Implementing the Namaste Care programme for people with advanced dementia at the end of their lives: an action research study in six care homes with nursing.

Min Stacpoole
Amanda Thompsell
Jo Hockley
Joyce Simard
Ladislav Volicer
First and foremost, we would like to thank the families and friends of care home residents who kindly agreed to their inclusion in this study of the Namaste Care programme. We are especially grateful to those relatives who also took part in the focus groups.

Without the enthusiasm and co-operation of the managers and the Namaste champions at each of the care homes, the study would have been impossible. We are tremendously grateful for the welcome we received; the hard work all the staff undertook in order to establish the Namaste Care programme; and, their helpful feedback. We would like to thank them wholeheartedly.

Many fellow professionals have helped us with the study. We would like to thank Dr Jeffrey Cummings who kindly gave permission for us to use the Neuro-psychiatric Inventory (Nursing Home version) in the study, and Dr Bernard Wary and the Doloplus group for permission to use the Doloplus-2 pain assessment scale. We approached several people initially with requests to use various scales and met with unfailing helpfulness and generosity. We would like to thank Sharon Scott and Dr Aisha Begum for their valuable advice about the ethical challenges of conducting research with people who are unable to give valid consent. Professor Rob Howard at the Institute of Psychiatry advised on the study and facilitated the partnership with the Clinical Advisory Group for the Mental Health for Older Adults and Dementia Department of the South London and Maudsley NHS Foundation Hospital Trust. Dr Susanne Reeves at the Institute of Psychiatry kindly helped us review the research measures we chose. Sharon Eldridge and Roy Bhojraz, (students at King’s College London working within the Specialist Care Units at the South London and Maudsley Foundation Hospital Trust) chose to engage with the study as part of their MSc dissertations, and offered their support with data collection in the Specialist Care Units. We are very grateful for their contributions to the study.

At St Christopher’s Hospice, Dr Victor Pace has given unstinting support at every stage of the study; Penny Hansford, Director of Nursing, has leant support and enthusiasm from the outset; Julie Kinley, Nurse Consultant for Care Homes, has supported us practically and professionally, helping with editing and unlimited cups of tea; and Denise Brady, librarian, with Ruth Hathaway, library volunteer, have answered our many queries and requests with their usual speed and helpfulness. Heather McPheat, Ruth Dawe and Edna Pellett,
volunteers with the Care Home Project team at St Christopher’s Hospice, organised the office and the administration. Their efficiency and enthusiasm have been crucial to the completion of the study.

Finally, we would like to thank our sponsors, Dame Barbara Monroe and Dr Nigel Sykes at St Christopher’s Hospice, for bravely giving us this exciting opportunity to research a neglected aspect of the care of people with dementia at the end of their lives.

More people have helped us than it is possible to record here. We would like to thank everyone involved with the study, and we hope that others have enjoyed it as much as we have.

Namaste!

Min Stacpoole
Amanda Thompsell
Jo Hockley
Joyce Simard
Ladislav Volicer
## Contents

- **Abstract**  
  5-7

- **Introduction and review of literature**  
  8-11

- **Methodology**  
  12-19

- **Context and culture of the Care Homes**  
  20-32

- **Implementing Change**  
  33-42

- **The impact of the Namaste Care programme**  
  43-66
  
  1. Quantitative results  
  2. Qualitative findings

- **Discussion, conclusion and recommendations**  
  67-73

- **References**  
  74-80

- **Appendices (I – 5)**  
  81-86
Abstract

Background
Most people with advanced dementia in the UK live and die in care homes. In the later stages of dementia, people are profoundly physically and cognitively disabled and their psychological well-being is threatened by loneliness, boredom and helplessness. People with dementia usually decline gradually, and families and professionals often fail to recognise the terminal phase. At this point, active treatments and costly hospital admissions are almost always inappropriate, as well as distressing and traumatic. Families feel hopeless and sometimes angry when told nothing more can be done.

The Namaste Care programme is a seven days a week enhanced nursing programme that integrates compassionate nursing care with individualised meaningful activities. “Namaste” means “to honour the spirit within”. The care programme was developed in the USA and seeks to engage people with advanced dementia through sensory input, especially touch, and to enrich their quality of life. Families are supported to acknowledge the progression of dementia in the positive context of seeking to provide quality of life to the end of life. The programme claims not to require additional staff or expensive equipment.

Aim
To implement the Namaste Care programme in six dementia care homes with nursing in the UK, and evaluate its effect on the quality of life of people with advanced dementia in care homes, and those who care for them, families and staff.

Methodology
The researchers invited six dementia care homes with nursing to volunteer and collaborate in an action research study to implement the Namaste Care programme. Introductory workshops were held for all staff in the care homes following an initial workshop for care managers and a core team from their care home. Residents were recruited through the consultee process. Inclusion criteria were: a dementia diagnosis and a Bedford Alzheimer’s Severity Scale score of 17+. Primary research measures for residents were: the Neuro-psychiatric Inventory - Nursing Home version (NPI-NH) and the Doloplus-2 behavioural pain assessment scale. Measures were recorded at baseline, and at three intervals of one to two months after the care programme started. Focus groups were held with care staff in each care home before implementing Namaste and again at the end of the study. Focus groups were held for relatives at the end of the study in each care home. Care home managers
were interviewed. Transcripts were analysed thematically. The nurse researcher kept a reflective diary throughout the study. Ethical approval was granted.

**Results**

Five care homes took part in the study (one withdrew before the programme started). Four care homes fully implemented the Namaste Care programme, whilst one managed only morning sessions. Four of the five homes continued the Namaste Care programme after the research period. There was a change of manager, or disruption of management, in all six care homes.

**Residents:** Thirty seven residents were recruited: five died during the study; 30 residents had all four sets of measures recorded. Comparison of severity of behavioural symptoms (NPI–NH) showed that the severity was significantly lower after initiation of Namaste Care than before (p <0.001). Occupational disruptiveness (NPI–NH) was also lower after initiation of Namaste Care (p < 0.001). However, longitudinal analysis of the care homes collectively showed that reductions in behavioural symptom severity and occupational disruption were not significant over time, probably because pain management differed between care homes. Pain management reflected the quality of nursing and medical care: pain was most prevalent in the home with most disruption. In four care homes with good pain management (average Doloplus-2 scores <5), Namaste was effective in reducing behavioural symptom severity and occupational disruptiveness significantly over time (p=0.033 and p=0.044 respectively). In the care home with the highest average pain score, where the pain score increased during the study, residents also showed increased behavioural symptom severity. However, the overall decrease of behavioural symptoms during Namaste Care was not due to an increase of analgesic medications. Twenty residents had no change in analgesic administration during Namaste Care and there was significant decrease of behavioural symptom prevalence and occupational disruption in this subgroup which cannot be attributed to an increase in analgesic medication.

**Relatives:** reported no negative responses to Namaste, and felt the care programme benefitted their family members; and in some cases themselves. Relatives who participated enjoyed Namaste; some experienced better communication with their family member; some felt the overall atmosphere of the care home changed for the better. Relatives described better communication with care staff, and expressed appreciation of their work and commitment.

