Contents

North East London NHS
NHS Foundation Trust

Research and Development Office
North East London NHS Foundation Trust,
1st Floor Maggie Lilley Suite,
Goodmayes Hospital,
Barley Lane,
Goodmayes,
Essex, IG3 8XJ

Date: 19.04.2010

Dear Andrew Balfour,

Letter of access for research

As **an existing NHS employee** you do not require an additional honorary research contract with the North East London NHS Foundation Trust. We are satisfied that such checks as are necessary have been carried out by your employer. This letter confirms your right of access to conduct research through the North East London NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 19/04/10 and ends on 31/03/13 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct activities associated with such projects as you have received authorisation confirmed in writing from the Research and Development Director of the North East London NHS Foundation Trust. Please note that you cannot start the research until the Chief Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to the North East London NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this Trust, in particular that of an employee.

While undertaking research through the North East London NHS Foundation Trust, you will remain accountable to your employer Tavistock & Portman NHS Foundation Trust but you are required to follow the reasonable instructions of your nominated manager Laura Capellino in this Trust or those given on her behalf in relation to the terms of this right of access.

You must act in accordance with the North East London NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer Tavistock & Portman NHS Foundation Trust is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

You are required to co-operate with the North East London NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on North East London NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998.

Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The North East London NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by the North East London NHS Foundation Trust in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Please also ensure that while on the premises you wear your NHS ID badge at all times, or are able to prove your identity if challenged. Please note that this Trust accepts no responsibility for damage to or loss of personal property.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform your employer through its normal procedures. You must also inform the Research and Development Department and your nominated manager in North East London NHS Foundation Trust.

Yours sincerely

[redacted]

Sandeep Sandhu

Research and Development Manager North East London NHS Foundation Trust

NHS
National Patient Safety Agency

National Research Ethics Service

RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

After ethical review – guidance for sponsors and investigators

This document sets out important guidance for sponsors and investigators on the conduct and management of research with a favourable opinion from a NHS Research Ethics Committee. Please read the guidance carefully. A failure to follow the guidance could lead to the committee reviewing its opinion on the research.

1. Further communications with the Research Ethics Committee

1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.

2. Commencement of the research

2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2 In the case of research requiring site-specific assessment (SSA) the research must not commence at any site until the Committee has notified the Chief Investigator that the favourable ethical opinion is extended to the site.

2.3 The research must not commence at any site until the local Principal Investigator (PI) or research collaborator has obtained management permission or approval from the organisation with responsibility for the research participants at the site.

2.4 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay. It is open to the Committee to allow a further period of 12 months within which the research must commence.

2.5 Should the research not commence within 24 months, the favourable opinion may be suspended and the application would need to be re-submitted for ethical review.

3. Duration of ethical approval

3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

3.2 Where the research involves the use of “relevant material” for the purposes of the Human Tissue Act 2004, authority to hold the material under the terms of the ethical approval applies until the end of the period declared in the application and approved by the Committee.

4. Progress reports

4.1 Research Ethics Committees are expected to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be in the format prescribed by NRES and published on the website (see www.nres.npsa.nhs.uk/applicants/after-ethical-review/).

4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5. Amendments

5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

(a) the safety or physical or mental integrity of the trial participants
(b) the scientific value of the trial
(c) the conduct or management of the trial.

5.3 Notices of amendment should be in the format prescribed by NRES and published on the website, and should be personally signed by the Chief Investigator. The agreement of the sponsor should be sought before submitting the notice of amendment.

5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

5.5 Amendments that are not substantial amendments (“minor amendments”) may be made at any time and do not need to be notified to the Committee.

6. Changes to sites *(studies requiring site-specific assessment only)*

6.1 Where it is proposed to include a new site in the research, there is no requirement to submit a notice of amendment form to the Committee. The SSI Form together with the local Principal Investigator's CV should be submitted to the relevant local REC for site-specific assessment (SSA).

6.2 Similarly, where it is proposed to make significant changes in the management of a site (in particular, the appointment of a new PI), a notice of amendment form is not required. A revised SSI form for the site (together with the CV for the new PI if applicable) should be submitted to the relevant local REC for SSA.

6.3 The relevant local REC will notify the Committee whether there is any objection to the new site or Principal Investigator. The Committee will notify the Chief Investigator of its opinion within 35 days of receipt of the valid application for SSA.

6.4 For studies designated by the Committee as exempt from SSA, there is no requirement to notify the Committee of the inclusion of new sites.

7. Urgent safety measures

7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

8. Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

(a) results in death
(b) is life-threatening
(c) requires hospitalisation or prolongation of existing hospitalisation
(d) results in persistent or significant disability or incapacity
(e) consists of a congenital anomaly or birth defect
(f) is otherwise considered medically significant by the investigator.

8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

8.3 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by NRES and published on the website.

8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.

8.5 Reports should not be sent to other RECs in the case of multi-site studies.

9. Conclusion or early termination of the research

9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website.

10. Final report

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

11. Review of ethical opinion

11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.

Health Research Authority

NRES Committee London - Camberwell St Giles
Bristol Research Ethics Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1333
Facsimile: 0117 342 0445

05 March 2014

Mr Andrew Balfour
Tavistock Institute of Medical Psychology
70 Warren St
W1T 5PB

Dear Mr Balfour

Study title:	**Title: Living Together with Dementia: a Psychosocial Intervention for Couples**
REC reference:	**14/LO/0112**
Protocol number:	**N/A**
IRAS project ID:	**137317**

Thank you for your letter of 04 March 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Mr Thomas Fairman, nrescommittee.london-camberwellstgiles@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

- The committee agreed the research is connected with an impairing condition affecting persons lacking capacity, or with the treatment of the condition.

- The committee agreed that the research could not be carried out as effectively if it was confined to participants able to give consent.

- The REC noted that the research may benefit participants lacking capacity. Furthermore it is intended to provide knowledge of the causes or the treatment or care of their dementia. After discussion, the REC agreed that the risk to participants is likely to be negligible and the research will not significantly interfere with their freedom of action or privacy or be unduly invasive or restrictive.

- The REC have considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act to advise on whether participants lacking capacity should take part and on what their wishes and feelings would be likely to be if they had capacity.

- The REC agree that reasonable arrangements were in place for identifying personal consultees, and for appointing nominated consultees independent of the project where no person can be identified to act as a personal consultee.

- The REC reviewed the information to be provided to consultees about the proposed research and their role and responsibilities as a consultee. The REC was satisfied that the information was adequate to enable consultees to give informed advice about the participation of persons lacking capacity.

- The REC is satisfied that reasonable arrangements would be in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act.

I confirm that the Committee has approved this research project for the purposes of the Mental Capacity Act 2005. The Committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

I am pleased to confirm that the favourable opinion applies to the following research site(s), subject to site management permission being obtained prior to the start of the study at the site (see under ‘Conditions of the favourable opinion below’).

Research Site	Principal Investigator / Local Collaborator
Age UK Camden	Dr Maria Alicia Vicencio-Silva

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Please add, to clause 5 of both participant consent forms, the phrase ' ... and I consent to this'.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Advertisement	1	20 December 2013
Covering Letter		20 December 2013
Evidence of insurance or indemnity		20 December 2013
GP/Consultant Information Sheets	1	20 December 2013
Letter from Sponsor		18 December 2013
Letter of invitation to participant	1	20 December 2013
Other: CV - A Balfour		20 December 2013
Other: CV - Professor Fonagy		18 December 2013
Other: SSI Documents - Tavistock Centre for Couple Relationships		20 December 2013
Other: SSI Documents - Age UK Camden		20 December 2013
Other: Flyer, TCCR	2	31 January 2014
Other: Flyer Age UK	2	31 January 2014
Other: Independent Review from Professor Fearon		08 February 2014
Other: Email response to Professor Fearon		18 February 2014
Other: Email from Professor Fearon confirming changes have been made		28 February 2014
Participant Consent Form: Consultee Declaration Form TCCR	2	31 January 2014
Participant Consent Form: Consultee Declaration Form Age UK	2	31 January 2014
Participant Consent Form: Consent Form TCCR	2	31 January 2014
Participant Consent Form: Consent Form Age UK	2	31 January 2014
Participant Information Sheet: Consultee Information Sheet TCCR	2	31 January 2014
Participant Information Sheet: Consultee Information Sheet Age UK	2	31 January 2014
Participant Information Sheet: Information Sheet Competent Adult TCCR	2	31 January 2014
Participant Information Sheet: Information Sheet Competent Adult Age UK	2	31 January 2014
Participant Information Sheet: Information Sheet Vulnerable Adult TCCR	2	31 January 2014
Participant Information Sheet: Information Sheet, Vulnerable Adult Age UK	2	31 January 2014
Protocol	2	01 March 2014
REC application		18 December 2013
Response to Request for Further Information		04 March 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/LO/0112	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

[redacted]

Mr John Richardson
Chair

Email: nrescommittee.london-camberwellstgiles@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

“After ethical review – guidance for researchers”

Copy to: *Dr David Hewison*
Ms Tumi Kaminskas, CNWL/Noclor

NRES Committee London - Camberwell St Giles

Attendance at Sub-Committee of the REC meeting on 07 March 2014

Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Ana Bajo	Research Psychologist	Yes	
Mrs Jennifer Bostock	Philosopher of Psychiatry	Yes	
Ms Sally Gordon Boyd	Medical Ethicist	Yes	
Mr John Richardson	Retired Director of COREC; Ecumenical Officer for Churches Together in South London	Yes	
Mr Evan Stone QC	Retired Queen's Counsel	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Miss Elizabeth Hearn	REC Assistant

NHS
Health Research Authority

NRES Committee London - Camberwell St Giles
Bristol Research Ethics Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT
Telephone: 0117 3421385

28 March 2014

Mr Andrew Balfour
Tavistock Institute of Medical Psychology
70 Warren St
W1T 5PB

Dear Mr Balfour

Study title:	**Title: Living Together with Dementia: a Psychosocial Intervention for Couples**
REC reference:	**14/LO/0112**
Protocol number:	**N/A**
IRAS project ID:	**137317**

Thank you for your letter of 7th March 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 05 March 2014.

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant Consent Form: LTWD Consent Form TCCR	3	06 March 2014
Participant Consent Form: LTwD Consultee Declaration Form TCCR	3	06 March 2014
Participant Consent Form: LTWD Consent Form Age UK	3	06 March 2014
Participant Consent Form: LTwD Consultee Declaration Age UK	3	06 March 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Advertisement	1	20 December 2013
Covering Letter		20 December 2013
Evidence of insurance or indemnity		20 December 2013
GP/Consultant Information Sheets	1	20 December 2013

Letter from Sponsor		18 December 2013
Letter of invitation to participant	1	20 December 2013
Other: CV - A Balfour		20 December 2013
Other: CV - Professor Fonagy		18 December 2013
Other: SSI Documents - Tavistock Centre for Couple Relationships		20 December 2013
Other: SSI Documents - Age UK Camden		20 December 2013
Other: Flyer, TCCR	2	31 January 2014
Other: Flyer Age UK	2	31 January 2014
Other: Independent Review from Professor Fearon		08 February 2014
Other: Email response to Professor Fearon		18 February 2014
Other: Email from Professor Fearon confirming changes have been made		28 February 2014
Participant Consent Form: LTWD Consent Form TCCR	3	06 March 2014
Participant Consent Form: LTwD Consultee Declaration Form TCCR	3	06 March 2014
Participant Consent Form: LTWD Consent Form Age UK	3	06 March 2014
Participant Consent Form: LTwD Consultee Declaration Age UK	3	06 March 2014
Participant Information Sheet: Consultee Information Sheet TCCR	2	31 January 2014
Participant Information Sheet: Consultee Information Sheet Age UK	2	31 January 2014
Participant Information Sheet: Information Sheet Competent Adult TCCR	2	31 January 2014
Participant Information Sheet: Information Sheet Competent Adult Age UK	2	31 January 2014
Participant Information Sheet: Information Sheet Vulnerable Adult TCCR	2	31 January 2014
Participant Information Sheet: Information Sheet, Vulnerable Adult Age UK	2	31 January 2014
Protocol	2	01 March 2014
REC application		18 December 2013
Response to Request for Further Information		04 March 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/LO/0112 Please quote this number on all correspondence

Yours sincerely

[redacted]

Miss Elizabeth Hearn
REC Assistant

E-mail: nrescommittee.london-camberwellstgiles@nhs.net

Copy to: *Dr David Hewison,*
Ms Tumi Kaminskas, CNWL/Noclor

NHS
Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048055

21 June 2016

Mr Andrew Balfour
Tavistock Institute of Medical Psychology
70 Warren St
W1T 5PB

Dear Mr Balfour

Study title:	**Title: Living Together with Dementia: a Psychosocial Intervention for Couples**
REC reference number:	**14/LO/0112**
SSA reference number:	**16/LO/1089**
Protocol number:	**N/A**
IRAS project ID:	**137317**

The REC gave a favourable ethical opinion to this study on 05 March 2014.

Following site-specific assessment by the Committee, I am pleased to confirm the extension of the favourable opinion to the new site(s) and investigator(s) listed below:

Research site	*Principal Investigator / Local Collaborator*
St Joseph's Hospice	Ms Valentina Hamilton

The favourable opinion is subject to management permission or approval being obtained from the host organisation prior to the start of the study at the site concerned.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/LO/0112	**Please quote this number on all correspondence**

Yours sincerely

[redacted]

Aliki Sifostratoudaki
REC Manager

Email: nrescommittee.london-camberwellstgiles@nhs.net

Copy to: *Ms Tumi Kaminskas, CNWL/Noclor Dr David Hewison,*

NHS
Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Tel: 0207 104 8037

<u>Please note: This is the favourable opinion of the REC only and does not allow</u> the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

24 March 2017

Mr Andrew Balfour
Tavistock Institute of Medical Psychology
70 Warren St
W1T 5PB

Dear Mr Balfour

Study title:	**Title: Living Together with Dementia: a Psychosocial Intervention for Couples**
REC reference:	**14/LO/0112**
Protocol number:	**N/A**
Amendment number:	**3**
Amendment date:	**18 November 2016**
IRAS project ID:	**137317**

The above amendment was reviewed at the meeting of the Sub-Committee held on 13 March 2017 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*

Letters of invitation to participant [17112016LetterInvitingCamdenCoupleToFollowUpInterview.docx]	1	17 November 2016
Letters of invitation to participant [17112016CamdenFollowUpInterviewReplySlip.docx]	1	17 November 2016
Notice of Substantial Amendment (non-CTIMP) [AmendmentForm.pdf]	3	18 November 2016
Participant consent form [17112016ParticipantConsentFormCamdenFollowUpInterview.docx]	1	17 November 2016
Participant information sheet (PIS) [17112016ParticipantInfoSheetCamdenFollowUpInterview.docx]	1	17 November 2016
Research protocol or project proposal [20170130LTwDProtocolVersion2]	2	30 January 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

14/LO/0112: Please quote this number on all correspondence

Yours sincerely

Pp [redacted]

Mr John Richardson
Chair

E-mail: nrescommittee.london-camberwellstgiles@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Tumi Kaminskas, CNWL/Noclor*
Dr David Hewison

London - Camberwell St Giles Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 10 March 2017

Committee Members:

Name	*Profession*	*Present*	*Notes*
Ms Biddy Gillman	Retired Biology Teacher/ Head of year 12	Yes	
Mr John Richardson (Chair)	Retired Director of COREC: former Ecumenical Officer for Churches Together in South London	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Alex Martin	REC Assistant

North East London NHS
NHS Foundation Trust

Research and Development Office
North East London NHS Foundation Trust,
1st Floor Maggie Lilley Suite,
Goodmayes Hospital,
Barley Lane,
Goodmayes,
Essex, IG3 8XJ

Date: 19.04.2010

Dear Andrew Balfour,

Re: **Guided Participation and Awareness: Developing Interventions for Older Couples Living with Alzheimer's Disease**
R&D Reference Number: 2282

I am pleased to inform you that the above named study has been granted approval and indemnity by Professor Martin Orrell, Director of Research and Development North East London NHS Foundation Trust. You must act in accordance with the North East London NHS Foundation Trust's policies and procedures, which are available to you upon request, and the Research Governance Framework. Should any untoward events occur, it is **essential** that you contact your Trust supervisor and the Research and Development Office immediately. If patients or staff are involved in an incident, you should also contact the Governance and Assurance department, in Goodmayes Hospital, and complete the Incident and Reporting Form, namely the IR1 form.

