers permission to disclose information to the treating clinician in five cases, and permission was granted in four cases. In the fifth case, after discussion of the

## **START (STrAtegies for RelaTives) study: Version 0.1 18/05/2009**

situation with the project supervisors, it was not deemed necessary or appropriate to disclose information against the carer's wishes. As a psychological intervention, this trial is exempt from registration under the Medicines for Human Use (Clinical Trials) Regulations 2004. We will however ensure that the trial is registered with the appropriate body ([www.controlledtrials.com](http://www.controlledtrials.com)) and assigned an ISRCTN number in accordance with good practice. In line with UCL data protection policy, we will retain relevant trial documentation for 10 years.

### **Research governance**

University College London will act as nominated sponsor for the project. We will form a Data Monitoring Committee and Trial Steering Committee.

#### **Data Monitoring Committee (DMC)**

We will set up a Data Monitoring Committee (DMC) that will have access to the comparative data. The DMC will consider whether any interim analysis is necessary, review data from any analysis and consider requests for data release. The members will monitor these data and make recommendations to the Trial Steering Committee (TSC) on whether there are any ethical or safety reasons why the trial should not continue with the safety, rights and well-being of the Trial Participants being paramount. Membership of the DMC will be completely independent, and comprise three members (a consumer, a clinician with experience in the relevant area and an independent trial statistician). We propose and have approached, as chair, Professor Cornelius Katona, a clinician experienced in dementia research; a carer, U Hlay Hty (a carer representative with experience of working with mental health researchers) and a statistician (from PRIMENT). They will meet before the trial starts, for an interim analysis and annually or as needed after that. The chief investigator will arrange the meetings with the chair of the DMC. The project team will provide the DMC with a comprehensive report, the content to be agreed in advance by the Chair of the DMC and they will feed this into the TSC.

#### **Trial Steering Committee (TSC)**

The TSC will have an independent Chair and the following proposed membership.

| Name  | Affiliation                           | Role                                    |
|---|---------------------------------------|---|
| Dr Joanna Murray  | Institute of Psychiatry               | Independent chair/<br>psychologist      |
| Dr Kate Maxmin  | North East London<br>Foundation Trust | Independent<br>psychiatrist/member      |
| Dr TBS Baamurali  | East London Foundation<br>Trust       | Independent<br>member/psychiatrist      |
| Professor Gill Livingston   | University College<br>London          | Lead investigator/<br>psychiatrist      |
| Lynne Ramsey  |                                       | Independent carer<br>representative     |
| HTA representative  | HTA                                   |   |
| Membership as<br>appropriate: trial<br>statistician, trial<br>coordinator | University College<br>London          | Trial coordinator and co-<br>applicants |

The TSC will meet annually and more often if indicated. The role of the TSC is to provide overall supervision for the trial, concentrate on the progress of the trial and adherence to the protocol and provide advice through its independent Chairman. The ultimate decision for the continuation of the trial lies with the TSC. The TSC will report to the sponsors (University of College London) and the HTA.

**START (STrategies for RelaTives) study: Version 0.1 18/05/2009**

**4. Project timetable and milestones**

We will start pre-trial work by 15-4-09. This will include obtaining ethics and local trust research governance approvals, finalising our training programme, arranging adoption of study by DeNDRoN, and advertising for and recruiting research staff. We will start the trial on 1-8-09.

**Time Milestones**

| Time                                      | Milestones   |   |   |
|---|--|---|---|
|   | Management   | Recruitment and therapy delivered (n)   | Follow-up (n)   |
| First 3 months<br>(1-8-09 – 1-11-09)      | Orientate and train staff<br>Set up database<br>First meeting of TSC   |   |   |
| 3 months – 6 months<br>(1-11-09 – 1-2-10) | Begin fortnightly therapist supervision meetings<br>Begin therapy fidelity monitoring process  | Begin recruitment<br>Control arm: 16<br>Intervention arm: 26<br>Therapy sessions:208  |   |
| 6– 12 months<br>(1-3-10 – 1-8-10)         |  | Recruitment<br>Control arm: 30<br>Intervention arm: 54<br>Therapy sessions:432  | 4 months: 84<br>8 months: 42                                |
| Year 2<br>(1-8-10 – 1-8-11)               | Continue fortnightly therapist supervision meetings and therapy fidelity monitoring process  | Finish recruitment by beginning of 4 <sup>th</sup> quarter<br>Control arm: 44<br>Intervention arm: 88<br>Therapy sessions:704 | 4 months: 142<br>8 months: 150<br>1 year: 126               |
| Year 3<br>(1-8-11 – 1-8-12)               | Discuss with stakeholders dissemination policy   |   | 4 months: 32<br>8 months: 66<br>1 year: 132<br>2 years: 126 |
| Year 4<br>(1-8-12 – 1-8-13)               | Complete data entry, lock data and analyse; write up project, publish in high impact international journal; implement dissemination policy (if successful); submit final report to HTA |   | 2 years: 132  |

**Dissemination**

We will provide a summary sheet of the findings or let participants know where they can access the results. We will also discuss with stakeholders (academics clinicians, carers representatives) the dissemination policy depending on results

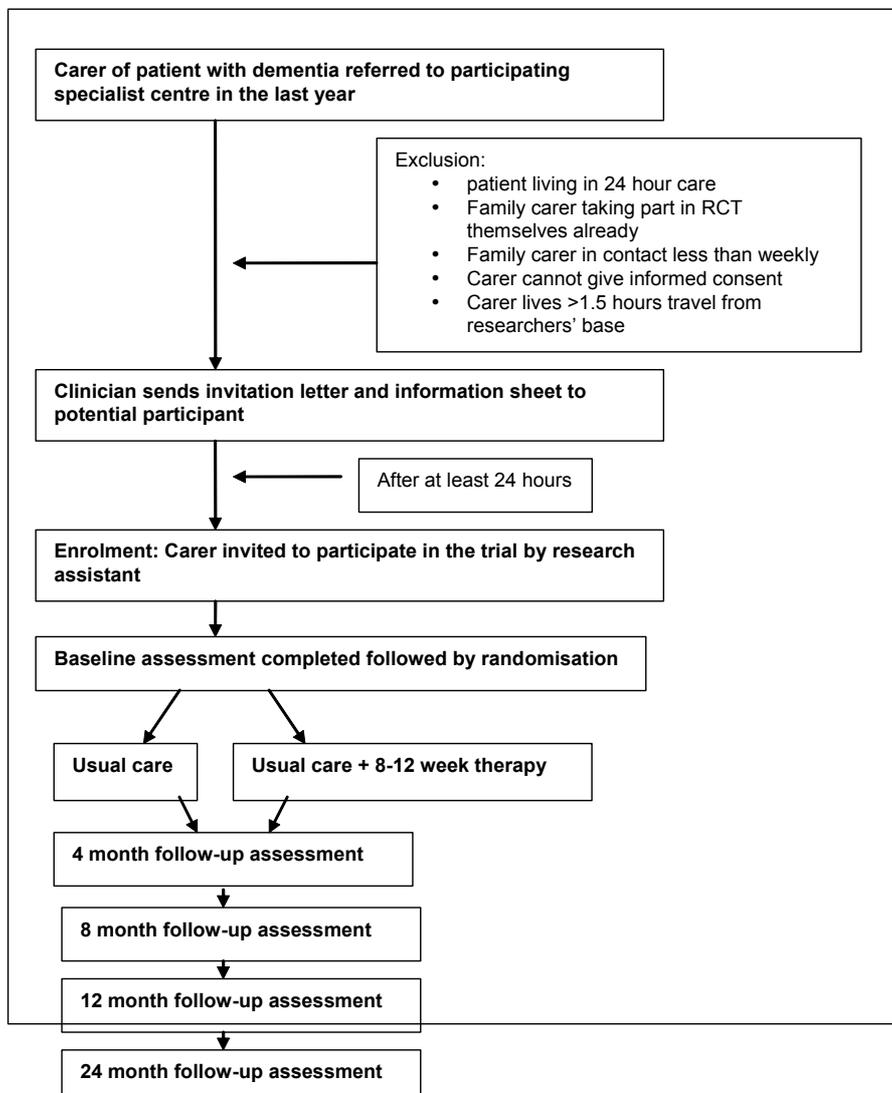
**Service users**

SN (co-applicant) is an ex-carer whose expertise within the group is the carer perspective. She has worked with our groups on previous large studies and has been involved in the development and design of this study proposal. *For Dementia*, a

## START (STrategies for RelaTives) study: Version 0.1 18/05/2009

voluntary organisation dedicated to training and development of dementia services including Admiral Nurses, is supportive of this application. We have agreement from an independent user representative to join our DMC and will invite an independent user representative to join our TSC.

CONSORT Flow Diagram



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**Ref Type: Report**

Leader Version

# The START Manual: STrAtegies for RelaTives



Adapted from the original *Coping with Caregiving* with thanks to Dolores Gallagher-Thompson, Stanford University School of Medicine, for her kind permission.

Produced by MHSU UCL

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# Introduction

These sessions are about *you*, and how to maintain or improve your well-being when caring is stressful.

Some people find it helpful to think of themselves as a carer, others describe themselves as just acting the way a relative does.

How would you describe yourself?

**Leader:** Remember this and use their preferred description throughout if different to carer, the term used in this manual.

Caring is challenging, and many skills are needed. The sessions will focus on your thoughts, feelings, and reactions to looking after someone with memory loss. We will look at:

- Strategies to manage the difficult behaviours which are often associated with memory problems, so they are less upsetting.
- Strategies focusing on your sense of well-being, including ways to relax.

Although we can't guarantee that all difficult behaviours will change, we hope to provide you with some tools to improve your situation.

**During my visits we will cover some strategies which help many people. You may be doing some already and not all will apply to you.**

## Here is an outline of what the programme covers:

Today is an introduction, in which we will discuss dementia, carer stress and understanding behaviours.

Throughout the sessions we will be focusing on:

- Providing you with skills to manage the problem behaviours that are associated with your relative's memory problems.
- Developing skills to take better care of yourself including changing unhelpful thoughts, communication, assertiveness, relaxation, and pleasant activities.
- Planning for the needs of your relative in the future
- Providing you with helpful hints for maintaining the skills you have learned over time.

After completing each session there will be a written exercise for you do at home, before the next session. Although you may find it difficult to find time, often people benefit from completing these exercises and are able to gain more from the session. It will allow you to become more aware of your own or your relative's behaviour and help you put into practice the tools, skills and techniques that we discuss.

This booklet is for you to keep and each time I visit I will give you more information covering what we talk about.



# Session 1: Stress and Well-Being

## Session Plan

- 1. Introduction to the Course**
- 2. Overview of Memory Loss**
- 3. Behaviour and Emotions**
- 4. Managing the Stress that Caring brings**
- 5. Stress**
- 6. Stress Reduction Technique: *The Signal Breath***
- 7. Summary**



## Overview of Memory Loss

- Memory Loss is associated with more than 50 different disorders. The most common cause is Alzheimer's disease, followed by Vascular Dementia and then Lewy Body Dementia.
- Dementia is not a normal part of ageing. It is an illness.
- Memory loss and dementia can affect several areas of a person's life, making it difficult to function as usual. Some of these areas include:

### **Memory**

### **Concentration**

### **Thinking**

### **Judgement**

### **Behaviour**

- Dementia affects the lives of many different people, including the individual with dementia and his or her family members. It can result in significant emotional and financial strain.
- Family carers can learn skills to manage the behavioural and emotional symptoms associated with dementia. Learning skills can allow carers to feel more able to manage and in control of their life circumstances.

- Each individual's experience and expression of dementia is different, because different areas of the brain are affected depending on the type of dementia and people are different to start with. Nearly everybody has difficulty in remembering and learning new things.
- Although dementia is very serious, and there is no known cure for it, there is *hope*. Research is being done all over the world. New treatments slow the progression of dementia, and are improving all the time.





Can you tell me the problems and symptoms you have noticed?

1.

2.

3.

4.

5.

## Behaviour and emotion

A behaviour is something specific and observable that someone does. Some behavioural changes that can occur with memory loss include:

- Asking the same question repeatedly
- Accusing people of stealing when they forget where they have put things
- Wandering
- Doing embarrassing things in public
- Sleep difficulties

These behaviours are frustrating and difficult to manage. However, it is important to remember that they are the result of brain changes and not intentional.



Behaviours that you or your relative do are often related to feelings. It is important to understand that:

- Behaviours may not mean what you think
- Sometimes people cannot express what they feel in words as well as they used to. Sometimes what they do can be a clue to finding out what they are feeling

To illustrate this use the table below to identify behaviours that you or your relative do when experiencing the feelings (emotions) listed in the table.

| <b>Feeling or Emotion</b> | <b>Related Behaviours</b>           |
|---------------------------|-------------------------------------|
| <b>Sad</b>                | 1. Talks less<br>2.                 |
| <b>Pain</b>               | 1. Doesn't want to be touched<br>2. |
| <b>Angry</b>              | 1. Shouts<br>2.                     |

**Leader:** If carer struggles to think of some behaviours you can prompt

- Loosing interest in family / hobbies
- Saying tactless / insensitive / uncharacteristic things
- Talking more / less / differently

Let's look at the problem behaviours on page 8.

Which of these most concern you?

Out of these, which one causes you the most stress?

If your relative does not have any problem behaviours you want to change, is there anything else about the situation that causes you stress?

## Behaviour record

During the next week, please use this to write down the things your relative does (or you do in when caring for your relative) that you would like to change.

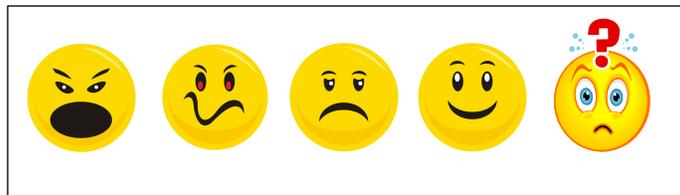
| <b>Date/<br/>Day of<br/>week</b> | <b>Time</b> | <b>Behaviour<br/>(what your relative does)</b> | <b>How did you feel when<br/>this happened?</b> |
|----------------------------------|-------------|--|---|
|                                  |             |  |   |

## Managing the Stress that Caregiving Brings

We will now turn our focus to family and what they feel. Some common reactions include feelings of:

*Sadness*  
*Anger*  
*Despair*  
*Ambivalence*  
*Fatigue*

*Confusion*  
*Grief*  
*Guilt*  
*Frustration*



Do these describe how you have felt recently?

Stress describes a physical, emotional or mental strain which often results from difficult circumstances, many carers experience this.

We want to consider skills for coping with the difficulties that arise when caring for someone with memory problems, in order for you to take better care of both of you.

## How stressed are you at the moment?

Caring for another person for a long period of time can be physically and emotionally draining. Over time, stress can impact on your health and well-being. Therefore, it is especially important for you to pay attention to your own physical and emotional health.

While the challenges cannot be avoided, you can take steps to manage them.





# Stress and your body

There are a number of possible consequences of stress.

## Physical Consequences of Stress

When a person is under stress, the body releases a stress hormone called cortisol. This explains why stress can cause symptoms such as sweating, breathlessness, nausea, and an increased heart rate.

## Other Consequences of Stress

When left untreated, chronic stress can cause problems such as:

|              |                     |
|--------------|---------------------|
| Depression   | Changes in appetite |
| Anxiety      | Sleep problems      |
| Anger        | Lack of energy      |
| Irritability | Hopelessness        |
| Helplessness |                     |

The psychological consequences of stress can take away your quality of life by lowering your ability to experience pleasure or a sense of accomplishment and can make it harder to care.

## Social changes

The responsibilities of caring for someone can make it difficult to keep up with friends and relations. Talking things over can relieve stress by giving people a chance to discuss their thoughts and feelings. It is common to feel that no one understands what you are going through.

**However, caring for someone with memory problems does not have to be a lonely experience.**

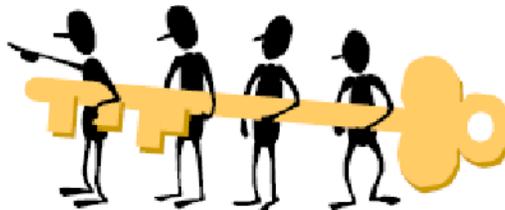
**Let friends and family members know when you need help, or maybe just a break.**

Caring is a very big job for a person. It can be particularly difficult if the person you are looking after is reluctant to accept help from anyone else. There are many local support groups, e.g. the Alzheimer's Society (for all carers of someone with memory problems) that can help you to meet others who have similar experiences. You probably find it difficult to have time for these kind of things, but it is important for your health and well-being.

Leader: Discuss with carer

- What social support do you have / find helpful?
- Have you thought about contacting the Alzheimer's Society?
- Would you ever consider it?

**Seeing your friends and relatives socially can help you to feel less stressed.**



## Techniques for reducing stress

To help you reduce stress and tension, **I am going to show you some short techniques over the coming weeks** that you can use. Our aim is not to say, “When you are stressed, just relax”. It is to help you gain control over stress, so you can concentrate your efforts on managing the stressful situation more effectively.

Of course, you may well have your own strategies for reducing stress that work for you already, such as listening to music, art or exercise. Our aim is to provide you with some new possibilities for reducing stress. As you try them out, you will come to find those that work best for you.

I will also ask you to practice them at home in stressful situations.



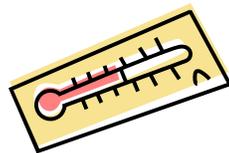
# Stress reduction technique: *The signal breath*

## Introduction

The Signal Breath is a simple stress reduction technique that can sometimes help you to cope better when stressful situations arise. It is useful because you can use it *anywhere*, at *any time*, and it is *quick*.

The Signal Breath is aimed at giving you immediate stress relief and is accomplished by creating a slight increase in tension in your body, by taking in a deep breath, and then letting go of the tension by breathing out. It also slows your breathing, which can become too fast when you are stressed. Slowing your breathing regulates the amount of oxygen and carbon dioxide in your blood. We will practice it in just a few moments.

## Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now, before we practice the Signal Breath. On a scale of 1 to 5, how would you rate your tension?

## Signal breath: Practice session

Script for Leader:

“The Signal Breath is very easy. It is a breathing technique that requires you to take in a deep breath.

When you will take this breath, you will need to tense your jaw, shoulders and arms... You will hold the breath for 2 to 3 seconds, then let the breath go and relax your jaw, shoulders and arms... As you exhale, you will mentally say a soothing word to yourself, such as ‘calm’ or ‘relax’...

Watch as I demonstrate....

Leader: Demonstrate a signal breath

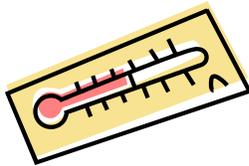
Okay, now you try... Take in a deep breath, tightening your shoulders and arms, hold it for a few seconds...

*[Pause for 2 or 3 seconds]*

Now, let it go and say the soothing word you have chosen to yourself... Allow your jaw, shoulders, and arms to go loose and limp...

Are you happy? Or, shall we try it again?”

## Tension rating after exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Now, please rate your tension or stress level from 1 to 5. How would you rate your tension level now, after practicing the Signal Breath?

1. Did your level of tension change?
  
2. What was this experience like for you?
  
3. Can you think of a specific event when you think this technique might have been helpful during a stressful caregiving situation?

Please, practise this at least once a day. You can do it 2-3 times at once, but don't do it more than this, or it could make you dizzy.