**Care staff:** developed new skills and found their work more rewarding. The structure of the Namaste Care programme, especially therapeutic touch, supported greater interaction with residents helping staff to develop closer relationships and better communication with residents. Staff also reported improved communication with relatives. The themes of ‘seeing the person ‘ and ‘reaching out to each other’, which emerged from the study, reflected a shift in the culture of care from the ‘rushing around’ and ‘chaos and confusion’ found at the outset.
Managers: were enthusiastic about Namaste, and reported that the care programme developed teamwork; raised staff self-esteem; improved relations between staff and relatives; and supported the development of a person-centred culture of care. Care staff, managers and relatives recognised that Namaste fostered dignified and compassionate care.

Conclusions
Where there is strong leadership, adequate staffing and good nursing and medical care, the Namaste Care programme can improve quality of life for people with advanced dementia in UK care homes with nursing. The Namaste Care programme has the potential to put abstract concepts such as ‘person-centred care’ into practice: the structure of the care programme supported closer relationships between residents, staff and relatives and helped care homes to deliver dignified, compassionate care to older people with dementia. Namaste Care was welcomed by care staff, managers and relatives and did not require significant investment, or additional staff.

This study shows that meaningful research with people with very advanced dementia in care homes is possible. Developing more sensitive measures of psycho-social well-being would enable better evaluation of the effectiveness of interventions. More interventional research studies should be undertaken with this population and those who care for them so that practice can be developed and improved, and people with dementia can experience quality of life to the end of life.
Chapter 1
Introduction and brief review of relevant literature on end of life care for people with dementia in care homes

A YouGov poll of 2000 people commissioned by the Alzheimer’s Society found that dementia is feared more than cancer and more than death (Alzheimer’s Society 2011). Press reports of the abuse of older people in care homes, hospitals and their own homes and the publication of the Francis Inquiry (Francis 2013) have done nothing to alleviate such fears.

Dementia is a progressive neuro-degenerative disease which carries a heavy symptom burden in the later stages (Mitchell et al 2009), and the highest disability burden after spinal cord injury and terminal cancer (Murray et al 1996 cited in WHO 2004). The particular challenges of dementia care include coping with behavioural and psychological symptoms and distress, and the prolonged, unpredictable course of deterioration over years. There are currently 800,000 people with dementia in the UK, and it is estimated that 60,000 people die each year as a result of advanced dementia (Knapp and Price 2007), with 59% of people dying in care homes, 32% in hospital, 8% in their own homes and 1% in a hospice or elsewhere (Pace et al 2011). A recent report (The Alzheimer’s Society, 2013) found that 80% of care home residents have a diagnosis of dementia or serious memory problems.

1.1 End of life care for people with advanced dementia
Hospital is rarely a good option for people with end stage dementia. Patients often become distressed and more confused by the alien, busy environment (Alzheimer’s Society 2009). Sampson et al (2006) found that hospital stays for people with dementia were longer by around 50%, often followed by readmission; that patients with dementia were receiving poor pain and other symptom control as well as undergoing inappropriate levels of medical interventions (Mitchell et al 2009; Morrison & Siu 2000). A National Audit Office report indicated that about 50% of care home residents who died in hospital could have been cared for in the care home (Bourne 2007). Inappropriate hospital admissions often occur because professionals and families do not recognise that dementia is a terminal illness, and families are expected to make decisions in a crisis situation (Sampson 2008).

The National Dementia Strategy identifies improving end of life care for people with dementia as a key objective (DoH 2009), and the National Council for Palliative Care promotes planning ahead and good symptom management as core elements of best practice in end of life care for people with dementia (NCPC 2009). The Gold Standards Framework end of life care programme has provided a model to enable care homes to
deliver good end of life care for residents, including those with dementia (Hockley et al 2010; GSF 2009). Nonetheless, despite some progress, there remains a widespread failure to recognise dementia as a terminal illness, and a lack of appropriate training for health care professionals in providing end of life care for people with dementia (Chang and Walter 2010).

1.2 The role of supportive palliative care in advanced dementia
Little is known about the later stages of dementia (Pace et al 2011), and understanding of the palliative care needs of people with advanced dementia and their families remains limited (Sampson et al. 2008). The slow and unpredictable disease trajectory of dementia requires a different model of care from traditional specialist palliative care which was developed to meet the needs of cancer patients (NCPC 2009; Hughes et al 2010; Pace et al. 2011). While future health care planning and symptom management promote comfort and protect residents with advanced dementia from inappropriate admissions and futile medical interventions when they are dying, such strategies do nothing to address their psycho-social and spiritual needs.

The essence of hospice care was captured by Dame Cicely Saunders, the founder of the modern Hospice movement, when she said, “You matter because you are you and you matter to the end of your life, and we will help you not only to die peacefully, but to live until you die”. Quality of life is a core element of palliative care, but for those with advanced dementia many questions remain unanswered about what constitutes psycho-social and spiritual well-being, and how it can be recognised and supported. The bulk of research into quality of life focuses on the earlier stages of dementia when people are more responsive and articulate (Smith et al 2005).

There is shared ground between the philosophy of person-centred dementia care and a palliative care approach: both are life affirming and respectful of the person’s individuality; both recognize the centrality of relationships, and the importance of addressing the physical, psychological, social and spiritual aspects of care and taking a ‘whole person’ approach to achieving the best possible quality of life (Hughes et al 2006). The expertise needed to support quality of life for people with advanced dementia at the end of their lives needs to be drawn from the field of dementia care as well as palliative care.

1.3 The Namaste Care programme for people with advanced dementia
An Alzheimer’s society survey (2007) found that a care home resident typically spent only two minutes interacting with care staff or other residents over a 6 hour period, not including interaction with staff during care. In the same report a number of carers of people with
advanced dementia said that their relative was left alone in their room for hours without staff attempting to engage with them. Over the past few years several person-centred programmes and interventions have been developed to provide people with mild to moderate dementia with activity and engagement, so making a positive contribution to their quality of life (Simard & Volicer 2010; Moniz-Cook et al 2008; Brooker & Woolley 2005, Douglas et al 2004). Equivalent programmes for people with advanced dementia are not widely established.

In the USA, Professor Simard developed Namaste Care programme for residents with advanced dementia (Simard, 2013). Simard & Volicer (2010) found that the Namaste Care programme benefitted residents with advanced dementia who were socially withdrawn; the programme decreased the need for anti-anxiety medications, and families reported Namaste Care improved their communication with staff. ‘Namaste’ is the Indian greeting meaning ‘to honour the spirit within’ and the Namaste Care programme was developed for residents with advanced dementia who are no longer able to benefit from group activities such as singing or reminiscence. Namaste Care is an enhanced nursing programme that integrates compassionate nursing care with individualised meaningful activities. Comfort and pleasure are set as the aim of care with an ultimate goal of a peaceful dignified death in the care home. The programme claims to require no additional staff or space. Namaste Care is a seven days a week enhanced nursing programme that integrates compassionate nursing care with individualised meaningful activities. The Namaste Care worker engages with participants providing communication and meaningful activity in the form of personal care alongside sensory input, touch, sound, taste, and scents in a calm, pleasant environment.

A core element of the Namaste Care programme is a ‘family meeting’. Residents with advanced dementia join the programme as their condition deteriorates, and when they can no longer benefit from conventional care home activities. At this point, a ‘family meeting’ is held to explain the change in care, and seek the family/friend’s help in finding meaningful activities and sources of comfort and pleasure for their relative. The discussion includes acknowledging the progression of the dementia and establishing the goal of a peaceful, dignified death in familiar surroundings. The subject of end of life care is raised earlier in the disease trajectory and in the context of positive, tangible benefits for the resident, which makes the conversation easier for care staff. Families are encouraged to participate in the Namaste Care programme, sharing care staff’s efforts to connect with the person they care for and to give pleasure and comfort. Families have more time to acknowledge disease progression; to understand the likely deterioration of their relative; to consider the burdens and benefits of acute medical interventions; and to prepare themselves for loss.