You must inform the Research and Development Office if your project is amended and you need to re-submit it to the ethics committee or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records.

You are also required to inform the Research and Development Office of any changes to the research team membership, or any changes in the circumstances of investigators that may have an impact on their suitability to conduct research.

Yours sincerely,

[redacted]

Sandeep Sandhu

Research and Development Manager, North East London NHS Foundation Trust

National Institute for Health Research

Clinical Research Network
North Thames

NHS PERMISSION FOR RESEARCH (R&D Approval)

06 May 2014

Dear Colleagues,

IRAS ID: **137317**
REC Ref: **14/LO/0112**
Study Title: **Living Together with Dementia: a Psychosocial Intervention for Couples.**

NHS permission for the above research has been granted for the following NHS Trusts and/or Independent Contractors:

Trust/Independent Contractor	Name of PI / LC	Date of Permission
Camden & Islington NHS Foundation Trust Camden Services for Ageing and Mental Health	**Dr. Stefania Battistella**	06 May 2014
Tavistock Centre for Couple Relationships Tavistock Institute of Medical Psychology	**Mr. Andrew Balfour**	06 May 2014

Permission is based on the REC favourable opinion given on **05 March 2013**.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP, and the policies and procedures of the Trust. http://www.crn.nihr.ac.uk/about_us

Permission is only granted for the activities for which a favourable opinion has been given by the REC.

Specific Conditions of Permission (if applicable)

Please ensure that all amendments are notified to the Permission Centre governance office in line with current NIHR guidance[1]. Please also ensure that the office is notified of any changes in status to the project, for example if the site should close before the stated end date and of any urgent safety measures enacted.

Yours sincerely,

[redacted]

Pushpsen Joshi
Research Operations Manager

Cc: Chief Investigator, Sponsor Contact, Research Site R&D Office/s

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[1] http://www.crn.nihr.ac.uk/Resources/NIHR%20CRN%20CC/CSP/20130503_CSP%20amendments%20guidance_v1.0Final.pdf

THE TAVISTOCK CENTRE FOR COUPLE RELATIONSHIPS
Training ▪ Counselling ▪ Psychotherapy ▪ Research

NHS
City and Hackney
Clinical Commissioning Group

LIVING TOGETHER WITH DEMENTIA (LTwD)
MAY 2016 TRAINING PROGRAMME

Aims and Learning Outcomes of the Programme

Programme contents:

1. Working with Couples
2. Attachment
3. Video-based Approaches
4. The Living Together with Dementia Couple Intervention

Training Timetable

Supervision Groups

Documents relating to LTwD will be provided including

- All Clinical Papers referenced in the programme
- Relevant documentation including Patient Information Sheets, Consent forms and Outcome Measures

Living Together with DementiaTraining (LTwD)

Main Aims

a) To give participants a thorough theoretical and practical grounding in this psychosocial intervention enabling them to act as an expert resource in the clinical field of dementia care with couples

b) To enable participants to deliver this intervention to couples when one partner has dementia by enhancing and developing participants' existing clinical skills and knowledge base acquired from previous training and experience

c) To develop participants' understanding of the impact of dementia on the couple relationship and preserve the critically important couple bond thus increasing closeness between the couple and their resilience to cope better and for longer

d) To enable participants to use routine outcome measures for the purpose of assessment and evaluation

Learning Outcomes

At the end of this training and supervised clinical practice participants will be able to:

Knowledge

1. Demonstrate a knowledge and understanding of Living Together with Dementia and its application to couples when one partner has dementia
2. Demonstrate a knowledge and understanding of the concepts, research and theoretical paradigms that have contributed to and informed the development of the LTwD intervention

Thinking Skills

3. Demonstrate a questioning attitude to technique and concepts in working with couples and be able to draw on and discuss in supervision the integration of psychodynamic concepts with LTwD concepts and techniques
4. Use their reflective capacity to critique their own and other clinician's work in the light of the LTwD approach

Clinical Skills

5. Undertake assessment and formulation to determine when LTwD is indicated as the treatment of choice
6. Apply and demonstrate in delivering LTwD an attunement to the couple's experience thereby providing containment and support for the couple

Teaching/Learning Methods

A blended learning approach will be adopted incorporating theory presentations, discussions, role plays and filmed vignettes from couples participating in the intervention.
Clinical and theoretical papers and the LTwD Training Handbook will be used as a basis for the training.

Structure

Two consecutive days training followed by a third day which will focus on clinical application. There will be fortnightly group supervision lasting 75-90 minutes to support trainees undertaking two cases in order to gain accreditation in delivering the LTwD intervention

Content

An overview of concepts informing Living Together with Dementia including Couple Psychotherapy, Attachment, Theory and Research and Video based approaches to clinical intervention

1. An overview of the research on the Couple Relationship in Dementia

2. Detailed presentation and examination of the intervention using video clips, role play and group discussion

Programme

1. Couple Psychotherapy

Learning Outcomes:

a) To develop knowledge and understanding of some key concepts that apply to the psychodynamic conceptualization of the adult couple relationship and couple therapy.

b) To develop knowledge and understanding of the nature of particular interactive elements in therapeutic work with couples – transference and counter transference responses

c) To develop knowledge and understanding of how partners have made use of unconscious processes in their relationship- including shared defences, “couple fit” and the relationship as a “psychological container”

d) Knowledge and understanding of how dementia may disrupt this and stimulate early feelings of dependency and loss

e) Knowledge and understanding of how to intervene with partners that promote communication by facilitating closeness and sensitivity

Reading

Ruszczynski, S. (1993), Thinking about and working with couples. *Psychotherapy with Couples: Theory and Practice at the Tavistock Institute*. Ruszczynski, S. London, Karnac. 70-96.

2. Attachment Theory

Learning Outcomes:

a) Knowledge and understanding of main theoretical framework and concepts of Attachment Theory including its roots in infancy and its relevance to couples when one partner has dementia

b) Knowledge and understanding of the links between attachment status and reflective self function and the relevance to couples when one partner has dementia

c) Knowledge and understanding of the concepts of internal working models and affect regulation in couples when one partner has dementia

d) Knowledge and understanding of how attachment status influences presentation and clinical technique in the clinical setting

e) Knowledge and understanding of how these clinical skills fit into the characteristics of LTwD acquired through application of the intervention

Reading

Holmes, J. (2001) The Six Domains of Attachment Theory. *The Search for the Secure Base: Attachment Theory and Psychotherapy*. London: Brunner-Routledge. Chapter 2, pp 6-19.

Browne, C. J, & Shlosberg, E. (2006) Attachment theory, ageing and dementia: A review of the literature. *Ageing and Mental Health,* 10 (2): 134-142

3. Video based Approaches

Learning Outcomes:

a) To enable participants to understand how video based methods can be made use of in working with older couples when one partner has dementia to enhance communication

b) Knowledge and understanding of how this links with developing reflective function and responsiveness in the couple when one partner has dementia

c) To develop competence in video recording of couples engaged in an ordinary task and editing clips for discussion with the couple to promote more satisfying interpersonal engagement for the couple

d) To develop self efficacy in partner with dementia and carer partner responsiveness

Reading

Woodhead, J.,Bland, K., & Baradon, T. (2006.) 'Focusing the lens: The use of digital video in the practice and evaluation of parental infant psychotherapy'.
Infant Observation, August 2006; 9(2): 139_15. Routledge

4. The Living Together with Dementia Module

Learning Outcomes*:*

a) Knowledge and understanding of how to identify and undertake assessment and formulation to determine couples suitable for the intervention

b) Knowledge and understanding of the challenges in introducing the intervention, obtaining informed consent and engaging the couple

c) Knowledge and understanding to sensitively manage time spent with partners separately and together

d) Demonstrate knowledge from theoretical concepts from Couple Psychotherapy and Attachment theory to hold a couple focus, provide containment and allow opportunity to explore the experience of the couple facing an ending to the therapy.

Reading

Balfour, A.W. (2006). Thinking about the Experience of Dementia: the Importance of the Unconscious. *Journal of Social Work Practice, 20, 3,* 329-347.

Martindale, B. (1989) Becoming dependent again: The fears of some elderly persons and their younger Therapists. *Psychoanalytic Psychotherapy* Volume 4, Issue 1

LTwD Training Timetable

Day 1	**Subject**	**Staff**	**Room No.**
Friday 17th June 2016			TR NEW STREET
9.45 – 10.00	Registration and refreshments		
10.00 – 11.15	Welcome, introductions and outline of Living Together with Dementia training and intervention	Andrew Balfour Liz Salter Sabah Khan	
11.15 – 11.30	BREAK		
11.30 –12.00	Attachment: a brief overview	Liz Salter	
12.30 – 1.15	Film: Attachment and Separation Discussion		
1.15 – 2.15	LUNCH PROVIDED		
2.15 – 3.00	Group work		
3.30 – 3.45	TEA		
3.45 – 4.15	Attachment and Couples with Dementia	Andrew Balfour (Lecture/discussion)	
4.15 – 4.30	Closing comments		

Day 2	Subject	Staff	Room No.
Friday 1st July 2016			TR NEW STREET
9.45 – 10.00	Registration and refreshments		
10.00 – 11.15	Thinking about couple dynamics and the challenges facing couples when one partner has dementia	Andrew Balfour	
11.15 – 11.30	BREAK		
11.30 – 12.00	Assessment process	Liz Salter	
12.00 – 12.30	Video based approaches to therapy	Liz Salter	
12.30 –1.00	Application: video clips and case examples/discussion Film: The carer's experience	Andrew Balfour	
1.00 – 1.45	LUNCH PROVIDED		
1.45 – 2.15	Using the LTwD Manual: Delivering the intervention - to include: *Documentation- Patient Information Sheets and relevant consent forms. Lone worker policy. Site specific considerations*	Liz Salter	
2.15 – 2.30	Learning Hub/USB	Heather Williamson	
2.30 – 3.50	Video recording, editing and storage	Sabah Khan	
3.50 – 4.15	Film presentations		
4.15 – 4.30	Closing thoughts/feedback		

Supervision	Subject	Staff	Room No.
Ongoing supervision	Case Work with Couples & Fortnightly Group Supervision	Andrew Balfour Liz Salter Sabah Khan	

NHS

Living Together with Dementia:
A service for couples in City and Hackney

TRAINING, POLICY & RESEARCH
TAVISTOCK
RELATIONSHIPS

City and Hackney
Clinical Commissioning Group

Living Together with Dementia
A Relationship Intervention for Couples in City and Hackney

HANDBOOK

A treatment manual for practitioners to deliver the intervention ‘Living Together with Dementia’ to couples where one partner has dementia.

Andrew Balfour

Contents

PART 1.

LIVING TOGETHER WITH DEMENTIA

1. INTRODUCTION

Living Together with Dementia (LTwD) has been developed to improve the life experience of couples where one partner has a dementia by fostering more satisfying interpersonal engagement in such couples and strengthening their resilience in managing the illness together. The intervention draws on a range of psychotherapeutic approaches including couple psychotherapy, attachment theory and video-based methods.

It is an 8 session intervention: an assessment, followed by six sessions and then a further session to evaluate the outcome of the intervention and to re-assess the couple's needs. This may also include further intermittent follow-up, on a 4- 8 week basis. The intervention is delivered by trained therapists, clinical psychologists, psychiatrists, nurses, counsellors, social workers, occupational therapists, and other professionals who are experienced in dementia care.

Advantages of LTwD

The LTWD approach is unique in that it targets the person with dementia and their partner, focussing on the relationship between them. It aims to help people living with dementia to manage the trauma of the diagnosis, the loss and the changes it brings and to maintain, or recover, the protective aspects of the relationship – which research indicates are to do with emotional contact and understanding, positive interactions, shared activity and involvement and the overall quality of the relationship between the partners.

As it is an innovation we will be evaluating the intervention and incorporating couples' and trainees' experience and feedback to refine and further develop the intervention. All sites delivering LTwD have undergone and obtained NHS Research Ethics & R & D approval.

2. AIMS OF LTwD

- To increase understanding, sensitivity and improve communication between spouse, carer and the person with dementia.

- Preserve the critically important relationship between spouse carer and person living with dementia, thereby reducing carer stress and breakdown.

- Increase the closeness in the couple relationship, the capacity to engage together in everyday activities, and to address negative cycles of interaction and withdrawal and secondary disablement of the person with dementia.

- Find strategies for both partners to learn to become more inter-dependent, rather than the partner with dementia simply becoming dependent earlier and more completely than they need to.

- Provide support and containment for both partners in coming to terms with the diagnosis, making optimal adjustment, maximising the potential for engagement and activity, and addressing the challenge of social isolation and the adverse consequences on mental and physical health stemming from such isolation

3. RATIONALE FOR LTwD

The stark facts are these: **at the age of 60 we have a one in twenty chance of developing dementia, at 80 this rises to one in five**. Approximately 700 000 people living in the UK currently have dementia (NICE 2004), and with an ageing population, the number of older people living with dementia is set to increase exponentially. Many people diagnosed with dementia are looked after by their partners at home, at least in the early stages. The cost of this in financial terms is huge, and in human terms it is profound though difficult to quantify (Balfour 2006). The burden of cost on the carer is more than economic as a recent Government strategy document for carers (DoH 2008) observes: **"carer provision can place a mental and physical burden upon some of the 6 million carers in England leading to poorer outcomes and health inequalities".**

a) Many governments stress the importance of early detection in their dementia policies, and in the UK this is the focus of the National Dementia Strategy (2008). As a consequence of increased awareness of the dementias in health professionals and others, and improved diagnostic procedures, we have a new cohort of people, diagnosed much earlier with dementia.

b) The experience of receiving a diagnosis of dementia is profoundly difficult, and yet there is a dearth of specialist therapeutic services set up to address the psychological impact of receiving such a diagnosis. There is the potential for a 'care gap' (Iliffe and Manthorpe, 2004) when people are left with a diagnosis but little support during the early stages of their dementia.

c) The double-stigma of old age and dementia appear to be associated with the fostering of the belief, apparent in the services across Europe, that nothing can be done in early dementia (Vernooij-Dassen et al. 2005) thus perhaps unfairly disqualifying people with dementia from rehabilitation services (Moniz-Cook and Manthorpe, 2009)

d) There are studies showing that people with dementia living at home and in care homes are capable of learning new information (Bird 2000; Camp, Bird and Cherry 2000; Clare and Woods 2001.) and that they may have 'cognitive reserve' suggesting that the brain may actively attempt to compensate for the challenge represented by damage due to dementia (Stern2007; Moniz-Cook and Manthorpe, 2009).

e) Interventions that have developed have tended to concentrate on the position of family carers and this has tended to overshadow efforts to develop approaches which directly include people with dementia themselves, and yet there is evidence that the most effective interventions are those that include both the person with dementia and their family caregiver.

f) There is no simple relationship between disease stage and the extent of the burden experienced by the spouse carer and there is evidence that the maintenance of the person with dementia in the community has more to do with the attitudes and well being of the spouse carer than factors such as severity of the disease itself.

g) Where family members become distressed, few options for the continued support of the person with dementia in the home exist. One consequence of this is inappropriate and undesired admission to care homes, rather than tailored community-based services of the sort that are increasingly available for younger people with disabilities across Europe (Moniz-Cook, 2009)

h) This is supported by studies that show that (i) training carers delays admission to nursing home by an average of 20 months (Brodaty, Gresham & Luscome 1997); (ii) providing carers with emotional support delays admission to residential care by an average of 500 days (Mittelman, Hayley, Clay & Roth 2006).

i) Loss of intimacy is also associated with carer spouse depression, and low levels of interaction between the partners in the marriages of people with dementia predict the move to hospital care. One researcher (Bull, 1998) comments, "…the feeling of the loss of the partner is associated with the loss of sharing or interaction with the partner. Some carers expressed this loss of communication as: `if only I knew what he/she was thinking`" (also see Lewis, 1998; Morris, Morris & Britton, 1988: Murray, Schneider, Banerjee, & Mann, 1999).

j) Emotional factors are therefore crucial – and the carer's experience of loss of intimacy and understanding of their partner with dementia has been found to be one important factor. Loss of intimacy is associated with carer spouse depression (Morris, Morris, & Britton, 1988*a* and Morris, Morris, & Britton, 1988*b*), and low levels of interaction between the partners in the marriages of people with dementia predict the move to hospital care (Wright 1991, 1994).

k) Indeed, the importance of developing an intervention for couples living with dementia is illustrated by the finding of Wright (1991, 1994) of a link between ***low levels of caregiver commitment and lack of positive interaction with their spouse and moves to residential care, and the death of that spouse two years later.***

l) Closer relationships between carer and the person with dementia are associated with slower decline in dementia, and this effect is highest for couple relationships. In other words, the closer the relationship between the partners in couples living with dementia, the slower the rate of decline in the person with dementia. The authors of this research (Norton, Piercy, Rabins, Green, Breitner &, Ostbye *et al* (2009) comment that future interventions designed to enhance the care giving dyadic relationship may help slow decline in AD.

