Norfolk and Waveney NHS
Mental Health
NHS Foundation Trust

Norfolk & Waveney Mental Health NHS Foundation Trust working together with Doughty's Hospital

'Making a difference' with Doughty's Ladies

Sharing skills to create social opportunities for people living in community settings using cognitive stimulation therapy (CST)

Spring 2010

This is a summary report

Members of the first cognitive stimulation therapy (CST) group at Doughty's were asked for their views.
We gathered these comments during the last two sessions of the group's fourteen meetings.

"I wouldn't have been interested if it had been a gossip group"

"Very helpful"

"Enjoyable"

"The helpers seemed to learn a lot!"

"Liked the different themes each week"

"Stimulated my memory"

"Got you off your backside!"

Linen lines used to be the place for us to meet"

Cognitive Stimulation Therapy (CST) and Doughty's Hospital

In 2010 Doughty's Hospital & Norfolk and Waveney Mental Health NHS Foundation Trust (NWMHFT) joined forces to hold the first cognitive stimulation therapy group for residents at Doughty's.

This report will describe the rationale behind the first group, record the planning and organisation, describe the highlights from the work for individuals and the group, and conclude with recommendations for future work based on our shared experiences.

Members of 'Doughty's Ladies'

This shared venture aimed to:

- To support staff at Doughty's Hospital in learning more about cognitive stimulation therapy group work
- To create a community-based learning experience in group work for trust-based educational facilitators
- For the team of facilitators to use a combination of evaluation methods to find out more about CST group work

The value in agencies 'working together' to improve the quality of care and quality of life for people with dementia is a key feature of the national dementia strategy ('Living well with dementia', Department of Health, 2009).

What is cognitive stimulation therapy?

'Cognitive stimulation therapy' (CST) was first used as part of a research project running from 1997 to 2002 at University College London (UCL).

The aim at UCL was to create an evidence-based group intervention programme for people with memory difficulties namely dementia.

Since then CST has been used with other special populations, for example people experiencing social isolation, extreme loneliness and unhappiness and young people with schizophrenia.

The CST group programme contains a mixture of approaches to memory management – each planned session will have elements of reminiscence, reality orientation and multi-sensory interventions and activities.

For example the CST group at Doughty's featured singing, tea and cake, word association puzzles, physical exercise, talking about treasured people in our lives, sharing favourite personal objects, doll therapy with some unstructured fun along the way.

The recent NICE guidelines on dementia in November 2006 state that:

"People with mild / moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care workers with training and supervision. This should be delivered irrespective of any anti-dementia drug received by the person with dementia".

"Cognitive stimulation is the only non-pharmacological intervention to be recommended for cognitive symptoms and maintenance of function. As NICE only recommend drugs for people in the moderate stages of Alzheimer's disease, Cognitive Stimulation is the treatment of choice for people in earlier stages of dementia (with a Mini-Mental State Score above 20). This points to the importance of CST being offered routinely in services."

National Institute for Health and Clinical Excellence (2006). Dementia: supporting people with dementia and their carers in health and social care. NICE clinical guideline 42, November 2006. www.nice.org.uk/guidance/cg42

Eating cake and joining in at the CST group

The background to our shared venture in CST

In 2009, Doughty's Hospital approached (OPTED) the Older Peoples Training Education and Development team at Norfolk and Waveney Mental Health NHS Foundation trust for help with dementia care training. The trust offers a range of dementia care education and learning workshops that have a strong emphasis on care practice.

Doughty's, alongside many care organisations, has an increasing proportion of people in their service with challenges to their memory, and the care team had identified a corresponding need to improve their collective awareness, confidence and competence in dementia care. Doughty's staff joined a pathway of person-centred dementia care learning with the OPTED team at the Mental Health Trust.

At OPTED, a person-centred training team of mental health nurses, we spend the majority of our working time delivering dementia care training. We recognised that as part of our team portfolio of skills and competencies, we needed to include and develop our contact time with people living outside of hospital care.

Three team members at OPTED were also keen to practice facilitating a CST group. Doughty's is a large and respected community care resource within the city centre, and we wanted to strengthen our links and knowledge of life in a community care setting for people with dementia and their carers.

With this background of interests we planned a shared learning venture using CST as our framework.

How did we recruit people to our first group?

Karlene Parry, matron at Doughty's, was extremely interested in how we could make this venture as inclusive as possible from the outset. After securing approval from Doughty's Trustees, OPTED was invited to the regular weekly community coffee morning to describe the aims of the group and to ask for volunteers to attend each of the 14 sessions.