Professor Simard also devised a care programme of appropriate activities for residents with moderate dementia, called ‘The Club’. The two programmes often run in tandem in the U.S.
1.4 St Christopher’s Hospice and the Care Home Project Team

Nineteen percent of all UK deaths now occur in care homes (DH 2012). In recognition of this, St Christopher’s Hospice set up the Care Home Project Team in 2008, (www.stchristophers.org.uk/care-homes). St Christopher’s is situated in South London and serves inner and outer London boroughs. The Hospice is a regional centre for the Gold Standards Framework for Care Homes (GSFCH), and the St Christopher’s Care Home Project and Research team have close links with over 90 local care homes through various training and research initiatives. It was while one of the team (JH) was presenting at the EAPC Congress in Lisbon in 2011, that contact was made with Professor Ladislav Volicer and his wife, Professor Joyce Simard. The ensuing conversation about the Namaste Care programme was the origin of this study. St Christopher’s have supported the study as part of a commitment to excellent care for all.
This study was undertaken to implement and evaluate the Namaste Care programme in six care homes.

**Aim:**

To implement the Namaste Care programme in six dementia care homes with nursing and evaluate its effect on the quality of life of people with advanced dementia in care homes, and those who care for them, families and staff.

**Objectives:**

- To collaborate with care staff to establish whether the Namaste Care programme can be implemented in UK care homes.
- To collaborate with care staff to understand which elements of the Namaste Care programme are transferable to UK care homes.
- To establish whether the introduction of the Namaste Care programme has an effect on agitated behaviour and changes the levels of psycho-tropic medication prescribed for people with advanced dementia.
- To explore the effect of introducing the Namaste Care programme on family perceptions of care.
- To collaborate with care staff and families to develop a dementia specific end of life care educational resource ‘toolkit’ for wider dissemination.

**2.1 Design**

The research used an experimental/organisational action research (Hart & Bond 1996) study. The origins of action research as a distinct form of inquiry were first published by Kurt Lewin in 1946 (Elden & Chisholm 1993). Over the last 20 years however there has been considerable discussion over where action research sits in the paradigm debate (Hockley et al 2013). There is variety in the definitions of action research. For the purposes of this study, the definition is as follows: action research is conducted with and for people rather than on people (Reason & Bradbury 2000). Action research aims to produce new knowledge that contributes both to practical solutions to immediate problems and to general knowledge (Elden & Chisholm 1993: 124).

Elden & Chisholm (1993) argue that no single model can accommodate the variety of new thinking about action research. Hart & Bond (1996) take on Elden & Chisholm’s arguments in describing a typology of action research ranging from an experimental type at one end of
the continuum through to organisational, professionalising, and then to empowering at the extreme end of the continuum. They also highlight three distinguishing criteria for each type: an educative base, a problem-focus, and, improvement and involvement. The typology has been created to define the researcher’s purpose in undertaking the study.

In the current study the purpose was to introduce the Namaste Care programme and evaluate its effect through close collaboration with staff implementing the programme across the six care homes. The idea for the study came from the researchers rather than staff in care homes and to that extent leaned more to the experimental/organisational type of action research described by Hart & Bond (1996). In this type of action research, the topic for the study is thought through by the researchers, and usually has a greater social scientific base, rather than having a practitioner focus. However, the study also had a strong educative base which matches the professionalising type of action research. We encouraged as many staff as possible in the care homes to embrace and participate in the Namaste Care programme. A reflective diary was kept by MS to record the process of the implementation in each care home.

2.2 Role of members of the core team
Five people took overall responsibility for the study. JH, MS and LV took responsibility for the design of the study and JS, MS and AT helped implement the Namaste Care programme. In the tradition of action research, MS had responsibility for both the implementation of the Namaste Care programme as well as collecting process and outcome data in order to understand barriers and facilitators of change.

MS has a background in specialist palliative care and has experience of visiting care homes as a specialist palliative care nurse over five years. Her interest in dementia care is both personal and professional: both her parents died with moderate to advanced dementia; and she has developed a professional interest in end of life care for people with advanced dementia.

2.3 Outline of research

2.3.1 Recruitment
The participatory nature of action research meant that we depended on local dementia care homes with nursing and local mental health for older adults/dementia specialist care units to volunteer to take part. The managers of four dementia care homes with nursing and two specialist care units were approached and agreed to receive further information. A preliminary letter was then sent to each care home manager with an invitation to meet to discuss the study.
After selecting six nursing homes, managers were invited, along with up to five of their staff, to attend a workshop on the Namaste Care programme led by JS. They were also asked to appoint a minimum of two staff who would be involved in leading the implementation within their home. The intention was to start recruiting residents and their families within each of the homes selected immediately after the workshop. Unfortunately, before the start of each cohort, the timeframe needed to be extended because MS’s family bereavements.

2.3.2 Implementation of the Namaste Care programme

The Namaste Care programme is described in section 1.3. Implementation consisted of an initial workshop; care home huddles; role-modelling; day to day Namaste Care; and, monthly collaborative meetings. These are described below.

Initial ‘day’ workshop

Care home managers and care staff responsible for leading the implementation of the Namaste Care programme in each of the care homes were invited to attend a workshop led by JS where the Namaste Care programme was explained. This included teaching on advanced dementia and end of life care for people with advanced dementia as well as explaining the implementation and overall aim of the study. Each care home manager was given a folder which contained information about the research study along with information about the Namaste Day (see Appendix 1).

Care Home ‘huddles’

Following the initial workshop, JS & MS then visited each of the care homes for a whole day to educate staff about the Namaste Care programme. This was done in ‘huddles’ – a small group of staff who were freed up for 20 minutes to attend the teaching. Huddles were repeated until all staff on duty were seen and included maintenance, reception, catering staff as well as nurses and care workers.

JS & MS also spent time with the care home manager walking through the care home discussing the best place where the Namaste Care programme could be established and identifying existing resources.

Role-modelling the Namaste Care programme

Equipment such as fresh flowers, lavender oil, baby lotion, calming music, food treats were taken to each of the care homes where the Namaste Care programme was set up, and JS role-modelled the role of a Namaste Care worker. This included: ‘welcoming’ residents to the Namaste Care space, washing hands and faces and applying moisturising cream, hair care and hand massage (see Appendix 1).
Day to day Namaste Care
Namaste Care was introduced into each care home to be carried out for two hours in the morning and two hours in the afternoon – seven days/week.

Monthly collaborative meetings with Namaste champions across the care homes.
Monthly meetings were held with the managers and Namaste champions of each care home to reflect on the process and to contribute ideas towards the ‘toolkit’.

Care home managers were encouraged to keep a monthly Namaste Care checklist of materials and supplies required and ordered as appropriate.

2.3.3 Base-line data prior to implementation of the Namaste Care programme
A variety of methods were used to build a picture of the current culture in relation to the care of people with advanced dementia within the care homes prior to the Namaste Care programme being implemented.

Staff questionnaire
‘Comfort Around Dying’ scale [CAD-EoLD] (Kiely et al., 2006) is a one-page questionnaire that was completed by the key worker involved at the time of the death alongside the nurse researcher.