Leader: Encourage carers to practise the Signal Breath at least one time each day this week.

Establish if they can make use of a CD, for next week. If they cannot use CDs, would they prefer a tape or mp3?

## Summary

Today, we have talked about:

- **Memory loss**
- **How to define a behaviour and keep track of it**
- **Stress**
- **The relationship between stress and well-being**
- **The importance of taking care of oneself**
- **The Signal Breath**

## FOR NEXT WEEK

**It is important for you to practice what we have done.** I really would like you to use these techniques in your everyday life, so they become almost second nature, helping both yourself and your relative.

√ **The signal breath:** Try to practice this every day and to use it in stressful situations. See if it helps.

√ **Behaviour record:** Please use the record **on page 12** to write down the things your relative does that upsets you. Please, try to use it **every day**.

When do you think you might have the opportunity to do these?

What might get in the way?

# Session 2: Reasons For Behaviour

## Session Plan

1. Review Behaviour Record from Last Week
2. Purpose of Behaviour
3. The “Trigger-Behaviour-Reaction” Chain
4. Stress Reduction Technique: *Focused Breathing*
5. Summary



# Review Behaviour Record



Leader:

- Discuss their experience completing their first Behavioural Record. If they did not complete the record, ask them to think back on the week.
- Look at the Behavioural Record and read through it with them.
- Problem-solve any difficulties that might have occurred. For example:
  - “My relative did not have any behaviour problems this week.”
  - “There was no time to record in the log. I was too busy.”
  - “I didn’t understand what I was supposed to do.”
  - “There were too many problems, and I did not know what to record.”

Identify with them a recent problematical event and write it in.

- Encourage continued practice using the Behaviour Record

## Why Is The Behaviour Occurring?

All behaviours have a purpose. For someone with memory problems, there may be several reasons why a difficult behaviour occurs.

**Example:** Some people with memory problems have trouble understanding their feelings or expressing themselves. Your relative may not like being on their own or may phone you repeatedly to check when you are coming home. This may be because your relative is feeling lonely, bored or worried about something. If we want to stop these behaviours, first we have to understand why they are happening.

**All behaviours have a cause, it does not mean they are doing the behaviours on purpose.**

Behaviours can have many purposes, and these may change over time and from person to person. For people with memory problems there can be many causes for difficult behaviours, some common examples are:

- Forgetfulness
- No longer knowing what is socially acceptable
- Frustration
- No longer being able to entertain themselves
- Difficulty communicating distress

Trying to make sense of why your relative does something can be hard. We will think first how their surroundings may affect them.

## Understanding the Causes of Behaviour

Now let's look at the behaviour record again and try to answer these questions. Which behaviour would you like to focus on?

- Does the behaviour happen at the same time of the day?
  - If yes, what time is it?
  
  - What is usually happening at this time?
  
- Is your relative trying to communicate something (e.g. pain, thirst)?
  
- Is your relative frustrated, frightened or upset? (e.g. because they can't do something anymore or they do not know who someone is)
  
- Is your relative restless and trying to find something to do?
  
- Is your relative trying to get away from something you are asking her/him to do? (e.g. bathing, toileting, taking medications)
  - If yes, what activity is your relative trying to get away from?

## Ruling out Medical Problems

Before trying to change your relative's problem behaviours, it is important to make sure that his/her behaviour changes are not related to a medical problem. Some common medical problems that can affect behaviour include:

**1. Medical conditions** e.g. urinary tract infections (symptoms are burning pain on passing urine, urinating more frequently, cloudy or different smelling urine), constipation, pain or fever. MS multiple sites



**2. Medication side effects**



**3. Sensory impairments** e.g. hearing loss or poor vision.



It is important that these conditions, as well as others, be adequately diagnosed and treated by your doctor, as there may be underlying sources to your relative's behaviour problems.

**Important Note: Always contact your relative's doctor if there is any sudden change in their functioning.**

**Leader:** It is important that you *do not* try to solve medical problems for carers. You should encourage them to seek medical attention for their relatives immediately if there is any concern.

## The Trigger-Behaviour-Reaction Chain

The first step in identifying the cause of someone's behaviour is to pay attention to what happens before and after the behaviour.

**TRIGGERS** occur before the behaviour and can be any of the following:

- An event or activity, such as *noise* or a *demand* that is being placed on the person (e.g. bathing).



- General things that affect a person for a long period of time (e.g. time of day, season, and/or physical illness).



- Cues in the environment, such as keys to the car may remind someone of driving or the presence of another person.



**BEHAVIOUR** is what your relative does or what you do.

**REACTIONS** occur immediately after the behaviour.

- They include what you do, how you feel, what the person you care for does. In other words, what happens after the behaviour.

**Reactions are very important to pay attention to, because they may cause, affect or change the problem behaviour.**

It is helpful to think about the different phases of behaviour as a **Trigger-**

## Behaviour-Reaction Chain:



A person with memory problems has a lot of difficulty learning new information or judging a situation.

The only things you as a carer have control over are triggers and reactions. Occasionally, we can't change the triggers. During these times, changing how *you* react to the behaviour may improve the situation.

### Example:

When John goes to the shops with his brother Peter, it is often busy or loud. Peter finds this confusing, he becomes agitated and wants to go home. Although John may not be able to change the environment, he can reassure Peter and remain calm. As a result Peter is less distressed and able to continue shopping with John.

## RECORDING the Trigger-Behaviour-Reaction Chain

We are now going to take a few moments to record a Trigger - Behaviour - Reaction Chain.

**Example:**

Every morning at 8am, Jim gets the car keys from the key hook and tells his wife, Pat, "I am going out for a drive."  
 Pat reminds him that he no longer has a driving licence and is not allowed to drive. Jim responds by shouting "I don't know what you are talking about" and walks towards the car. Pat says, "Alright, let's go for a ride, but let me drive." Jim lets Pat drive. Pat is upset with herself because she gave in to Jim's behaviour.

| Date/<br>Day of<br>week | Time | Person<br>Present | Trigger   | Behaviour                            | Reaction   |
|-------------------------|------|-------------------|---|--------------------------------------|--|
| Every<br>morning        | 8am  | Pat<br>Jim        | Jim sees the car keys on the hook   | Jim shouts and walks towards the car | Pat feels upset and gives in to Jim's behaviour<br><br>Pat takes Jim for a drive |
|                         |      |                   | Pat reminds Jim that he no longer has a driving licence and is not allowed to drive |                                      |  |

**Leader:** Make sure that carer understands:

- Pat's reaction is reinforcing Jim's shouting and walking to the car as she is giving in to him when he does it
- Trigger is also important as not having keys on hook could solve problem

**Exercise:** Let's complete this Behaviour Record now, using the behaviour you identified earlier (see page 27). See the next page for helpful questions to refer to as you do this exercise.

| <b>Date/<br/>Day of<br/>week</b> | <b>Time</b> | <b>Person<br/>Present</b> | <b>Trigger</b> | <b>Behaviour</b> | <b>Reaction</b> |
|----------------------------------|-------------|---------------------------|----------------|------------------|-----------------|
|                                  |             |                           |                |                  |                 |

When completing the Behaviour Record, keep in mind the following questions:

To work out the **triggers**:

1. What time of day was it?
2. Was the environment quiet or noisy?
3. Was the environment dark or bright?
4. Was your relative alone or was someone present? If so, who?
5. Was a particular event occurring, such as bathing, administering medications, or providing other direct care?
6. Did your relative want something such as food, a beverage, or keys?
7. How stressed did your relative feel?
8. Did your relative appear to be seeking attention?

To work out the **reaction**:

9. Did you stop the event (e.g. bathing, administering medications, or providing other direct care)?
10. Did your relative gain access to an object s/he wanted (e.g. food, beverage, keys)?
11. Did your relative receive attention?
12. Did your level of stress increase or decrease?

We will now discuss the different ways we can change behaviours. These include the following:

Changing the *trigger*

Changing our *reactions*

Changing the *trigger and our reactions*

We will begin with an example:

**Example 1: Betty**

**Problem behaviour: Wandering at night**

It is three o'clock in the morning and Betty wakes up and begins to walk around the house. Jane, her daughter, is sleeping. Betty paces throughout the house and wakes Jane up. Jane is upset, because she has a long day at work tomorrow. Jane says, "Mum, you need to go back to bed, it is 3 am." Betty says, "I am not sleepy." Jane shouts, "I can't take this anymore." Betty starts to cry.

| <u>Trigger</u>   | <u>Behaviour</u>       | <u>Reaction</u>  |
|--|------------------------|--|
| Betty wakes up at 3 am.<br>Jane is sleeping.<br>Betty does not want to go to bed; she is not sleepy. | Betty wanders at 3 am. | Jane tells her Mum to go to sleep.<br>Jane shouts.<br>Betty cries. |

**If Jane wants to keep her Mum from wandering at 3 am, what can she do?**

**1. Change the T (*trigger*) to prevent the wandering from occurring:**

\* Make an appointment with Betty's doctor to find out if there is a medical reason for her trouble sleeping (e.g. urinary tract infection, pain).

***If there is no medical problem, then. . .***

\* Plan some activities to keep Betty awake during the day. Don't let her nap!

\* Encourage Betty to exercise during the day (e.g., walking, stretching).

\* Develop a bedtime routine that takes place at the same time every night.

\* Do not allow Betty to have caffeine after lunch.

\* As a LAST RESORT, talk to Betty's doctor, and ask her if there is anything Betty can take to improve her sleep.

**2. Change the R (*reaction*) to prevent the behaviour from occurring again:**

\* Gently remind Betty that it is dark outside and time to go to sleep; lead her back to bed; play soothing music or do something else that will help Betty to relax.

\* Jane could remind herself to approach the situation calmly and focus on the goal of the task (getting Betty back to sleep). This way, she will use her energy in a positive manner to problem-solve the situation, rather than reacting emotionally.

**Leader:**

- Remind carer this is how we will be developing strategies for them next session

***Example 2: Joe***

**Problem behaviour: Asking the same question repeatedly**

After breakfast, Joe asks his wife, Sandy, "What are you doing?" Sandy says, "I am cleaning up." Five minutes later, Joe asks Sandy, "What are you doing?" Sandy says, "Washing the dishes." Five minutes later, Joe asks, "What are you doing?" Sandy begins to get annoyed and says, "I just told you, I am doing the dishes. Stop asking me the same question." Five minutes later Joe asks, "What are you doing?" Sandy is frustrated and feels helpless.

Using Joe's example, let's complete the following log and questions together:

First, identify the:     **T**rigger            **B**ehaviour            **R**eaction

What could be the purpose of Joe's behaviour?

If Sandy wants to prevent the behaviour from occurring, what are some strategies she can use to prevent Joe's behaviour from being triggered?

How might Sandy react differently?

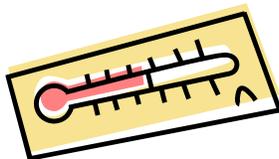
## Stress Reduction Technique: *Focused Breathing*

**Leader:** Ask if they managed to try last weeks exercise, *the Signal Breath*. Ask what their experience was like. Discuss barriers that may have prevented practice. Praise all attempts.

Focused Breathing can be beneficial to carers for a number of reasons:

- It can be used to bring about a state of deep relaxation and ease the tension and stress that can be brought on by caring.
- It can help you learn to briefly focus your attention on something else, other than caring, allowing you time to focus on just you.
- Most importantly, through learning how to relax and take time for yourself, it will be easier to provide quality of care for the person you care for.

### Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now before we practice the Focused Breathing. On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

I am going to talk you through the Focused Breathing exercise now.

## Focused Breathing: Practice Session

### Script for Leader:

“You should begin this exercise by getting yourself into a comfortable position in your chair... Just settle back, and let the chair completely support your body...

Feel yourself sinking into the chair, allowing all of your muscles to go loose and floppy...

Now, take in a deep, signal breath, filling your lungs with air... holding it in until you notice a little tension building in your chest and then let the air out slowly, relaxing as you do...

Close your eyes and take in another breath, holding the air in until you feel the tension, and then relax, let go completely...

Now, let your breathing return to a normal and natural rhythm...

Start to focus your mind on your breathing... Become very aware of your breathing. Pay close and careful attention to each and every breath... Just watch it... Observe it...

Simply become aware of how easily and naturally your body breathes by itself, free and easy, in and out...

At all times your body is breathing by itself, you don't even have to think about it, your body breathes automatically, at all times, whether you are sound asleep or wide awake, aware or unaware... as long as you are alive, you are constantly breathing...

And all you have to do right now is to simply become aware of this process, this process of your body breathing by itself...

Notice the steady rhythm... the air coming in and going out again...

*[Pause]*

Allow your breathing to be natural and free... without trying to change and without trying to interfere... If your breathing is slow, let it be slow... If it is deep, let it be deep... If your breathing is shallow, let it be shallow... Just watch your body breathing by itself...

Be aware of the cool air coming in through your nostrils... and then the warm air flowing out...

Notice the slight pause between each inhalation and each exhalation...

Notice your chest as it ever so slightly rises and falls with each automatic breath... as your lungs expand when the air flows in and then contracts when the air flows out...

You may also notice your abdomen rising... and falling... each time you breathe in and breathe out... Experience the natural tides of your breath, the ebb... and the flow, as the air comes in... and flows out again...

If your mind should wander or your attention is pulled somewhere else, simply catch yourself and refocus on your breathing... refocusing again and again if necessary... Do your best to keep your mind focused on your breathing... Just watching and observing...

Nothing to change, nothing to hold onto, nothing to do... just awareness... watching... observing... and allowing your body to breathe free and easy... natural and automatic...

*[Longer pause]*

And now, as you continue to observe your body breathing by itself, you can begin to add a simple mental suggestion, a suggestion aimed at helping you experience even more relaxation and comfort...

Right now, as you focus your mind on your breathing, you can begin to imagine that each time you breathe out, each time you exhale, you are letting go of unnecessary tension, letting go of negative thoughts or worries, letting go of more and more discomfort... Just let it all go...

Allow yourself to breathe in fresh, positive, and healthy thoughts and feelings... Breathe in the good... Breathe out the bad... And so with each complete breath cycle, you can allow and experience both your body and mind becoming more comfortable, more relaxed, and more at ease...

Enjoy the natural mental and physical cleansing that your breathing can bring you, letting it carry you into a deeper and deeper state of relaxation and comfort...

Enjoy the mental tranquility and the peacefulness that this breathing can bring to you...

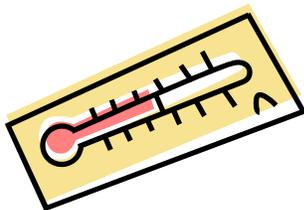
*[Longer pause]*

In a moment, you are going to open your eyes and return to a more normal, alert, and wide-awake state...

*[Pause]*

Ok, I would like you to take in a nice, deep, refreshing, and energising breath, stretch comfortably and open your eyes, to end this relaxation...”

## Tension Rating After Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Now, please rate your tension or stress level from 1 to 5. How would you rate your tension level now after practicing the Focused Breathing exercise \_\_\_\_\_ ?

1. How are you feeling now?
2. Did your level of tension change?
3. What was this experience like for you?
4. Can you think of a specific event when you think this technique might have been helpful during a stressful caring situation?

**Leader:** Encourage carers to practice the Focused Breathing at least one time each day this week. Check that they have been able to make use of the CD and if so give them this week's. If they cannot use CD, would they prefer a tape?

## Summary

Today we have talked about;

- The purpose of behaviour
- Ruling out medical problems
- Trigger-Behaviour-Reaction Chain
- Stress reduction technique: *Focused Breathing*



## FOR NEXT WEEK

√ **Focused Breathing:** Before next week try and do this stress reduction exercise.

√ **Behaviour Record:** Complete this record, on the next page, when your relative's target behaviour occurs. We understand it may be difficult to complete the record each time the behaviour occurs, but please complete it as frequently as possible.

## Behaviour Record

Please use this log to write down the things your relative does (or that you do) that upset you.

| Date/<br>Day of<br>week | Time | Person<br>Present | Trigger | Behaviour | Reaction |
|-------------------------|------|-------------------|---------|-----------|----------|
|                         |      |                   |         |           |          |



# Session 3: Making a Behaviour Plan

## Session Plan

1. Review Behaviour Record from Last Week
2. Behavioural Strategies
3. Changing Behaviours by Changing Reactions
4. Stress Reduction Technique: *Physical Grounding*
5. Summary



## Review Behaviour Record

Leader:

Review the behaviour record from last week. Look at each trigger, behaviour and reaction in turn and allow carer to discuss and reflect on what happened.

Could they have avoided the trigger or changed the reaction to prevent the behaviour (or encourage a helpful behaviour?)

## Developing Behavioural Strategies

Now that you have recorded triggers and reactions, we will discuss how we want the behaviour to change.

There are three different things that can happen:

1. The behaviour can increase.
2. The behaviour can be maintained (no change).
3. The behaviour can decrease.



### Identifying a behaviour you would like to change

Your relative's behaviour (or your behaviour) has probably been going on for a while. It would be unrealistic for us to think we can change it right away. So, we want to start out small and we want to be as specific as possible. Remember to set a realistic goal or you may set yourself up to fail.

On the next page are some examples of behaviours some people want to change:

**Examples:**

If Mrs. Smith refuses to eat lunch, a possible strategy would be: *Mrs. Smith will eat a small plate of food you know she likes for lunch at least 3 times per week.*

If Mr. Johnson follows you around every afternoon, a possible strategy would be:

*Mr. Johnson will engage in an activity for 20 minutes between 4 and 5 pm without following you around at least 3 times this week.*

## Individual Plan to Change Behaviour

**Using Mr. Johnson's example:**

*The behaviour that I want to change is:*

**Following you around**

*Do I want to increase or decrease it?*

**Decrease**



*What is the strategy for a new behaviour?*

**You or family member will listen to music with Mr. Johnson for 20 minutes between 4 and 5 pm without him following you around**

*What is the goal for the frequency of this new behaviour?*

**At least 3 times this week**

Leader:

Make sure that carer understands that it is what they do that will change the behaviour

**YOUR TURN:**

Please turn to the Behaviour Record you completed at home and pick the behaviour you want to focus on changing:

The behaviour that I want to change is:

Do I want to increase or decrease it?

What is the strategy?

## Let's think about Triggers and Reactions

Could the problem behaviour be related to your relative's health?



Could the problem behaviour be related to triggers in the environment?



Could the problem behaviour be related to your reaction?



We will now develop a list of *strategies* that you can use to *prevent* the behaviour from occurring or to help you respond differently. Be creative, and write down at least two.

- 1.
- 2.
- 3.
- 4.

Which one do you think you might try first? Write it down in the space below.

- **Try to use this strategy and complete the behaviour log to find out if the behaviour has changed.** You may feel that you can “mentally” keep track of whether the behaviour has changed, but we would like you to keep the record. The reason for this is that it is helpful to write the information down.
- **It might feel hard to stick with a strategy when there are so many things to think about.** Regardless of which behaviour and strategies you choose, remember to try to be consistent and use the strategy every time even if you do not achieve your desired behaviour change each time.
- **Problem-solving is a process of trial and error. There is no right or wrong answers.** Once this problem is solved, another one may develop. It’s possible that the strategy that you came up with may work at some times and not others. Be flexible, patient and creative!