We needed volunteers from residents and from the care team at Doughty's.

- For residents we asked for anyone concerned about their memory to consider joining the group, and who was able to commit to following the whole course – attending twice a week for seven weeks.
- For staff members we asked for anyone interested in joining the group as 'apprentice co-facilitators' to learn more about group skills and CST, and who was able to commit to all sessions whenever possible and practicable.

Who attended the group?

Residents were keen to come to the group and we welcomed anyone with concerns about their memory.

This first group was made up of 9 willing volunteers from the residents of Doughty's, 2 staff members, and 3 mental health nurses from NWMHFT.

How often did people meet?

We met twice a week - Mondays and Thursdays for an hour at 2pm in the Reading room at Doughty's.

Who completed the course?

Eight people completed the course and absences from group sessions were rare - a few occasions only. Unfortunately one person had to leave the group due to ill-health.
This was an outstanding 'attendance record'. We believe that the thoughtful reminders placed on notice boards in people's homes and verbal prompts from the care team really supported people being able to attend as regularly.

How was the course structured?

The programme follows a prescribed format from the 'Making a Difference' manual for group leaders (Spector, Thorgrimsen, Woods and Orrell, 2006).

Spector and colleagues provide a detailed blueprint for each of the 14 sessions with supporting advice.

The manual encourages group leaders to be flexible and responsive to the needs and interests of the group, this blueprint was adapted as the course progressed and we all got to know each other better.

Here is an example of the framework for a session that we used:

Week One:

- Welcoming in to the group, focus on peoples' first names and how we could remember each person - we used sticky labels to start with
- Choosing a name for the group
  "Doughty's Ladies" came in as the favourite
- Choosing a theme song to mark the start and end of the group
  "You are my Sunshine"
- Discussion around the group about day, month, season with reminders about the date and time of each session
- Current affairs at Doughty's and in the news
- A main activity - we used a soft ball and everyone joined in passing the ball around the circle with an associated word connected to a former occupation
- Finishing the session with our theme song and a thank you to everyone

Each session had a similar structure with a different theme or main activity. Over the time spent together we have learnt so much about people's backgrounds, jobs, families and friends - past and present.

We celebrated a birthday; formed a percussion band; brought in childhood memorabilia; talked about food and sampled some; tried on a variety of hats; heard lots of poetry; heard many proverbs; cuddled a doll; celebrated people's creativity; focused on the price of food past and present; greeted a visiting dog.

In amongst much laughter in each meeting, we also heard and supported people sharing some sadder personal reflections especially regarding personal loss and bereavement.

By the end of the course of 14 sessions we had learnt much about each other and what can be shared and enjoyed together.

Were any screening measures used prior to the group starting?

The ethos of the first group was about shared learning for all, we wanted to minimise any formal procedures so deliberately did not include any formal testing of memory relying on self-selection.

How we evaluated the experience of participating in the CST course

We did however want to create an evaluation of the group that could explore the benefits and learning from the whole experience for all. In order to maximise our learning we incorporated person to person interviews with residents and evaluated each session carefully with all facilitators.

We know that asking people about any experience is the best way of finding out how it was for the person; however we also know that telling someone about an experience or giving feedback can be difficult for many people. We used three different, but complementary methods of obtaining feedback about the experiences of people in the group.

1. **Asking each person in an interview about their quality of life, before and again after the CST course**
2. **Completing a progress monitoring record after each session, when all the helpers focussed on individuals**
3. **Observing people during the group on more than one occasion using a structured form of observation**

For the purposes of this summary report we wanted to respect everyone's identity and unique contribution to the group, so we decided to omit personal details from the reporting.

1. Asking each person about their quality of life before and after the group

We wanted to find out more about the group members' personal beliefs about their quality of life pre and post the CST course.

Prior to the group starting, members of OPTED met with each group member; we gathered a brief biographical profile and gained a general impression of how life is for each person in one-to-one interviews. To assist this initial assessment we used a brief 13-item measure called Quality of Life-AD (QOL-AD) (Logsdon, 1996).

QOL-AD has been a mainstay measure used throughout the research in the use of CST.
QOL-AD is based on a rating about people's quality of life from their own perspective (self-reporting) obtained through face-to-face interviews.