Focus groups
A focus group was held in each nursing home with a range of staff to help us understand the challenges they faced in the care of people with very advanced dementia; communication with the families of these residents; and with end of life care (see Appendix 2).

2.3.4 Base-line data prior to a resident enrolling in Namaste Care programme. Some measures (indicated by **) were repeated every one to two monthly until death or end of study
Completed by nurse researcher (MS):
Demographics
A demographic sheet was completed from case notes of a resident enrolling on the Namaste Care programme. It included details of: age, sex, ethnicity, next of kin, medical history, medications and case note review of previous 3 months including evidence of hospitalisation, other medical interventions, weight loss pressure ulcers and place/date of death.
Talking Mats

The nurse researcher attempted to communicate directly with residents using ‘Talking Mats’ a series of picture cards designed to support communication, which have been effective in enhancing communication in people with dementia.

Charlson Index of co-morbidities (Charson et al 1987)

This index was completed by the nurse researcher with the resident – it was an indication of physical frailty and prognosis related to co-morbidity.

Bedford Alzheimer’s Nursing Severity Scale (BANS-S) (Volicer et al 1994)

This scale evaluates the cognitive abilities doe basic day to day living and pathological symptoms in people severely affected by dementia.

Neuro-psychiatric Inventory Nursing Home version** (NPI-NH) (Cummings J. 1997)

This inventory is the gold standard for a comprehensive assessment of psychopathology in care home residents with dementia.

Doloplus-2 Scale Behavioural pain assessment scale for the elderly** (Lefebvre-Chapiro et al 2001)

This is an observational/behavioural pain assessment scale developed specifically for people with advanced dementia who cannot communicate their pain.

Comfort Around Dying’ questionnaire (CAD-EOLD) (Kiely et al., 2006)

If a resident died the nurse researcher went through the CAD-EOLD scale with a member of staff who was present/on duty when the resident died.

Satisfaction With Care questionnaire (SWC-EoLD) (Kiely et al., 2006)

When a resident died, the care home managers were asked to send this one page questionnaire to family members two months after the death, if they judged this was appropriate.

Collecting comments

A NAMASTE CARE book for comments and suggestions was kept in the NAMASTE CARE room. The book was an opportunity for families to write down their feelings and thoughts.

2.3.5 Qualitative evaluation of the impact of the Namaste Care programme

Reflective diary:

The nurse researcher kept a reflective diary in order to capture insights into the process of introducing the Namaste Care programme: the learning from family conferences;
understandings from reflective de-briefing following a death; and the development of the education resource.

*Interviews (see Appendix 3)*

Semi structured interviews were held with care home managers

*Staff and family focus group (see Appendices 4 & 5)*

Staff focus groups and family focus groups were held in each individual nursing home after 3 months after the implementation of the Namaste Care programme.

Thematic analysis was used to analyse the qualitative data from the focus groups and interviews. Content analysis (Polit & Beck 2006) was initially undertaken with each group transcript: the care staff transcripts and the family member transcripts, and the care home manager transcripts. Themes were identified and following analysis of the separate groups similar main categories emerged. All transcripts were read and re-read for themes and then collapsed under categories. Themes and categories from the care staff, family and managers groups were merged to form a more coherent whole.

### 2.3.6 Quantitative Analysis

The quantitative data were collated and uploaded onto SPSS version 20. Descriptive statistics were used for analysing demographic characteristics. Paired t-test compared scores before and after the implementation of the programme. General Linear Model Repeated Measures were used to investigate changes over time. Pearson’s correlation coefficient was used to analyse the relationship between measures.

### 2.4 Ethics

Ethical approval was granted by the East Anglia Research Ethics Committee and the South London and Maudsley Foundation Hospital Trust NHS Research and Development Committee. Consideration was given to the following: consent; the Mental Capacity Act and people who are unable to give valid consent to research; confidentiality; the possibility of uncovering poor practice; and the appropriateness of research at the end of life.

#### 2.4.1 Consent

As part of action research, the care home managers acted as collaborators. They enabled access to staff and families within each of the six care homes, and to the records of Namaste Care residents and deceased residents.

Written, informed consent was obtained from those attending focus groups/interviews. The consent form explained the use of a digital recorder. Staff were asked whether verbatim
quotes from the transcription could be used as long as they were anonymised. After each
focus group the nurse researcher allowed sufficient time to check that the participants felt
comfortable with the discussion, and each participant was offered the chance of another
discussion if they wanted to talk further. No-one did.

2.4.2 Mental Capacity Act
The first principle of the Mental Capacity Act (2005) is to presume a person has capacity to
make a specific decision. Care home managers therefore were asked to use a standard
mental capacity assessment form to undertake a preliminary assessment of each identified
person’s capacity to give valid consent to the collection of data in order to evaluate the
Namaste Care programme. When a resident with advanced dementia was assessed by the
care home manager as lacking capacity to give valid consent, then the care home manager
contacted the family member to invite them to consider acting as a personal consultee. If a
family member did not want to act as a personal consultee, they were given the option to
suggest someone else. If there was no family member, or if the family member declined to
act as a personal consultee, then the nurse researcher sought out another person with a
long term relationship with the resident. If no-one suitable was found, then the nurse
researcher sought a nominated consultee (e.g. general practitioner – someone with no
financial or other interest in the study).

If a consultee advised that the resident would not have wished to take part in the action
research study, then the person was not included in the data collection; however, this did
not exclude them from involvement in the Namaste Care programme which was implemented as best practice. If at any point in the research a personal or nominated consultee decided that the resident should be withdrawn from the study, then the nurse researcher would immediately withdraw the resident. The nurse researcher took
responsibility for discontinuing any resident’s involvement in the action research study if
they signalled distress or an unwillingness to take part at any time.

2.4.3 Confidentiality
All data was anonymised and confidentiality upheld; neither any individual nor any care
home is identifiable within this report. All data was stored in locked cabinets and electronic
data was protected by passwords. No notes were removed from the care home. Ground
rules agreeing confidentiality within the group were set up within all focus groups.

2.4.4 Possibility of uncovering poor practice
Provision was made for the possibility of witnessing, or learning about poor practice in the
care homes. In the event that poor practice was uncovered, we agreed that we would seek
to address this initially through management, but would at all times be guided by the NMC
code of conduct and local policies for safeguarding adults at risk.
2.4.5 Research and end of life care
Talking about end of life care at the family meeting marking the transition to the Namaste Care programme can be distressing for family members and/or staff in care homes, because it involves discussion of end of life care. However, discussing end of life care for people with dementia is considered best practice by the Department of Health; also, the research literature suggests that families usually want to be involved in end of life care research (Emanuel et al 2004; Takesaka et al 2004).
In this chapter we describe the context and culture of the dementia care homes with nursing selected for the Namaste Care programme study. We outline some of the challenges and barriers to change faced by the care homes when implementing the Namaste Care programme. The evidence is drawn from the nurse researcher’s reflective diary and observations during the study; from the staff focus groups held in each care home at the outset of the study; and from consultees during recruitment.

Care homes looking after people with dementia have a shared purpose: to provide care for the people with dementia placed in their care; they are all under the same regulations; and they operate in the same market. South London care homes tend to be staffed by an ethnically and culturally diverse work force, and although the majority of residents are White British, the residents are also ethnically and culturally diverse. As elsewhere but particularly in London there is frequent turnover of staff. Care homes generally tend to be somewhat remote from the wider community and from mainstream health and social services (Owen & Meyer 2012). General Practitioners (GPs) provide medical support and there is local variation in the support they provide to care homes. While there is a shared care home culture, each care home is a separate ‘eco-system’, where different management structures, working practices, values and personalities interact to create a unique culture.