## Behaviour Record

Please use this Behaviour Record to write down something your relative does (or that you do) that upset you and the strategy you used to change it.

| Date and time | People Present | Trigger | Behaviour | Reaction | The strategy you used to change the behaviour was:       |
|---------------|----------------|---------|-----------|----------|--|
|               |                |         |           |          |  |
|               |                |         |           |          | <b>What happened when you tried using this strategy?</b> |
|               |                |         |           |          |  |

# Changing Behaviours by Changing Reactions

There are various ways we can react to behaviours:

## A. Encourage desired behaviour

In our daily lives it is normal to pay more attention to negative events than positive ones. Therefore you may find yourself focusing on your relative's difficult behaviours. However, if you are thinking about your relative's behaviour it is important to notice when things are going well and to encourage them.

For example, if your relative has been refusing to eat lunch everyday, but on Monday s/he does, then encourage your relative by giving her/him something positive. A positive reaction would be:

- Giving her/him something s/he likes: attention, a smile, or something else they like
- Saying something positive, praising
- Doing something kind, assisting, comforting, hugging.

You can consider this as "rewarding".

### **Guidelines for rewarding desired behaviour**

1. Give a reward immediately after the desired behaviour.
2. Give a reward every time the desired behaviour occurs.
3. Make sure the reward is personal and meaningful to your relative.
4. Do not give a reward unless the desired behaviour occurs.

## **B. Do not reward problem behaviours**

When your relative's problem behaviour occurs, it is important not reward the behaviour. It is easy to make this mistake without meaning to. One example is providing attention when they don't eat lunch. The reason to avoid giving attention when they don't eat lunch is so they don't learn a link between refusing to eat and attention. Otherwise the most likely result will be that they do it again.

The best option is to not reward the problem behaviour.

- Ignore the problem behaviour, or
- Draw attention away from the upsetting situation.

It is not always easy to ignore problem behaviours – it can feel unfair or unkind, but you are doing this as part of a strategy to help.

**Let's look back at your behaviour record from last week**

A. Did you reward the problem behaviour?    **Yes**            **No**

B. If so, how did you reward it?

**Can you think of a time during the last week when the problem behaviour did not happen or you noticed a more desired behaviour?**

C. Did you reward the desired behaviour?    **Yes**            **No**

D. If so, how did you reward the desired behaviour?

# Stress Reduction Technique: *Physical Grounding*

Leader: Ask if they managed to try last weeks exercise, *Focused Breathing*. Ask what their experience was like. Discuss barriers that may have prevented practice. Praise all attempts.



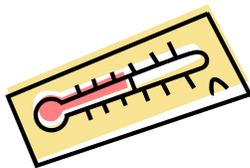
## Introduction

Grounding can also be called “distraction.”

This technique is particularly powerful, because it can be used whenever you are caught in a stressful situation, and can be done anytime, anywhere, by yourself, without anyone else noticing it. With practice, it can help you control your reaction to stressful situations that can arise during caring. Even though this technique is simple, it is very important to practice it to get the maximum benefit.

It is important to note that grounding is not a relaxation exercise. It is an active strategy that works through distraction and connection with the world around you. Keep your eyes open, as you are being taught to notice everything about the world in front of you and about the present.

## Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now before we practice Physical Grounding. On a scale of 1 to 5, how would you rate your tension?

## Physical Grounding: Practice Session

### Script for Leader:

“First, I want you to get into a comfortable position in your chair with your feet flat on the floor and your hands resting by your side. You should keep your eyes open during this exercise and look around the room if you want.

I will ask you some simple questions, which I would like you to answer silently to yourself. If you notice distracting feelings during this physical grounding technique, I want you to let the distractions go, like leaves in an autumn breeze. Turn away from them, focusing your attention on the world around you. Remember that you are always in control. And, try not to judge anything – just notice what there ‘is’.

*[Pause for about 10 seconds].*

Remind yourself that you are safe, and at home.

*[Pause].*

Now, we’ll try to imagine putting a buffer between you and all of your uncomfortable thoughts and feelings; feelings that could lead to stress and tension. Imagine that your uncomfortable feelings are bundled up and put in a box.

*[Pause for about 10 seconds].*

Next, visualise something between you and the uncomfortable feelings stored in this box: perhaps a wall, a large lake, or a big open field in the country, anything that creates safe distance between you and your uncomfortable feelings.

*[Pause for about 10 seconds].*

Now we are going to try physical grounding. Please keep following along with me. Notice your feet on the floor. They are literally grounded, connected to the floor.

*[Pause for 10 seconds].*

Wiggle your toes. Dig your heels gently into the floor to ground yourself even more.

Now, touch your chair. Say everything you can about it silently to yourself. Concentrate on its physical properties.

*[Pause for 30 seconds, with prompts: What is it made of? Is it cold, or warm? What colour is it?]*

Now touch a different piece of furniture. What is it made of? Is it colder or warmer than the chair?

Now, find any object that is near you – perhaps a pen, or your keys, or anything else on the table or desk. Pick it up and hold it, and say everything you can about it.

*[Pause for 30 seconds, with prompts: What is it made of? How heavy is it? Is it cold, or is it warm? What colour is it?]*

Just experience it for a moment.

*[Pause for 15 seconds].*

Now put it down.

Now, slightly clench your fists; notice the tension in your hands as you do that.

*[Pause for 20 seconds].*

Now, release your fists. Notice the difference.

*[Pause for about 7 seconds].*

Now press your palms together, with elbows to the side; press as tightly as you can. Focus all of your attention on your palms.

*[Pause for 7 seconds].*

Now, let go. Grab onto your chair as tightly as you can.

*[Pause for 15 seconds].*

Now let go. Notice the difference.

Then, gently turn your head to the left.

*[Pause for 5 seconds].*

Now turn it to the right.

*[Pause for 5 seconds].*

Bring your head back to the centre and gently drop your chin to your chest, as far as you can.

*[Pause for 5 seconds].*

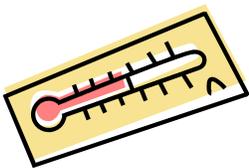
Take a deep breath.

*[Pause].*

Breathe Out.

Finally, bring your head up to your normal position, to bring this session to a close”

### **Tension Rating After Exercise**



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Now, please rate your tension or stress level from 1 to 5. How would you rate your tension level now after practicing the Physical Grounding exercise \_\_\_\_\_ ?

1. Did your level of tension change?
2. What was this experience like for you?
3. Can you think of a specific event when you think this technique might have been helpful during a stressful caregiving situation?

**Leader:** Encourage carers to practice the Physical Grounding at least once a day this week.

## Summary

Today we have looked at:

- Identifying a problem behaviour that you want to change
- Developing a plan to try and do this
- Rewarding desired behaviour and not rewarding problem behaviour
- Stress reduction technique: *Physical Grounding*



## FOR NEXT WEEK

✓ **Behaviour Record:** Please fill in the new Behaviour Record (**on the next page**) including your strategy for behaviour change.

✓ **Physical Grounding:** Before next week, try and do this stress reduction exercise.

## Behaviour Record

Please use this Behavioural Record to write something your relative does (or that you do) that upset you and the strategy you used to change it.

| Date and time | People Present | Trigger | Behaviour | Reaction | The strategy you used to change the behaviour was:       |
|---------------|----------------|---------|-----------|----------|--|
|               |                |         |           |          |  |
|               |                |         |           |          | <b>What happened when you tried using this strategy?</b> |
|               |                |         |           |          |  |



# Session 4: Behaviour Strategies and Unhelpful Thoughts

## Session Plan

1. Review Behaviour Record from Last Week
2. Choosing a New Behaviour and Reviewing the Steps to Changing Behaviour
3. Changing Unhelpful Thoughts
4. Stress Reduction Technique: *Guided Imagery – Meadow and Stream*
5. Summary



## Refining Behavioural Strategies

Please review the Behaviour Record you completed last week and fill in the following information.

The strategy I developed last week to prevent the problem behaviour from occurring is:

Did you use the strategy?            Yes                            No

If **no**, why did you not use it?

If **yes**, was it effective? Why or why not?

## Choosing a New Behaviour

We identified one problem behaviour in session 3 that you wanted to focus on first. However, **there are likely to be other behaviours that your relative is doing that are causing you stress that can be changed.**

If there is a new behaviour you would like to change in the person you care for or yourself, then we will help you develop a new behaviour plan.

**If your relative does not have any other behaviours that you would like to change, then choose something about yourself to change.** We will follow the same steps as last session.

### Step one: Choose the behaviour to focus on

The new behaviour that I want to change is:

Do I want to increase or decrease it?



## **Step two: What are the triggers and reactions?**

In order to answer this question, you can keep track of the behaviour for next week by using the behaviour record.

However, you may be aware of some of these already.

Possible triggers:

Possible reactions:

Thinking about these, what possible strategies can you use to decrease the problem behaviour?

## Changing Unhelpful Thoughts

Looking after someone with dementia may make you feel overwhelmed and stressed. When anyone feels like this, it can be helpful to pay attention to our thoughts. In general, our feelings are linked to our thoughts. **The way you think about something directly affects the way you feel about it.** These thoughts may be unhelpful and make you feel worse.

The first step to changing this cycle is to **stop** and **focus**. When you are in a stressful situation, take a moment to think about the thoughts and feelings you are having.

To help you better understand the relationship between thoughts and feelings, let's review the following example:

### Lydia and David

Lydia is providing care for her husband David, who has Alzheimer's disease. Although David can still take care of some of his own basic needs, he can't follow any of Lydia's instructions.

In this situation, Lydia's thoughts are:

*"David refuses to listen to me, even though he is able to. He is purposely not following my suggestions."*

Lydia then feels frustrated and sad.

What strikes you about this example?

**Learning how to change the unhelpful thoughts people have in stressful situations can help reduce frustration and sadness.**

## What am I thinking?

There are three steps to changing your unhelpful thoughts:

- *Stop and identify your current thoughts.*
- *Challenge and replace your unhelpful thoughts with more helpful ones.*
- *Pay attention to how you feel now.*

We will start by focusing on step one, which is to stop and identify the thoughts that are contributing to your unpleasant feelings. This process often happens so quickly that you are unaware that you have thoughts that occur between a stressful event and your unpleasant feelings.

The way to stop and identify your thoughts is by keeping track of what you are thinking in a stressful situation. To do this we will use a **Thought Record**.



## Thought Record

The Thought Record has **three** columns for the following information:

- a.) the stressful situation
- b.) the thoughts you had in connection with this
- c.) the feelings that you experienced in the situation

Recording the situation, your current thoughts and feelings may help you find new ways to cope with the stress.

Lydia is providing care for her husband David, who has Alzheimer's disease.

The Thought Record can be filled in as below.

Although David can still take care of some of his own basic needs, he can't follow any of Lydia's directions.

### Lydia's Thought Record

| Situation                             | Current Thoughts   | Feelings          |
|---------------------------------------|--|-------------------|
| David is not following my directions. | 1. David refuses to listen to me, even though he is able to.<br><br>2. He is purposely not following my suggestions. | Frustrated<br>Sad |

We will now try to practice this, thinking about things which have happened to you. It is natural to find it difficult when someone you care for has dementia and lots of things are outside your control, but there are some things that you can control and improve.

Think about this past week and tell me about a difficult or stressful situation where you felt that you would have liked to react differently. Try to complete a Thought Record using your own example.

### Your Thought Record

| <b>Situation</b>   | <b>Current thoughts</b>         | <b>Feelings</b>                                    |
|--|---------------------------------|--|
| Describe the events that led to your unpleasant feelings | What did you think at the time? | What were you feeling? (sad, angry, anxious, etc.) |
|  |                                 |  |

Leader: Did you think about (the person, the action, yourself). Other useful prompts for identifying thoughts and emotions: “Can you tell me a bit more?” “Anything else?”; also saying – “Can I see if I’ve got this right?” Then summarising what you understand they have said back to them.

We are now going to add two more columns to the Thought Record.

The additional steps we are adding are:

- 4.) **Challenge and replace** unhelpful thoughts with more helpful thoughts
- 5.) Describe any change of **feelings** you have as a result

**This is the five column Thought Record.**

| <b>Situation</b> | <b>Current thoughts</b> | <b>Feelings</b> | <b>Challenge and replace with more helpful thoughts</b> | <b>New feelings</b> |
|------------------|-------------------------|-----------------|---|---------------------|
|                  |                         |                 |   |                     |

Challenging and replacing your thoughts can be difficult at first, but with practice you may find **it useful**. There are common patterns of thinking called “automatic thought patterns”. To change these, there are some techniques.

Some require you to perform actual behaviours in challenging your thoughts and others ask you to analyse the thoughts from a different perspective.

1. Look at it from someone else’s point of view.
2. Ask other people what they think or get more information.
3. Change how you talk to yourself.
4. Try not to jump to conclusions.

*Consider the following example while going through the list below.*



MS

Alice is a 64 year old woman caring for her 90 year old mother. She believes that she is not a dependable carer. She feels guilty when she wants to visit her friends. Alice thinks, "I should always stay with my mother because something bad will happen to her when I leave. Other people can't take care of her the way I do. If something happens I will never forgive myself for not being a good daughter."

**Look at it from a different point of view:** Talk to yourself as if someone who cares about you is talking to you.

In our example, as Alice blames herself for wanting to spend time away from home, she could ask herself: "How would my close friend Marie view this - and what would she have to say about my situation?" Alice could also imagine what her friend (who cares about her) would think about her leaving her mother for short periods.

### **Discussion**

1. What do you think Alice's friend Marie would say?
2. If your friend was here what would they say to you?
3. What if your friend was in your situation, what would you say to them?

**Take action/ Ask others:**

Some carers find it helpful to get additional information to challenge their unhelpful thoughts.

Alice could challenge her thoughts about “not being a dependable carer” by talking to other carers about how they handle similar situations.

Alice could also plan to leave her mother with someone she trusts for a short period, to test out her concerns that her mother will have a crisis when she is gone.

**Discussion**

1. Have you ever talked to other carers? Is this something you have considered?
2. What do you believe you need to do, to be a dependable carer?
3. Do you have any concerns? What could you do to test out your concerns?

### **Change how you talk to yourself:**

We often create negative labels for others or ourselves without realising what we are doing, for example thinking “If I can’t be there all the time, I am not a good enough carer, I am not giving what my relative deserves”.

We also may believe that we must behave, think, or feel a certain way. This might often include us saying things to ourselves like “I must/ I should do ...”. Allowing yourself to think “It’s OK not to be perfect” and “It’s also important I look after myself” can help you see the situation from a different point of view.

If Alice tried to think about what her label of "Not being a dependable carer" really meant, she would see that she was expecting the impossible and this expectation would set herself up to fail.

She could also change, "I should always stay with mother" to, "My mother likes me being there, but she could enjoy being with others too, and it would be good for both of us if I get a break and feel a bit better".

### **Discussion**

1. Do you ever have these kinds of thoughts?
2. How else could you think about your situation? Is there any other way you could think about your situation?

## Try not to think of things as all or nothing:

Remind yourself to think of different options. Don't assume that if you can't do something perfectly; it is not worth doing at all.

Could Alice consider other alternatives to never going out? Must she think of herself as either a dependable carer **OR** *not* a dependable carer?

It's important Alice recognises all the good things she is doing and how much she is coping with.

## Discussion

1. Do you ever have these kinds of thoughts?
2. Tell me some of the positives about caring for your relative

**PRACTISING THE THOUGHT RECORD** Let's use the 5-column Thought Record to expand the example that you thought of earlier, or, if you prefer, choose a new example.

| <b>Situation</b>   | <b>Current thoughts</b>                 | <b>Feelings</b>                                   | <b>Challenge and replace with more helpful thoughts</b>     | <b>New feelings</b>                                   |
|--|---|---|---|---|
| Describe the events that led to your unpleasant feelings | Identify your thoughts in the situation | What are you feeling? (sad, angry, anxious, etc.) | What is a more helpful way of thinking about the situation? | What are you feeling now? (sad, angry, anxious, etc.) |
|  |   |   |   |   |

## Stress Reduction Technique: *Guided Imagery - Meadow and Stream*

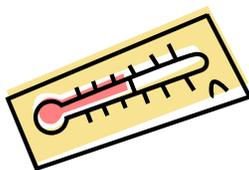


Leader: Ask if they managed to try last week's exercise, *Physical Grounding*. Ask what their experience was like. Discuss barriers that may have prevented practice. Praise all attempts.

### Introduction

Guided Imagery is a stress reduction technique that allows one to have a “time out” from daily concerns. It should be done in a quiet setting where you will not be disturbed. Some carers find that this type of exercise works best when they do it right before they go to bed in the evening, when all is quiet around them. Practice is important in order to maximize your benefits from this exercise.

### Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now, before we practice the Guided Imagery exercise. On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

## Guided Imagery: Practice Session

### Script for Leader:

“This is a guided relaxation imagery exercise. First of all, get yourself into a comfortable position. Just settle back into your chair.

Close your eyes and take in a deep signal breath, holding the breath for a few moments, and then let it out slowly, feeling relaxation as you do so.

And now take in another deep breath... hold it ... until you feel a little tension in your chest and then let go... relax... allow all the muscles in your body to become loose, limp, soft like a rag doll;

Just allow pleasant waves of relaxation to flow through you, soothing and relaxing each and every part of your body... including your arms and hands... your neck and shoulders... your scalp and all the muscles in your face...

And as you rest there quietly, breathing freely and evenly, allow the muscles of your chest to become loose and relaxed... and then your stomach and your back... both your upper back and lower back... your hips and legs... allow the relaxation to flow through your legs all the way down your feet and ankles...

And as I continue talking to you, these waves of relaxation can continue to spread throughout your body... penetrating deeply into every cell... but no matter how relaxed you feel right now, it is possible to become even more deeply relaxed and yet awake and aware of my voice.”

“Now, ... even though your attention may wander from time to time, simply bring it back to the images that I am going to describe.

Imagine yourself about to open a very large door...

and as the door opens, you find yourself transported to another place.  
You step out into a grassy meadow ...a peaceful, quiet meadow.

And flowing through the meadow is a small winding stream,

and on each side of the stream are tall, shady trees...

Now picture yourself, right now, sitting down... along the bank of this stream.

You sit and rest against the trunk of one of the trees...

notice the pale blue sky and the ... white clouds,....feel the warmth of the sun  
with pleasant rays shining down, ... sparkling as it reflects on the flowing water...  
it is a beautiful, ..... pleasant,... peaceful day,....not too warm or too cold... the  
air is fresh and clean and you are aware of sounds of birds chirping...of the  
sound of the water, as it flows along the stream...

It is so peaceful here... so calm and tranquil... just look around you... taking it all  
in... enjoy the simple beauty of this place..."

*[Long pause]*

"And now look more closely at the stream... notice the clear, cool water as it  
flows by... wondering where the water comes from and where it goes..."

Then, as you look upstream you notice a very large leaf, floating on the water,

and your eyes observe this leaf as it is getting closer, closer and closer to the  
place where you are sitting...

and then, the leaf is in front of you...

Now you find yourself transferring to this leaf all of your concerns, and all of your discomfort ...

All of your cares, all of your worries are transferred to the leaf.

...and so the leaf continues, floating down the stream, floating away,....  
The leaf carries away all of your discomfort,... all of your cares and worries...

just watch it float along... Watch it getting further, and further away from you...

until it finally disappears completely and you are left feeling even more relaxed, more comfortable, and more at ease than you have felt for a long time..."