QOL-AD suggests the same formula of questions may be posed to family, friends and caregivers connected to the person, to gain their perspective of the individual's quality of life. Due to the high degree of independence with each group member at Doughty's, we opted not to use this part of QOL-AD.

OPTED members used QOL-AD with each resident at the outset of the group and again after the 14 sessions.

An example from QOL-AD
One of the thirteen questions, concerns memory and asks people to choose one of four possible descriptors – poor, fair, good or excellent.
Pre-CST / Nine participants in total

One person believed their memory to be poor	(11%)
5 believed their memory to be fair	(56%)
2 believed their memory was good	(22%)
One believed their memory to be excellent	(11%)

Other topics covered in the questions include physical health, energy, mood, living situation, family, marriage, friends, self as a whole, ability to do things chores around the house, ability to do things for fun, money, and life as a whole.

The chart on page 10 summarises data gathered from each person at the end of the course about their quality of life. To protect confidentiality we have represented each member with a number 1 to 8.

The questionnaire is a series of simple questions and of course, can not reflect the depth of feelings that people may have about areas of their life. We were aware that for many, some of the topics were highly sensitive and probably not so relevant for us to pursue at this moment in time – for example we omitted to discuss money and marriage with most people.

QOL-AD is a frequently used measure in health and social care research. However we understand how direct questions pose particular challenges for some people. For one person, this was particularly difficult. In this case the interviewer used the structure of QOL-AD to get to know the person better, and we recorded N/A throughout the summary chart.

‘Doughty’s Ladies’ on the last day of the CST course

The chart below reflects any change in peoples' expressed beliefs about their quality of life at the end of the CST course

We have used **'UP'** to show an improvement; **'Same'** to indicate no change; **'Down'** to indicate a downward movement.

Each person was asked to select how they felt about each area of their life using the scale: **POOR / FAIR / GOOD / EXCELLENT**

Group member	1	2	3	4	5	6	7	8
Physical Health (1)	UP	UP	Same	Same	Same	N/A	Same	UP
Energy (2)	Same	UP	Same	UP	UP	N/A	Same	Same
Mood (3)	UP	UP	Same	Same	Same	N/A	Down	UP
Living situation (4)	Down	UP	UP	UP	Down	N/A	UP	Same
Memory (5)	Down	UP	UP	Same	Down	N/A	UP	UP
Family (6)	Down	Same	Same	Same	Down	N/A	Down	Same
Marriage (7)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Friends (8)	UP	Same	Down	UP	Down	N/A	Down	Same
Self as a whole (9)	Same	Down	Same	Same	Same	N/A	Down	Same
Ability to do chores around the house (10)	Same	UP	Down	N/A	Down	N/A	Same	Same
Ability to do things for fun (11)	UP	UP	Same	Down	N/A	N/A	Same	Same
Money (12)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Life as a Whole (13)	UP	Same	Same	Same	Same	N/A	UP	UP

This information helps us to see potential benefits from the CST group therapy for each person, and to make some generalisations about the group as a whole.

It would be an oversimplification to claim that the CST group alone was responsible for any improvements – life is a complex business and the people in the group are living full lives with many other influences. However these results help to shape an overall impression of the value obtained for each group member – summarised here below.

In total

Living situation: **4 out of 7 selected a higher rating**
Memory: **4 out of 7 selected a higher rating**

Health: **3 out of 7 selected a higher rating**
Mood: **3 out of 7 selected a higher rating**
Life as a whole: **3 out of 7 selected a higher rating**

A special visitor was welcomed into the group

2. Completing a progress monitoring record to examine each person's experience during that session.

A progress monitoring record is the suggested format for reviewing individuals after each session as per manual ('Making a difference: The manual for group leaders', 2006).

Monitoring progress

After each session the group leaders and co-facilitators talked through the session generally and used a monitoring progress chart to rate each person's participation.
The chart is focused on four domains – mood, enjoyment, communication and interest for each person at the session. The scale for each domain is 1 to 5.
Interest:
1 = shows no interest; 3 = shows some interest; 5 = shows great interest
Communication:
1 = little or no communication; 3 = some response; 5 = communicates well

Enjoyment:
1 = does not show any enjoyment of the session today; 3 = shows some enjoyment; 5 = enjoys session greatly
Mood:
1 = in low mood today appears anxious or depressed; 3 = some signs of good mood; 5 = appears happy and relaxed today

Participant name	Attended?	Interest	communication	enjoyment	mood
1	✓	5	5	3	4
2	✓	5	4	5	5
3	✓	3	4	4	4
4	✓	5	5	5	5
5	✓	5	5	5	5
6	✓	3	3	3-4	3
7	✓	3	4	3	3
8	✓	5	5	5	5
9	✓	5	5	5	5

(Example from session One: 1.02.10)

3. Observing people during the group using a structured form of observation.

We complemented the monitoring progress form assessment with a structured non-participant form of observation that focuses on wellbeing called dementia care mapping (DCM) on three occasions.