3.1 Selecting six care homes
The researchers sought six care home partners to collaborate in the implementation and evaluation of the Namaste Care programme, and looked purposively for dementia care home managers who were enthusiastic about the study and willing to collaborate in research. Within this group we sought diversity: in size and locality of care homes; in provider organizations; in the physical environment, whether the care home was purpose built care or in converted older buildings; and care homes which had undertaken the Gold Standards Framework end of life care programme (GSF), and homes which had not.

Despite the St Christopher’s catchment area spanning five London boroughs, it was not easy to find six care homes specifically registered for dementia care and willing to engage with a research study. Some homes were busy implementing the two year GSF programme; others were experiencing difficulties with staff shortages.
### Table 3.1 - The Nursing Care Homes selected for the study

<table>
<thead>
<tr>
<th>Care Home and number of beds</th>
<th>Type of Care Home</th>
<th>GSFCH status</th>
<th>Medical support</th>
<th>Gatekeeper consent</th>
<th>Management disruption during study</th>
</tr>
</thead>
</table>
| **A** Medium                | Corporate – (60-beds)  
2 floors  
30 dementia care nursing beds | Accredited | Single GP practice, with allocated GP | Regional Manager; Manager Deputy manager | Manager left suddenly followed by regional manager. Company decided to withdraw from study before recruitment began |
| **B** Large                 | Corporate – (not for profit) purpose built (85 beds)  
2 dementia care nursing units -38 beds | Accredited | Single GP practice, with allocated GP – new to CH work | Manager; Deputy Manager; Regional level (no response) | Manager resigned during study/replaced by administrator who also left at end of study |
| **C** Small                 | Family owned – converted Victorian houses over 2 floors  
– 35 beds for dementia care | Dropped out of programme | Single GP practice, visited randomly by GP partners | Owner; Manager | Two managers resigned during study - replaced by owner/manager |
| **D** Medium                | Corporate – purpose built  
3 floors for dementia care  
2 nursing & 1 residential unit - 65 beds | Accredited | Single GP practice with allocated GP + weekly input from old age psychiatrist | Regional Manager; Manager; Deputy manager | Manager left suddenly along with deputy and regional manager on the same day one month into study. Temporary manager + deputy manager engaged with study |
| **E** Small                 | NHS specialist care unit – older adults: mental health + dementia on one floor.  30 beds | Not engaged | Overseen by old age psychiatrist + single GP practice with allocated GP (funded to support CHs) | SCU Service Manager; Deputy manager (Manager consented once back in post) | Manager not present for initial stages but senior manager and deputy took initial responsibility |
| **F** Small                 | NHS specialist care unit – older adults: mental health dementia  
3 units across 2 wings over 2 floors. 27 - beds | Not engaged | Overseen by old age psychiatrist + single GP practice with allocated GP (funded to support CHs) | SCU Service Manager; SCU Manager; Deputy manager | Manager’s personal circumstances led to them taking time out. Management taken over temporarily by clinical nurse specialist (mental health for older adults) |

*Small = less than 39 beds  
Medium = 40 – 79 beds  
Large = 80 beds and over  
SCU - Specialist Care Unit  
CH – Care Home*
The Specialist Care Units

The Clinical Advisory Group for the Mental Health for Older Adults and Dementia department of the South London and Maudsley NHS Foundation Hospital Trust were partners in this research study. The management team were enthusiastic collaborators with the researchers and two Specialist Care Units (SCUs) were chosen to participate. The Specialist Care Units provide NHS funded care for older people with mental health needs and people with dementia whose complex care needs cannot be met by local care homes. An old age psychiatrist oversees the patients’ mental health, supported by Clinical Nurse Specialists and staffed by registered Mental Health Nurses and care workers. Patients’ physical health needs are covered by a local GP practice and a designated GP provides continuity.

The SCUs did not participate in the GSFCH programme, but they did have in-house end of life care training.

3.2 The culture of the care homes prior to implementation

Certain observations were made across the care homes generally during recruitment, and within each of the care homes as a result of the pre-Namaste implementation focus groups.

Across the care homes a number of challenges to the implementation of the Namaste Care programme were identified. These challenges are described below, and included:

- unstable management
- distracted leadership
- staffing and understaffing
- staff morale
- the frailty and complex needs of residents
- lack of trust
- resources

3.2.1 Unstable Management teams

The first challenge to the study came from Care Home A, when, before recruitment started, the manager announced he was leaving and that his regional manager had already left. No explanation was offered, and the temporary incoming replacements did not want to take on a new project. Care Home A was the only care home lost to the study, but the instability of management was a feature of all the care homes we worked with throughout the study. Despite selecting care homes that were thought to be stable, by the end of the action research study only the manager of Care Home E remained in post, and she had been working in another area before the study started, and so missed out on recruitment and initial preparations. Such instability in the management teams is not uncommon in care homes, especially in London, and makes changes to practice and culture in the care homes
hard to achieve.

3.2.2 Distracted leadership
Throughout the research period while the Namaste Care programme was being implemented all the managers were extremely busy. Managers were under pressure and distracted from Namaste by important clinical, administrative and legal issues. This distracted, disengaged leadership was a feature of all the research care homes to a greater or lesser extent, and presented a challenge to implementing the Namaste Care programme.

3.2.3 Staffing and understaffing
Unstable staffing like unstable management has a negative impact in the care homes. Rapid staff turnover was 30-37% in the private care homes, and 9% in the SCUs over 6 months. Changing personnel makes it more difficult to change practice and culture within a care home. All the care homes experienced periods of understaffing during the study. The problem of under-staffing preoccupied staff in one home particularly.

‘….. some of them will be sick, you have to call ambulance, there’s telephone calls, ........ so it’s a very rushed time. They don’t get the maximum quality care. So in fact in the dementia units staffing level must be looked at. It’s very, very important.

(CH B pre Namaste FG nurse p9)

One care home manager confirmed that they were experiencing unusually low occupancy and explained that the care home’s corporate owners demanded that he reduce staffing levels accordingly, which had a negative impact on staff morale.

Staffing levels were higher in the Specialist Care Units than the other care homes because of the higher level of need in their patient group. Nevertheless, in one Specialist Care Unit understaffing was acknowledged as a chronic problem, while in the other there were specific problems with staff sickness and the disruption caused by the merging of staff and patients from two separate units.

Shift patterns present an obstacle to innovation and flexibility. In the privately owned care homes most staff work ‘long days’, (12-14 hour shifts). With ‘long days’ there is rarely an ‘overlap’ at shift change and opportunities for training and team building are reduced. ‘Long days’ deliver good continuity of care through the day, but overall continuity suffers because staff are only at work for 3 or 4 days a week. The nurse researcher noted that care staff were often tired and hungry at meetings at 14.30 hours because they hadn’t had lunch. In the SCUs ‘long days’ are not the norm but are common.

3.2.4 Staff Morale
Staff morale was a concern in all the care homes at different times in the study. One manager described his staff as, “flat and exhausted” from the outset; weary after the completion of the GSFCH through to accreditation, and a prolonged and chaotic period of
refurbishment. Another manager reported that a very experienced care worker was so unhappy in her work that she was talking of leaving the week the research study began. The disruption caused by management changes affected staff morale adversely. The NHS staff in particular had experienced a succession of new initiatives, and an underlying scepticism had to be overcome before the Namaste Care programme could be successfully implemented. A manager described her initial responses to the research study as ‘cynical’.