*[Longer pause]*

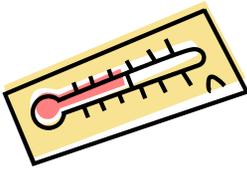
"For in this state of deep relaxation all parts of your body are working together harmoniously, smoothly, and healthily...

a deep sense of well-being fills your mind... a feeling of healthy energy and vitality fills your body...

and as you prepare to eventually leave this special place of relaxation, you can carry back with you many of these pleasant feelings and sensations, knowing that as you practice this exercise and similar exercises, it will become easier... to use the powers of your mind...to experience these positive effects..."

"And now I will bring you back slowly from this relaxation by counting backwards from 3 to 1. When I get to 1, you will be alert, refreshed, and comfortable. Okay: "3," much more alert; "2," feeling refreshed and comfortable; and "1," as you open your eyes and return your awareness to the room you are in."

## Tension Rating After Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Now, please rate your tension or stress level from 1 to 5. How would you rate your tension level now, after practicing the Guided Imagery exercise? \_\_\_\_\_

1. Did \_\_\_\_\_ your level of tension change?
2. What was this experience like for you?
3. Do you think that the person you care for might like to try listening \_\_\_\_\_ to a tape of this exercise with you?

**Leader:** Encourage carers to practice the Guided Imagery at least one time each day this week.

## Summary

Today we looked at:

- Choosing a new behaviour to change and revising the steps that need to be followed when developing a new plan
- How unhelpful thoughts contribute to how we feel
- How to identify automatic thoughts and complete a record of unhelpful thoughts
- Strategies for challenging these thoughts and trying to change them
- Stress reduction technique: *Guided Imagery – Meadow and Stream*



### FOR NEXT WEEK:

√ **Thought Record:** Please complete this (**on the next page**).

√ **Behaviour Record:** You may also like to complete the behaviour record (**on page 79**).

√ **Stress Reduction:** Please try to practice one of the stress reduction exercises.

## Thought Record

| <b>Situation</b><br>Describe the events that led to your unpleasant feelings | <b>Current thoughts</b><br>Identify your thoughts in the situation | <b>Feelings</b><br>What are you feeling? (sad, angry, anxious, etc.) | <b>Challenge and replace with more helpful thoughts</b><br>What is a more helpful way of thinking about the situation? | <b>New feelings</b><br>What are you feeling now? (sad, angry, anxious, etc.) |
|--|--|--|--|--|
|  |  |  |  |  |
|  |  |  |  |  |

## Optional Exercise: Behaviour Record

Please use this Behavioural Record to write down something your relative does (or that you do) that upsets you and the strategy you used to change it.

| <b>Date and time</b> | <b>People Present</b> | <b>Trigger</b> | <b>Behaviour</b> | <b>Reaction</b> | <b>The strategy you used to change the behaviour was:</b> |
|----------------------|-----------------------|----------------|------------------|-----------------|---|
|                      |                       |                |                  |                 |   |
|                      |                       |                |                  |                 | <b>What happened when you tried using this strategy?</b>  |
|                      |                       |                |                  |                 |   |

# Session 5: Communication Styles

## Session Plan

1. Review Thought Record and Behaviour Record, if completed
2. How to Express Yourself Effectively
3. Practicing Assertiveness Skills
4. Communicating with Someone with Memory Problems
5. Stress Reduction Technique: *Meditation*
6. Summary



# Review

Leader

## **Behaviour Record**

Review the Behaviour Record completed last week. Ask if they used the strategy?

If **no**, why not?

If **yes**, was it effective?

Why or why not?

## **Thought Record**

Did they have any trouble filling out the Thought Record? Was it helpful?

Why or why not?

If there is a problem, spend some time thinking about a solution.

# How to Express Yourself Effectively

We all communicate in different ways. We are going to talk about three styles of communicating today: We will call these passive, aggressive and assertive. Most people use these different styles at different times or in different situations.

## Passive Communication

### **EXAMPLE: Passive Communication**

Sylvia takes care of her husband, who has memory problems. She has arranged for her husband to stay with her brother, Daniel, while she attends a weekly exercise class. An hour before the class, Daniel calls to say that he has changed his mind and doesn't want to take care of her husband after all. Sylvia responds by saying, "That's okay, I really didn't need to go after all."

### **Discussion**

How might you feel after this kind of experience?



### **Passive Communication**

- Can involve communicating thoughts and feelings indirectly and apologetically, allowing others to easily disregard them
- Can involve reluctance to express difficult feelings openly
- Puts other peoples needs above your own
- Seeks to please others and to avoid conflict at any cost
- Sends the following message:

*"I don't count. My feelings don't matter; only yours do. I'm not important."*

## Aggressive Communication

### EXAMPLE: Aggressive Communication

Sylvia responds to Daniel's decision not to take care of her husband by saying, "I'm sick and tired of you not thinking of me. You promised to take care of him, and I'm going to hold you to that promise whether you like it or not! I'm not interested in hearing any excuses!"

### Discussion

How might Daniel react?  
How might you feel after this kind of experience?  
What might be the effect?



### Aggressive Communication

- Can involve standing up for personal rights and expressing thoughts in an unhelpful way (e.g., becoming angry, verbally attacking)
- Can ignore other people's points of view
- Seeks to force the other person to agree with you
- Sends out the following message:

*"This is what I think; you're wrong to think differently. This is what I want; what you want doesn't matter. This is what I feel; I don't care about your feelings."*

## Assertive Communication

### EXAMPLE: Assertive Communication

Sylvia responds to Daniel's statement that he doesn't want to take care of her husband by saying, "It's important that I get a break. I know you're busy, but can you find time to give me a break even if its not today."

### Discussion

How might the effects of this interaction be different from the previous examples?

### Assertive Communication

- Can involve expressing your own opinions while respecting the views of others
- Can involve expressing your thoughts directly and honestly
- Can increase the chance that your requests are understood, and that you will have a better result
- Leads to problem solving and negotiation
- Communicates the following message:

*"This is what I think. This is what I feel. This is how I see the situation. Your thoughts and feelings are also important."*



**Leader:** Ask carer "Which do you think is the most useful method of communication?"

## How do you communicate?

1. How do you think you communicate with doctors, health care workers or with other service professionals?
2. What about in situations with family members or friends? Or when trying to obtain help from others?
3. What about with the person you care for with memory loss?
4. Would you like to change your communication pattern in any of these situations (e.g., with family, friends, health care professionals, or the person you look after with memory loss)?

# Practicing Assertiveness Skills

## Analysing the situation

We are going to look at how you communicate with your relative a little later. Now we are going to be looking at asking for help. Think of a situation you were recently in where you asked someone for help with or information relating to your relative and things didn't go right.



## Practicing assertive communication

In a minute, we will talk through a situation that occurred with someone you have asked for help when it didn't go as you would have liked.

Try to be aware of how to be effective and assertive in your approach. On the next page are some tips to consider first.

### Leader:

- Ask carer to think of a specific situation relating to their relative and create a simple description of the scene. Be very specific! You take the role of the person the carer is negotiating with.
- Prior to this session, think of an example the carer has told you about recently that would be a good example to use for this exercise.
- Try prompting e.g. "If you were to ask 'x' for help, what would you say?"
- If carers do not have an example, use this alternative role play:

*"If you cannot think of a specific example to role play, try to imagine this scene:*

You are in need of a "break" (to go shopping, go to the dentist, pay bills, etc.), so you can get things done without your relative coming along and distracting you. You want to ask your sister (or whoever is appropriate) to come over and be with the person you care for 4 hours while you go out. Your relative usually doesn't agree when you've asked for this kind of help in the past, or usually says yes and then cancels at the last minute. This time you really want a solid yes."

## TIPS TO REMEMBER FOR ASSERTIVE COMMUNICATION

1. Think about what do you want or need
2. What exactly is the problem? Formulate this in one or two sentences
3. Try to describe your thoughts and feelings clearly
4. Give detailed information about what you need. E.g. Taking care of Mum for two hours involves feeding her a snack, turning the radio to her favourite station, and taking her to the bathroom
5. Be persistent and flexible: Maybe you won't get exactly what you asked for, but you will get something that will be helpful
6. Break it down into smaller parts or ask for things one at a time – it's usually easier for people to say yes to a little request than to a big one!
7. If you feel stuck – agree to think about it and talk again
8. Recognise that sometimes there isn't a solution
9. Remember to recognise the difference between what you want and what the person you care for wants. They might not always be the same
10. DON'T GIVE UP! It may take many attempts before things change

Discussion:

How did you find practicing assertive communication?

What could you have done differently?

What went well and what techniques would you use again?

**Leader:** Discuss whether they found it difficult to communicate assertively?  
What are the barriers to doing this in real life situations?

## Communicating with Someone with Memory Problems

Communicating with someone with memory problems can be challenging. You may now or in the future, feel as if you have to jump over many hurdles. When we feel frustrated it can be even harder to communicate clearly.

You may know some of the following already, or it may be new information:

Memory problems affect communication in a number of ways:

- They may affect your relative's ability to understand what you say.
  - They may limit your relative's ability to express what he or she wants to say.
- Increased memory problems may lead to an inability to remember thoughts from one moment to the next.

**IMPORTANT POINT: Because people with memory problems often cannot change their communication patterns, we need to find other ways to communicate with them.**

Let's look at an example.



Gloria wants her husband John to go to bed. He is watching television. She shouts from the kitchen that it's time for bed. He ignores her. She shouts louder for him to turn off the television and get ready for bed. John continues to ignore her so she begins to cry and locks herself in the bathroom.

How could Gloria have done things differently?

## How to talk to someone with memory problems

### Helping you or your relatives listening and understanding

#### Attention

---

- Try to catch the attention of your relative before beginning to speak.
- Reduce distractions when talking to your relative, e.g. switching off the television.
- Position yourself so that your relative can see you clearly and make eye contact.
- Touching your relative may help you to attract their attention.

#### Environment

---

7. Sit closely, ensure that background noise is minimal and that lighting is good.

#### Aiding understanding / listening

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- Try to listen carefully to what your relative is saying and gently encourage them.
- If they find it difficult to communicate what they mean, listen for clues, allow plenty of time, encourage them to explain in other ways.
- If you have had to guess what they mean, check out with your relative that you have understood them correctly.
- If you become frustrated or irritated, change the subject or take a break and talk about it later.

## Being understood

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- Speak clearly, slowly and calmly, try not to raise your voice.
- Try counting to ten in your mind after asking your relative a question, to allow them time to answer.
- Make instructions clear and simple, using short sentences.
- Try to ask only simple questions, one at a time, allowing for yes/no answers or try to avoid questions.
- If you are not being understood, try again in a different way, perhaps using actions, objects or signs as well as words.

**You may have to try some different communication techniques and see what works for both of you. You may also have to change and adapt your communication over time.**

### Discussion

What changes have you noticed in your relative's ability to express themselves?

How have you changed the way you communicate with him/her?

Which of these tips do you already use?

Which of these tips do you think you will start using?

## Communication Record

If you would like we can record an example of difficult communication with your relative.

| <b>Situation</b> | <b>What I said or did in the situation</b> | <b>How the situation turned out</b> | <b>How I felt</b> |
|------------------|--|-------------------------------------|-------------------|
|                  |  |                                     |                   |

## Stress Reduction Practice: *Meditation*

Leader: Ask if they managed to try last week's exercise, *Guided Imagery- Meadow and Stream*. Ask what their experience was like. Discuss barriers that may have prevented practice. Praise all attempts.

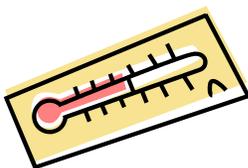


### Introduction

Today we are going to do a meditation technique. This technique will involve combining pleasant imagery with various physical sensations. The theory behind this technique is that visualizing yourself in a relaxing scene (e.g. a beach, forest, etc...) helps you to become less tense and focus better. Focusing on pleasant images will make it easier for you to focus on the relaxing physical sensations that I am going to repeat to you.

Throughout this procedure adopt a relaxed, passive and casual attitude. You can't force relaxation to occur. Try to give up conscious control of your body and allow your physical processes to flow naturally.

### Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now, before we practice the Meditation. On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

## Meditation: Practice Session

### Script for Leader:

“Let’s begin... Settle comfortably in your chair and take in a deep, cleansing breath...

When you are ready, close your eyes and feel yourself becoming more and more relaxed with every breath...

Continue to breathe normally, as you picture yourself in a relaxing setting... You may be at the beach, or in a forest, or wherever you feel comfortable and at ease...

Take a moment to notice the details around you in this peaceful place and notice that you are becoming more and more relaxed...

Once you feel at ease in your special place, think to yourself, *‘I am at peace... My right arm is heavy... My left arm is heavy...’*

Now continue on your own, noticing your calm breathing and heartbeat, and the heavy, warm sensation in your arms and legs...

*‘I am at peace... My arms and legs are heavy and warm, my heartbeat is regular and calm... My breathing is calm... My breathing is calm... My abdomen is warm... I am at peace... My abdomen is warm... My abdomen is warm... I am at peace... My arms and legs are heavy and warm... my heartbeat is calm and regular... My breathing is calm... My abdomen is warm... My abdomen is warm...’*

Now, continue to notice the heaviness and warmth in your legs, and your calm and regular heartbeat and breathing and the warmth of your abdomen...

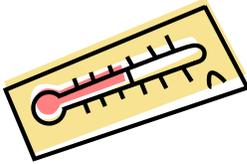
*‘I am at peace... My arms and legs are heavy and warm... my heartbeat is calm and regular... My breathing is calm... My breathing is calm... My abdomen is warm... My forehead is cool... My forehead is cool... I am at peace... My forehead is cool... My forehead is cool... I am at peace...’*

Now, continue to notice the sensations you feel throughout your body as you relax in your peaceful place...

Now, I am going to count from 3 to 1, and as I do, you will open your eyes and become more alert and aware of your surroundings... By the time I say 1, your eyes will be completely open, and you will feel alert, refreshed, and relaxed...

Here we go... Three... two... one... Your eyes are open and you are awake, alert, relaxed and aware of your surroundings...”

## Stress Rating after Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

1. Did your level of tension change?
2. What was this experience like for you?
3. Can you think of a specific event when this technique might have been helpful during a stressful caregiving situation?

Leader – Encourage carers to practice this exercise, or another one of their choice, at least one time each day this week.

## Summary

### Today we looked at:

- Different communication styles
- Passive communication
- Aggressive communication
- Assertive communication
- Communicating with someone with memory problems
- Stress reduction technique: *Meditation*

### For next week:

√ **Planning for the Future:** Please read over the material for next week. It will help you to process this important information. Feel free to invite another family member who is helping you care to come to the session if you would like to.

√ **Communication Record:** Please use the sheet on **page 97** to monitor your verbal and non-verbal communication style over the next week.

√ **Stress Reduction Exercises:** Please carry on regularly practicing your preferred stress reduction exercises.

### ***Optional Exercises (Recommended):***

√ **Behaviour Record:** Please complete the Behavioural Record on **page 98** when your relative's target behaviour occurs. We understand it may be difficult to complete the Record each time the Behaviour occurs, but please complete it as frequently as possible.

√ **Thought Record:** When a situation occurs that stresses you, please record your unhelpful thoughts and challenge and replace them with more helpful thoughts. Use the Thought Record **on page 99**.

## Communication Record

Use this sheet to write down difficulties with communicating both verbally and nonverbally with your relative this week.

Write down a specific situation, how you communicate, how it turned out and what your feelings were. Try to complete this once a day, if you see them.

| <b>Situation</b> | <b>What I said or did in the situation</b> | <b>How the situation turned out</b> | <b>How I felt</b> |
|------------------|--|-------------------------------------|-------------------|
|                  |  |                                     |                   |

### ***Optional Exercise: Behaviour Record***

Please use this Record to write something your relative does (or that you do) that upset you and the strategy you used to change it.

| Date and time | People Present | Trigger | Behaviour | Reaction | The strategy you used to change the behaviour was: |
|---------------|----------------|---------|-----------|----------|--|
|               |                |         |           |          |  |
|               |                |         |           |          | What happened when you tried using this strategy?  |
|               |                |         |           |          |  |

### ***Optional Exercise: Thought Record***

| <b>Situation</b><br><br>Describe the events that led to your unpleasant feelings. | <b>Current thoughts</b><br><br>Identify your thoughts in the situation. | <b>Feelings</b><br><br>What are you feeling? (sad, angry, anxious, etc.) | <b>Challenge &amp; replace with more helpful thoughts</b><br><br>What is a more helpful way of thinking about the situation? | <b>New feelings</b><br><br>What are you feeling now? (sad, angry, anxious, etc.) |
|---|---|--|--|--|
|   |   |  |  |  |

# Session 6: Planning for the Future

## Session Plan

1. Review Communication, Thought and Behaviour Records from last week
2. Introduction to Planning for the Future
3. Options for Care
4. Managing Your Relative's Physical Health
5. Legal Issues in Care Planning
6. Making a Plan
7. Stress Reduction Technique: *Guided Imagery – Ocean Escape*
8. Summary



# Review Home Practice

## Leader:

### **A. Communication Record**

What was your experience of using communication skills with the person you care for? What happened?

Did you use the strategy? **Yes**                      **No**

If **no**, why did you not use it?

If **yes**, was it effective?

Why or why not?

Discuss what worked and what might be helpful in the future.

*If carer completed the Behaviour or Thought Record, go through it:*

### **B. Behaviour Record**

Did you use the strategy? **Yes No** If **no**,  
why did you not use it?

If **yes**, was it effective?

Why or why not?

### **C. Thought Record**

Did you have any trouble filling out the Thought Record? Was it helpful? Why or why not?

## Planning for the Future

In this session, we will discuss some of the issues surrounding planning for the future care of your relative. We realise that these issues are hard to talk about, but it can be helpful to plan ahead.

Families often find themselves making important decisions when a crisis occurs. However, making decisions when you are under stress can be more difficult.

Planning *before* a crisis can help your family prepare for potentially difficult decisions you might face. Of course, you can always change these plans as things change.

We will discuss some of the most common concerns that relatives express including the following:

- Options for care
- Managing the physical health of someone with dementia
- Legal issues

You may have other concerns, if so let me know and we can talk about these. The goal is to help you feel more confident and informed when making difficult decisions about care.

## Talking About the Future

I would like you take a moment to think about your concerns regarding the future.

### 1. What concerns do you have about caring for your relative in the future?

Is there anything else?

Leader:

If carer can't think of any concerns, prompt:

“Some people worry about caring in the future if things become more difficult, for example if they become ill or the person with memory problems get worse? Are these things that worry you?”

### 2. Have you discussed these concerns and how you plan to handle them?

**If yes**, what decisions have you made?

**If no**, who would you want to include in a discussion of these issues?

# Options for Care

In this section, we will discuss some of the options available for caring for someone with memory problems over the course of their illness. We will discuss the advantages and disadvantages of each option.

## The Present Situation

We will start by looking at the table on the next page and thinking about any help that you have now and the resulting advantages and disadvantages.

1. Could you tell me what help your relative receives from family friends, or local community?
2. What other support is your relative receiving, from NHS, social services, or voluntary services?

Leader:

Go through the types of help the carer has mentioned in the last two questions and fill in the advantages and disadvantages in the table on the next page.

Use *Descriptions: Options for Care* section on the following pages to augment participants' answers to the previous questions.

The goal is to provide them with an understanding of the different options available for their situations. If they are unsure or decline a service go over the section so they are fully aware of what is on offer.