The three OPTED facilitators are trained in DCM; DCM originates from the University of Bradford, pioneered by the late Professor Tom Kitwood.

In brief, Dementia Care Mapping (DCM) is interested in assessing a person's behaviour and their associated level of wellbeing and engagement.
DCM is a unique form of observation because it aims to take the perspective of the person - the observer tries to see life from their standpoint. We used the latest edition of the DCM method, Edition 8 (Brooker and Surr, 2005).

For the Doughty's CST group using DCM meant that at each of three sessions, one facilitator stepped out of the group activity and watched how people fared throughout the group session.
The DCM assessment of Behaviour is weighted to record the most positive aspect of the observed behaviour and really helps us to understand what activities have the most potential to support wellbeing – always unique to that individual.

- **Behaviour** is coded to one of 24 letters –for example if a person was eating we would use the code letter F to represent the behaviour.
- **Wellbeing** is examined throughout the observation by close attention to a person's mood and their level of engagement with the world around them.
  Mood and engagement, abbreviated to a ME value has a six point scale. The value range is -5, -3, -1, +1, +3, and +5.

For example the -5 value would be for extreme distress, and the +5 is for the best possible experience for the individual.

Chart to show the range of values attached to mood and engagement:

Mood	**ME value**	**Engagement**
Very happy, cheerful. Very high positive mood.	+5	Very absorbed, deeply engrossed/engaged.
Content, happy, relaxed. Considerable positive mood.	+3	Concentrating but distractible. Considerable engagement.
Neutral. Absence of overt signs of positive or negative mood.	+1	Alert and focussed on surroundings. Brief or intermittent engagement.
Small signs of negative mood.	-1	Withdrawn and out of contact.
Considerable signs of negative mood.	-3	
Very distressed. Very great signs of negative mood.	-5	

Routinely, observers break the observation period up into 5 minute time spans which happened on two of the three DCM observations. On the third occasion the observer tracked behaviour and Mood/Engagement every minute. This in-depth assessment really helped to 'shine a spotlight' on the person's experience.

The observer focused on the same two people twice, one of whom was observed in-depth on a third occasion. The people selected for the observations were chosen by the team of helpers so that we could gain an extra insight into their experience.
Of course the observer is also able to watch the whole group with some detachment, giving valuable general feedback about individuals and the group as a whole.

How did this help our understanding of the CST group?

The information gathered helped to assure the facilitators that the group experience was positive for the two people featured in the observation.

The information gathered through observation can be developed and expanded on to a greater depth, for this CST group it served to confirm that the content and style of running the group was suitable for many of the group. For the two individuals who featured in the observation this was clearly evident.

Reviewing the content of each session

The content of each session was reviewed by the facilitators after the group and at session seven, the half-way point, we asked everyone for feedback about what they liked and what they did not like.

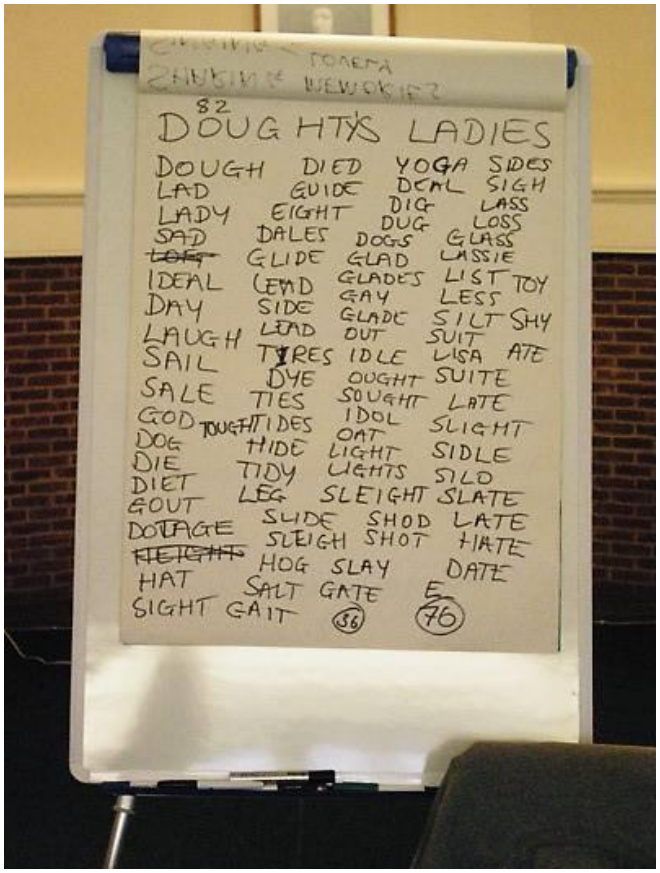
By this time it was clear that some activities were very popular and others not so.