3.2.5 The frailty and complex needs of residents
The residents in all the care homes were extremely frail with complex health needs; some experienced distressing symptoms; some were within months of their death. All required skilled nursing and medical care. The skills and experience of the nurses and care workers varied across the care homes, e.g. in the NHS Specialist Care Units which had higher levels of trained nurses and were overseen by a designated GP and an old age psychiatrist, every resident had a regular pain assessment using a validated pain assessment scale, and no pain was uncovered during the baseline assessments. Whereas in another care home there was no routine pain assessment and when each of the research participants was first assessed he/she was found to be experiencing some pain. The medical support also varied between the care homes: the two NHS homes received consistent support from a designated GP; one care home had a designated GP who was new to care home work and admitted that he was inexperienced in palliative care; another GP practice provided an essentially reactive service, with different doctors responding to the care home’s requests.

3.2.6 Lack of trust
A lack of trust was found within the care homes between care staff and management, nurses and care workers, and extended to relations with families and GPs. For example, a resident returned from hospital without his usual prescription for paracetamol. His care worker and the nurse researcher identified pain using the Doloplus-2 pain assessment scale and the floor manager was asked to request a prescription from the GP. However, the GP decided not to prescribe because the hospital had stopped the paracetamol and then the floor manager accepted this. When the care worker and the nurse researcher reassessed the pain, the resident remained resistive to care with the Doloplus-2 score still indicating pain. The care worker was reluctant to mention the problem again because she worried the floor manager would be upset. The floor manager asked the nurse researcher to request the medication via the hospice. As a result, the paracetamol was prescribed, and the patient was once again comfortable. This illustrates the complexity of care homes and multi-professional working, and the scope for poor communications and lack of trust to interfere with fundamental care.

3.2.7 Resources
In the current climate of economic austerity, care home resources are stretched in the private sector and in the NHS. The research tested the claim that the Namaste Care programme does not require additional staff, or space or expensive equipment because no
additional funding was provided. What was spent on the implementation of the Namaste care programme was the decision of the individual care home managers (initially most spent less than £150).

The most expensive items for the programme are comfortable chairs. Appropriate seating for people with advanced dementia is theoretically available from the NHS. In the two NHS care homes comfortable seating was never a problem because an in-house occupational therapist assessed and ordered suitable chairs for residents, but although a resident in one of the private care homes was referred for a seating assessment at the start of the study, a year later the chair was ordered but had still not been delivered. No care home bought lounge chairs for Namaste research participants during the study.

Comfort is fundamental to the Namaste Care programme and the lack of provision of comfortable, appropriate seating in care homes is a barrier to implementing Namaste. It is also a barrier to providing comfortable, dignified care of any description for people immobilised by advanced dementia.

3.3 The pre Namaste staff focus groups
Before the implementation of the Namaste Care programme nurses and carers were brought together in each care home to explore what they thought and felt about caring for people with advanced dementia at the end of their lives. The intention was to gain an understanding of the existing culture of care (ways of working, values and attitudes) in each care home. Six themes were extracted:

- ‘rushing about’ – workload and time pressures
- ‘chaos and confusion’ - ‘challenging behaviour’
- emotional rewards of dementia care
- problems with teamwork
- relations between care staff and families
- end of life care

These themes are discussed below. All were present in all the focus groups to a greater or lesser extent, but in each care home a different theme dominated the discussion. Such dominant cultures are difficult to change and some of these preoccupations continued to characterise the care homes throughout the study.

3.3.1 ‘Rushing around’ - workload and time pressures
It was evident in all the care homes that the care staff were under pressure with a heavy workload. One senior nurse was concerned that understaffing put additional pressure on care staff which resulted in a poorer standard of care than he would wish for.
Really, I feel very, very bad because [our residents] need the maximum care. They need people to stay with them but you don’t have the staff. In the morning, you just rush.... that’s it from 8 - 9 for about 19 highly dependent residents, we have only ...... three carers with one nurse. The nurse will be doing medication, the carers will be rushing, to wash them and clean them, at least wash their face, clean them so at least they can eat breakfast. So you see them rushing, you see everybody sweating. (CH B pre Namaste FG nurse p9)

Almost all residents in these care homes are extremely physically frail. The staff’s time is taken up with meeting immediate physical needs: many are hoisted and dependent for all activities of daily living; many are resistive to care and require two care workers to help them; nurses’ time is taken up dispensing medicines and dealing with the problems of the day. Care workers are not only responsible for residents’ personal care but also for housekeeping jobs such as filling water jugs and sorting laundry. All these tasks take time.

By the time you’ve done breakfast, you’ve done beds and other things. Maybe somebody wants a shower, the morning’s gone...(CH D pre Namaste FG care worker p11)

As well as the physical effort, the pressures of time and the workload are an emotional burden for nurses and care workers. There is a tension between the need to complete the daily round of essential tasks and the desire to respond to the needs of residents for company and comfort. This tension is dissatisfying and disturbing for the care staff.

After she said, “Please can you stay with me,” I said, “Sorry I can’t stay with you, we have other patients and things to do.” She need us to be there for her, the time wasn’t there for us.
(CHB pre Namaste FG care worker  p12)

Care staff know the people they care for well, and recognise their need for comfort and social interaction: they feel guilty that they can’t sit and spend time with residents and are forced into untruthfulness by the demands of work.

Somebody is stopping and asking you, “Can you come back? Can you come back and talk to me?” “I will come in 5 minutes.” Knowing full well that you will not be able to go back in 5 minutes. I feel bad that I have to lie to the person, well, what can I do?
(CH B pre Namaste FG care worker  p13)

An important part of the daily routine of the care homes was how the residents spent the time in the gaps between the care staff actively giving them care and their mealtimes. Commonly, a care worker was allocated the task of ‘watching over’ residents in the lounge after breakfast and after lunch, to prevent falls and ‘incidents’. The television was usually on, and almost never watched by residents; very often the care worker used this time to fill in fluid charts or other paper work for which they are responsible. Paradoxically, although staff said in the focus groups that they wanted to spend more time with residents in response to the resident’s plea ‘stay with me’, there was less interaction between the care worker and residents during this ‘empty’ time than when physical care was given.
3.3.2 ‘Chaos and confusion’ - ‘challenging behaviours’

The behavioural and psychological symptoms of dementia are inevitably a feature of dementia care homes with nursing. Asked what they found hardest about caring for people with advanced dementia, a care worker in one of the care homes instantly responded “aggression”, and others took up the theme. One of the floors in this care home was designated the ‘challenging behaviour floor’. Staff reported that residents would often swear, hit out, throw chairs and interfere with other residents. A care worker in another care home reflected on the difficulties of managing a group of people with dementia, and painted a vivid picture.

We had a scenario yesterday. We had the music playing, yes? So the music is playing and we have got a person out in the garden who is looking at his reflection in the glass and dancing. And he’s really happy with the music. And we have got another person who hears the music and hates it and wants it off. So we have got all these mixtures of people’s emotions in one room. It becomes quite chaotic and confusing. (CHF pre Namaste FG care worker p11)

This sense of chaos and confusion was reinforced by family carers’ descriptions of visiting their relatives in the care homes. Two spoke of the care homes as ‘another world’. One daughter often felt she couldn’t face visiting and would have to ‘psych ‘ herself up to visit her father: she was never sure if he would recognise her or how he would respond; she was also scared of other residents who might be violent at times, or strip naked in front of her.