If you have gone over a particular section in detail or they already know about it, there is no need to repeat it. Just fill in the gaps with this material.

## PULL OUT THIS PAGE

| Care Options                            | Advantages | Disadvantages |
|---|------------|---------------|
| Family/Friends help                     |            |               |
| Health care                             |            |               |
| Home care                               |            |               |
| Telecare                                |            |               |
| Day centres and lunch clubs             |            |               |
| Respite care including sitting services |            |               |
| Care home                               |            |               |

## Health Care Options



### **Specialist health services for dementia**

GPs refer people with memory problems to memory clinics or other dementia services with psychiatrists (or, less often, neurologists or geriatricians).

If your relative has been seen and discharged from these specialist services, the GP is able to re-refer them if further advice is needed in the future.

Your relative will continue using their usual services for other health issues.

## Social Care Options

### Home care services

Range from reminders, e.g. to eat or change clothes, to the care workers doing the task.

- Included are bathing, grooming, dressing, and cooking.
- Home carers can remind someone to take their tablets if they are in a blister pack.
- Care workers have training in dementia and how to provide care safely, effectively and safeguarding the person's dignity.
- They can come in up to 4x a day depending on what is needed.

### Telecare

Is an electronic monitoring system that social services can provide, that allows people to remain independent for as long as possible. This could be helpful if your relative is at risk of falling, leaves the gas or water on, or if you are concerned about them leaving the house alone.

### Day centres and lunch clubs

Some are for all older people; others are for people with dementia.

- They focus on keeping the body and mind active, and social contact to improve quality of life.
- They can give carers a break.
- They often provide transport to and from home.

### Respite care

Allows a carer to have some time off.

- *Residential* respite care is at a care home or hospital.
- *At home* respite is where someone sits with your relative in their own home, or takes them out for a few hours, while you have a break.

**Sometimes the budget for social care is handled by the person with dementia and their family, deciding what to buy themselves. This is called "direct payments".**

## Residential Care Options



### Sheltered housing

This enables people to continue to live independently but with the reassurance that help is at hand. It may be suitable for some people with memory problems.

### Long term care

If you or a relative can no longer manage at home, you may want to consider long term residential or nursing care.

- A *residential* home can offer assistance with personal care,
- Whereas a *nursing* home can provide specialised nursing care.

The decision about whether someone should move to a care home is very personal and complicated.

**We have included some fact sheets in the appendix that give comments and advice from family members who have made these decisions.**

#### Leader:

Ask if they have any questions about care options available. Talk about any concerns they have.

If they ask a question you can't answer, tell them you will try and find the answer and ring them or tell them next time. You won't be able to answer questions specific to the person they care for, but you can suggest to them who can.

We have included some sheets, produced by our team which you may find helpful. These are:

- When does the local authority pay for care?
- Choices in care
- How to select a care home

# Managing Your Relative's Physical Health

Now, we will move on to talk about physical health and pain management.

As anyone (including people with dementia) gets older, they are more likely to experience physical illnesses. People with memory problems often need help to look after their physical health. This support can include:

- Reminding them about medical appointments
- Attending appointments with them
- Helping them to make decisions about medical care, or giving your opinion or advice, or
- Making these decisions on their behalf.

For example, as a carer you may be asked whether you think your relative should have an operation or receive certain treatments.

## **Some points to consider**

- Some people with dementia continue to make (or at least contribute to) decisions about their own health.
- You can always discuss these issues with friends, family members and healthcare professionals. If you are asked to make decisions like this, you will be given information about the advantages and disadvantages of any treatment.
- It can be helpful to discuss these issues with your relative in the early stages of their illness.

**We have included some fact sheets that give comments and advice from family members who have made these decisions.**

## Pain management



Although dementia does not cause pain, like all of us people with dementia can become physically unwell.

- Sometimes people with dementia are not able to tell you that they are in pain. You may notice instead that their behaviour changes, they become irritable or agitated, or they do not seem themselves.
- In most cases, severe pain and physical discomfort can be managed through effective use of painkillers and non-medical means, such as relaxation therapies, massage and good nursing care.

### Ways to ensure good pain management

- Don't be afraid to tell professional carers that your relative is in pain. You probably know them best.
- Consider the compromises you and your relative are willing to make for pain management. Some people would rather be sedated and in less pain and others would not.

## What if something happens to me?

Some carers make a plan in case something happens to them, and they can no longer provide care for their relative.

- If you suddenly could not provide care (perhaps because you were taken ill) and there was no plan, Social Services would arrange any necessary emergency care for your relative.
- You can discuss with your family what would happen to your relative, so that you can make a decision together for this eventuality.
- The **Carers Emergency Card** Scheme operates in most areas, allowing carers to draw up and register a plan. The carer has a card, and in emergencies they (or someone with them) can call the 24-hour helpline, who will make the agreed arrangements. Details of where to find out about the scheme are in the CHOICE factsheets provided with this session.

## Decisions for the future

Planning for a time when a person with memory problems cannot make their own decisions about physical health care is difficult.

Let's read the following conversation between two sisters whose mother has memory problems:

83-year-old Gloria has had memory problems for many years. She has two daughters, Paula and Mary. Gloria's doctor told Mary that Gloria's memory is likely to get worse. Mary decides it's time to talk with her sister, Paula, about future decisions for their Mum.



**Leader:** Suggest carer reads Mary in the following script

**Mary:** I saw Mum's doctor last week and he told me that Mum's memory will probably get worse.

**Paula:** You know, doctors aren't always right. I don't think you should worry.

**Mary:** But the doctor said we will need to make some decisions pretty soon. It would make me feel better if we could discuss this.

**Paula:** I don't think there is anything to talk about. We can handle things as they come up.

**Mary:** I'd prefer to discuss it now. I think that if we wait till the last minute, it will be too late. I know it's not easy, but ignoring it won't make it go away.

### Discussion questions:

- Have you thought about or discussed similar issues?
- If so, was this helpful?

## Legal Issues in Care Planning

In this third section, we will introduce some legal issues that may come up in the future. Please tell me if you already know of, or have dealt with, these issues, and we can move on.

### What is mental capacity?

Legally, people who make decisions must be able to understand what they are doing. If someone cannot make a particular decision for themselves, they are said to lack the **mental capacity** to make that decision.

This is one reason why someone might set up a Lasting Power of Attorney (which will be explained on the next page), so that if someone with dementia is not able to make an important decision in the future, they have already chosen someone who can make that decision for them.

#### Leader:

Be aware: LPAs replaced enduring power of attorney in October 2007 when the Mental Capacity Act (2005) came into effect. Enduring power of attorney (EPA) completed before this date are still valid. Any existing EPA only applies to finance and property matters, so even if someone already has one, they can also make an additional LPA for personal welfare decisions under the Act.

Ask the carer if they have ever considered a power of attorney. If they would like more information, you can give them a fact sheet. **Encourage them to think about Power of Attorney.**

## Lasting Power of Attorney (LPA)



Anyone who still has capacity can complete legal documents giving another person (who is then called the *attorney*) the authority to act on their behalf.

People with memory problems usually appoint a family member or close friend as their attorney.

There are two types of Lasting Power of Attorney (LPA):

### **Property and Affairs LPA**

Gives the attorney the power to make decisions about financial and property matters, such as managing a bank account and paying bills.

### **Personal Welfare LPA**

Gives the attorney the power to make decisions about health and personal welfare, such as day-to-day care, medical treatment, or where the person should live.

A Personal Welfare LPA only ever takes effect when the person with memory problems lacks capacity to make decisions.

A Property and Affairs LPA can take effect as soon as it is registered, even while the person with memory problems still has capacity, unless they specify otherwise.



## Advance Decisions

Many people think about how and where they would like to be cared for if they became very unwell in the future. For example, whether they would prefer to be at home if at all possible, or in a hospital, nursing home or a hospice.

Discussing this with family and friends can be difficult. Many people with memory problems and their families find it helpful to have these discussions, while others prefer not to.

As well as talking with family and friends, the Mental Capacity Act allows anyone with capacity to make an **Advance Decision**. This specifies particular types of treatment they do not want should they lack the mental capacity to decide in the future.

The advance decision will only be used if the person making it is not capable of deciding at the time that the treatment is needed.

## Tips for Planning for the Future

**GATHER** the information you need to make informed choices for you and your family as early as you can. If possible, discuss the following questions:

- How do you want to be treated at the end of your life?
- Are there treatments you want to receive or refuse?
- What are you afraid might happen if you can't make decisions yourself?
- Do you have any particular fears or concerns about medical treatments?

**TALK** about decisions with your family, friends, doctor, and any others close to you to help with decisions that are important to you and the person you care for.

**PREPARE** and sign Lasting Power of Attorney or advance directives that accurately reflect your decisions.

**INFORM** the person you care for and doctor about your preferences and give them copies of your advance directives.

### **If your relative cannot talk about these issues:**

Think about what he or she may have said in the past on this topic.

Think about his or her values.

## Making a Plan

For next week, think about a possible stressful situation that may occur in the next few months.

What information from this session might help?

Is there any further information you need to help cope with this situation?

## FOR NEXT WEEK



√ **Planning for the future:** Think about the questions we covered on **page 118** and read through the CHOICE factsheets. These were written after interviewing family members of people with memory problems, about decisions they found difficult. Make a note of any questions you have and we can discuss these next week.

√ **Relaxation:** At home, please practise the ***Guided Imagery–Ocean Escape*** exercise that we will do shortly, or a relaxation exercise of your choice.

### ***Optional Exercises (Recommended):***

√ **Behaviour Record:** Please complete the Behavioural Record on **page 126** when your relative's target behaviour occurs. I understand it may be difficult to complete the Record each time the Behaviour occurs, but please complete it as frequently as possible.

√ **Thought Record:** When a situation occurs that stresses you, please record your unhelpful thoughts and challenge and replace them with more helpful thoughts. Use the Thought Record **on page 127**.

**Leader:** If they do not have time to do all of these tasks, tell them the most important task is to read over the information from this session and in the CHOICE factsheets.

# Stress Reduction: *Guided Imagery– Ocean Escape*

Leader: Ask if they managed to try last week's exercise, Meditation. Ask what their experience was like. Discuss barriers that may have prevented practice. Praise all attempts.

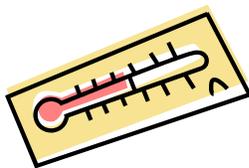


## Introduction

Today we are going to do another Guided Imagery exercise. This exercise will involve imaging your experience at the ocean, far away from the cares of everyday life.

I am providing you with a wide range of options, as different people find different images or scenes relaxing. We hope this one will be helpful for you.

## Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now, before we practise the Guided Imagery. On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

## Stress Reduction Technique: *Guided Imagery - Ocean*

### Script for Leader:

We are about to begin the guided relaxation imagery exercise. Soon, I will be describing a relaxing scene for you.

But first of all, make sure you get yourself into a comfortable position in your chair, with your arms by your side.

Close your eyes, and take in a deep signal breath, holding it for a few moments... and then let go, relaxing as you do so.

Now as I continue talking to you, you can allow a calm relaxed feeling to settle over your body and mind.

Let go of any unnecessary tension in your shoulders, arms, and hands.... As your shoulders and arms hang loosely by your side, let all of the tension drain out through the tips of your fingers.

Let the relaxation flow from your shoulders into the back of your neck, ... as the tension dissolves and melts away... relaxing your neck and scalp...

... and also your face, including your mouth, tongue, and jaw.

Let the relaxation flow down the rest of your body... your chest... abdomen... and back.

Feel all the muscles of your body becoming loose and relaxed.

Letting the relaxing feelings flow into your legs, ankles, and feet.

Just allow your entire body to become loose, heavy, and relaxed.

And now... picture yourself somewhere by the ocean.

Just project yourself to any relaxing place along the ocean... perhaps a place you have been to or a place you would like to go...

It may be a sandy beach or a rocky beach... you may be on a pier or even on a cliff, overlooking the ocean... any place you choose is fine.

Look around... what do you see?

Can you see it clearly in your mind? ... Do you notice the vastness of the ocean... stretching out as far as you can see?

Perhaps you see a dolphin or whale swimming by...

Now inhale deeply, smelling the fresh sea air....

Feel the warmth of the sun,... the cool breeze. How peaceful and relaxing it is...

And now listen more closely to the sounds... especially the sound of the waves. Pay close attention to the sound of the waves and notice how soothing and relaxing the sound is...

...as you hear the waves roll in... and out again...

In... and out...

the constant rhythm of the waves... the ebb... and flow...

And each time the waves flow in... and out, you find yourself becoming more deeply relaxed...

deeper... and deeper... as your muscles go loose... and limp... and the tranquility of this place surrounds you.

*[Long pause]*

And now spend a few minutes doing whatever you would like.

You may just want to lie on the sand and soak up the sun...

you may want to walk along the beach... or swim in the cool water...

perhaps you would like to do some fishing... go sailing...

Whatever you would like to do at the ocean is okay... but no matter what you do, just continue being aware of this relaxation...

*[Allow participants a few minutes to enjoy this imagery].*

And now. I will bring you back slowly from this relaxation by counting backwards from 3 to 1. When I get to 1, you'll be alert, refreshed, and comfortable.

Okay,

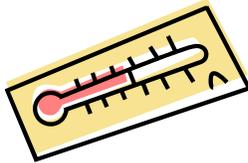
"3" much more alert;

"2" feeling refreshed and comfortable,

and

"1" as you open your eyes and return your awareness to the room you are in."

## Stress Rating after Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

1. Did your level of tension change?
2. What was this experience like for you?
3. Can you think of a specific event when you think this technique might have been helpful during a stressful caregiving situation?

Leader:

Encourage carers to practise the Guided Imagery, or an exercise of their choice, at least one time each day this week.

## Summary

Today, we have talked about:

- Planning for the future
- Options for care
- Managing your relative's physical health
- Legal issues in care planning
- Stress reduction technique: *Guided Imagery–Ocean Escape*

**Remember, if you only have time for one exercise over the next week, please read over the information from this session and have a look at the CHOICE factsheets.**



## Optional Exercise: Behaviour Record

Please use this Record to write something your relative does (or that you do) that upset you and the strategy you used to change it.

| Date and time | People Present | Trigger | Behaviour | Reaction | The strategy you used to change the behaviour was: |
|---------------|----------------|---------|-----------|----------|--|
|               |                |         |           |          |  |
|               |                |         |           |          | What happened when you tried using this strategy?  |
|               |                |         |           |          |  |

### ***Optional Exercise: Thought Record***

| <b>Situation</b><br><br>Describe the events that led to your unpleasant feelings. | <b>Current thoughts</b><br><br>Identify your thoughts in the situation. | <b>Feelings</b><br><br>What are you feeling? (sad, angry, anxious, etc.) | <b>Challenge &amp; replace with more helpful thoughts</b><br><br>What is a more helpful way of thinking about the situation? | <b>New feelings</b><br><br>What are you feeling now? (sad, angry, anxious, etc.) |
|---|---|--|--|--|
|   |   |  |  |  |

# Session 7: Introduction to Pleasant Events and your Mood

## Session Plan

1. Review of Planning for the Future
2. How Events Affect Your Mood
3. How to Identify Pleasant Events
4. Creating a List of Pleasant Events
5. Pleasant Events Planning
6. Monitoring Your Mood
7. Relaxation: *Stretching*
8. Summary



# Review of Planning for the Future

Leader:

- Review Planning for the Future – review future possible stressful situation from last week.
- If they have indicated they need more information, talk with them about from where this could be obtained.
- Review Thought and Behaviour Records

## How Events Affect Your Mood

Although being a carer is time consuming, it is important that you make the time for activities you enjoy. This is because if all your activities are limited to caring, you may begin to feel burned out and frustrated.

For example, feeling down is often related to having too few pleasant events. A lack of balance between unpleasant and pleasant events can make you feel like you have no control. You may think “It seems like there’s nothing I can do to make things better.” However, you can feel better by making sure your day has a few events that bring you pleasure

### Rollercoaster of Moods

Pleasant  
events



Unpleasant events

We can make choices about many of the events that occur in our lives. Increasing pleasant events can help reduce stress and therefore make you feel more able to care.

## What Counts As A Pleasant Event?

Pleasant events don't have to be long or need a lot of planning. They aren't just big events like holidays. Reading the newspaper, a leisurely cup of coffee, gardening or talking to a friend can all be pleasant activities.

**Key Point: Anything you like to do is a pleasant event**

List two activities that are pleasant for you:

- a.
- b.

Adding pleasant events to your daily life can be difficult. You may think "I don't have the time to do pleasant activities!" or feel guilty about making time for yourself or having time apart from the person you care for. These can be barriers but it is important to overcome them. **Being a good carer means taking care of yourself too!**

## **Pleasant Events for You and Your Relative**

Pleasant events can be for you alone or for you and your relative. It is important to have pleasant activities to do with the person you care for. This can be hard since you may have many tasks to do as a carer, but it is valuable if you can continue to enjoy each other's company.

I'd like to work with you to develop a list of pleasant events that you can enjoy together, and things you can enjoy by yourself.



Here are some examples of pleasurable events, not all of these activities will be for you. Take a few moments to look over this list and tick the activities you think you would enjoy either together or separately.

| Activities   | You | You and your relative |
|--|-----|-----------------------|
| Listen to music  |     |                       |
| Go to the shops  |     |                       |
| Go for a walk  |     |                       |
| Read/listen to books, newspapers, magazines or spiritual texts |     |                       |
| Go out for coffee or to eat with friends or family             |     |                       |
| Cook or bake   |     |                       |
| Write letters or cards etc.                                    |     |                       |
| Drawing, painting, doing crafts                                |     |                       |
| Exercise e.g. jogging, yoga, cycling, football                 |     |                       |
| Go to the cinema or watch a film                               |     |                       |
| Go for a drive   |     |                       |
| Go to the park with a picnic                                   |     |                       |
| Have friends over  |     |                       |
| Gardening / DIY  |     |                       |
| Be with children / grandchildren                               |     |                       |
| Listen to the radio  |     |                       |
| Watch your favourite TV programme                              |     |                       |
| Watch wildlife or be around animals or pets                    |     |                       |
| Look at photos   |     |                       |
| Go to place of worship   |     |                       |
| Watch sports   |     |                       |
| Recall or discuss happy memories                               |     |                       |
| Dance  |     |                       |
| Have a leisurely bath  |     |                       |
| Chat to friends or family on the phone                         |     |                       |
| Spend time on the computer                                     |     |                       |
| Play cards, computer games, crosswords or puzzles              |     |                       |
| Talk about family or current events                            |     |                       |
| Buy a ready prepared meal or take away                         |     |                       |
| Get your hair / nails done                                     |     |                       |
| Massage  |     |                       |
| Have a glass of wine or beer                                   |     |                       |
| Bingo  |     |                       |
| Other activity:  |     |                       |
| Other activity:  |     |                       |

**Highlighting these activities and doing two or three of them each day can make a huge difference to how you feel.**

## Creating a List of Pleasant Events

**Rule A: *Start small and be simple.*** The most important thing to remember is to choose events that you can do everyday or a few times a week. You may enjoy travelling, but realistically you cannot take a trip every day. A smaller and more realistic activity would be going to the shops, cycling or walking.

**Rule B: *Focus on events you want to do more often.***

Let's think of four pleasant activities for you

Leader: use list from page before if necessary

1

2

3

4

## Creating a List of Pleasant Events for You and Your Relative

It can be helpful to plan activities or events that are manageable and achievable. Think about events you used to enjoy together in the past.