PART 2.

BACKGROUND AND INFLUENCES ON THE DEVELOPMENT OF LTwD

Research suggests that the maintenance of the person with dementia in the community has more to do with the attitudes and well being of the spouse carer than factors such as severity of the disease. Indeed, studies show that quality of relationship in dementia is of vital importance: from convergent evidence that insecure attachment in people with dementia as well as their caregivers is related to higher levels of BPSD (Behavioural and Psychological Symptoms in Dementia) – see van Assche et al 2013; to research which shows that dementia impacts on spousal relationships by causing decline in reciprocity, communication, opportunities for shared activities and happiness – and the evidence is that the ability to *maintain* a sense of mutuality in the relationship is an important determinant of the experience of both the person with dementia and their partner, across the stages of the illness (Ablitt et al 2009).

1. COUPLE RELATIONSHIPS AND PSYCHOTHERAPY

The urge to form partnerships is a powerful human drive (Ludlum and Nyberg 2007). Couple relationships present many challenges as well as opportunities for emotional development. Couple psychotherapy recognises both the importance and value of stable relationships (as evidenced in the research that shows poor outcomes for people with dementia where relationships are less close, or less positive) but also recognises the potential challenges and difficulties facing couples living with dementia. Partners in couples affect each other in many conscious and unconscious ways, and the fundamental stance is one of recognising both the individual differences of the partners, but also on the interactional field of the relationship, looking at how the individuals affect one another.

Working with Couples

To explore and understand the dynamics of the couple relationship, the therapist uses three sources of information:

- What each partner tells us about the relationship
- What we can observe about the interaction between the partners
- What we notice about our own emotional experience as we engage with the couple (countertransference)

Although, of course, the partner with dementia is the identified ‘patient’ LTwD seeks to understand the dementia as also a shared problem, that will be experienced in a way that is particular to each couple, based upon the underlying dynamics of the relationship and the shared histories of the partners. It is this ‘interactional approach’ looking at both partners and how they work together, and the difficulties they experience in being together, that is the focus of the work.

The therapist looks, therefore, at how they behave towards each other, tries to understand their experience of each other – what they think they are doing, how they feel their partner is responding to them. For couples in the earlier stages of dementia both partners may be able to express much in verbal interaction. Later, the therapist will need to look more at behavioural and other aspects of the communication between them.

Technically, the therapist needs to be able to move her attention from one partner to another – empathising and seeking to understand first one partner's experience, and then the other's – and then, trying to link the two – how does one impact upon the other. It is this process, of movements between vantage points, the perspective of one, and the perspective of the other – seeking clarification from them as you go along – that leads towards 'putting it together' in terms of an attempt to understand how the partners affect one another.

This requires the therapist learning to be able to hold in mind two or more perspectives, to be able to be subjectively involved with both individuals, but also to be able to stand outside the relationship and observe it. This capacity to understand the dynamics of a couple and arrive at a formulation of the areas of difficulty is a fundamental aspect of a couple approach and requires supervised work within the context of the training in order to develop this skill.

2. VIDEO BASED APPROACHES

Video based approaches aim to enhance communication within relationships. They are most commonly used for looking at interactions between children and adults – either parents or professionals. In general such approaches involve filming people in interaction together, and then selecting out significant segments to show them. The aim is to highlight elements of their interaction that are successful and some approaches also emphasise the value of helping them to notice and to think about aspects that might be less successful and that they might wish to change or to understand better.

Principles underlying Video based Approaches

The process involves filming the interactions between the participants and then editing this to produce a short film that focuses upon aspects of the transactions between them. There is then a video feedback session that follows, in which the family and the professional review the film clip together, particularly focusing on those moments when the adult has responded in an attuned way to the child's actions or initiative, using a combination of verbal and non-verbal responses. The professional and participant reflect collaboratively on what they are doing that is successful and formulate together further goals for change. These reflections move very quickly from analysis of behaviour to the exploration of feelings, thoughts wishes and intentions – to help the adult to become more mindful and understanding of the feelings underlying the child's manifest behaviours. The approach needs to convey respect for strengths and capacities and to avoid drawing too much attention to difficulties.

The principles underpinning these approaches make them very suitable to working with the couple relationship in the context of dementia. In particular, carer partners are helped through the filming and feedback sessions, to become more sensitive to the communicative attempts of their partner with dementia, and to develop greater awareness of how they can respond in an attuned way. In the process of 'standing back' and looking at themselves on screen, partners are able to examine and to think about what they were doing when things were going better than usual – and in this way, helped to think about how they might behave differently in situations that are more problematic.

3. ATTACHMENT AND THE IMPACT OF DEMENTIA ON THE COUPLE

People with dementia gradually lose engagement with things that they used to do and that they may have enjoyed with their partner. Hirschfeld (1983) found that a continued sense of mutuality in couples where one partner had a dementia was the most important factor in determining whether a person would continue to be cared for at home, or go into residential care. Wright (1991, 1994) found that low levels of interaction between the partners in the marriages of people with dementia predicted the move to hospital care. Closer relationships between carer and the person with dementia are associated with slower decline in Alzheimer's Disease, and this effect is highest for couple relationships (Norton et al, 2009).

Indeed, the tremendous importance of the quality of the care giving relationship is underscored by the research cited above that shows that low levels of interaction between the partners in the marriages of people with dementia predict the move to hospital care, and even the mortality of the individual with dementia two years later and that, conversely, closeness in the relationship is associated with slower decline in Alzheimer's Disease. This has powerful implications, and shows the clinical significance of the LTWD approach that aims to support and provide containment for carers and the person with dementia, and to strengthen and support the relationship between them.

Attachment in later life

As adults we do not outgrow our need for security and the concept of containment is important in thinking about how to respond to the attachment needs of the individual with dementia. Miesen (1993) in a series of studies, reports a high incidence of 'attachment seeking' behaviour in people with dementia, including those in later stage dementia. Innovative approaches to addressing attachment needs in people with dementia have been suggested (Woods and Ashley 1995), but in thinking about how to respond to such attachment needs in the care-giving situation, an important link can be made with research into infant attachment. Fonagy, Steele, Moran and Higgitt (1993) noted that the strength of the bond between infant and their primary carer is linked to parental sensitivity to and understanding of, the infant's mental world. This has implications for our understanding of the importance of the relationship between the person with dementia and their carers, and how crucial is the capacity of the carer to engage emotionally with their partner with dementia, highlighting the need for an intervention that can increase the carer partner's capacity to do this, enhancing their understanding and sensitivity to their partner with dementia.

Example of the Importance of the Couple Relationship for the Person with Dementia

Mr A, an 80 year old man in the early stages of AD, conveyed the importance for him of the containing function of the relationship with his wife. During the interview, whilst expressing his fears of what it meant that he now attended the "nut hatch" (the local day hospital, situated in a psychiatric hospital), he expressed his sense that his family might lose him:

"I said to my missus, I am going to the "nut hatch" you are going to lose me".
She cried her eyes out and said, "Don't talk like that"".

He conveyed his need of his wife. Her role in serving as a memory aid, as a reassurance of his continuance and maintenance of identity was eloquently expressed by him. For example:

"My wife will come back with what I've lost . . . then I'll carry on because I know I musn't let it get hold of me…I've got a good wife and she's a good thinker for me. I feel dodgy sometimes that I should be like I am, that she has to suffer, but she says, "I don't suffer you, you are the same old C. that I married years ago" she says,
"You're the same one . . . well that helps me".

Impact of dementia on couple attachment: recognising the emotional challenge for the carer partner

If we pause to imagine what it may be like for a husband, wife, or other family member to witness the changes wrought by dementia, facing the prospect that, eventually, they may no longer even be recognized any more by their loved one, we are faced with just how difficult the task of sustaining emotional contact can be under such circumstances. Having emotional contact with fragmented experience is very difficult, and it is understandable that carers who are themselves less contained may be less able to tolerate emotional contact with the person with dementia (Woods and Phipps 2000). Carers need considerable support and containment in order to be able to provide containment for those in their care. Whilst there is a great deal of awareness in terms of the needs of mothers with newborn babies for help and support early on in combating post-natal depression, there is relatively little media interest in the needs of the caring relationship at the other end of the lifespan.

It is important to recognise the tremendous challenge facing the carer partner, and the importance of not glossing over or idealising what is possible. This draws our attention to the importance of the state of mind of the carer, and their need for support and containment. The carer partner may have all kinds of feelings towards the individual with dementia in their care, apart from compassionate ones, such as disgust or revulsion, resentment or hatred. Such feelings might arouse tremendous guilt or anxiety, and there may be a great need for help and containment with this.

Case Example: Changes Brought to the Couple Following the Diagnosis

Henry and Jane:

Henry and Jane are a couple in their mid-80s. Henry has had a diagnosis of dementia for some 18 months, and at the first interview with them, she told me she had been finding it hard, noticing that he was getting confused about things that he wouldn't have done a few weeks ago. "I don't say anything though – that would only upset him and he would also forget soon" – so she is more alone with it. She thinks sometimes about what is to come – hates the thought of when she will have to ask for help. And the council will send different people, she wants one person who they can make a relationship with. That feels very important – feels lucky that they have the wherewithal to find somebody for themselves – maybe that's what we have been working all these years for – that is a bit of the world we can control. Both were getting upset about things that are going wrong that they can do nothing about, situations that they cannot control. She gave the example of how Henry had become preoccupied by things outside – the builders leaving the window open of the house opposite – their forgetfulness – he had fears of an intruder coming in.

The therapist said that he thought that this was a projection of the anxieties about his forgetfulness, his dementia, which has been the intruder into their lives. She told the therapist that it felt as though their old life had been stolen from them, the old Henry and the future she had thought that they would have together.

What can go wrong in the couple relationship?

a) Stigma, leading to high internalised shame and low levels of personal control can be particularly marked in dementia in comparison with other neurological impairments (Burgner and Berger 2008, cited by Moniz-Cook).

b) Lack of emotional involvement and secondary disablement of the person with dementia – for example, the carer partner taking over activities that the person with dementia could still do with support, so becoming more functionally 'disabled' than they could be if they were helped to stay involved together.

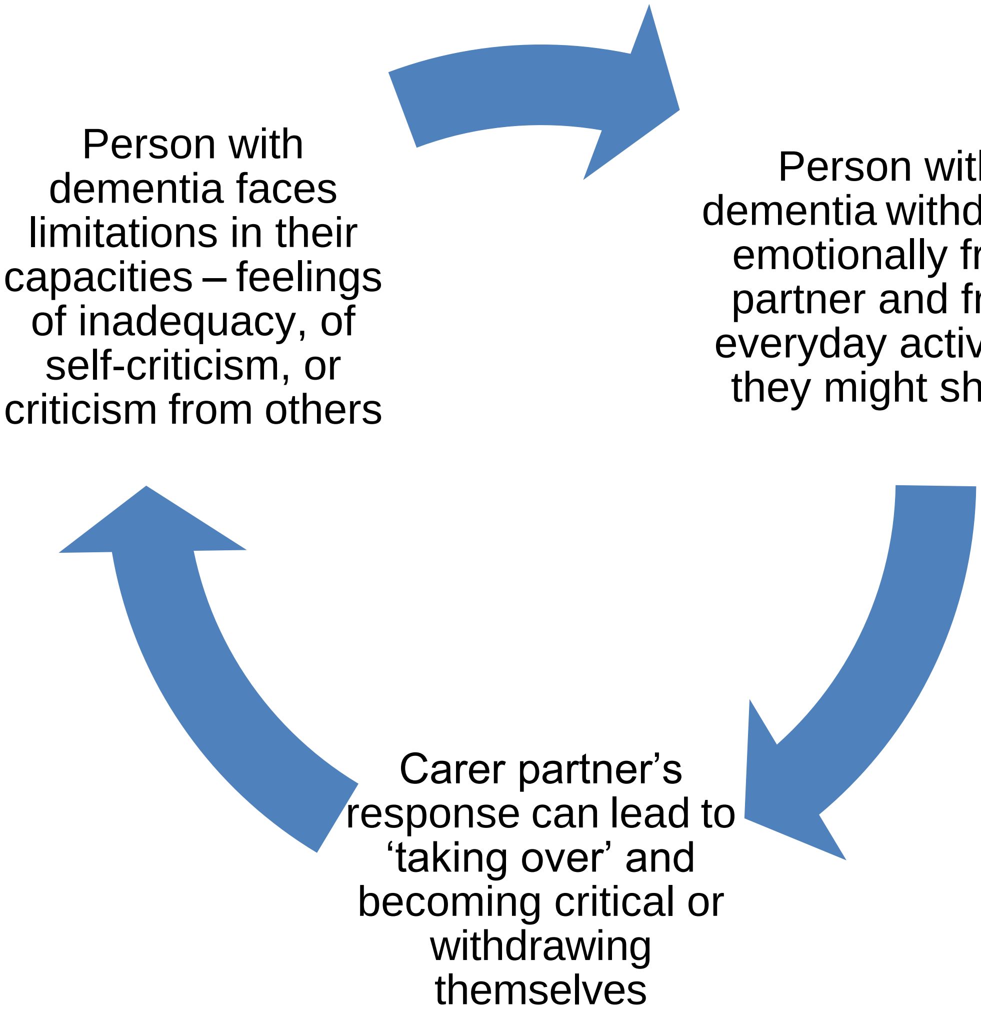
c) Spouses of people with dementia are often the carers who experience the most burden (Cantor, 1983). Carers experience stress and burnout – at worst, unsupported carers in difficult and pressurised home situations can in some cases, act out violently or neglectfully, and elder abuse is increasingly recognised as a major social problem.

d) Withdrawal on the part of the person with dementia and frustration/criticism felt towards the person with dementia by the healthy partner.

e) This can be associated with volatility, aggression and risk to either partner, both of whom are likely to be vulnerable adults.

f) Lack of containment of feelings in the relationship, can also lead professionals to feel that they have no alternative but to push for residential care placement for the person with dementia, particularly if there is an anxiety about violence occurring in the relationship.

g) **<u>Negative loop of withdrawal: Secondary Disablement of Person with Dementia</u>**



Person with dementia faces limitations in their capacities – feelings of inadequacy, of self-criticism, or criticism from others

Person with dementia withdraws emotionally from partner and from everyday activities they might share

Carer partner's response can lead to 'taking over' and becoming critical or withdrawing themselves

PART 3.

CLINICAL PRACTICE

1. ASSESSMENT

The assessment is a consultative process that can involve several meetings with the couple depending on their capacities and presentation. There will be the opportunity to discuss and reflect on this process in supervision and to establish a focus to the work.

a) Eligibility criteria

Both partners need to be prepared to be involved in the intervention and able to give informed consent or have a suitable person available to act as a consultee.

- English speaking couples who are married, in a long-term relationship, or in a civil partnership
- One partner has a diagnosis of Dementia: preferably in the early to mid stage of dementia
- Where couples are interested in the intervention yet have more severe impairment, we would have a discussion with the referrer, and if appropriate, we would meet with the couple to explore their suitability for the intervention. This would be based on clinical judgement, input from carers and professionals involved and in accordance with Good Clinical Practice Guidelines
- Couples in which one partner had a concurrent diagnosis of a major psychiatric disorder would be excluded at this stage in the project.