‘Challenging behaviours’ were not dwelt upon in all the focus groups, although the nurse researcher was aware of a background of agitation, inappropriate behaviour and distressed reactions among residents, punctuated by acute incidents. The everyday realities of dementia care are often taken for granted by care staff and the emotional impact of care is rarely acknowledged openly. Given the chance to talk, one care worker spoke very honestly about her sense of disgust:

What I find so hard dealing with somebody, we’ve got this client downstairs and she spits so much. I find it hard to sort of... deal with spitting and it really, actually make me feel physically sick, myself. Because, I know she can’t help it and its part, probably part of her illness but... I don’t know if anybody else feel the same but that’s how I feel. I feel physically sick about it. But attending to her personal care, I will do it but that, it just make me feel sick. (CHE pre Namaste FG care worker p12)

However, care staff in all the care homes found using their skills to meet the challenges of dementia care rewarding. A care worker described the pleasure in helping someone who is agitated to calm down and accept care.

I find it really rewarding to do. It’s nice when you achieve something. If a person, you know, has been... maybe has got aggression, that you actually manage to get them calmer and manage to get them showered, you know and make them look nice. (CHD pre Namaste FG care worker p5)

3.3.3 Emotional rewards

The emotional rewards of dementia care were a constant theme of all the focus groups.
Care staff enjoy getting to know the people they care for and are touched by their interactions and relationships with residents. In every focus group, care staff spoke of ‘feeling good’, and their work making them happy.

*When they’re happy, it makes me feel very happy, you know. When they are not happy, it makes me feel sad because I sort of think of myself in that situation, you know. But when you really succeed, for the day, you know, it makes you feel, it lifts your spirits, makes you feel good.* (CHC pre Namaste FG care worker p7)

Often staff spoke of reflecting on the resident’s situation and identifying with them, empathising, and finding satisfaction in caring for the resident as they would wish to be cared for themselves. Equally close to their hearts, many care staff related the experience of caring for residents to caring for their own parents, identifying the resident with their own mother or father.

*In my opinion is when I deal with a person with heavy dementia, if I succeed my task, I feel great inside. And I feel, what about if it’s my Dad or my Mum, who’s going to look after him? So I feel great if I succeed with that task.* (CHC pre Namaste FG care worker p6)

Although the financial returns for care work may be poor, an experienced care worker expressed her sense that the rewards of caring for people with dementia are rich.

*I feel different now because I wouldn’t, to be honest with you, I wouldn’t do another job. I wouldn’t do a 9.00 to 5.00, I love my job and I love to see my patients. Coming in in the morning, seeing what they’re like. Getting them up, talking to them, seeing their bad days, their good days; it’s sort of, make me feel good……*(CH E pre FG care worker p5)

### 3.3.4 Teamwork

Given the opportunity to sit and talk about their work, the care staff in a couple of care homes used the focus groups to share some raw emotions within staff relationships. There was clear evidence from the discussion that some members of the team did not relate well together. A staff nurse suggested that the ethnic and cultural diversity of the group appeared to threaten their ability to work as a team, and these difficulties were not being addressed.

*…..we are people from different cultures, different backgrounds, we all not think alike, we don’t always speak the same way ……. We’ve got to give and take, and listen very carefully. The important thing like (name of care worker) said, the resident we are here for the main objective is our resident.* (CHC pre Namaste FG nurse p2)

Apart from ethnic and cultural differences, the team in this particular home was also split between nurses and care workers; senior care workers and nurses; and senior care workers and care workers. The team dynamics felt uncomfortable. However, clearly the focus group was being used as an opportunity to sit down together; one nurse raised serious concerns, including bullying.

*OK. I just wanted to say something that I’ve also observed is there’s a little bit of bullying sometimes from other staff. And also there are some staff who does not accept constructive criticism.* (CH C pre Namaste FG nurse p18)
As we started to try and change the culture in this home through the Namaste Care programme, the management team were dealing with staffing issues. Nonetheless, the friction between staff members was an immediate challenge to any sense of working together for the sake of residents and their families.

Difficulties within teams were not raised explicitly in any other focus group, and good teamwork was generally taken for granted, with one group clearly demonstrating their support for each other as they explored some personal losses in an emotional discussion. However, the split of opinions arising from a different group suggested that other teams were also not united, and in the course of the study we learned that divisions and communication difficulties between the nurses and the care staff were present to varying extents in all the participating care homes.

3.3.5 Relations between staff and families
There was a sense, from several care staff, that it was the resident who was in sole need of care; some saw relatives as an extra complication and they were often perceived as unhelpful. A senior nurse described relations between staff and families very negatively.

I find this very challenging. The families... I will say, only about 1% of the family do understand and do co-operate with the staff especially on the dementia unit. About 90% of the relatives, they don’t cooperate at all........They always come and find faults. They always come in with question, no matter what you do. (CHB pre Namaste FG nurse p30)

He was not alone, in another care home relations appeared to be almost at breaking point: with two nurses describing families as an obstacle to their work, even a threat to health and safety!

They come to visit the person they are visiting, and not to interfere with our work. It’s not possible that probably like to say that, if there’s a visiting time and there’s a visiting area, they should really stay there because health and safety, they are all over the place. Always all over the place. If they had an accident while I’m pushing the machine, I still have to write an accident form. (CH C pre Namaste FG nurse p21)

Nevertheless, in the same care home care workers clearly had made good relationships with families. The care homes often befriended lonely relatives and were in turn befriended. Inevitably the strength and quality of the relationships vary.

3.3.6 End of life care
When it came to speaking about end of life care with families and friends of residents who were deteriorating, there was great variety in the confidence and competence amongst staff. It seemed that confidence to talk about death and dying lay with individual staff members, generally the nurses.

Yes, I try to. I think it’s good to actually prepare them beforehand. So actually talking to them about it, I think that’s necessary and vital. I do tend to, I mean, some, they will obviously find it
quite difficult, so you have to be quite tactful. But I think their preparation up to, you know, you need to lift the person through that. (CH E pre Namaste FG nurse p24)

However, most of the care workers in all the care homes felt it was ‘risky’ for them to talk to relatives about disease progression, death and dying. They were apprehensive about causing distress, taking responsibility, knowing what to say.

I wouldn’t feel comfort... I wouldn’t know what to say, to be honest with you. I wouldn’t know where to start from. I know it’s probably wrong for me to avoid it but I, myself, would probably need some sort of training to sort of say, well, you know....... I couldn’t...

(CH E pre Namaste FG care worker p25)

In care homes where there had been little end of life care training, nurses too were unprepared and felt apprehensive about talking to families about death and dying as they had not been encouraged to discuss end of life care with families.

But you cannot really be talking to them in those kind of difficulties because it’s dangerous, because you have to use the word properly and all this kind of thing. You cannot be messing around telling them, “Look, the person is dying.” (CHC pre Namaste FG nurse p25)

However, for a care worker who took the risk that she might cause distress and spoke openly with a daughter about her father’s deterioration, the response was positive.

And she would come and talk to me about it. It is almost like she couldn’t accept the fact that her Dad’s not going to get any better. One day, I saw, when I went in I thought, oh my God, I hope I haven’t caused her any distress, but I had to tell her. He has got a progressive disease. It’s not going to get any better, so you need to accept what’s going on. And do you know, she went away, came back and she thanked me. (CHF pre Namaste FG care worker p20)

In one of the care homes end of life care was the dominant theme of discussion with care staff sharing their own personal experiences of loss (which were considerable) as well as the sense of loss they felt when caring for residents when they are dying. Care staff described the death of a patient in terms of a death in the family.