Is it possible to still do those activities? If not, can they be changed in any way? For example, if you used to take long walks together, can you now take short walks? As long as you find things your relative enjoys and is able to do, you will be helping them to feel better. Things to remember when selecting and planning activities for your relative:

- Don't force them to participate: Encourage or reward him/her often.
- Try to think of things that are similar to some hobbies, interests, or games they used to enjoy.
- Have a few activities available, so if they become bored you can switch easily.
- Plan to do activities in short bursts.
- Try to involve other friends or family if at all possible.
- Activities that involve movement can be good, since people are often restless and have relatively short attention spans.
- There is no harm if your relative enjoys crafts, games, or music that are simpler than before.

Let's think of four pleasant activities for you and your relative

**Leader:** use list from page before if necessary

1

2

3

4

## Pleasant Events Planning

Some activities require more planning than others. Because we want you to be successful in planning pleasant events for both you and your relative, we have put together a list of questions you may ask yourself beforehand so that things will go as smoothly as possible. It may be that planning beforehand will help you manage to do pleasant activities. Take a look at these questions:

Leader: Encourage carer to work through the questions for one activity they plan to do in the next week.

### **Pleasant Activity:**

Materials or preparation needed

When it will take place?

How often can it be done?

How much time will it take?

## Monitoring Your Mood

In order to understand the difference pleasant events make to you, I want you to keep track of how you are feeling. This means asking yourself, "How am I feeling today?"

By keeping a daily record of your feelings, this will allow you to identify whether your mood follows a particular pattern.



**The number 1** represents the lowest you could possibly feel.

**The number 9** represents the best you could possibly feel.

Record a number on your pleasant events sheet (on the next page) at the end of each day. This number will represent the way you felt on that day. You will rate your mood on a scale 1 to 9.

When you fill in this number at the end of each day, think about how you felt *overall*. Most of us have lots of ups and downs over the course of the day, so try to take an average of these feelings.

Next to your mood score for each day, is a space for any comments about that day's events that may have contributed to your mood.

**Leader:** Fill in the days and events you wrote down before for the table on the next page now. Ask them to use these during the week. Complete the first line as an example.

## Pleasant Events For My Relative and Me

| Day     | Events for Me                        | Events for My Relative and Me        | Total Events Today | My Mood Score (1-9) | Comments |
|---------|--------------------------------------|--------------------------------------|--------------------|---------------------|----------|
|         | a.....<br>b.....<br>c.....<br>d..... | a.....<br>b.....<br>c.....<br>d..... |                    |                     |          |
|         | Which events (a,b,c,or d)            | Which events (a,b,c,or d)            |                    |                     |          |
| Example |                                      |                                      |                    |                     |          |
|         |                                      |                                      |                    |                     |          |
|         |                                      |                                      |                    |                     |          |
|         |                                      |                                      |                    |                     |          |
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# Relaxation: Stretching

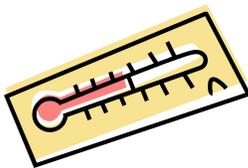
## Leader:

- Ask if they managed to try last week's exercise. Ask what their experience was like. Discuss barriers that may have prevented practice. Praise all attempts.
- Check with the person that you are working with that they are fit and well enough to do these exercises i.e. do not feel dizzy or have funny turns when standing. **If so do it all sitting or another relaxation exercise**

## Introduction

Simply stretching tired muscles can go a long way toward reducing tension and stress. Stretching exercises can be used almost anywhere, at any time, for as long as you want, so they can be an especially convenient relaxation technique for carers. It is important to do stretching exercises that feel good to you. As we practise this today, please tell me if you experience any discomfort and we will stop and try something else.

## Stress Rating Before Exercise

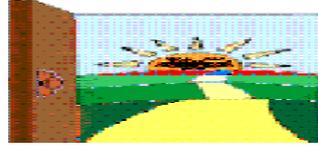


- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now, before we practise the Stretching Exercise. On a scale of 1 to 5, how would you rate your tension?

## Stretching: Practice Session

Script for Leader:



“Today, we will do a few stretching exercises that will help you relax. First, let’s start by standing up, or if you prefer, you may choose to do this exercise in your chair. Whatever is the most comfortable for you is all right.

Take a deep signal breath, all the way down to the bottom of your stomach, (pause 2s) and slowly let it out. Feel the tension drain from your body. (*pause*) Take one more breath and hold it for a moment (*pause 2s*) and let it out slowly. With each breath you are becoming more and more relaxed.

Now, gently reach your arms out to the sides, as though you were trying to touch the walls. Relax your shoulders and stretch yourself a little.

Gently reach your arms out in front of you. Feel the muscles in your back and shoulders loosen up. Stretch out in front a little further.

And now reach up as high as you can. Push up your arms towards the sky, as if you were trying to reach the sun.

Again, reach your arms out to the sides as though you were trying to touch the walls, as though you were trying to push the walls outward.

Reach out in front of you. Feel your muscles in your back and shoulders become looser and less tense.

Reach up toward the sky one more time. Reach as high as you can. Try to touch the sun.

Lower your arms to your sides.

Now, roll your shoulders back. Feel the tension drain from your body. Roll your shoulders back again. One more time roll your shoulders back.

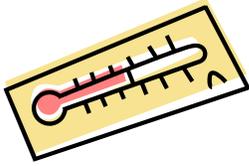
Now roll them forward. Roll them forward again. One more time forward.

Now shrug your shoulders, lifting them up and then pushing them down. Shrug your shoulders again. Shrug them one more time.

Now another take in a deep and refreshing breath, and exhale all of the tension in your body. To complete this session, take one more breath... and exhale, letting go of any remaining tension..

Are you feeling calmer and more relaxed now? If not, consider completing this exercise a second time.”

## Stress Rating after Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Now rate your level of stress or tension after practicing the Stretching Exercise. On a scale of 1 to 5, how would you rate your tension?

\_\_\_\_\_

1. Did your level of tension change?
2. What was this experience like for you?
3. Can you think of a time when you could use the stretching exercise (i.e., during a stressful caregiving situation)?

### Leader:

- Praise carers for any success they had with the exercise
- Encourage carers to practise stretching at least once per day this week

## Summary:

Today we have talked about:

- Being aware of your feelings/mood.
- The connection between mood and Pleasant Events.
- Increasing Pleasant Events as a way to improve your mood.  
Relaxation: Stretching.

FOR NEXT WEEK:

√ **Pleasant Events Tracking Form:** Please complete the form on **page 140** each day this week. Try to fill it out at the end of each day. Feel free to add new Pleasant Events or change the ones you have written down.

√ **Relaxation:** Please try to practise the **Stretching** exercise that we have just done.

√ **Optional Exercises (recommended):**

**Behaviour Record:** Please complete the Behavioural Record, on **page 147**, when your relative's target behaviour occurs. We understand it may be difficult to complete the record each time, but please complete it as frequently as possible.



**Thought Record:**

When a situation occurs that stresses you, please record your unhelpful thoughts and challenge and replace them with more helpful thoughts. Use the Thought Record **on page 148**.

## Optional Exercise: Behaviour Record

Please use this Record to write down something your relative does (or that you do) that upsets you.

| Date and time | People Present | Trigger | Behaviour | Reaction | The strategy you used to change the behaviour was: |
|---------------|----------------|---------|-----------|----------|--|
|               |                |         |           |          |  |
|               |                |         |           |          | What happened when you tried using this strategy?  |
|               |                |         |           |          |  |

## Optional Exercise: Thought Record

| <b>Situation</b><br><br>Describe the events that led to your unpleasant feelings. | <b>Current thoughts</b><br><br>Identify your thoughts in the situation. | <b>Feelings</b><br><br>What are you feeling? (sad, angry, anxious, etc.) | <b>Challenge &amp; replace with more helpful thoughts</b><br><br>What is a more helpful way of thinking about the situation? | <b>New feelings</b><br><br>What are you feeling now? (sad, angry, anxious, etc.) |
|---|---|--|--|--|
|   |   |  |  |  |

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# Session 8: Using your Skills in the Future

## Session Plan

1. Review Pleasant Events Tracking Form
2. Review Relaxation
3. Review Behavioural Records
4. Review Thought Records
5. Review Assertive Communication
6. Review Communicating with Your Relative
7. Review Planning for the Future
8. Putting it all Together
9. Relaxation: *Mountain Cabin*
10. Summary



# Review Pleasant Events Tracking Form

## Leader: Prior to Session 8

Look at your notes from all prior sessions with carer before session 8 so that you are able to suggest review ideas around each of the sessions.

e.g. "Do you think that using this strategy helped to change this behaviour"

## Leader:

Please take out the Pleasant Events Tracking Form you completed last week.

Ask if their mood follows any patterns? Did they feel better on certain days versus others?

Ask about their Pleasant Events Tracking Form:

1. How many were you able to do?
2. How did you feel **during** and **after** your pleasant activities?
3. Looking at your mood scores 1-9, how do you think your pleasant activities affected your mood?

Are there any new events that you would like to **add** or **remove** from your list? If so, you can make these changes on the blank form on the following page. Please continue to use this new form next week - and in the future.

## Pleasant Events for My Relative and Me

| Day     | Events for Me                        | Events for My Relative and Me        | Total Events Today | My Mood Score (1-9) | Comments |
|---------|--------------------------------------|--------------------------------------|--------------------|---------------------|----------|
|         | a.....<br>b.....<br>c.....<br>d..... | a.....<br>b.....<br>c.....<br>d..... |                    |                     |          |
|         | Which events (a,b,c or d)            | Which events (a,b,c or d)            |                    |                     |          |
| Example |                                      |                                      |                    |                     |          |
|         |                                      |                                      |                    |                     |          |
|         |                                      |                                      |                    |                     |          |
|         |                                      |                                      |                    |                     |          |
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# Reviewing Pleasant Events

## Overcoming Obstacles

Although you might have completed the pleasant events you scheduled last week, you may find problems in the future. Adding pleasant events into your daily life can be difficult.

1. An obstacle that keeps me from increasing pleasant events into my life is:

2. How might you be able to overcome this?

Leader: If carer cannot think of an answer to question Q1, prompt:  
Is there an obstacle related to money, guilty feelings, stress, or a physical limitation?

Leader: The purpose of the rest of the session is to give carers a structure/techniques which they will use in the future. If they haven't completed/agreed with/found useful certain aspects of the manual then move on to the next review.

## Review of Relaxation

**We have looked at different stress reduction/relaxation exercises each week. You also have these on a CD or tape to use.**

Leader: If carer has not liked using the relaxation CD or tape. Use this time to reflect with carer how they do like to relax

Have you had a chance to use any of these? If so, which have you found helpful?

Do you have set times when you use them?

Do things get in the way? If so, how could you overcome them?

How do you think you will use these in future?

Leader: Encourage carer to continue using the relaxation techniques that have worked best for them and to use them in stressful situations.

## Review of Behaviour Records (Session 1 onwards)

**We are now going to review the Behaviour Records that you have been keeping (pages 12, 32/42, 50/59).**

**Leader:** Have a look at the Behaviour Records the carer has completed.

Have you had a chance to use any of these? If so, which have you found helpful?

Have you been using the strategies we developed?

Have they been helpful? Do things get in the way? If so, how could you overcome them?

Have you developed any new strategies?

How do you think you will use these in future?

**Leader:** Encourage them to continue using these and the skills acquired. Draw their attention to the blank Behaviour Records at the end of this session.

## Review of Thought Records (Session 4 onwards)

**We are now going to review the Thought Records that you have been keeping (pages 73/80).**

Leader: Have a look at the Thought Records the carer has completed over the course.

Have you found completing these helpful? If so, how?

Do you feel you have used some of the techniques to challenge unhelpful thoughts? (e.g. looking at it from a different point of view or trying not to think of things as all or nothing)

Can you identify any thoughts that you have changed?

How will you continue thinking in this changed way in the future?

Leader: Encourage them to continue using these and the skills acquired. Draw their attention to the blank Thought Records at the end of this session.

## Review of Assertive Communication (Session 5)

We have looked at different communication styles. This has included assertive communication and how to use these skills when asking for help from others.

Have you had a chance to use assertiveness skills? If so, have you found it helpful?

Do you use these skills in certain situations?

Do things get in the way? If so, how could you overcome them?

How do you think you will use these skills in future?

Leader: Encourage carer to continue using these skills.

## **Review of Communicating with Someone with Memory Problems (Session 5)**

**We have looked at how memory problems can affect your relative's communication in a number of ways. We have also looked at some techniques for you to consider in aiding clearer communication with them.**

Have you had a chance to use any of these techniques? If so, which have you found helpful?

Have you had any difficulties using these techniques? If so, how could you overcome them?

How do you think you will use these techniques in the future?

Leader: Encourage carer to continue using these techniques and to refer back to Session 5 if they need to use other techniques.

## Review of Planning for the Future (Session 6)

**We have discussed different issues surrounding planning for your relative's future care, and how hard it can be to talk about important decisions with your relative and other family members.**

Have you had a chance to think about or have these discussions with your relative or other family members? If so, have you found this helpful?

If not, what gets in the way? How could you overcome them?

Have you made any decisions or taken any actions?

How do you think you will discuss other difficult decisions about the care of your relative in the future with them or other family members?

**Leader:** Encourage carer to continue discussing the future and to refer back to Session 6 if they need to think more. If they say they still require more information, signpost them to the relevant resource (e.g. Choice leaflets, GP, local memory service).

## Putting it all Together



Now, let's make a list of the things you found most helpful in the sessions:

Leader: You can remind them of things that helped. You can add more, but it's better not to pressurise by having too many.

1.

2.

3.

4.

Using the list on the page before, let's make a list of skills/techniques/strategies that you intend to keep using in the future:

1

2

3

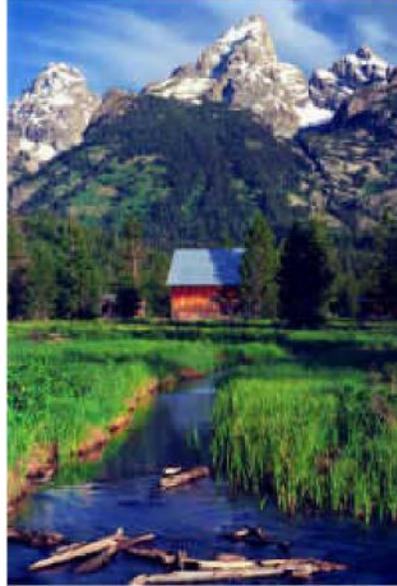
4

1. What stressful situation do you anticipate occurring in the next few months?

2. Of the skills you have learned, which will help you with the stressful situation you described above?

**IMPORTANT POINT:** The key to understanding the concepts discussed in these sessions is to practice. With practice, you can then share these techniques with your family members or friends.

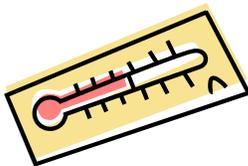
## Relaxation: *Guided Imagery - Mountain Cabin*



### Introduction

Today we are going to do another guided imagery exercise. This exercise will involve imagining your experience in a relaxing cabin, high up in the mountains, far away from the cares of everyday life. We are providing you with a wide range of options, as different people find different images or scenes relaxing. We hope this one will be helpful for you.

### Stress Rating Before Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

First, please rate your level of stress or tension right now, before we practice the Guided Imagery exercise. On a scale of 1 to 5, how would you rate your tension? \_\_\_\_\_

## Guided Imagery: Practice Session

### Script for Leader:

“This is a guided relaxation imagery exercise. Soon I shall describe a relaxing scene. First of all, make sure you get yourself into a comfortable position in your chair.

Close your eyes, and take in a deep signal breath, holding it for a few moments... (*pause*) and then let go, relaxing as you do so. Now as I continue talking to you, you can allow a calm, relaxed feeling to settle over your body and mind.

Let go of any unnecessary tension in your shoulders, arms, and hands. As your shoulders and arms hang loosely by your sides, let all of the tension drain out through the tips of your fingers.

Let the relaxation flow from your shoulders, into the back of your neck (...), as the tension dissolves and melts away, relaxing your neck and scalp, and also your face, including your mouth, tongue and jaw.

Let the relaxation flow down the rest of your body... your chest... abdomen... and back. Feel all the muscles of your body becoming loose and relaxed.

Let the relaxing feelings flow into your legs, ankles and feet. Just allow your entire body to become loose, heavy and relaxed.

And as your body is becoming more and more relaxed, you can now picture yourself inside a log cabin, (*pause*) somewhere high in the mountains. (..) It's wintertime. Even though it is very cold outside, you can enjoy the warmth and comfort of the cabin... inside this cabin is a large fireplace with a blazing fire, providing just the right amount of heat. You can feel so comfortable, so peaceful and so deeply relaxed inside of this cabin.

Now, look around this cabin. Scan the layout and contents of the room (*pause*). You can go up to one of the windows. Notice the frost

on the window pane... you can even put your warm hand on the cold, hard glass of the window pane. Feel the heat from your hand melting the frost... and then look outside, you see many tall evergreen trees, and lots of snow on the ground...

To get an even better view, you can begin to open the window, (...) feeling it give way against the pressure of your hand. As the window opens, you take in a deep breath of that pure, fresh, cool mountain air (...) It feels so good, so healthy, so alive.

Then look outside, seeing more clearly the green trees against the whiteness of the snow... looking out and seeing a beautiful view, perhaps of the valley down below (..), the mountain peaks far off in the distance. (*pause*)

And now, you can close the window and walk over to the fireplace, feeling its relaxing warmth as you get closer... you can go ahead and sit back in a comfortable chair facing the fire, (...) or you may even want to lie down next to the fire on a soft blanket, feeling the soothing warmth of the fire against your skin... let your body absorb the warmth, bringing you deep relaxation and comfort...

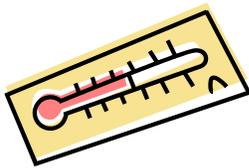
You can enjoy watching the flames, (...) seeing the burning logs, (...) hearing the crackling of the logs (..), smelling the smoke from the logs. (..) You can even look around you, noting what the room looks like, as it is illuminated by the fire. Notice the flickering shadows on the walls... notice the furniture in the room... just look around you, taking in all the sights, the sounds, the smells... feeling so peaceful, so calm and so deeply relaxed in this place. (*pause for 10 seconds*)

As your attention returns to the fire, you can feel so comfortable and so relaxed... even though the cold wind is howling outside, you feel so warm inside... nothing to worry about, nothing to concern you... (*pause*) all that really matters, is that you allow yourself to enjoy the peace, (...) the comfort (...), the deep tranquility of being in this relaxing place. (*pause for 10 seconds*)

And now, I shall bring you back slowly from this relaxing place by counting backwards from 3 to 1. When I get to 1, you'll be alert, refreshed, and comfortable.

Okay: '3', much more alert; '2', feeling refreshed and comfortable; and '1', as you open your eyes and return your awareness to the room you are in."

### Stress Rating after Exercise



- 1 = Not at all tense
- 2 = Slightly tense
- 3 = Moderately tense
- 4 = Really tense
- 5 = Terribly tense

Now, please rate your level of stress on a scale of 1 to 5, how would you rate your tension level now after practicing the Guided Imagery exercise? \_\_\_\_\_

1. Did \_\_\_\_\_ your level of tension change?
2. What was this experience like for you?
3. Do you think that the person you care for might like to try listening to a tape of this exercise with you?