If couples do not meet these criteria then consider signposting to other support agencies.

b) **Responding to referrals: initial contact by therapist to include:**

i. A brief description of intervention and note any particular concerns expressed by couple
ii. Offer an initial meeting to discuss the intervention with the couple in more detail before making a decision
iii. Clarify where the couple would prefer to be seen and ensure consulting room space is available or explain the need to have privacy to talk at their home
iv. Gain basic background information ie name, address, DOB, GP other professionals involved, referrer
v. Appointments to be confirmed in writing or email and to send relevant Patient Information Sheets. However it may be more appropriate with some couples to meet first and take these with you and go through them in person

vi. Log on database/ record contact and booked appointment/ complete referral form according to site specific administration requirements and inform referrer
vii. Be familiar with your agency's 'lone worker policy' and adhere to site requirements
viii. On day of appointment it is recommended to telephone the couple in advance to check that it is still convenient to meet

c) Patient Information Sheet (PIS) and Consent

Patient Information sheets outlining the intervention and what it involves are given to the couple allowing time to discuss and respond to questions and concerns. The therapist needs to explain as clearly and as simply as possible and, where necessary, involve the carer partner in doing so.

The intervention is primarily aimed at couples where both partners are likely to be able to give their informed consent to participate, in the relatively early stages of dementia. Both partners consent to participate in LTwd which involves signing 2 copies of the consent forms- (one copy to be retained by each partner).

However in the case of one partner being unable to give an informed consent then there is the option to ask the other partner to act as a consultee. This involves checking that the partner feels confident that in their best knowledge their partner would have no objection to taking part in the intervention. Therapists use the Consultee Information Sheet and Consent form which are then signed.

Nevertheless, the capacity of the person with dementia to give informed consent to participation in the therapy may change as time goes on. Consent to participate for both partners must not be treated as a once and for all thing and is re-checked throughout their participation. The therapist needs to check retention and understanding on the part of the partner with dementia.

d) Administering Outcome Measures

Psychometric measures are used so that audit of outcome is embedded throughout and are administered at the start (following informed consent) and end of the intervention.

There is a separate booklet of measures for the patient with dementia and a booklet for the carer partner. These questionnaires contain measures of cognitive functioning, depression, perceived burden, communication, physical functioning and quality of relationship. The therapist needs to complete the measures with the partner with dementia and if possible to complete the measures with the carer too without the partner present.

Measures are useful for evaluating the intervention but can be a useful clinical tool for the therapist to highlight the sorts of difficulties the couple are facing.

Completing these questionnaires can feel daunting and care and sensitivity is needed to respond to both partners' experience. It can bring to the surface thoughts and feelings about their situation and the impact of the dementia, and so allowing time to respond to these reactions is important.

e) 10 point Assessment Guide

These headings are a guide – you do not need to (and cannot) cover everything and these issues may not all be equally appropriate for all couples. Above all, the 'assessment' is about trying to make an **emotional connection** with the couple, and to **engage them** in the process of the work.

10 point assessment interview

- Individual histories of both partners
- History of the couple's relationship
- Changes in the relationship
- Experience of the diagnosis
- Current situation
- What is going well/strengths?
- Difficult areas - list
- Assessment of time carer partner has for themselves
- Sexuality
- Need to instil hope

Finally,

- Video assessment exercise
- Assessing the couple interaction (In discussion with supervision group)

1) **Individual histories of each partner** (not too exhaustive – but a little background on their experience of growing up, family of origin) – sometimes, knowing about their parents can be important – how did their own parents fare in old age, did either of them get ill/have a dementia; be prepared to talk about death – perhaps you may be told about how their own parents died. This can be very significant in terms of the next generation's anxieties and fears about their own ageing and death.

2) **History of the couple's relationship** (again, ask about this, but don't push for too much detail, let them tell you in their words what they feel to be the most salient aspects). Try to get a feel for what the relationship has been like, what it was like

when they were younger and how things were before the diagnosis. You might try to get a feel for what the dynamics of the relationship were – was she apparently more dominant, he more vulnerable, perhaps? What sorts of qualities did the partners hold for each other in the relationship – was she the sociable one, for example?

3) **How have things changed in the relationship?** Although not necessarily the case, this area may need to be something that is primarily discussed with the carer partner. Give room for the carer partner to speak on their own about feelings that they may be struggling with – If the counsellor can listen and acknowledge these feelings – and **normalise** them, it can be very important for the carer partner.

4) **The experience of the diagnosis.** There may be a need to talk about this and often there is considerable trauma in relation to it – what led up to it? What are their feelings about it now? Need for space to explore this – allowing for fears to be put into words by both partners, including the partner with dementia, to meet the couple where they are, emotionally

5) **What is the current situation?** Are there children? Do they live nearby? Do they visit? What are the relationships like with them now? How were the relationships growing up? Do the couple have friends now? Is there other support? Do the couple get out much? Or at all? What help do they get from statutory or voluntary services?

6) **Assessment of the time the carer partner has for themselves.** Does the carer partner have time/space for their own interests? This is very important to explore and discuss. Both partners may need help to think about this as it signals the changes and losses for both partners from the impact of dementia.

7) **Are there things that they feel are going well? (If appropriate, think with them about strengths)**

8) **Can you make a list with them of areas which they feel are particularly difficult for them?** There may be a need to speak to the carer partner alone in relation to this aspect – though this may not necessarily be the case (and you can discuss this question in supervision if you are unsure). **Try to elicit two or three key themes/or areas which are difficult for them or which they recognise they struggle with – it might be, for example, that he/she feels their partner is withdrawn, or gets angry. What situations do these difficulties tend to arise in?**

(You may then refer back to these issues or themes as the work goes on: for example, when looking at the video, you might think back to what they spoke of in terms of difficulties – your partner gets irritated here, or you back off there – what

were you feeling at that moment? So you are not just helping with thinking about a different practical response, but the feelings which it evokes in them.)

9) **Sexuality. The therapist should signal a willingness to explore/discuss this area.**

10) **Need to instil hope.** As part of engaging the couple in the work, the therapist needs to find a way of instilling some hope into the situation. The aim is to engage their interest in understanding things that could be improved – and how tackling the secondary system (see, for example the 'negative loop of withdrawal', the secondary disablement of the person with dementia) might reveal more capacity and possibility in the present and also offer new approaches that will help them in the future, as the disease progresses.

a) Assessment Video

1. This involves making a video of the couple spending 15 minutes on an everyday activity together. Therapists will watch the video recordings as part of the supervision before agreeing on clips to edit and feedback to the couple later.

2. At this stage, the rationale for videoing is explained again, and the couple are told that the therapist will bring back the videos to subsequent sessions, to discuss them with the couple. The aim of the videoing can be explained in the following way: it involves filming people in interaction together and then selecting out segments to show them next time they meet. The aim of this is to highlight things that are going well and to help them to notice and to think about aspects that might be less successful, and that they might wish to change.

3. The therapist may remind the couple of the issues of confidentiality and where the videos will be kept as was detailed on the consent form. They will be stored securely, safely and anonymously. Transporting edited videos to couples homes for viewing will be done on a password protected memory stick.

4. The therapist checks again that the couple are happy to proceed with the videoing. At this stage, it can be helpful to show the couple the 'Flip' camera.

b) Instructions/Set-up

1. The therapist discusses with the couple that he or she would like to video them for 15 minutes – and that the aim is to get a sense of how they work together as a team doing an everyday activity.

2. The therapist gives the couple the following instructions: I want you to work together as a team. Can you think of something that needs to be done around the house- eg cleaning the fridge – something that feels natural to them – could they do it as a couple?

3. The therapist can bring different activities of different levels - the couple could select what they like. It is interesting to see what they choose- could be too difficult/too easy.

4. Need a natural activity – to engage together in – this could be sorting out the washing; playing a game they like to play; going through the fridge; cooking something together; tidying up; making a salad together, doing something in the garden together etc.

5. The therapist observes and in particular notices their interaction, the quality of the communication between them and are there moments of greater contact?

6. A second video is made of the couple towards the end of the intervention and this is shown to the couple as before.

2) ENGAGING THE COUPLE

A central element of the LTWD approach is that the therapist tries to meet the couple where they are, emotionally. In practice this means that the therapist refrains from making a judgement about how the couple ought to be responding to their situation, maintaining where possible a receptive state of mind, listening for the emotion behind the things that the couple say, and trying to understand their experience, and to put this into words in the service of trying to make an emotional connection with each partner.

Couples need space to explore the emotional impact of dementia and it is important that the therapist helps to create an environment where both partners, including the partner with dementia, can put their fears into words. This involves listening to, and trying to understand their experiences, leaving space for both partners to speak.

At this stage the focus is on listening and trying to understand, rather than trying to *do* and this means that things like information giving should be avoided. Sometimes the temptation may be to offer advice or information about dementia, but this is likely to be more to do with the anxiety of the therapist, and their difficulty in maintaining an emotional availability to the couple’s experiences. However, an educative role may later be important.

The carer partner may find it hard to bear feelings such as anger or disappointment, in particular at this time when their partner is more vulnerable, and so the therapist must listen for these feelings and pick them up, and help the carer partner to be able to put them into words and to think about them.

At this point the therapist aims to engage the couple’s interest in understanding how things might be improved, what they could realistically hope to gain from participating. Whilst they are living with the losses imposed, there may be more capacity and possibility in the present.

Example of couple who needed their emotional experience taken in and understood before they could make use of possible services

Couple Caught between Two Worlds

Henry and Jane

Henry had been diagnosed earlier that year, and Jane felt that the diagnosis had been made very early in the illness, almost by accident. She had mixed feelings about this: in one way she could see that it offered them time to come to terms with it, and to address things whilst he was still able to. On the other hand, she felt perhaps they had been shunted out of their old life, into the new world of Alzheimer's, sooner than was necessary. When I first met them, they conveyed to me how they felt that they were living between two worlds, and did not know where to place themselves: between the world of dementia- represented firstly by the offer of an Alzheimer's Society day trip, where they would be with people who were very much more impaired than Henry, and secondly, by the prospect of travelling across the country to attend a family wedding, their old world. In the end they did both – here is what they said.

She spoke of how she felt that his dementia diagnosis was an alien intrusion – and then she said: 'so is the things we are given – don't want to offend anyone but we have people phoning up wanting us to sign up for things but we aren't ready and it isn't what we want at the moment – coach trip to Clacton isn't us.

I want to keep control and don't want other people coming in and telling us what we should be doing it's an intrusion into how we have always been – very private couple. And this very lovely person has visited, but she wants to give us things, leaflets, things to do....People need to be allowed to go at their own pace, to have things available that they can call on if they want to, when they are ready. Otherwise it's like being taken over by it.

It was a difficult year, till we came to terms with it (the diagnosis)….We had the wedding, but at times he was quite overwhelmed when we were there. And there was also an Alz Soc trip to Heaver Castle – don't want to cause offence –but it isn't a welcome picture of the future – which isn't helpful at the moment, of people who are more deteriorated. In 2 or 3 years' time maybe, when we're not doing things for ourselves so much.'

Seeing partners separately

The focus on the couple together is crucial. However, individual partners need to be seen separately too in order to be free to say things that might otherwise be difficult to articulate in front of their partner. This requires the therapist negotiating this in a clear and thoughtful way so as not to intensify feelings of insecurity, mistrust or exclusion. This will be a feature throughout the intervention to allow space for individuals to have their individual responses and space for them to come together and think about each other too. In exceptional cases where this is particularly difficult to organise, it may be that the therapist has to organise a separate time to meet with one of the partners when the other is not around.

An example of a partner, Ray with dementia being able to express feelings that he had not discussed with his wife, Barbara before

Ray alone: I am forgetting a lot...I suppose the time will come when I become quite peculiar. I asked what he meant by that. Well you are what you remember and I will lose my memory...It's a race between my memory going and my death. I am quite an age you know, 82 – that's regarded as a good age for men to reach. Some people believe in God, but I think that when you die, that's it. You don't get comfort from religion – yes, religion is a comfort. Do you speak to B about these thoughts – no, I don't, I suppose I should, to let her know how the direction my mind is going in.

Therapist providing containment

- **It is very important for couples facing the diagnosis of dementia that such a containing mind is available because, as a consequence of the disease, the partners who may have contained one another very well earlier in their relationship, are inevitably becoming less able to do so.**

- It is important to bear in mind the type stage and the process of the dementia and that the needs of the couple will change as it progresses.

- Initially during the post-diagnosis phase, the emphasis of assessment and intervention is on containment. However throughout the trajectory of the illness, couples are having to manage considerable anxiety – there has been the intrusion of something very persecuting and disturbing into their lives which will bring with it many fears and fantasies and mobilisation of defences.

- For example, the dementia may carry the threat of being abandoned to a state of utter helplessness, which may, at least for some people, carry fears of a traumatic return to earlier states of dependency, particularly if their earlier history was a traumatic one.

- It may also, for the carer, carry memories of earlier times of looking after, for example of a mentally or physically disabled parent. It is important that the therapist is alert to the meanings or interpretations of the current experiences of the partners, and is open to thinking with them about how it feels – for example, enabling the carer partner to talk about how now to be looking after a husband with dementia, it might feel like history repeating itself, taking her back to the feelings she had when her mother had a breakdown when she was a child.

Case Example: Bill and Ivy –Importance of containing difficulties in the couple relationship

Bill and Ivy have been married for more than fifty years. Their marriage had always been a difficult one, though they had stayed together and had three children. His dementia started just after retirement, and she feels cheated of the retirement they had planned together. Looking after him repeats, for her, a version of her experience as an only child, whose mother developed profound mental health problems after the death of her father. Then, as now, she feels left alone with a burden, with no one able to understand how difficult it is for her. In recent months, his dementia has progressed significantly and psychometric tests confirmed that his memory is now very impaired.

Increasingly, he responds to the anxiety of not knowing what to do, moments when he is disorientated, by getting angry. For her, it is much like the angry exchanges they have had for years and she retaliates, with anger and criticism of him. I explored with her that it seemed that this is worst at times when he is in a panic and feeling lost –for example, he doesn't know where his suit goes or where his pyjamas are. She described how when she tells him to get keys off the hook in the hallway– he tells her, he doesn't know what she is talking about, she isn't making any sense and she spoke of how she feels angered by this. She conveyed how there had always been a lot of blame in the marriage and I thought she was showing me how she now finds it hard to distinguish between things he can't do and what he simply won't do.

It was clear that it is when she becomes critical or angry at the moments when he is most vulnerable that he becomes aggressive towards her. They showed me how quickly things could flare up between them. She spoke of how she can get very frustrated with him, and is angry about what has happened – angry that the retirement they had planned has been taken away. She wants him to take responsibility, so pushes him to do things, or tells him where to look for things and gets frustrated and shouts when he makes mistakes.

The therapist thought that she was letting him know how she feels she is trying to stop the illness, to hold it back, and fears that Bill will stop doing anything and withdraw completely and so she pushes him. She gave the example of his asking her how to do something in the garden and her telling him what to do in a way, which was complicated and which Bill would not be able to hold in mind, and then his responding – well you're out here, you do it, and going inside. For example, she issued instructions/explanations that he did not have the capacity to follow or to hold onto, as if she were speaking to the old Bill, of earlier times, and it was this that he would respond to either by saying, 'you're not making sense' or, 'do it yourself then'. She heard this as examples of his refusal to do things, his deliberately being difficult, and it took a lot of work with her, for her to gradually begin to shift her perceptions of such episodes, and to think about what might be happening in his mind, to put herself, to some extent, into his shoes.

Crucial to this shift was the therapist's stance of listening and empathising with her feelings, so that she had the experience of someone taking her in and trying to understand how she felt and how she saw things. Once this process was established, where she started to feel 'taken in' emotionally, she began to be able to allow herself to start to think about what his experience might be.

3. DYNAMICS AND COUPLE INTERACTION

a) Formulation

- This is an important part of the assessment task. The therapist needs to use all of the information they have, including the clinical discussions with each partner, and then, adding to the formulation from the evidence of the video assessment.

- It involves listening to how the couple describe their difficulties and anxieties, and exploring with the couple and with each individual partner where possible, how they affect one another. What are they fearful of? What problems do they feel they have, if any, with the other partner's behaviour/reactions to them? How does one partner's behaviour affect another's?

- It is important to think about this from the point of view of each partner. The therapist must include an attempt to understand the experience of the person with dementia, as well as thinking about how the person with dementia is affecting their partner.