Top favourites have been:

- Bringing personal items to the group - photos, ornaments, carefully presented past achievements, favourite poems and singing.

- Around the group's enjoyment of certain activities there has been room for individual preferences. For example one person hugely enjoyed the presence of a doll so we purposefully made this available in every following session for the individual.

- As important were the cups of tea / coffee and selections of nibbles that greeted people as they arrived at 2pm, helping to seal friendships and reminded us all of individual needs and choices around food and drinks.

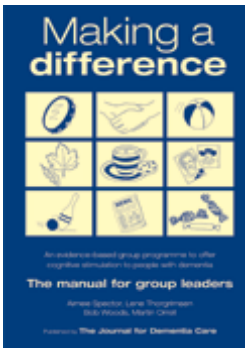


Word exercises such as this one were enjoyed by everyone

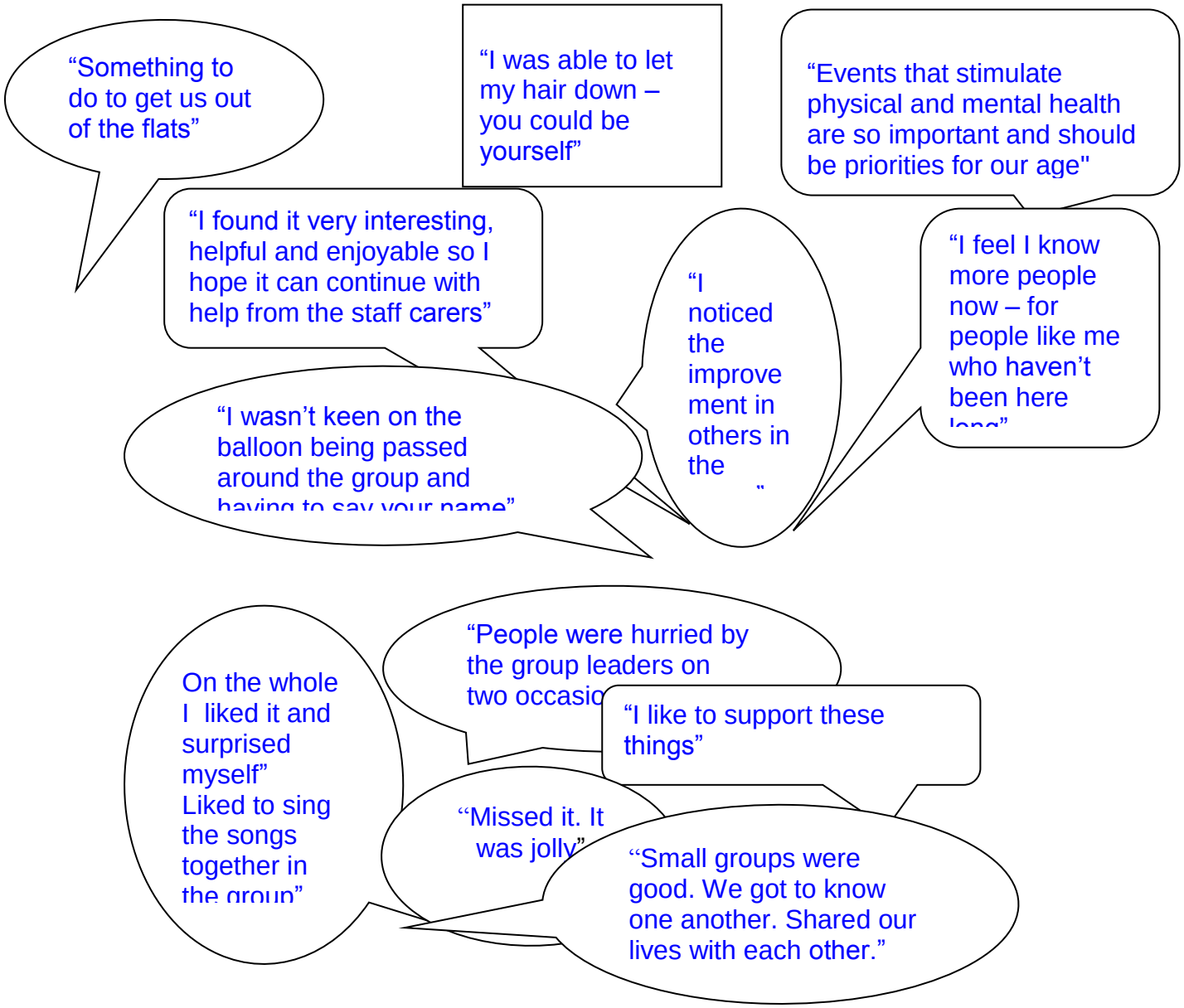
What was less popular?