**Leader:** Encourage carers to practice a relaxation/stress reduction technique at least once each day this week.

## Summary

We have now looked back at the skills covered in these sessions.

- How to relax in stressful situations.
- How to identify and change problem behaviours.
- How to challenge your own negative thoughts and replace them with more helpful thoughts.
- How to ask for help from others.
- How to communicate better with the person with memory problems you look after.
- How to plan for the future and talk to your family about difficult decisions.
- How to increase and maintain a happier and healthier mood by engaging in more pleasant activities.

**We hope you have found these sessions helpful and will in future keep using the skills you have listed as useful in this session.**

Please try to keep using the skills that work for you and refer back to this manual to remind yourself of the techniques discussed in these sessions. There are blank copies of the Thought, Behaviour and Pleasant Event records in the appendix for you to use in the future. Please also feel free to share this manual with anyone else involved in the care of your relative.

**Thank you for taking part**

Leader: Highlight to carer that there are blank copies of the Thought, Behaviour and Pleasant Event Records in the Appendix for continued use.



# **End of Manual**

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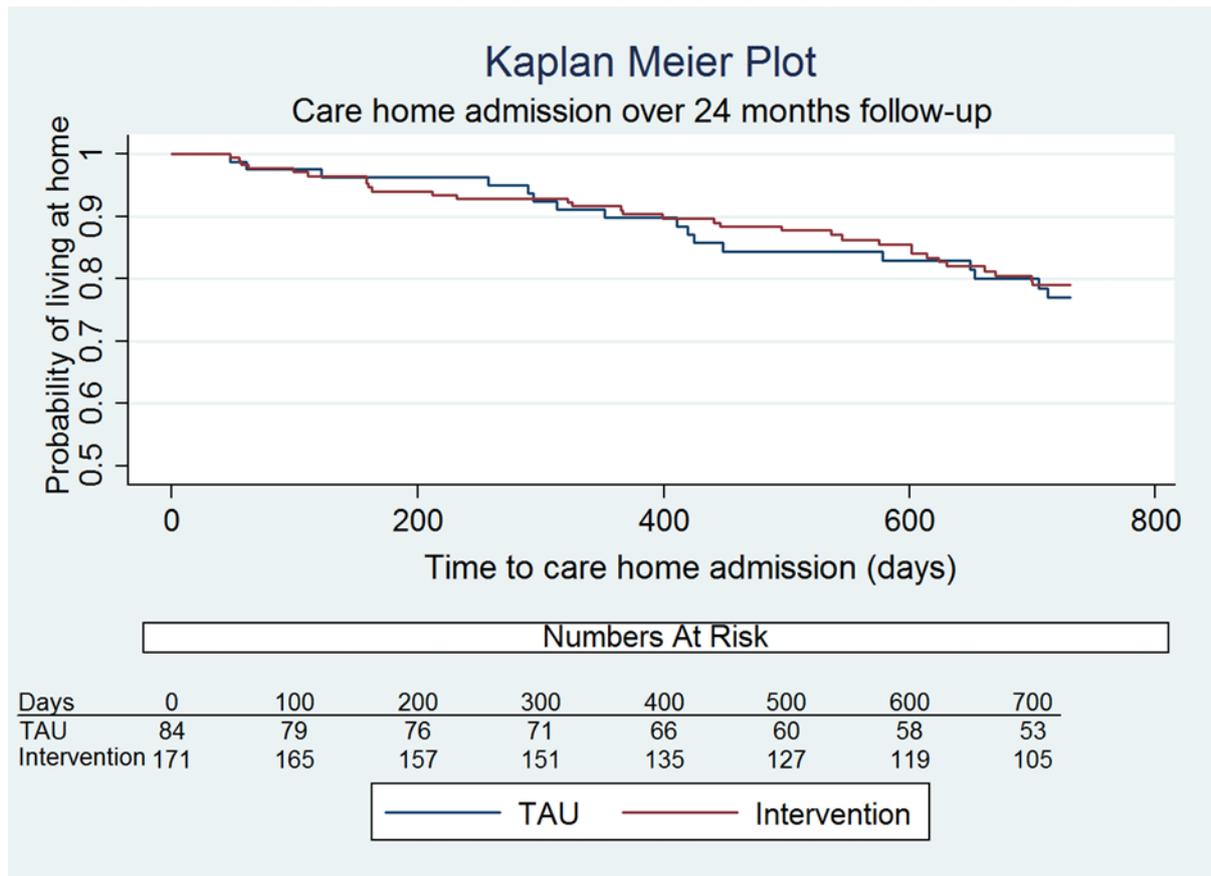
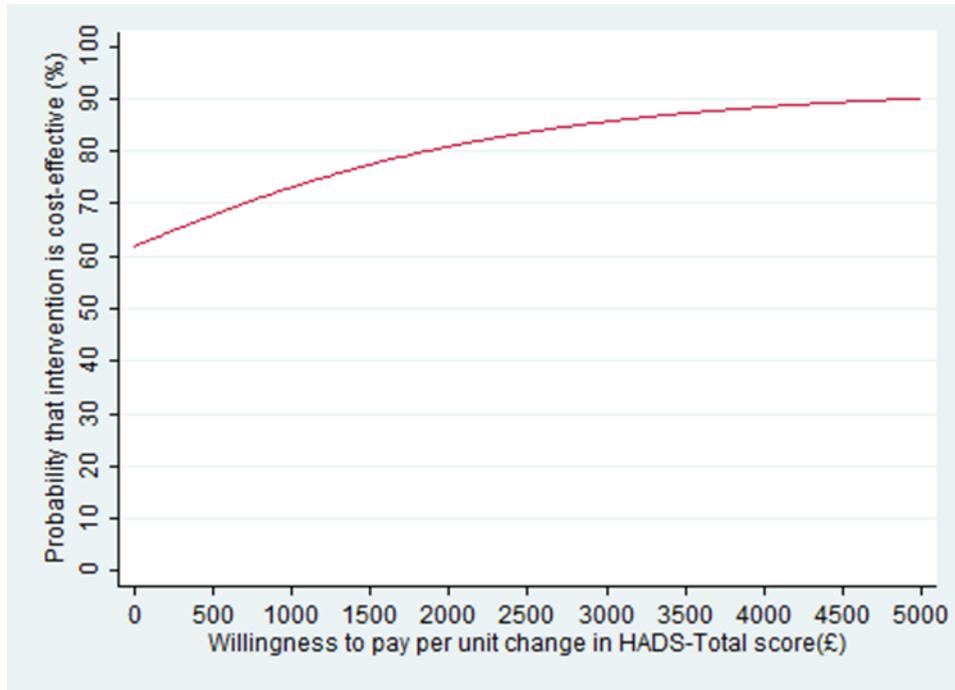
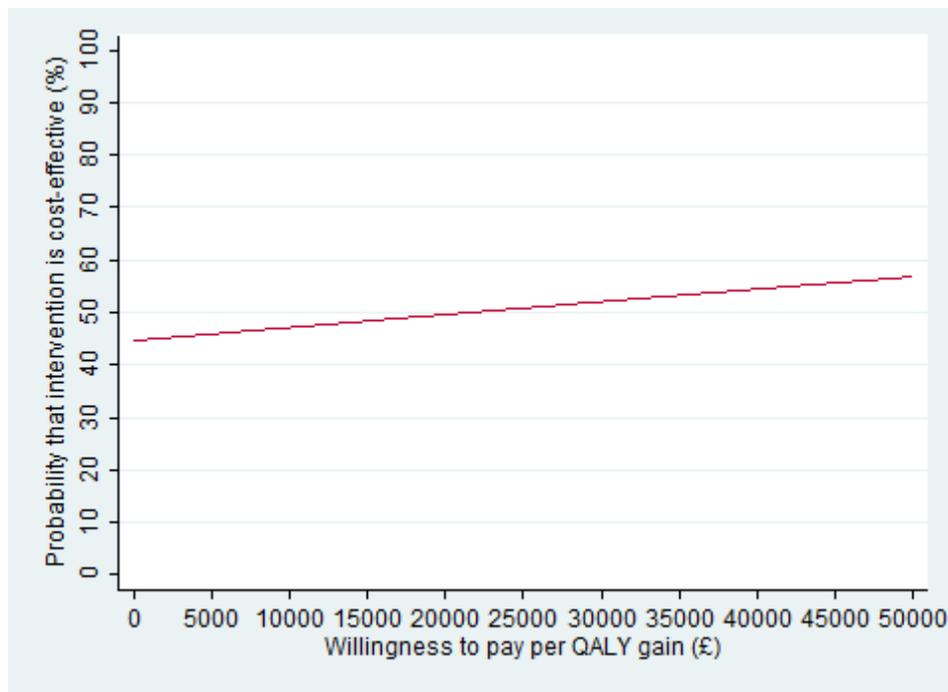


Figure A1 Kaplan Meier Plot of time to care home admission

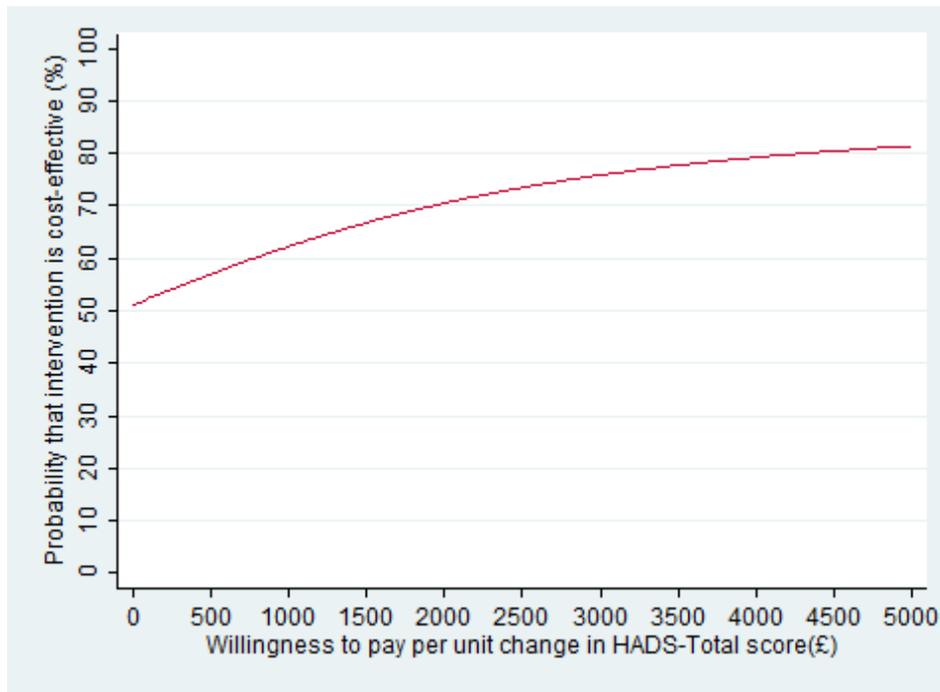
Figure A2: Cost-effectiveness acceptability curve for carer HADS-T gain over 24 months, main analyses



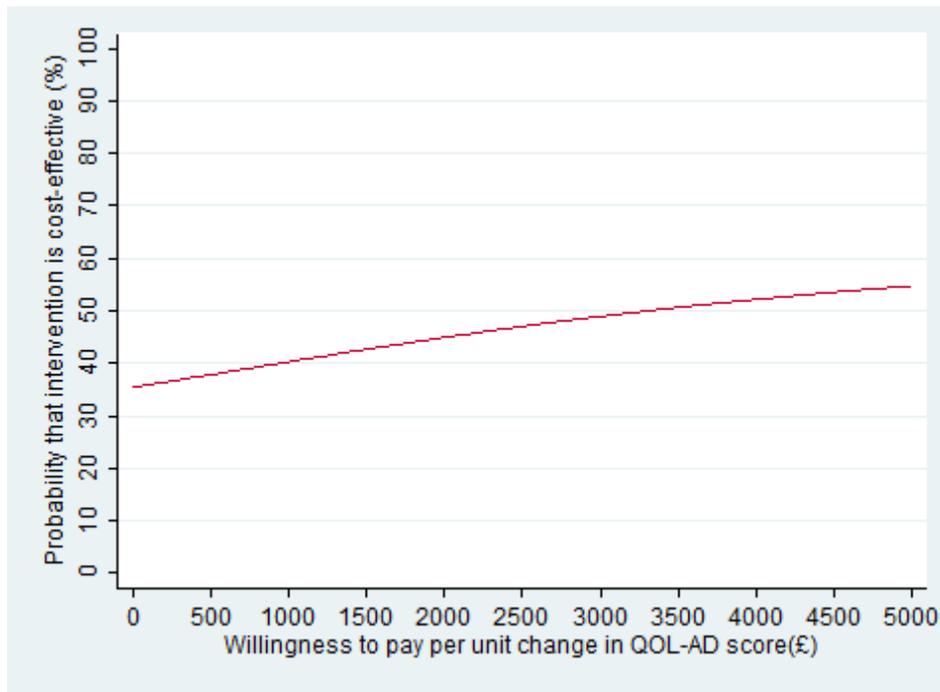
**Figure A3: Cost-effectiveness acceptability curve for carer QALY gain over 24 months, sensitivity analysis adjusting for imbalance in baseline characteristics**



**Figure A4: Cost-effectiveness acceptability curve for carer HADS-T outcome over 24 months, sensitivity analysis adjusting for imbalance in baseline characteristics**



**Figure A5: Cost-effectiveness acceptability curve for patient QOL-AD outcome over 24 months, sensitivity analysis adjusting for imbalance in baseline characteristics**



**Table A1 Carer use of health and social care services during the periods 9-12 months and 21-24 months**

| Services                               | 9-12 months         |                     | 21-24 months        |                     |
|--|---------------------|---------------------|---------------------|---------------------|
|  | TAU                 | Intervention        | TAU                 | Intervention        |
|  | % (n) using service |
| <b>Carers' service use</b>             |                     |                     |                     |                     |
|  | (n=67)              | (n=138)             | (n=64)              | (n=132)             |
| <b>Outpatient hospital services</b>    | 24.7% (19)          | 32.7% (50)          | 27.6% (24)          | 32.9% (53)          |
| <b>Admiral Nurse</b>                   | 3.9% (3)            | 3.3 % (5)           | 1.3% (1)            | 1.9% (3)            |
| <b>Chiropodist</b>                     | 6.5% (5)            | 11.1% (17)          | 6.5% (5)            | 8.5% (13)           |
| <b>Counsellor</b>                      | 3.9% (3)            | 3.3% (5)            | 2.6% (2)            | 1.9% (3)            |
| <b>Dentist</b>                         | 28.6% (22)          | 27.0% (40)          | 23.4% (18)          | 31.3% (48)          |
| <b>GP</b>                              | 42.9% (33)          | 35.2% (53)          | 48.1% (37)          | 44.4% (68)          |
| <b>Optician</b>                        | 10.4% (8)           | 8.5% (13)           | 16.4% (25)          | 16.4% (25)          |
| <b>Outreach worker</b>                 | 1.3% (1)            | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            |
| <b>Home care worker/Care attendant</b> | 0.0% (0)            | 0.7% (1)            | 3.9% (6)            | 0.0% (0)            |
| <b>Physiotherapist</b>                 | 1.3% (1)            | 2.1% (3)            | 1.4% (2)            | 1.4% (2)            |
| <b>District nurse</b>                  | 2.6% (2)            | 0.7% (1)            | 0.7% (1)            | 0.7% (1)            |
| <b>Support worker</b>                  | 0.0% (0)            | 0.7% (1)            | 0.7% (1)            | 0.7% (1)            |
| <b>Psychotherapist</b>                 | 0.0% (0)            | 0.7% (1)            | 0.0% (0)            | 0.7% (1)            |
| <b>Occupational Therapist</b>          | 0.0% (0)            | 0.7% (1)            | 0.7% (1)            | 0.7% (1)            |
| <b>Speech and language therapist</b>   | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Practice nurse</b>                  | 1.3% (1)            | 0.7% (1)            | 0.0% (0)            | 3.9% (6)            |
| <b>Cardiac nurse</b>                   | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Ambulance transport</b>             | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Social worker</b>                   | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Other services</b>                  | 2.6% (2)            | 0.7% (1)            | 0.0% (0)            | 2.7% (3)            |

**Table A2: Patient use of health and social care services during the periods 9-12 months and 21-24 months**

| Services                     | 9-12 months         |                     | 21-24 months        |                     |
|------------------------------|---------------------|---------------------|---------------------|---------------------|
|                              | TAU                 | Intervention        | TAU                 | Intervention        |
|                              | % (n) using service |
| <b>Patients' service use</b> | (n=67)              | (n=138)             | (n=64)              | (n=132)             |
| Inpatient hospital services  | 31.3% (21)          | 23.2% (32)          | 35.9% (23)          | 34.8% (46)          |
| Outpatient hospital services | 55.2% (37)          | 51.4% (71)          | 53.1% (34)          | 53.8% (71)          |
| Day hospital                 | 13.4% (9)           | 13.0% (18)          | 21.9% (14)          | 20.5% (27)          |
| Memory clinic                | 85.1% (57)          | 18.8% (26)          | 39.1% (25)          | 47.0% (62)          |
| CPN                          | 17.9% (12)          | 13.0% (18)          | 25.0% (16)          | 25.0% (33)          |
| District nurse               | 31.3% (21)          | 27.5% (38)          | 39.1% (25)          | 30.3% (40)          |
| Specialist nurse             | 17.9% (12)          | 15.9% (22)          | 20.3% (13)          | 22.7% (30)          |
| GP                           | 73.1% (49)          | 73.2% (101)         | 76.6% (49)          | 78.0% (103)         |
| Dentist                      | 38.8% (26)          | 31.2% (43)          | 43.8% (28)          | 40.9% (54)          |
| Optician                     | 32.8% (22)          | 26.8% (37)          | 31.3% (20)          | 27.3% (36)          |
| NHS direct                   | 14.9% (10)          | 13.0% (18)          | 23.4% (15)          | 21.2% (28)          |
| Occupational therapist       | 26.9% (18)          | 18.8% (26)          | 29.7% (19)          | 28.0% (37)          |
| Paramedic                    | 22.4% (15)          | 20.3% (28)          | 35.9% (23)          | 32.6% (43)          |
| Practice nurse               | 29.9% (20)          | 30.0% (40)          | 28.1% (18)          | 30.3% (40)          |
| Physiotherapist              | 22.4% (15)          | 17.4% (24)          | 26.6% (17)          | 27.3% (36)          |
| Other community doctor       | 17.9% (12)          | 13.0% (18)          | 23.4% (15)          | 20.5% (27)          |
| Chiropodist                  | 50.7% (34)          | 41.3% (57)          | 50.0% (32)          | 39.4% (52)          |
| Befriender                   | 17.9% (12)          | 15.2% (21)          | 26.6% (17)          | 23.5% (31)          |
| Home help                    | 37.3% (25)          | 37.0% (51)          | 46.9% (30)          | 45.5% (60)          |
| Laundry                      | 14.9% (10)          | 13.8% (19)          | 20.3% (13)          | 22.0% (29)          |
| Meals on wheels              | 23.9% (16)          | 13.8% (19)          | 23.4% (15)          | 22.7% (30)          |
| Night sitter                 | 16.4% (11)          | 11.6% (16)          | 21.9% (14)          | 21.2% (28)          |
| Sitting scheme               | 17.9% (12)          | 18.1% (25)          | 25.0% (16)          | 24.2% (32)          |
| Social worker                | 28.4% (19)          | 25.4% (35)          | 39.1% (25)          | 37.9% (50)          |
| Psychiatrist                 | 17.9% (12)          | 15.2% (21)          | 25.0% (16)          | 25.8% (34)          |
| Day care services            | 23.9% (16)          | 21.0% (29)          | 17.2% (11)          | 16.7% (22)          |