- The therapist needs to move her attention from one partner to another, empathising with, and seeking to understand, first one partner's experience and then the other's. This is an ongoing process, of movements between vantage points, and is the technical challenge facing the therapist throughout the work.

- It is the process of moving between the partners, seeking clarification where necessary from them as you go along, that leads towards 'putting it together' - that is, to an attempt to understand how the partners affect one another, expressed in the **formulation of the dynamic issues of the couple**.

- This requires the therapist to learn to be able to hold in mind two or more perspectives, to be able to be subjectively involved with both individuals, but also to stand outside the relationship and observe it.

- Supervision and discussion in the training group is important here: this capacity to formulate the dynamic interaction of the couple and to develop a view of how their difficulties are maintained through their interactional patterns is a fundamental aspect of the intervention.

b) Assessing couple interaction

How are they affecting each other? Perhaps, for example, his tendency is to give up and hers to give up on him. Sometimes, the carer partner may be resistant to change, to involving their partner more – they may feel that being productively engaged may slow things down. However some difficulties can be secondary difficulties to the organic illness, and therefore might be amenable to change.

Case Example: Ray and Barbara

I asked him what sorts of things he'd like to be doing – going for a drive seeing new places – and with B around the house. Yes she's v active, I would like to change things – he is not exerting himself because he had a stroke and no one's explained what is safe to do – but am afraid of having a heart attack, so I don't move very much (No one had explored this with him before, it seemed.)

I asked how he felt about his lack of activity; Sometimes feel bad about what I am not doing anymore with B – but then other times it doesn't worry me and I think that is to do with my memory – that I don't remember
He asked me again, what is the purpose of the videoing? – I explained – it seemed to make sense to him, and I noticed he engaged more actively with me. Afterwards I said to them both that he had told me that he would like to do more things with B – I asked what – he said around the kitchen – chopping carrots that kind of thing. I said perhaps we could try something like that next time – she said – I don't know about that – and looked quite reluctant. He looked at her, smiling and said why not? The discussion led to more active agency on his part which challenged his wife, whose own anxiety/resistance to his becoming more involved was then thrown into relief.

In other situations, there may be a withdrawal on the part of the person with dementia, associated with criticism, real or imagined from the carer partner. We have found that it is important to establish a picture of this dynamic with the couple.

Case Example Natalie and Clive

Natalie and Clive

She was diagnosed with dementia more than two years ago. She was a well educated person who had been very competent in her professional life prior to retirement. She told the therapist when he met with her alone as part of the assessment, that she doesn't tell her husband about how frightened she is – she has noticed that she is finding it harder to find her way when in new environments – and it is scary. But if she tells him, he might rub salt into the wound. The therapist explored with her what she meant by this, and what emerged was that she feared that her husband would use her vulnerability to be more controlling of her. She said she wanted to maintain her independence as much as she can. He will take it away. She cries more than before, but thinks that this is more an anger – a sort of female way of expressing anger.

When the therapist met with her husband Clive he said that he felt that he can see that in the last week in particular, she is showing more evidence of recognising her difficulties. Both of them know that she is more anxious – yet they do not speak about it directly. He feels that he has to be careful about what he says to her – if he points out an area of difficulty, she may explode at him. Therefore, he intervenes/says something only when he believes the consequences of not doing so will cause problems.

The therapist formulated the problem in the following way: For him: situation of either holding back and keeping quiet about what he thinks, or else, when he does, it is when he feels he has to take over – so that at times when they do talk about an issue directly, it is when he is feeling he has to take over/take control. So when he does, in a sense, it confirms her fears. And he anticipates from her an explosive reaction to this. So the polarity is not to speak/address something directly – or else to come in to take over. All or nothing. One of the central issues for the therapy arises from this formulation: how to enable the couple to have more involvement with one another – to address this dynamic of not speaking/putting fears/difficulties into words – versus then taking control/taking over – which confirms for her, the danger of putting into words her fears or difficulties – that the takeover is the only response she can get.

c) Discussion of the Assessment Video

Therapists will watch the video recordings in supervision and have the chance to formulate potential areas on which to focus the work in conjunction with the information gathered from the assessment process.

Example: Henry and Jane

He does come forwards and offers to do things when he can see that she needs help. However – two aspects: one is the Henry who wants to help and to be involved and the other is a tendency she has noticed in him to retreat more into silence. What she seems to do, is to leave particular tasks to him – as his area, that she is not going to get involved in – wants to preserve his capacity to be involved and to resist taking over. Consequence is that they tend to do things "in parallel". He certainly does have the capacity to do things himself at the moment, though he is starting to forget where things go. I talked to her *about approaches that might aim to preserve the Henry that can have agency and take up an active role/be involved – and to try to counter the tendency towards withdrawal, his 'silence', that she had also described. To this end, the importance of not simply leaving tasks to him – and holding back from any involvement herself, so that he continues to hold onto the task and not give it over to her, but rather (and this is becoming increasingly important as time goes on) to work out ways of being involved together (ie at present it seems couched in dichotomous terms – either she takes over, or leaves it entirely to him – and it is very much 'in parallel' as a consequence.*

When viewing their interaction, she understood the formulation.

Looking at the video – she commented, quite spontaneously, "I am hovering, I don't have a role – he is doing it entirely on his own. We tend to do things in parallel" Although they feel in tune with each other, the challenge is how to build up ways of doing things more interactively? They have always had things as separate domains – so being asked to do it differently is strange – he commented that he didn't like to intrude on things that she did.

She has started to notice his withdrawal and wants to stop it worsening. However, the problem is how she is going about this – she leaves him to do it himself and stays away, or else she stands on the sidelines, instructing him. This is not interactive – and will not help as time goes on, and his capacities diminish –she will not have developed strategies for engaging alongside him, to support his continued involvement and the sharing of activities. Instead, his independence is likely to flip over into dependence – and the couple may miss the opportunity of developing ways of establishing a more inter-dependent approach together, whilst there was time to develop it. This is one of our central aims- to develop strategies now, which will become increasingly important later on.

d) Preparing the video clips

- The therapist prepares the video clips following a session where the couple have been videoed in preparation for the next session, using a basic editing package available on the internet.
- The therapist condenses a part, makes several 30 second clips and spotlight moments when there is contact between them.
- The therapist will also try to select moments which illustrate some of the core themes/issues between the couple in order to discuss these and to invite the partners to think about what they themselves, and their partner, were feeling at these moments.

The therapist should be careful to balance video clips which show positive aspects of interaction with others which show elements that may be more challenging or negative (great care needs to be taken in selecting clips, particularly if you are going to highlight something more difficult – this can be discussed in supervision.

After videoing an activity it is important to discuss the experience of doing it with each partner

- How do they feel about the experience of holding back, not coming in to 'correct mistakes' of their partner, withholding criticisms?

- How does it feel to be doing the exercise? What are they thinking at different points – for example if they found that they were being critical?

- As well as expressing frustration etc, when the carer partner is critical or frustrated, there may be protest in it. The therapist might say to the carer partner: when you are criticising your partner with dementia for not doing something right, you are perhaps speaking to the old image of them, the unimpaired partner of memory – reproaching them. In other words, perhaps it is based on holding onto them, not wanting to engage with the reality of diminished capacities. The difficulty is, that pushes the partner more into withdrawal – but for the carer partner does giving this up, and behaving as though partner can't be expected to do more, feel like a giving up, like becoming a parent, for example, to a child – and accepting the loss of an equal partner? This highlights the importance of talking to them about how it feels to do this, to take up this position – so that the feelings do not become more deadly – and underground. Therefore, it is important not to simply be asking the carer partner to be doing the exercise, but also to talk and explore the feelings about taking up this position – about doing things differently. This is part of helping with the adjustment to reality and facing the losses.

Discussion with carer partner about how they felt when doing the activity: Ray and Barbara

The therapist discussed with Barbara how part of the withdrawal on Ray's part is secondary. If he feels confident then the cognitive deficit does not have these effects, that is, he does not withdraw so much. The therapist explored Barbara's frustration when Ray got things wrong and put things back in the wrong places. She discussed with her what makes it wrong, where he puts things? The therapist tried to capture the dynamic, of what happened between them when Ray 'got it wrong', and was sympathetic about how hard it was for her because it is her natural tendency to have things organised, but discussed how there needed to be a compromise. The therapist pointed out that there is a risk of his withdrawal – and her either keeping him out or being critical, and she is showing that it is hard for her not to tell Ray she's feeling that it is wrong/showing him what is wrong. However, alongside this, the therapist explores with Barbara what it feels like for her – how difficult it is – having to give up her old image of him, the healthy him who she could get cross with for getting it wrong, because she could expect him to get it right. There was evidence too that Ray was reflecting on how he had done in the activity. He's very sensitive to the fact that he's getting things wrong – the problem with this is that he is more likely to withdraw if he feels that he is failing at things.

Discussion with both partners together after carrying out the video activity: Ray and Barbara

Afterwards, when they were together, Barbara commented that it was exhausting that she had had to hold back from saying, "...it doesn't go there, when he put things in the wrong place" – and she said this in front of him during the discussion, which in one way defeated the aim of increasing his sense of competence.
She said that she had found the exercise exhausting, having to hold back from saying that he was putting things away in the wrong place. He looked at her – was I putting them in the wrong place, then? Yes, you were, she said with a laugh. He grinned and In response, he looked at her and smiled ruefully, who would have believed it, him cleaning out the fridge, he said – the sense was that this was part of the strange new world of dementia – and the therapist felt that actually, this was a moment of truthful contact with him. Perhaps this had been made possible by the activity – his interest, and genuine question to her; his comment to her, about the strangeness of what they were doing – how out of context with how things had always been between them – this referenced the past in relation to the strangeness of what they were doing now, and was a moment of intimacy/truthful contact between them.

Session from video spotlighting competence and declarative statements

Try to show moments on video where the partner with dementia has engaged. And also think with the carer partner about what their partner might be feeling, or how they are responding to what the carer partner has said. For example, spotlighting for her what he is capable of – helps her to see something more of what may be possible. In one example, the effect of this was quite dramatic. The carer partner had said there was no point in carrying on, early on in the intervention, after the first videoing.

Case Example: spotlighting competence and using declarative statements

Before the visit, the carer spouse had said on the telephone that there was no point in going ahead with the intervention – her partner did not really do anything – his memory loss was too bad, and he had totally withdrawn. However, once the therapist had spotlighted examples of her partner's competence, she was very taken with the examples of his capacity that she was shown – and also of her capacity, to learn from the work done so far, to move away from her familiar, memory-testing interaction with him, to using declarative comments:
On the video there were impressive instances of where, instead of testing him she shows him a picture and says to him 'these are old buildings that were near your parents' house. She supplies the context and personal memory – a more declarative comment than the memory testing style of interaction that had been typical of their interaction. And then he supplies an association to it and a memory of his own – and they are both in more emotional contact with one another.

And this changed her mind completely – she re-engaged herself and became very interested in the process, seeing the therapy through to its end, some months later. At the time, her worry about engaging him in activities was also stopping him. The therapist needed to work with her, to help her to realise that the aim of involving him wasn't about the activities, themselves, not about the instrumental task. Instead, they were a means of keeping his mind working, keeping him involved in life – and the question of motivation is then also on her part, the extra work or effort involved in including him – and the therapist's task is to think about this with her.

Working on the video clip with both partners together

With many couples, depending upon the severity of the dementia, it will be possible to work through the video clips with both partners together. This can be very powerful, particularly if each partner can be asked at critical points in the video what they think their partner was feeling at each point. At other times, it may be more helpful to go through the video with each partner separately.

Case Example: working on the video with the couple together

The couple were watching a video clip of their attempts to sort out the videos in a display cabinet that belonged to the husband who had dementia. He had collected more and more videos of old movies, and she was frustrated at the mess that could be seen by visitors through the glass doors of the cabinet.

They had tried to carry out the activity of sorting through the videos together and deciding together which ones to keep and which to get rid of. The therapist stopped the video a little way into the clip, at a point where, on film, she had been seeming to be frustrated. He asked both partners what the other was feeling at this point. He thought that she had been 'peeved' because of his resistance and dragging his heels in relation to the task. She agreed and both laughed that he had signed up to it, but only reluctantly. She commented that she thought that he felt that parts of his life were being thrown away. The therapist picked this comment up and repeated it, asking him if this was accurate. He said that it was – and appeared moved that she had understood. He then started to wonder about more of a compromise – whether they could keep some tapes and throw others out. The therapist pointed out that perhaps he could think of a compromise now, and feel generous towards her, after he felt she had been able to think about him, and take in his feelings. He agreed with this. He went on to describe how the mess in his cabinet was like a 'booja' (Yiddish word for 'mess'). She said, quietly, that that was maybe how his mind was sometimes. The therapist took up what she had said and pointed out how the 'booja' in the cabinet was perhaps a picture of how it felt inside him at times: that the difficulty for them in helping each other with it was captured in the video: how it tended to turn into a battle between them when she tried to help, particularly if he felt that she was getting rid of him, or of parts of his life. They agreed with this, and it was the therapist's impression that he was able to follow this more symbolic thinking.

She then described how she tried to keep things tidy and organised but she had lost her purse that morning and then become very angry with him, and taken out her upset and anger on him. It was possible for the therapist to explore this with them: how it seemed that she could try to keep her mind 'tidy' but that when she lost her purse, it felt as though she was falling into the 'booja' of forgetfulness along with him – and this was frightening for her, and she then became angry and attacking of him – which served to create some distance from him again.

This made sense to both of them, and they were both very engaged in the exploration of the meaning for them of this activity and their feelings about it. This was a good example of how an everyday and apparently trivial domestic activity can contain within it much deeper significance for the couple.

Further Case Example: Looking at the Video with the Carer Partner Alone

Clearing the Fridge Together – Ray and Barbara

The therapist helps her to go slowly through the video. She points out to Barbara how her husband watches her put the items he has passed her from the fridge onto the counter and then turns back towards the fridge. He is not doing it automatically, he is deciding and trying to coordinate what he is doing with her. The therapist also notices how Barbara is being very patient, waiting for him to give each thing to her – and there is a physical connection between them when their hands meet. He is much more active in a coordination with her. There is a good example of evidence of his thinking – with one item, he takes it and opens the lid and checks it, has it gone off – he is involved as an active, thinking partner – and the therapist points out that it is quite giving on her part to allow him to take the time to do this, and then he hands it to her to check. There are other examples of how she's noticing and giving him the space – she is a more cooperative partner than was evident in earlier activities. The therapist talks to her about how she is able to do that? Perhaps as he's more active then she doesn't have to take up a controlling position so much.

At one point, there is a moving moment where they discover an old recipe book of his and they look at it together. She says to him you used to make this, didn't you – ie she is not asking an instrumental question, it is declarative, and he responds to it. The therapist stops the video to show her this, pointing out to her that what she is doing is hard work and contrasts with the way, at other times, she can move into teacher mode – which seems to be more linked to anxiety about his lacking the memories.

In the second part of the activity things become more difficult when his role is to put things back into the fridge– aim is to give him the experience that it is not necessarily the 'wrong' place (where he is putting things back). Watching the video, one can already see her tension from the outset. At this point, one of the aims of the activity is to help him to feel more competent – and her reaction to what he is doing is very important. And this is where she needs help to think about her feelings. She is more anxious – giving him things and getting out of it (ie this is where they are putting things back into the fridge). He is feeling anxious and needs reassurance or else withdraws. In this sense, the fridge is a metaphor for life: he withdraws if he is not sure.

The therapist finds an example which shows how when she gets anxious about it being wrong, she reduces the opportunity for sharing, reduces co-regulation *between them, and he withdraws. This is the secondary system – her frustration, followed by his withdrawal – that is highlighted and worked on here.*

The therapist is careful to show Barbara the positive interaction first and then shows her moment of frustration: She asks Barbara, what was she feeling? It seems that at that moment she becomes more concerned about where the items from the fridge are going, the sense that they are in the wrong place – she loses touch with the aims of the activity at this point, and the positive points of what he has been doing. It is hard for her to see what he is doing –difficult seeing him put things in the wrong place – The discussion with the therapist is helpful for Barbara and links to mourning, the man she used to have – but there is also a discussion of her ability to focus on what she does have with him, and what is possible now.