- People were not as keen on the inclusion of factual orientation for memory management (as suggested by the manual). For example – a ‘reminding-type’ of memory maintenance with a focus on day, date, month, season etc. We observed that people seemed less interested in this aspect and this was confirmed at the half-way review.

- Physical engagement in kicking or catching a soft ball was also probably less popular based again on observation as none gave this direct feedback.



How did group members describe the course a week or so after the course had finished?



We visited each person who had completed the course at home; here is a sample of direct quotes.

Most feedback was very positive & some was helpful in considering our style as facilitators and the content of each session for future group work.

People spoke about high levels of enjoyment and learning more about each other from being in the group.

Celebrating a birthday together

Summary of learning & issues to consider for care staff and facilitators:

Size of group

- We were all aware that this group was larger than recommended by the authors of the 'Making a Difference' manual , and would plan future group for around 4 to 6 people
- Ensuring everyone could hear and was able to participate, became more difficult the larger the group

Criteria for future new groups:

- We were aware that we asked for volunteers for this first group
- Future groups might benefit from a specific remit - for example only people with identified memory difficulties

Relationship Focussed

- Being together in the group helped everyone relate to each other in a person to person way
- The experience of participating and contributing to the group, led to increased confidence & a greater awareness of the social needs of residents
- We all witnessed supportive friendships develop within the group

New Skills

- The group gave everyone - residents and all helpers - many different opportunities in which to try out newly acquired skills in being in a group and group work
- The regular structure of reviewing the group at the end of each session, allowed Doughty's workers to focus on the needs of individuals, and to consider how these impact on daily life.
  For example we became aware of the challenges to people in a group - hearing, seating posture, confidence in speaking up, what happens for many when direct questions are posed and how facilitators can support people to participate as much as they want to
- A night worker joined the group for the entire course and got to know residents better
- Members of Doughty's staff became enthused about the benefits of CST groups - seeing residents in a different context supported a greater understanding of each person, and helped staff to form deeper relationships

Memories and social networks

- We watched people remind each other of important events and support each other when recalling aspects of their own lives
- Visitors to the group included several interested Doughty's colleagues, a student nurse on placement with the city community mental health team, a technical instructor based on the assessment wards at the Julian Hospital and OPTED's admin assistant
- We learnt to support identified individuals in the group with closer one-to-one support for the duration of the session to maximise their participation

Closure & Recommendations

After fourteen sessions we were all a little sad when the group closed - we had become a close, affectionate and fun group

The plans for a weekly maintenance group to be supported by Doughty's staff were shared with everyone and were warmly received, as supported in the literature and research findings of CST.

We hope that further working-in-partnership can develop between the two organisations.

OPTED would like to say thank you to all the group members and Doughty's care team for all their enthusiasm and support throughout this course making it such an unique experience.

References:

Brooker and Surr (2005) *Dementia Care Mapping: Principles and Practice,* University of Bradford, Bradford

Department of Health (2009) Living Well with Dementia – A National Dementia Strategy, Department of Health, London

National Institute for Health and Clinical Excellence (2006). Dementia: supporting people with dementia and their carers in health and social care. NICE clinical guideline 42, November 2006. www.nice.org.uk/guidance/cg42

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All the members at the outset of the first CST group