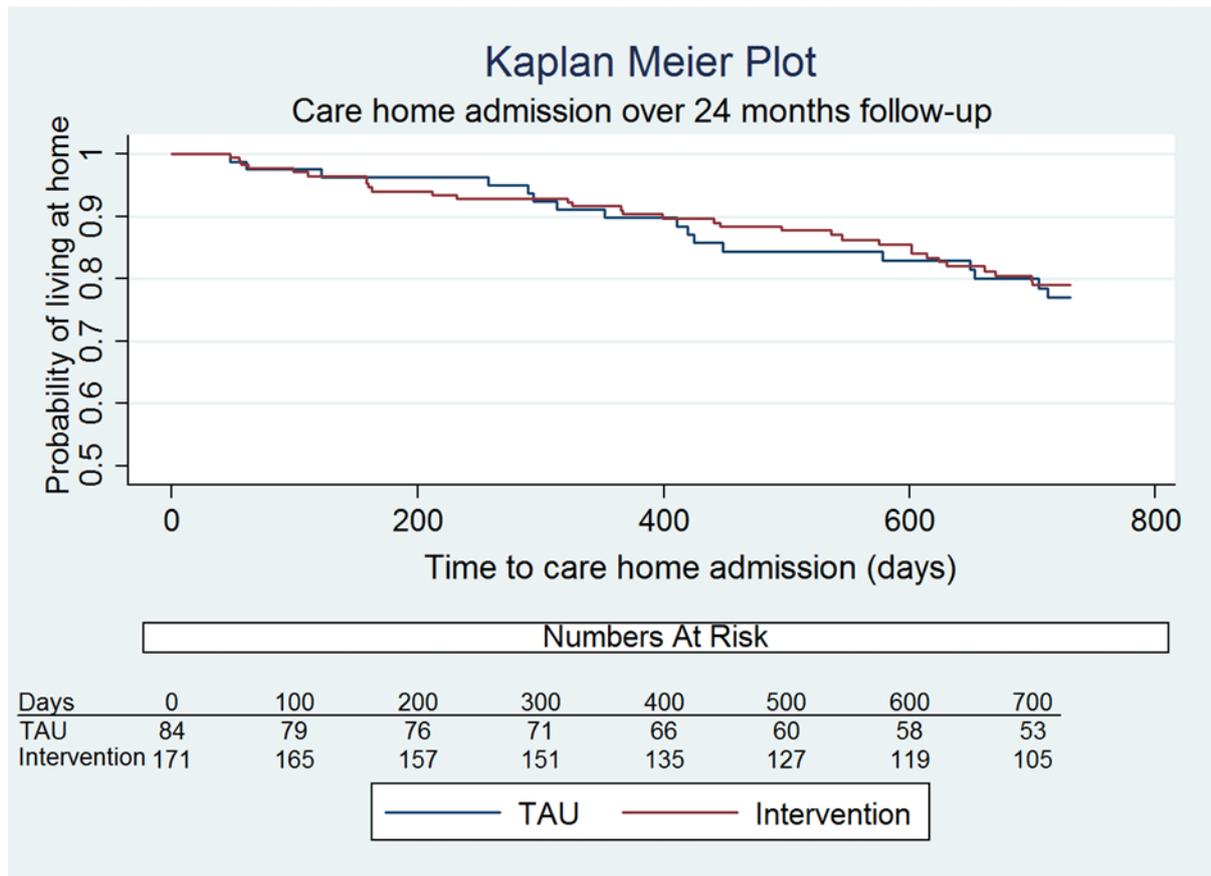
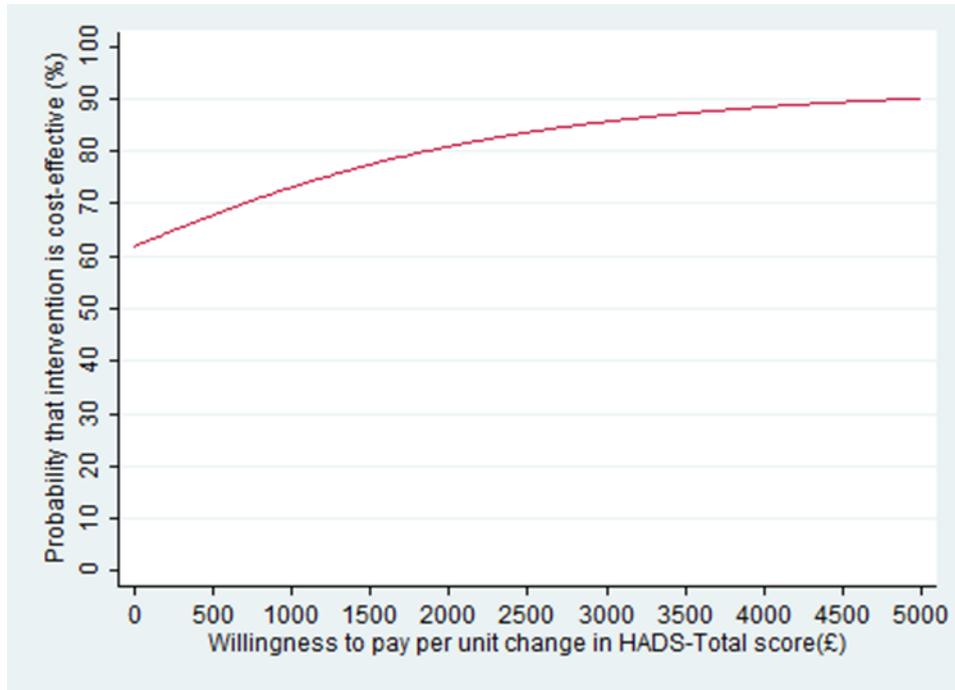
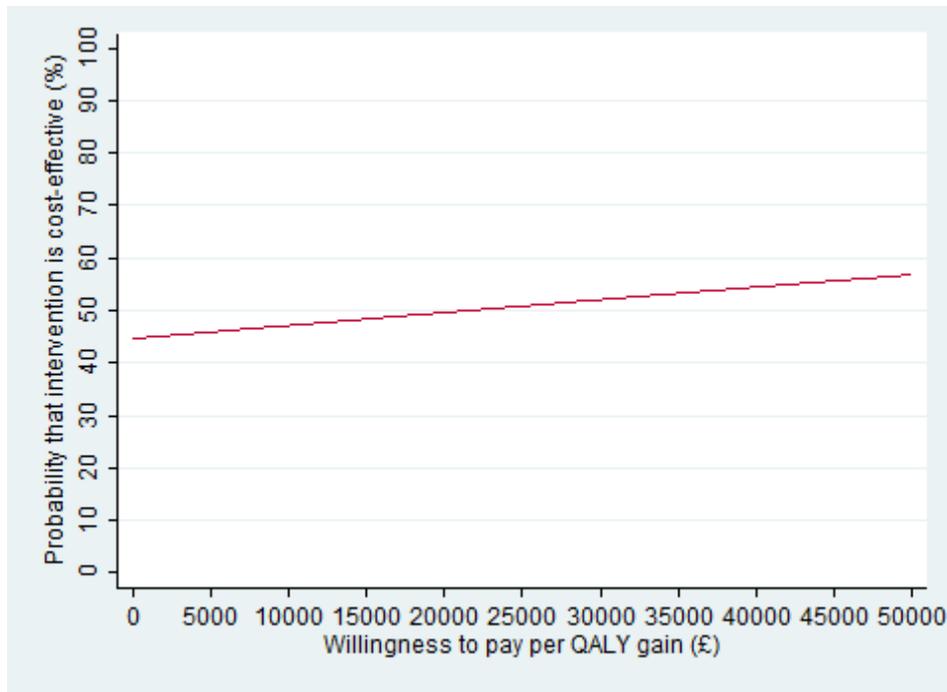


Figure A1 Kaplan Meier Plot of time to care home admission

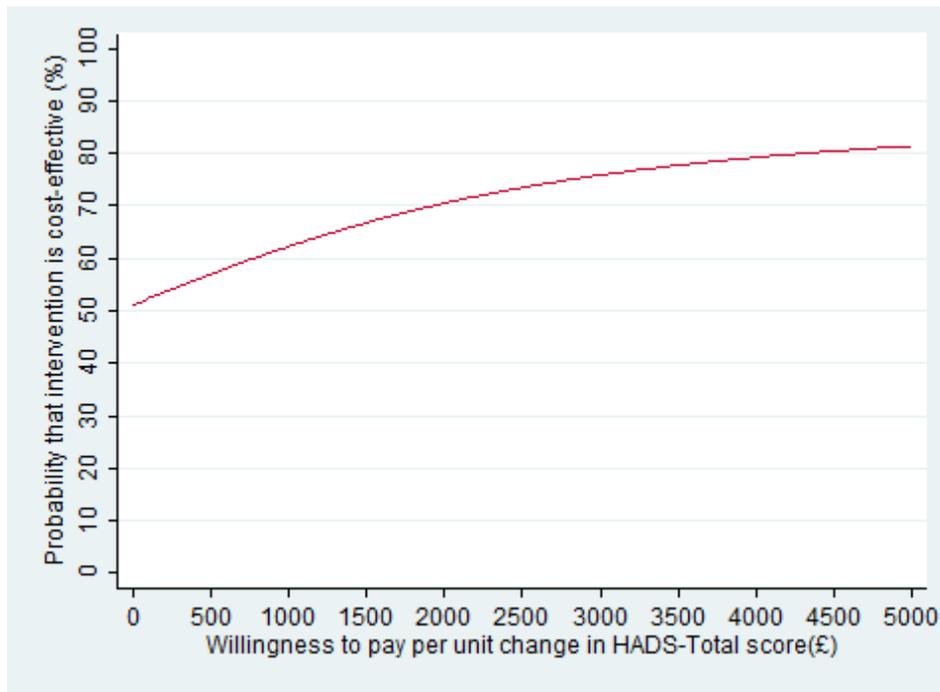
Figure A2: Cost-effectiveness acceptability curve for carer HADS-T gain over 24 months, main analyses



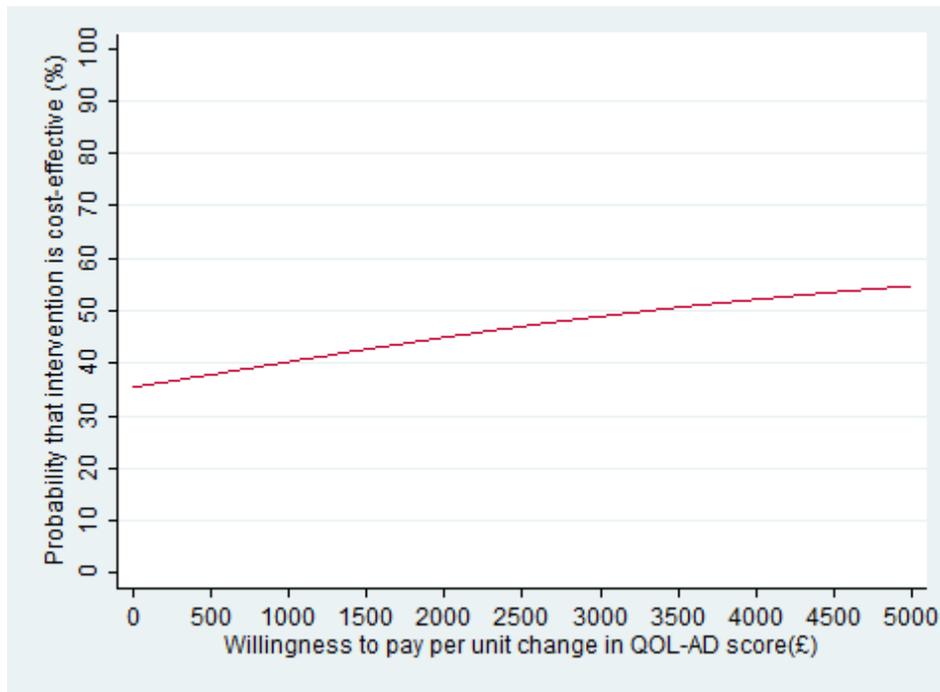
**Figure A3: Cost-effectiveness acceptability curve for carer QALY gain over 24 months, sensitivity analysis adjusting for imbalance in baseline characteristics**



**Figure A4: Cost-effectiveness acceptability curve for carer HADS-T outcome over 24 months, sensitivity analysis adjusting for imbalance in baseline characteristics**



**Figure A5: Cost-effectiveness acceptability curve for patient QOL-AD outcome over 24 months, sensitivity analysis adjusting for imbalance in baseline characteristics**



**Table A1 Carer use of health and social care services during the periods 9-12 months and 21-24 months**

| Services                               | 9-12 months         |                     | 21-24 months        |                     |
|--|---------------------|---------------------|---------------------|---------------------|
|  | TAU                 | Intervention        | TAU                 | Intervention        |
|  | % (n) using service |
| <b>Carers' service use</b>             |                     |                     |                     |                     |
|  | (n=67)              | (n=138)             | (n=64)              | (n=132)             |
| <b>Outpatient hospital services</b>    | 24.7% (19)          | 32.7% (50)          | 27.6% (24)          | 32.9% (53)          |
| <b>Admiral Nurse</b>                   | 3.9% (3)            | 3.3 % (5)           | 1.3% (1)            | 1.9% (3)            |
| <b>Chiropodist</b>                     | 6.5% (5)            | 11.1% (17)          | 6.5% (5)            | 8.5% (13)           |
| <b>Counsellor</b>                      | 3.9% (3)            | 3.3% (5)            | 2.6% (2)            | 1.9% (3)            |
| <b>Dentist</b>                         | 28.6% (22)          | 27.0% (40)          | 23.4% (18)          | 31.3% (48)          |
| <b>GP</b>                              | 42.9% (33)          | 35.2% (53)          | 48.1% (37)          | 44.4% (68)          |
| <b>Optician</b>                        | 10.4% (8)           | 8.5%(13 )           | 16.4% (25)          | 16.4% (25)          |
| <b>Outreach worker</b>                 | 1.3% (1)            | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            |
| <b>Home care worker/Care attendant</b> | 0.0% (0)            | 0.7% (1)            | 3.9% (6)            | 0.0% (0)            |
| <b>Physiotherapist</b>                 | 1.3% (1)            | 2.1% (3)            | 1.4% (2)            | 1.4% (2)            |
| <b>District nurse</b>                  | 2.6% (2)            | 0.7% (1)            | 0.7% (1)            | 0.7% (1)            |
| <b>Support worker</b>                  | 0.0% (0)            | 0.7% (1)            | 0.7% (1)            | 0.7% (1)            |
| <b>Psychotherapist</b>                 | 0.0% (0)            | 0.7% (1)            | 0.0% (0)            | 0.7% (1)            |
| <b>Occupational Therapist</b>          | 0.0% (0)            | 0.7% (1)            | 0.7% (1)            | 0.7% (1)            |
| <b>Speech and language therapist</b>   | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Practice nurse</b>                  | 1.3% (1)            | 0.7% (1)            | 0.0% (0)            | 3.9% (6)            |
| <b>Cardiac nurse</b>                   | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Ambulance transport</b>             | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Social worker</b>                   | 0.0% (0)            | 0.0% (0)            | 0.0% (0)            | 0.7% (1)            |
| <b>Other services</b>                  | 2.6% (2)            | 0.7% (1)            | 0.0% (0)            | 2.7% (3)            |

**Table A2: Patient use of health and social care services during the periods 9-12 months and 21-24 months**

| Services                     | 9-12 months         |                     | 21-24 months        |                     |
|------------------------------|---------------------|---------------------|---------------------|---------------------|
|                              | TAU                 | Intervention        | TAU                 | Intervention        |
|                              | % (n) using service |
| <b>Patients' service use</b> | (n=67)              | (n=138)             | (n=64)              | (n=132)             |
| Inpatient hospital services  | 31.3% (21)          | 23.2% (32)          | 35.9% (23)          | 34.8% (46)          |
| Outpatient hospital services | 55.2% (37)          | 51.4% (71)          | 53.1% (34)          | 53.8% (71)          |
| Day hospital                 | 13.4% (9)           | 13.0% (18)          | 21.9% (14)          | 20.5% (27)          |
| Memory clinic                | 85.1% (57)          | 18.8% (26)          | 39.1% (25)          | 47.0% (62)          |
| CPN                          | 17.9% (12)          | 13.0% (18)          | 25.0% (16)          | 25.0% (33)          |
| District nurse               | 31.3% (21)          | 27.5% (38)          | 39.1% (25)          | 30.3% (40)          |
| Specialist nurse             | 17.9% (12)          | 15.9% (22)          | 20.3% (13)          | 22.7% (30)          |
| GP                           | 73.1% (49)          | 73.2% (101)         | 76.6% (49)          | 78.0% (103)         |
| Dentist                      | 38.8% (26)          | 31.2% (43)          | 43.8% (28)          | 40.9% (54)          |
| Optician                     | 32.8% (22)          | 26.8% (37)          | 31.3% (20)          | 27.3% (36)          |
| NHS direct                   | 14.9% (10)          | 13.0% (18)          | 23.4% (15)          | 21.2% (28)          |
| Occupational therapist       | 26.9% (18)          | 18.8% (26)          | 29.7% (19)          | 28.0% (37)          |
| Paramedic                    | 22.4% (15)          | 20.3% (28)          | 35.9% (23)          | 32.6% (43)          |
| Practice nurse               | 29.9% (20)          | 30.0% (40)          | 28.1% (18)          | 30.3% (40)          |
| Physiotherapist              | 22.4% (15)          | 17.4% (24)          | 26.6% (17)          | 27.3% (36)          |
| Other community doctor       | 17.9% (12)          | 13.0% (18)          | 23.4% (15)          | 20.5% (27)          |
| Chiropodist                  | 50.7% (34)          | 41.3% (57)          | 50.0% (32)          | 39.4% (52)          |
| Befriender                   | 17.9% (12)          | 15.2% (21)          | 26.6% (17)          | 23.5% (31)          |
| Home help                    | 37.3% (25)          | 37.0% (51)          | 46.9% (30)          | 45.5% (60)          |
| Laundry                      | 14.9% (10)          | 13.8% (19)          | 20.3% (13)          | 22.0% (29)          |
| Meals on wheels              | 23.9% (16)          | 13.8% (19)          | 23.4% (15)          | 22.7% (30)          |
| Night sitter                 | 16.4% (11)          | 11.6% (16)          | 21.9% (14)          | 21.2% (28)          |
| Sitting scheme               | 17.9% (12)          | 18.1% (25)          | 25.0% (16)          | 24.2% (32)          |
| Social worker                | 28.4% (19)          | 25.4% (35)          | 39.1% (25)          | 37.9% (50)          |
| Psychiatrist                 | 17.9% (12)          | 15.2% (21)          | 25.0% (16)          | 25.8% (34)          |
| Day care services            | 23.9% (16)          | 21.0% (29)          | 17.2% (11)          | 16.7% (22)          |