Discussing Video with partner with dementia on own

Henry and Jane (Henry alone)

After Henry saw video of them looking at a photograph album together– He remembered doing it last time, he said, in a general sense. It is comforting to see it is so normal. I have moods – particularly when tinnitus is bad – different pitches one in each ear. She treads softly around me – she doesn't say anything – she is quietly responsive – I am a lucky man –we never had children and maybe because of that we are more dependent on each other than some couples.

My memory is not so good – I am a lucky man – you are looking at – She helps me, she's my rock. I do fear the couple being broken...not staying....that it will come to that.
Tinnitus – noise, intrusion in my head, hard work to get my thoughts out – to get around that barrier. He described how he felt that he had this intrusion in his mind, which he called his tinnitus – and this made it hard to get around, to put the thoughts he had into words – and to do that, he had to get around the barrier. Easier to sit in silence, and they could do that for long periods, he said.
Later, when she was talking about his preoccupation with his tinnitus, I made the link with her, that he might be talking about the intrusion in his mind that was his dementia, the barrier to his thinking. This made some sense to her

Later, when both partners watched the video together, it led to a moment of moving intimacy between them

Both were really taken with video of them looking at photograph album – evidence of his capacities – and their being together. He put his hands over hers as they were watching. Moment of real intimacy.

e) Post – Assessment Sessions

Following assessment phase and initial video interaction subsequent sessions combine both individual and couple psychotherapeutic discussion and review of recorded video tasks (Allow approx 90 mins per session.) It is important to end each session with a psychotherapeutic discussion including both partners together.

The aim of each activity is to try to hold the couple for longer, in a position where they are in contact with one another and to counteract the pressure towards withdrawal and loss of contact that is so often part of the picture. Also to enable the couple to think about and process their feelings – to offer containment for their emotional state. (And here it is hoped that if the partner is more contained, then they will need to take less recourse to defensive withdrawal, or the acting out of anger and frustration that is also so often a theme.)

i. A guiding question for the therapist is this: if the person loses memory, why do they also lose motivation. The therapist needs to wonder, in each case, what are the factors which underpin withdrawal or lack of contact in this couple?

ii. For some couples, the main feature may be that the person with dementia seems to have withdrawn their interest and does not seem to want to risk trying to do things anymore, particularly where the experience of difficulty or failure in the activity that was once easy for them to do, is a painful encounter with the realities of their illness.

iii. For other couples, the therapist may be more struck by the reluctance of the carer partner to allow the person with dementia to do anything anymore. Usually, there will be a contribution from both partners and the therapist's role is to help them to think about the importance and value of doing these activities together, see case example.

Case example: process of coming together is central rather than the goal of the task

Case Example: Natalie and Clive

When discussing with the couple what kinds of activities they might do together, Natalie turned to Clive and said that she wanted to be able to cook with him. He initially dismissed this idea, saying that whilst he could leave her to do it on, say, two days a week, he was worried that they would both end up with burnt potatoes and over cooked veg. She responded by saying that she needed to have a role, and wanted to be back in the kitchen again. When the therapist took up how perhaps the aim was not to have cordon-bleu meals, but to find a role for Natalie in the cooking – which she might be able to have, if Clive worked with her on it, rather than on leaving the meal to her to do alone, on some nights. They were thoughtful about this, and discussed how through much of their marriage they had cooked on their own, on alternate nights. She then reminded him that before they were married, they would cook from a Fanny Craddock cookbook together, both involved. This put them both in touch with warmer memories – and she added, she could be the potato peeler, or do other things – but she wanted to be involved. Although he was resistant, he did take this in, and spoke of how he didn't want to be like those carer partners he had

seen at their local Alz Soc meetings, who at times seemed to be trying to 'insulate' their partners, who consequently never did anything at all.
The therapist made use of the discussion to help move away from the idea of the goal as the meal itself, to highlight the importance of Natalie having a role; and then helped the couple to think of ways they could structure the activities so that Natalie could be a participant, pointing out to Clive her wish to do it with him, not alone.

The focus is both about increasing social engagement, and for the person with dementia it is about a focus upon competence and the motivation to keep taking part. Some of the art of this is how to look at activities that involve a degree of challenge, so the individual does not avoid being challenged, but the emphasis needs to be on involvement rather than challenge (the ratio being something like 90% involvement, 10% challenge. People often assume that we learn from our mistakes, so that failing to meet a challenge will spur us on. In dementia, however, research shows that whilst new learning is possible, being faced with mistakes is not productive for the person with dementia, and is likely to generate anxiety and defensive withdrawal (see the 'errorless learning approach', Clare et al 2000). So our emphasis is upon setting up experiences which, whilst they may be stretching for the individual with dementia, are about giving an experience of competence.

So the art is in going at the right pace, so that independence and competence and also sharing are highlighted.

The focus of activities must be about shifting the balance from **instrumental communication** to **experience-sharing communication**. What does this mean? Instrumental communication is focussed around achieving a particular end- eg a request to perform a particular action, or expressed, for example, in a question which requires the other person to do something, even to give a particular answer. One common occurrence is the carer partner asking the person with dementia if they remember a particular thing or event. It is instrumental in the sense that it requires a specific action/response from the other person–to supply an answer. We call this a 'memory-testing' style of interaction. Instead, the therapist needs to encourage the carer partner to ask few direct questions – and to try to make her communication in the form of a comment to her partner with dementia, and she then needs to wait a long time, allowing lots of space for a response. Asking questions is instrumental – the therapist needs instead to teach the partner to use experience-sharing, declarative memories – instead of saying do you remember this? The carer could supply a memory of her own in relation, for example, to a photograph they are looking at together, and then the person with dementia may be helped to find their own, related memories.

The carer partner needs to slow down the interaction and not ask for anything from the person with dementia – and then to pick up what they say…. And they need to learn to do this as much as possible in a comment, not a question – and then not to say anything for a while – for 5 seconds or so, to create a space for the partner with dementia

Overall, with each activity, the aim is to think about what they are doing and to take turns. The carer partner shouldn't give instructions. It is vital to **slow down** the activity, to think about it – mindfulness and slowing down are central to this. Consequently, 5 minutes' activity can become more like 15 or 20 minutes.

The therapist needs to remember that the focus of the activity should be based on the formulation, or the areas to work on, agreed with the couple after the assessment – based, that is, on the understanding of the current interactional system between the partners. For example, the assessment might indicate that, as he is more passive, she becomes more directive but then he becomes even more passive. In this case, the aim might be initially to set up activities which involve him having a role which involves making a decision – and the focus would be on points in the activity when he would have to make decisions. The therapist might get them to do something that would involve his having a specific task, so making an active role for him, where the role involves some communication with her, something that she gives to him to do but she does part of it. Before beginning the activity, the therapist needs to spend time talking to her about him becoming less engaged and that this is a concern and therefore the aim is to see how to keep him being productively engaged in an ongoing way. The aim is to orient her to the purpose of the task and to think with her about how to structure it, so that she is involved as an active agent in the design itself – and gradually becomes able to take on more of this way of thinking about how to organise these activities, so that once the therapist is no longer present, she has developed a sense in herself of how to carry on the approach.

f) The Psychotherapeutic Discussions

a) Individual discussion with each partner separately at each session

b) The carer needs the opportunity to say things that otherwise might be difficult to say in front of the other partner.

c) The therapist needs to hold an interest in references to the past, the need to go over memories of earlier times, reminiscences about earlier times in the life of the couple and their families, as well as moving into a focus on current experiences.

d) A flexibility in moving between past and present, early and current experiences is very important for the therapist.

e) In addition, the therapist needs to hold in mind that, particularly in the communications of the person with dementia, references to the past may be communications about the present – ie about the person's current state of mind.

Henry and Jane, contd.

Jane alone: At the end, she said that she noticed that after my visit, it has a therapeutic effect on her state of mind – it lasts a few days– sort of a feeling that there is light at the end of the tunnel. She doesn't think he is aware of the extent to which his condition is affecting her – though occasionally he will ask – are you OK? What are you feeling – anything wrong – and she will say, no, because she is trying to protect him. The analogy she thinks of is like a mother with a child – but she would never say that to him – she is the one having to take responsibility – she is a manager again, like she was at work – only in a domestic way now – she is the one who says – have you got your bus pass? Sometimes its a bad day, like he has just got up on the wrong side of the bed and is in a state. Other times, hes overwhelmed by all the people on the bus and he goes silent. But then at other times it is different – eg in bed, doing Times crossword – how do you spell nemesis – he knows the word he is looking for. Its patchy – though is frustrating with his asking the same question again and again, I try not to show it – not his fault.

The partner with dementia also needs the opportunity to express feelings on their own.

Henry alone. – She is a very stable person – a consistent person – I am a lucky man. Reaction to video – she wont do the computer at all – dont know why, ***think she is maybe trying to keep me involved in things – His insight.*** *He commented on how important she was to him. How steady she was – always = the two of them – never had children – no rancour about that – it just never happened. Don't know how people can split up – looked tearful*.

At each session, it is important that there is significant time allocated for joint discussion with both partners together

Example: Henry and Jane (contd.)

He was describing the experience of childhood wartime evacuation and she commented.. I find that curious that you remember back then…it should be the older stuff that you forget….

She said – it's as if your intelligence is still there – you say clever things – but then it's not there – like when you walked into the bedroom, when we were about to leave, asking whose wedding it was, and did we know them well?

H chipped in – I was his Godfather – then heard himself use the past tense – and added – I still am his Godfather.

I said that perhaps it comes and goes – there are times like now, when you feel H is with you, in thinking about it

J came in, adding – yes and other times, when he doesn't remember and doesn't know what is happening.

H said – yes, it comes and goes….I think of it as like a container with water, and some of it flowing over the sides – and once it's gone over, I can't get it back

He gave an example of how she'd done something for him, helped him to find his bearings again when he had become confused (eg when they were out shopping?)

I said that she helps anchor you

He looked tearful. She does a lot for me, I can acknowledge that.

Ongoing sessions; Important themes illustrated by case examples

Isolation and Withdrawal

Ray and Barbara contd.

R spoke about how he noticed how when he was reading a book he would fold down a page but when he went back to it, he could not remember anything of what happened. I asked how he felt when this happened and he said I don't like it. He conveyed how, in lots of every day ways he is brought up against his difficulties – and this is linked to his withdrawal.

She spoke about his withdrawal – how he retreats into books, how she is left to make decisions alone – and how alone she can feel. She is having to take on things that she never did before-like dealing with the heating system and other things around the house. And I am slowing down anyway. When father died mother, who had never had to do anything had to take on things like the finances and she did very well – that's my model – but she was 76 and I am 83 and those extra years make a difference.

He is forgetting more and more – keep finding things put away in strange places when he dries up – only thing he does – I don't say anything – but it is sad – I want to protect him
He's withdrawing from me and from the things I do. We used to have the serving hatch open and he would chat away to me – but now he doesn't he is stuck in his book (? Do you think he withdraws from things because he feels he won't be able to do them)
At same time, he isn't understanding the books so well any more – he can't remember what s happened. We watch TV together – but with the programmes we used to like, he can't follow or remember what has just happened – he is lost.

As time went on in the work, she made use of our discussions, noticing the tendency (that had been what she had worked on in herself, to take over, in other carers). She spoke of how she notices how other people, carers, can be so critical and negative. (And that would make the person with dementia withdraw more.) At the Alzheimer Society meetings, most of the carers cut up the food of the person with dementia – and she thinks 'no, you don't need to do that, not automatically anyway, not unless they are experiencing real difficulties with it'.
After telling me that he is pretty much withdrawn a lot of the time, or at least that he does not do much, has everything arranged around his chair, his reading light books magazines etc and the servant to bring him things (which is how she can feel). She said that she had noticed that he does come out into the kitchen now and say to her, is there anything I can do – and she thought he was making a link with what we had been doing. He had never ever done this before, and so she thought, thank you Andrew.

She also described other evidence of change. Normally when I bring him tea in bed in the morning he doesn't say anything much but the last few days it's been very *different = he was chatting a way, telling me about what he did, pointing out people walking past – noticing them saying things like he looks a bit funny. It is like having the old Ray back – like he's still there after all. There was the sense that she had thought his withdrawal was all due to cognitive deficit and now there was evidence of his remaining capacities and his willingness to engage.*

Further Sessions – How the therapy develops – back to Henry and Jane

Case Example: Henry and Jane

Discussion with her: it has been all right over the past week – but can notice the memory loss getting worse. When things happen, that he forgets, she doesn't point it out to him – she remembers the people down the road, he is dead now, but shortly before he was taken into a home, they had a terrible screaming row that all the neighbours could hear. That had stayed in her mind, as a warning to remember –I don't want it to be like that ever – what's the point in getting angry with someone who doesn't know what they are doing? But when they do argue, he forgets in a few minutes but she is left with it sometimes for a couple of hours...and he completely forgets. She is on her own with so many things – but don't want to say it's a burden, because it is probably much worse for people who are further down the line...Her feelings about what she is going through now are in the shadow of thoughts about how it will be in the future...And the emotional burden now is clear – the trauma of diagnosis – the unfairness of it – and she is left on her own with feelings that she can't tell him about because she wants to protect him – so that in that way, she is on her own – the CEO, having to manage everything. She had given me an example of warning light coming on cooker – Henry's denial that he had switched on the hob, but she could see that he had been trying to switch on the oven – he denied it, had forgotten completely, or was he needing not to face the evidence of his forgetting?, she wondered. Nobody really knows what it is like – except perhaps my brother, who sometimes takes them shopping – the other day Henry had done something, and my brother hadn't said anything but had looked at her – a witness to what she is going through – had understood.
She said that she felt that he knew that she knew, about his moods – that neither of them put it into words – a bit like the parallel world around the way they did the tasks. She said that it didn't take away her feelings, just by his saying 'sorry' about it. And then added, that this morning he had woken up and seemed low and she had asked what was the matter. He said, I wonder where I am going to end up?
She said, wherever it is, I will be with you. And that had settled him.

We discussed the issues around the activities – how it felt, the danger that he would become the one who 'hovered', that the dynamic would reverse. With one taking charge (her) and him out of it. Perhaps they have known where the other one was – in tune – but now, and in future, needed to make it more explicit. That is, they didn't have to think about it, they did things in parallel, but it didn't matter so much – they felt in tune with one another then – but now they needed to develop strategies for doing things together.

She then said, something happened the other day. She was cooking and he came along and started doing something, sort of joining in – she had to stop herself saying anything – what she would usually have said – Henry, do you want to do it instead, then? And he would have taken that as being pushed away, and gone off But she didn't do that and he stayed – and that sort of thing has been happening more often recently. - She thought that this was an example of how they might use such opportunities, in everyday activities, for becoming involved in something together.

g) Ending and Follow-up

The couple are videoed doing the same task that they did together for the assessment video. Again, this is for 15 minutes, and the instructions to the couple are the same as at the start of the therapy.

They are told that the therapist would like them to work together as a team doing the task that they did at the beginning.

No other discussion or instructions are given prior to the activity. This allows a comparison with how they interacted together at the start of the therapy now that it is at the end. It also allows some assessment to be made of the need for follow up and the frequency of the follow up sessions.

After the re-assessment video activity is finished, the therapist allows a few minutes for discussion of how the couple experienced it. The next stage is to give the couple the same assessment measures as they completed at the start of the therapy.

Therapists need to have the end in mind throughout the therapy and explore the significance of this ending with the couple. It is helpful to review the intervention with the couple and what they feel the experience has been like. It is also important to think about their histories and how endings are experienced and linked to other losses and the dementia.

Notify GP or other professionals involved of the ending.

Intermittent follow-up sessions can be offered. Therapist agrees the frequency of these with couple.

Psychometric assessment measures need to be repeated over time, at 3-6 monthly intervals for as long as the therapeutic contact continues.

References

1. Ablitt, A., Jones, G., V., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging& Mental Health.* Vol. 13, No. 4, July 2009, 497-511.

2. Alexopoulos, G.S., Abrams, R.C., Young, R.C., & Shamoian C.A. (1988). Cornell Scale for Depression in Dementia, *Biological Psychiatry, 23,* 271-284.

3. Balfour, A.W. (2006). Thinking About the Experience of Dementia: the Importance of the Unconscious. *Journal of Social Work Practice, 20, 3,* 329-347.

4. Beck, A., Ward, C., Mendelson, M., Mock, J., Erbaugh,J.,(1961). An inventory for measuring depression. *Arch Gen Psychiatry 4* 561-567

5. Bird 2000 Psychosocial Rehabilitation for Problems arising from Cognitive Deficits in Dementia.' In R.D. Hill, L. Backman and A.S. Neely (eds) *Cognitive Rehabilitation in Old Age.* Oxford: Oxford University Press.

6. Brodaty, H., Gresham, M., & Luscome, G., (1997). The Prince Henry Hospital dementia caregivers training programme. *International Journal of Geriatric Psychiatry 12*, pp183-193.

7. Bull, M.A. (1998). Losses in families affected by dementia: Coping strategies and service issues. *Journal of Family studies*, *4*, 187-199.

8. Camp, C. J., Bird, M., and Cherry, K.E. (2000) 'Retrieval Strategies as a Rehabilitation Aid for Cognitive Loss in Pathological Aging.' In R.D. Hill, L., Backman and A.S. Neely (eds) *Cognitive Rehabilitation in Old Age.* Oxford: Oxford University Press.

9. Cantor, M.H., (1983). Strain among caregivers. *The Gerontologist 23,* 597-604.

10. Clare, L, Wilson , B., L., Carter, G., & Hodges, J., R. (2003). Cognitive rehabilitation as a component of early intervention in Alzheimer's disease: a single case study. *Aging & Mental Health* & (1): 15-21.

11. Clare, L., and Woods, R.T. (eds) (2001)*Cognitive Rehabilitation in Dementia* Hove: Psychology Press
12. Gutstein, S., (2005) Relationship Development Intervention: Developing a treatment programme the address the unique social and emotional deficits of autism spectrum disorders. *Autism Spectrum Quarterly,* winter, 2005.

13. Iliffe, S., and Manthorpe, J. (2004) Editorial. 'The hazards of early recognition of dementia: a risk assessment.' *Aging and Mental Health 8,* 99-105)

14. HM Government (2008) *Carers at the Heart of 21st Century Families*, Strategy Document

15. Lawton M. P., Moss M., Fulcomer M. and Kleban M. H. A research and service oriented multilevel assessment instrument. *J. Geront.* 41, 114-119, 1986.

16. Lewis, R. (1998). The impact of marital relationship on the experience of caring for an elderly spouse with dementia. *Ageing and Society, 18,* 209-231.

17. Migliorelli, R., Teson, A., Sabe,L., Petracca G., Petracchi, M., Leiguarda, R., & Starkstein, S.E. (1995). Anosognosia in Alzheimer`s Disease: A study of associated factors. *Journal of Neuropsychiatry, and Clinical Neurosciences, 7,* 338-344.

18. Moniz-Cook, E., and Manthorpe, J.,(2009) *Early Psychosocial Interventions in Dementia Evidence-Based Practice* Jessica Kingsley Publishers London and Philadelphia

19. Morris, L.W., Morris, R.G., & Britton, P.G. (1988a). The relationship between marital intimacy, perceived strain and depression in spouse caregivers of dementia sufferers. *British Journal of Medical Psychology, 61,* 231-236

20. Morris, L. W., Morris, R.G. & Britton, P.G. (1988b). Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *British Journal of Psychiatry, 153*, 147-156.

21. Murray, J., Schneider, J., Banerjee, S., & Mann, A. (1999). Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's Disease: II- A qualitative analysis of the experience of caregiving. *International Journal of Geriatric Psychiatry, 14,* 662-667.

22. Norton, M.C., Piercy, K.W., Rabins, P.C., Green, R.C., Breitner, J.C.S., Ostbye, T., Corcoran, C., Welsh-Bohmer, K.M., Lykefsos, C.G., & Tschanz, J.T. (2009) Caregiver-Recipient Closeness and Symptom Progression in Alzheimer's Disease. The Cache County Dementia Progression Study. *Journal of Gerontology: Psychological Sciences, 64B* (5) 560-568.

23. Rogoff, B., Malkin, C., & Gilbride, K., (1984). Interaction with babies as guidance in development. In B. Rogoff & J. Wertsch (eds), Children's learning in the zone of proximal development. *New Directions for Child Developoment,* 23, 31-44.

24. Spanier G.B. and Thompson L. A confirmatory analysis of the dyadic adjustment scale. *J. Marriage Fam.* 38, 731-741, 1982.

25. Stern, Y. (ed) (2007) *Cognitive Reserve: Theory and Applications.* New York, NT: Taylor and Francis

26. Van Assche, L., V., Luyten, P., Bruffaerts, R., Perssons, P., van de Ven, L., & Vandenbulcke, M., (2013). Attachment in old age: Theoretical assumptions, empirical findings and implications for clinical practice. *Clinical Psychology Review.* 33, 67-81.

27. Vernooij-Danssen, M and Moniz-Cook, E., Woods, R., De Lepeleire,J., *et al* Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma.' *International Journal of Geriatric Psychiatry 20,* 377-386)

28. Woods, R.T., Phibbs, E., & Steele, H., (2000). Attachment and Care-giving in Dementia. Paper presented at the BPS PSIGE Annual Conference in Birmingham.

29. Wright, L. (1991). The impact of Alzheimer's disease on the marital relationship. *The Gerontologist, 31,* 224-326.

30. Wright, L. (1994) Alzheimer's Disease afflicted spouses who remain at home: Can human dialectics explain the findings? *Social Sciences and Medicine, 3* (8): 1037-1046.

31. Zarit S. H., Todd P. A. and Zarit J. M. Subjective burden of husbands and wives as caregivers: A longitudinal study. *Gerontologist* 26, 260 266. 1986.

32. Zeisel, J. *I'm Still Here*. *Creating a Better Life for a Loved One with Living with Alzheimer's Disease.* 2009.

Appendix 5

Living Together with Dementia
Semi-structured Interview Schedule

Can you tell me about your experience of Living Together with Dementia?
(I will firstly remind them who was involved, how often they met, where it was carried out and have an idea about what happened in the sessions)

- Why did you decide to do LTwD?
- What were your initial thoughts or expectations about it?
- How did you get on with your practitioner?
- Can you describe what it was like at the start, during the middle and at the end?
- What was good about it?
- What was challenging about it?
- Could it have been better? How?
- Can you describe what it was like as a couple during sessions and in-between the sessions? What were you like with each other?
- Can you tell me what it was like to talk about your feelings and relationship in the sessions? What was it like to hear your partner talk about how they felt in the sessions?
- How, if at all, has your relationship changed after LTwD? (why do you think that has changed?)
- Have your coping strategies as a couple changed as a result of having undergone LTwD? How so?
- Can you describe any changes in the way you communicate with each other?
- What are your experiences of living with dementia after having had the intervention? How do you feel about
- What are your thoughts and feelings for the future?
- Is there anything else you would like to add?

Partner A Booklet

Subject ID:

Couple No:

Centre No:

Assessment point:

The Mini Mental State Examination

Patient's Name_________________ Date_______________ Interviewer______________

'I should like to ask you some questions which we ask everybody routinely. Some of them seem very easy, and others may seem difficult, but please do not feel worried or offended.'

Orientation

1.Time

	Patient's response if incorrect	Score	
Day?	_______________	___	(1)
Date?	_______________	___	(1)
Month?	_______________	___	(1)
Year?	_______________	___	(1)
Season?	_______________	___	(1)

2. Place

County?	_______________	___	(1)
Town (city)?	_______________	___	(1)
What are two main streets nearby (or near your home)?	_______________	___	(1)
What floor of the building are we on?	_______________	___	(1)
What is this address? (*if subject is tested in hospital ask for home address)*	_______________	___	(1)

3. Expression: Naming

Show pencil (pen)	Pencil	___	(1)
Show wristwatch (watch)	Wristwatch	___	(1)

4. Expression: Repetition

I am going to say something and I would like you to repeat it after me: *'No ifs, ands or buts.'*	___	(1)

5. Registration

I am going to name three objects. After I have finished saying all three, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes.

Apple, Table, Penny.	___	(3)

6.Calculation

Now I would like you to take 7 away from 100.	93	___	
Now take 7 away from the number you get.	86	___	
Now keep subtracting 7 until I tell you to stop.	79	___	
	72	___	
	65	___	
	Total:	___	(5)

7. Recall

What were the three objects I asked you to repeat a little while ago?	___	(3)

8.Language: Reading Comprehension

I would like you to read this and do what it says. (See over). Close your eyes.	___	(1)

9.Copying and Drawing

Copy this design (pentagon, see over).	___	(1)

10.Writing: Spontaneous

Write a complete sentence on the space provided (see over).	___	(1)

11. Praxis: Ideational

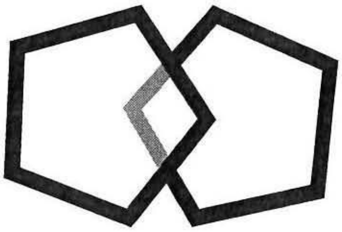
I am going to give you a piece of paper. When I do take the paper in your *right* hand. Fold the paper in half with your hands, and put the paper down on your lap. (DO NOT REPEAT)	Right hand	___	
	Folds	___	
	On lap	___	(3)
	TOTAL :		/30

8.

Close Your Eyes

10. Please write a sentence here

9. Copy this design.



Client ID______________________

Dyadic Adjustment Scale-7

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list, using the scale below (0-5). Please respond with respect to how your relationship is **now**, not how it used to be.

5	4	3	2	1	0
Always agree	**Almost always agree**	**Occasionally disagree**	**Frequently disagree**	**Almost always disagree**	**Always disagree**

1. Philosophy of life _____

2. Aims, goals, and things believed important _____

3. Amount of time spent together _____

How often would you say the following events occur between you and your partner?

0	1	2	3	4	5
Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**

4. Have a stimulating exchange of ideas _____

5. Calmly discuss something together _____

6. Work together on a project _____

7. The dots on the following line represent different degrees of happiness in your relationship. The middle point, “Happy”, represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	1	2	3	4	5	6
•	•	•	•	•	•	•
Extremely unhappy	**Fairly unhappy**	**A little unhappy**	**Happy**	**Very happy**	**Extremely happy**	**Perfect**

Camden

THE TAVISTOCK CENTRE FOR COUPLE RELATIONSHIPS
Training • Research • Psychotherapy • Counselling

Partner B Booklet

Subject ID:

Couple No:

Centre No:

Assessment point:

The Zarit Interview

Please circle the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
1. Do you feel your relative asks more help than he/she needs?	0	1	2	3	4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4
5. Do you feel angry when you are around your relative?	0	1	2	3	4
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7. Are you afraid of what future holds for your relative?	0	1	2	3	4
8. Do you feel your relative is dependent on you?	0	1	2	3	4
9. Do you feel strained when you are around your relative?	0	1	2	3	4
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4

	Never	Rarely	Sometimes	Quite frequently	Nearly always
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20. Do you feel you should be doing more for your relative?	0	1	2	3	4
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

TACI

1a. Does s/she have trouble understanding what you say to him?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
1b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

2a. When s/he is talking to you, do you find his/her speech is so jumbled that you can’t get to the bottom of what s/he is trying to say?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
2b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

3a. Does s/he wake you in the night and disturb you?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
3b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

4a. Does s/he ever not realise that you are talking to her/him, so s/he doesn’t listen to what you say?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
4b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

	1	2	3	4	5
5a. Does s/he get distracted when you are talking to her/him, and appear to stop listening?	Never	Not very often	Sometimes	Quite often	All the time
	1	2	3	4	5
5b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

6a. Does s/he forget what s/he is doing in the middle of an activity (e.g. dressing, fetching something)?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
	1	2	3	4	5
6b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

	1	2	3	4	5
7a. Is s/he ever incontinent?	Never	Not very often	Sometimes	Quite often	All the time
	1	2	3	4	5
7b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

8a. Do you find that when you ask her/him to decide what s/he wants to do, or eat for breakfast for instance, you can’t tell from her/his answer what s/he wants?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
8b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

9a Do you have to keep pointing out that s/he asked you the same question or discussed the same thing already several times during the day?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
9b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

10a. Does s/he forget what day it is?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
10b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

11a. Does s/he forget what time of day it is, for example whether it is morning or afternoon?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
11b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

12a. When s/he gets stuck for a word, or uses the wrong word for something, do you find it difficult to work out what s/he is saying (e.g. the thingummy, or calling her/his glasses a looking glass)?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
12b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

	1	2	3	4	5
13a. Does s/he wander around?	Never	Not very often	Sometimes	Quite often	All the time
	1	2	3	4	5
13b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

	1	2	3	4	5
14a. When s/he seems to be rambling on about something, do you find that you get tied in knots trying to make sense of it all?	Never	Not very often	Sometimes	Quite often	All the time
	1	2	3	4	5
14b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

	1	2	3	4	5
15a. Does s/he forget details about the here and now and, for example, think s/he has got to go to work/collect the children etc?	Never	Not very often	Sometimes	Quite often	All the time
	1	2	3	4	5
15b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

	1	2	3	4	5
16a. Do you have problems getting her/him to wear the right clothes (e.g. pyjamas, etc.)?	Never	Not very often	Sometimes	Quite often	All the time
	1	2	3	4	5
16b. How much does this upset you?	Not at all	A bit	Don’t know	Quite a lot	A great deal

17a. When s/he uses words that sound like words but aren’t quite right, do you spend a lot of time trying to work out what the word was?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
17b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

18a. Does s/he keep going over the same things over and over again, like arranging cushions, moving chairs, etc.?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
18b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

19a. Does s/he jump from one topic to another in the middle of a conversation so that you feel left behind, and you feel muddled about what s/he is trying to say?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
19b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

20a. Is s/he less fastidious than s/he used to be?	1 Never	2 Not very often	3 Sometimes	4 Quite often	5 All the time
20b. How much does this upset you?	1 Not at all	2 A bit	3 Don’t know	4 Quite a lot	5 A great deal

Health Status Questionnaire (HSQ-12)

1. In general would you say your health is?

Poor	Fair	Good	Very good	Excellent
1	2	3	4	5

The following items are about activities you might do during a typical day. Does your health now limit you these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not at all
2. Lifting or carrying groceries	1	2	3
3. Climbing several fights of stairs	1	2	3
4. Walking several blocks	1	2	3

5. During the past four weeks, how much difficulty did you have doing your work or other regular daily activities as a result of your physical health?

None at all	A little bit	Moderately	Quite a bit	Couldn’t do any work
1	2	3	4	5

During the past four weeks, to what extent:	None at all	A little bit	Moderately	Quite a bit	Extremely
6. Have you accomplished less than you would like in your work or other daily activities as a result of emotional problems	1	2	3	4	5
7. Has your physical health or emotional problems interfered with your social activities with family, friends, neighbours or groups.	1	2	3	4	5

8. How much body pain have you had in the last four weeks?

None	Very mild	Mild	Moderate	Severe	Very severe
1	2	3	4	5	6

These questions are about how you feel and how things have been with you <u>during the past four weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past four weeks…	All of the time	Most of the time	A good bit of the time	Some of the time	Little of the time	None of the time
9. Have you felt calm and peaceful	1	2	3	4	5	6
10. Did you have a lot of energy?	1	2	3	4	5	6
11. Have you felt downhearted and blue?	1	2	3	4	5	6
12. Have you been happy?	1	2	3	4	5	6

Please answer YES or NO for each question below by circling “1” or “2” on each line.

	YES	NO
13. In the past year have you had two weeks or more during which you felt sad, blue or depressed; or when you lost all interest or pleasure in things that you usually cared about or enjoyed?	1	2
14. Have you had two years or more in your life when you felt depressed or sad most days, even if you felt okay sometimes?	1	2
15. Have felt depressed or sad much of the time in the past year?	1	2

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out about your partner's diagnosis. There are many ways to deal with problems. These items ask what you have been doing to cope with this one. Obviously, different people deal with things in different ways, but we're interested in how you've tried to deal with it. Each item says something about a particular way of coping. We would like to know to what extent you've been doing what the items says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not- just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true for you as you can.

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1. I've been turning to work or other activities to take my mind off things.				
2. I've been concentrating my efforts on doing something about the situation I'm in.				
3. I've been saying to myself "this isn't real"				
4. I've been using alcohol or other drugs to make myself feel better.				
5. I've been getting emotional support from others.				
6. I've been giving up trying to deal with it.				
7. I've been taking action to try to make the situation better.				
8. I've been refusing to believe that it has happened.				
9. I've been saying things to let my unpleasant feelings escape.				
10. I've been getting help and advice from other people.				
11. I've been using alcohol or other drugs to help me get through it.				
12. I've been trying to see it in a different light, to make it seem more positive.				
13. I've been criticizing myself.				
14. I've been trying to come up with a strategy about what to do.				
15. I've been getting comfort and understanding from someone.				
16. I've been giving up the attempt to cope.				
17. I've been looking for something good in what is happening.				
18. I've been making jokes about it.				
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping.				

	I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
20. I've been accepting the reality of the fact that it has happened.				
21. I've been expressing my negative feelings.				
22. I've been trying to find comfort in my religion or spiritual beliefs.				
23. I've been trying to get advice or help from other people about what to do.				
24. I've been learning to live with it.				
25. I've been thinking hard about what steps to take.				
26. I've been blaming myself for things that happened.				
27. I've been praying or meditating.				
28. I've been making fun of the situation.				

Dyadic Adjustment Scale-7

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list, using the scale below (0-5).

5	**4**	**3**	**2**	**1**	**0**
Always agree	**Almost always agree**	**Occasionally disagree**	**Frequently disagree**	**Almost always disagree**	**Always disagree**

1. Philosophy of life ______

2. Aims, goals, and things believed important ______

3. Amount of time spent together _____

How often would you say the following events occur between you and your partner?

0	**1**	**2**	**3**	**4**	**5**
Never	**Less than once a month**	**Once or twice a month**	**Once or twice a week**	**Once a day**	**More often**

4. Have a stimulating exchange of ideas _____

5. Calmly discuss something together ______

6. Work together on a project ______

7. The dots on the following line represent different degrees of happiness in your relationship. The middle point, "Happy", represents the degree of happiness of most relationships. Please circle the dot which best describes the degree of happiness, all things considered, of your relationship.

0	**1**	**2**	**3**	**4**	**5**	**6**
●	●	●	●	●	●	●
Extremely unhappy	**Fairly unhappy**	**A little unhappy**	**Happy**	**Very happy**	**Extremely happy**	**Perfect**

Living Together with Dementia: Camden innovation

We invite you and your partner to take part together in the Living Together with Dementia project.

Our aim:

- To help communication and understanding in couples like yourselves.

What will happen if we take part?

- At the beginning, a therapist will meet with you and your partner.
- This will usually be at your home or at our centre in Warren St, Central London.
- You will be asked some questions about your health and about your feelings and experiences.
- You and your partner will be invited to do every day things together, like looking at a photo album, and we will videotape you doing this.
- You will be shown clips from this video to help you feel closer to each other

What happens after that?

- You will have up to 8 meetings with a therapist from the team spread out over several months.
- All the information about you will be kept confidential and securely.

- Clinical records may be looked at by members of the team from the NHS Trust, where it is relevant to your taking part in the research.

- Your clinical records may be reviewed where it is relevant to your taking part in the research.

- We would not keep your information for longer than 5 years.

- We will let you know about what we learn from the research.

- You are free to stop taking part at any time, without giving a reason.

- If you decide that you no longer want to take part, you will still receive your normal care as usual.

- If you take part we would let your doctor know.

- All research in the NHS is looked at by a group of people called a Research Ethics Committee, to protect you. This study has been checked and approved by them.

Further Information and Contact Details

- The Lead Researcher, Andrew Balfour, is happy to talk to you about any questions or difficulties that you may have- telephone number 0207 380 1951

- If you have a complaint, you should contact Andrew Balfour on 0207 380 1951

- You may ask your partner, friend, or care staff to tell us about any concerns you have on your behalf.

- If you want independent advice you can contact Dr David Hewison, Chair of Research and Clinical Governance, The Tavistock Centre for Couple Relationships, Warren St, London W1T 5PB or Telephone 02073801975

Living Together with Dementia (LTWD)

Helping couples when one partner has dementia

You are invited to take part in this new intervention which has been funded by Camden Council to help couples when one partner has dementia. This sheet gives you some information about the intervention. However, a member of the Living Together with Dementia team will talk this through with you directly and answer any questions you have before you decide.

Aims and potential benefits of taking part

Living Together with Dementia (LTWD) is an intervention designed to increase closeness and understanding in couples to promote greater resilience and health. The LTWD intervention provides support to address the impact of the disease on both partners and offers help to enable the person with dementia to engage with everyday tasks, thereby reducing the level of carer stress that can result in both partners withdrawing emotionally from each other.

At the moment, there is limited understanding of the shared experiences of older couples living with dementia, and few developments in terms of approaches to helping them cope together with the illness. We hope that this intervention will lead to the development of such an approach that may make a difference to the lives of older couples living with dementia. We will be inviting couples such as yourselves to take part, and anticipate that we will be working with 50 couples overall, in the course of the project.

What happens if we take part?

If you would like to participate we will ask you to sign two consent forms. One is for us to keep, and the other is for you as a record. We would inform your GP or other health professionals involved in your care of your participation.
You and your partner would meet with someone from the LTwD team for one or two initial meetings, where we would need to ask you some questions about your experiences (these questions would be repeated at the end of our work together as well) as part of the process of evaluating how helpful our approach is.

Some people would then begin straight away with the intervention, whilst others would wait for 12 weeks before starting. The decision as to which group couples are allocated is selected by chance. Allocation to either the group starting straight away or waiting 12 weeks is made by a computer. The reason for this is that this is the best way to compare how people feel when they have our intervention, with how they feel when they do not – and this is part of the process of evaluation.

The intervention consists of 8 sessions with a member of the LTWD team who will arrange to see you at your home or at The Tavistock Centre for Couple Relationships in Warren St. The appointment will involve talking with you together about your experiences and feelings about what is happening and there will also be time to talk individually with the therapist.

One part of the intervention involves making a brief video of you doing an everyday task together – for example looking at a photo album or tidying the fridge. You will then be shown clips from this video. Looking at these clips can help couples understand how the things they say and do can be experienced by their partner. This process can help couples to feel closer to each other.
As with any therapy we would like to know how effective it is. Therefore we will ask you to complete some questionnaires at the start and end of the process. There may be the option of additional follow up sessions later.

If later you change your mind and no longer wish to take part, you are free to withdraw at any time, without giving a reason or your decision affecting any future medical treatment.

We hope that participating in the intervention will be felt to be beneficial by the participants, but if anybody should become distressed, or need further help, we would endeavour to make sure that they received appropriate care.

What would happen to information you and your partner give?

- Clinical records may be looked at by members of the team from the NHS Trust, where it is relevant to your taking part in the research.
- All the information which is collected about you during the research will be kept strictly confidential, and any information about you will be kept in a way which removes your name and address and any other identifying features.
- The videotapes will only be viewed by trained clinicians working on the research, and would be disposed of securely.
- All such information will be stored carefully and securely. We would like the opportunity to contact you again in the future, to see whether you would be happy to speak to us again, so that we can look at longer-term follow-up. However, we would not keep your information for longer than 5 years, after which time it would be disposed of securely.

We will be publishing results, though you will not be identified in any publication. We will also let all the participants know about what we find out, and will give you a summary of the findings and you will be invited to a presentation and discussion of them.

All research in the NHS is looked at and approved by an independent group of people, called a Research Ethics Committee, to protect your interests.

Further Information and Contact Details

If you would like more information, or have any concerns or complaints, you should contact the Lead Researcher, **Andrew Balfour on 0207 380 1951**, in the first instance. He will be happy to talk to you about any questions or concerns you may have.

If you are concerned about any issues relating to the research and would prefer to talk to someone independently you can contact Dr David Hewison, Chair of Research and Clinical Governance, The Tavistock Centre for Couple Relationships, Warren St London W1T 5PB. Telephone 02073801975

Living Together with Dementia Project: Camden Innovation
Information Sheet for Clinicians

Aims of the Study and Possible Benefits

The study aims to look at ways in which we can help older couples living with dementia – to see whether there are approaches we can develop to promote closeness and understanding of each other so couples feel more resilient to face the losses associated with dementia. At the moment, there is very little research aimed at understanding the experiences of older couples living with dementia, and not much developed in terms of approaches to helping them cope together with the experience of the illness. We hope that this study will lead to the development of such an approach that may make a difference to the lives of older couples living with dementia.

What would happen if your patient(s) were to take part in the research?

- One or two of the practitioners would meet the couple either at their home or at TCCR to talk about the intervention and gain an understanding of their situation
- We would gain their informed consent to take part and ask a consultee to be involved if there was a concern about incapacity to give consent
- Meetings will involve talking to them together and individually so they have an opportunity to express feelings and concerns
- 8 meetings would be spread over several months and there is the option of follow-up
- One part of the intervention involves videoing the couple doing an ordinary task. This can highlight patterns of couple interaction that can then be talked about later with the couple to promote emotional closeness and wellbeing
- We would be collecting outcome measures and informing GP/relevant staff of their participation at the start and end of the intervention

What would happen to information your patient and their partner give during the study?

- Their clinical records may be looked at by members of the team from the NHS Trust, where it is relevant to their taking part in the research.
- All the information collected about them during the research will be kept strictly confidential, and any information will be kept in a way which removes name and address and any other identifying features.
- The videotapes will only be viewed by trained clinicians working on the research, and would be disposed of securely.
- All such information will be stored carefully and securely. We would keep the information in this way for some time, because we want to have the opportunity to contact participants again in the future, so that we can look at longer-term follow-up. We would not keep the information for longer than 5 years, and it would then be disposed of securely.

We will be publishing our findings (though patients will not be identified in any publication), and we will also let all the participants know about what we find out. All of the participants in the study will be given a summary of the findings and they will be invited to a presentation and discussion of them.

Further Information and Contact Details

If you would like more information about the research, or wish to discuss a particular referral please contact the **Lead Researcher, Andrew Balfour on 0207 380 1951.**

Living Together with Dementia:
A service for couples in Camden

Camden

THE TAVISTOCK CENTRE FOR COUPLE RELATIONSHIPS
Training • Research • Psychotherapy • Counselling

Living Together with Dementia Project: Camden Innovation
Information Sheet for Consultee

What is a Personal Consultee?

In order to understand illness and disability and improve treatment and care, research is essential. This requires inviting people with illness or disability to participate. Some people may have capacity to make their own decision about whether to take part in the research. Others, possibly those most affected by the illness or disability, may not have that capacity. They may not be able to understand enough about the research to be able to give informed consent or communicate a decision. The research provisions of the Mental Capacity Act are designed to allow such people to take part in research even though they cannot give valid consent of their own.

First, the research has to be approved by a Research Ethics Committee. Then, instead of asking the research participant for consent, the researcher must ask a consultee for an opinion about whether the research participant would have wished to take part in the research.

Who can be a personal consultee?

Any person interested in the welfare of the proposed participant, for example:

- A family member, unpaid carer or friend
- A person acting under a Lasting Power of Attorney
- A court appointed deputy

Who cannot be a personal consultee?

- Paid carers and professionals
- People connected with the research (e.g. members of the research team)

Why have I been asked?

You have been asked to act as a personal consultee by a researcher because the researcher thinks you might be willing and able to do this because of your close relation with the proposed research participant.

If I agree to be a personal consultee, what will I have to do?

You will need to think about what the proposed participant’s wishes and feelings about the research would be if they had capacity to make an informed decision and advise the researcher accordingly on whether, in your view, the person should be involved in the research or not. This means you need to

- Look at the information about the project that the researcher will provide for you.
- Think about whether or not the person would want to be involved in the research project if he or she had the capacity to make that decision.

You should not put forward your personal views on participation in the specific project or research in general, you must consider only what the person's views and interests are or would likely be. You should think about:

- What the broad aims of the research and the practicalities of taking part will mean for the proposed participant.
- How the specific activities in the research might impact the participant. For example, if the study involves activities in the afternoon when the person is most tired they might find it a strain or the research might involve an activity that the person particularly enjoys and thus would give them more pleasure.
- Any view previously expressed by the person on the overall nature of the research.

If you advise that the proposed participant would not have wanted to be involved in the research, the researcher cannot include them in the research.

If you advise that the proposed participant would want to be involved, they may be included in the research. If the research commences but at any stage the person shows any sign that they are not happy to be involved in the research, you can change your advice at any time without giving a reason, whereby the researcher must withdraw the person from the research. If the person seems unhappy at any point or shows any signs of objection, then they will be withdrawn from the research.

If you have any questions or concerns please contact **Andrew Balfour, Lead Researcher at The Tavistock Centre for Couple Relationships, Warren St London W1T 5PB on 02073801951.**

If you are concerned about any issues relating to the research and researcher and would like independent advice you can contact the **Dr David Hewison Chair of Research and Clinical Governance, The Tavistock Centre for Couple Relationships, Warren St London W1T 5PB. Telephone 02073801975**

I don't want to be a personal consultee- what do I do?

Tell the researcher and there is no further obligation. If you wish to suggest alternatives please do so.

Where can I get more information and guidance?

Department for Constitutional Affairs (2007) *Mental Capacity Act 2005 Code of Practice*
http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf
Department of Health (2007) *Guidance on nominating a consultee for research involving adults who lack capacity to consent* (consultation)
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076207
Mental Capacity Implementation Programme (2007) *Making Decisions: a guide for family, friends and unpaid carers. Second edition*
http://www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet02.pdf
A printed copy of this booklet is available by telephoning 023 80878038.

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70 Warren St,
London W1T 5PB

Dear Dr

This is to inform you that *(insert name and address and DOB)*

have consented to take part in the Living Together with Dementia Intervention.

Developed by The Tavistock Centre for Couple Relationships (TCCR) and supported by Camden Innovation Fund, Living Together with Dementia is a psychosocial intervention which focuses on supporting the couple when one partner has dementia.

It comprises a brief structured intervention, using everyday activities delivered in participants' homes. 'Flip' cameras are used to videotape the partners doing ordinary activities around the house and selected interchanges are then played back to the couple as a way to address dynamics between them.

The approach aims to increase shared activity, emotional contact and understanding between the partners, and to counter the tendency towards withdrawal and loss of contact, or the acting out of frustration and anger. The aim is to help people with dementia to manage the trauma of the diagnosis, the loss and the changes it brings and to maintain or recover the protective aspects of the relationship.

If you would like any more information about the project please contact Andrew Balfour or Liz Salter on 020 7380 1975 or visit http://www.tccr.org.uk/living-together-with-dementia.

Yours sincerely

Andrew Balfour

Director of Clinical Services

The Tavistock Centre for Couple Relationships

70 Warren Street

London W1T 5PB

020 7380 1975

Direct line - 0207 380 1951

Living Together with Dementia:
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Living Together with Dementia Project: Camden Innovation Consultee Declaration form

Participant Identification Number for this study:

CONSULTEE DECLARATION

Please initial the boxes

1. I ……………………………………….. have been consulted about ……………………………..'s participation in the LTWD intervention and research. I have had the opportunity to ask questions and understand what is involved. ☐

2. In my opinion he/she would have no objection to taking part. ☐

3. I understand that I can request he/she is withdrawn from the LTWD at any time, without giving any reason and without his/her care or legal rights being affected. ☐

4. I understand that relevant sections of his/her care record and data collected during the intervention and research may be looked at by responsible individuals of the team from the NHS Trust (site specific host organisation), where it is relevant to their taking part. ☐

5. I agree to their GP or other care professional being informed of their participation. ☐

Name of Consultee

Relationship to participant:

Date

Signature

RESEARCHER DECLARATION

I have explained the LTWD intervention and research to the personal consultee and have answered all their questions honestly and fully.

I am not aware of any objection held by the proposed participant to participate (for example, an advance directive).

If at any time I am advised by the consultee that the proposed participant would object to being included in the LTWD, I will withdraw the person immediately.

If I become aware of any apparent resistance or objection from the proposed participant I will withdraw them from the intervention and research immediately.

Name: __________________ Signature: ____________________ Date:

Living Together with Dementia: Camden Innovation

CONSENT FORM

Please initial all the boxes:

1. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
2. I understand that relevant sections of my medical notes may be looked at by members of the team from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
3. I agree to my GP being informed of my participation in the study. ☐
4. I agree to take part in the above study. ☐

Name of Participant (please print name)

Date

Signature

Name of Researcher (please print name)

Date

Signature