I think, you know, the bond, you know, that because they... we slowly build up this bond. That’s why when somebody is parting or going, that’s how, it’s just like a family...... Yes, you are losing one of your family members. (CHE pre Namaste FG care worker p12)

The experience of death and dying and the reactions to coping with end of life care for their residents varied across the five homes. The nurses from the care homes which had undertaken the GSFCH end of life care programme and achieved accreditation were more confident discussing end of life care: in both care homes the nurses who experienced the programme acknowledged the confidence and skills they had gained.

And it’s helpful to prepare relatives,...it helps to prepare in advance, like, funeral directors, arrangements, everything. So with that training, it helps and they [family members] say, when the end stage comes, it helps to bring everything at ease. (CHB pre Namaste FG nurse p38)

All the groups described emotional responses to the deterioration and death of residents.
Some found end of life care rewarding; while others found their experience of death was distressing and disturbing.

I find it quite distressing. I don’t like it. I know it is part of the caring thing that we have to do, but I find it is like, they have suffered so much. In the last stages now, I think they just want to die, basically. I find it can go on for a long, long while before their last breath. I just find it demoralising. (CH B pre Namaste FG care worker p25).

I’m not comfortable because I remember one time, one of our residents passed away. And [staff nurse] asked me and another girl to sit. I didn’t go inside. I didn’t feel comfortable because I’ve never seen a dead body. Yes, so I didn’t go inside.
(CH D pre Namaste FG care worker p23)

Care workers described lasting emotional distress in response to the death of residents; tears, heartfelt grief, pain at the suffering of others and the sadness for someone dying without family.

It was during the night and one of the residents, they had a cardiac arrest and later she died. Only last year. Every day I think about it and when I go to work I can’t even go into her room. I am so scared to be my own ….. She’s gone. It’s like a sudden death. I want to tell the manager, like I needed counselling. It pains me and takes a long time to get over it.
(CH D pre Namaste FG care worker p24).

Although the residents in the privately owned care homes almost without exception had advanced dementia, staff still perceived that many residents died “suddenly”; they described unexpected deaths, ‘out of the blue’, and several inappropriate and unsuccessful resuscitation attempts by the ambulance service. While the nurse recognises, ‘her time was reached’ there seems no acknowledgement of the unsuitability of cardio-pulmonary resuscitation for an elderly woman with advanced dementia.

While I was sitting at there, I have to call the nurse and everything and this woman condition just changed within seconds…… the ambulance came in, tried to get her back, do all resus, CPR and all these things however, but her time was reached. (CH B pre Namaste FG nurse p16)

Although the Specialist Care Units had not undergone the GSFCH programme there had been in house training for end of life care, and staff had grown more confident. One care worker talked of overcoming her fear of death.

Yes, that’s when (name of resident) died and we actually sort of took on board [the training] and we went in, sat with her, stroke her. Anne went in and read the bible, sing with her. And do you know, it sort of opened your eyes and think, this is all they need really, just TLC, somebody to be there for them...I’m not afraid of death any more.
(CHE pre Namaste FG care worker p20)

In this care home staff found talking about death and dying in the focus group helpful and supportive and said they wished they could have more similar discussions. There was no mention of management involvement in the emotional dimension of loss and bereavement for care staff in any other homes.
3.4 Conversations during the consultee process

Family carer burden

Conversations with relatives, during the consultee recruitment process before the study started in the care homes, uncovered a considerable emotional burden carried by families of people with advanced dementia living in care homes.

A daughter spoke of her sense of guilt that her mother was in a care home, compounded by guilt that while she had cared for her mother at home she had neglected her own children. She was fearful that she would inherit dementia since both her mother and grandmother had dementia. She was distressed by her mother’s distress (her mother cried a great deal) and on top of all this was an unnecessary guilt that she had ‘signed’ a ‘Do Not Attempt Cardio Pulmonary Resuscitation’ order for her mother. This daughter used the opportunity of speaking openly with a nurse to ask about how people die with dementia, and found being able to talk openly was a relief.

A husband described the date his wife entered the care home as being ‘engraved’ on his heart. Another daughter spoke of the stigma of dementia and said she felt, ‘ashamed of feeling ashamed’. Some family members visited daily or as often as they could manage. There was an overwhelming sense of commitment, and often personal sacrifice, from these care home visitors. For others the historic relationship with the person with dementia was not always straightforward and there were layers of complexity beneath the family ties.
Introducing and establishing the Namaste Care programme involved major changes for the care homes some of which were fully achieved and others that were not. In the previous chapter we highlighted specific challenges existing within the context and culture of the care homes. This chapter describes the challenges of bringing about that change.

The single most important challenge was motivating the team and this included: the manager, the Namaste Care champions, the care staff team, the nurses, and the wider team, such as activity co-ordinators, kitchen, laundry, maintenance and administrative staff. Sometimes it felt as if everyone in the care homes was overwhelmed with their current concerns which left no opportunity to think creatively how things could be different. Time, space and resources also presented challenges; and, while space and time cannot be changed, they can be used differently.

Each care home was a different context and each chose to implement the Namaste Care programme in ways that suited their own organisation. Table 2.1 highlights the different decisions each manager made regarding who was part of the core team and how space and resources were provided.

Core themes about what challenged and what facilitated the implementation of the programme are now presented and include: disengaged and engaged leadership; getting everyone on board; seeing is believing; and the Namaste Care programme as a structure facilitating change. Inevitably, some aspects of context and culture which were uncovered in the last chapter (Chapter 3) remained influential and in some instances persisted through the implementation phase of the programme.

4.1 Disengaged and engaged leadership

As was set out in Chapter 2 all the care home managers were encouraged to attend Professor Simard’s introductory workshop. However, two managers did not attend (see Table 4.1) which probably should have alerted us from the beginning to difficulties ahead. The manager of one of these homes was under considerable personal and professional pressures. With hindsight, it is clear she had been cajoled into consenting to participate in the research by senior management who were enthusiastic collaborators, although we were ignorant of this at the time. From the outset, this manager distanced herself from involvement with Namaste.
<table>
<thead>
<tr>
<th>Care Home</th>
<th>Attended workshop</th>
<th>Leadership</th>
<th>Namaste Core team</th>
<th>Engagement of wider team</th>
<th>Space</th>
<th>Resources</th>
<th>The Club</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Manager</td>
<td>Manager left within a week of the study starting – CH withdrew from research</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>Staff Nurse</td>
<td>Disengaged/then resigned</td>
<td>Champions: 2 Senior CWs SN on night duty. No core team formed Namaste supported by 2 dementia unit managers. Most care staff supportive</td>
<td>Intermittent contribution by activity team. Wider team marginally involved. Little engagement from trained nurses. No recognition from GP</td>
<td>Two separate Namaste groups run in separate lounges – not Activities Room. No sink or fridge</td>
<td>Delay with basic supplies – then supplemented by care staff + issues with re-stocking. Lounges painted as part of overall refurbishment but little change to environment – no new pictures/plants</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>Owner, Manager (left) Senior nurse Senior CWs 2 CWs</td>
<td>2 managers left Owner took over manager’s role – CH became fully engaged</td>
<td>Champions: 1 Senior CW Owner/manager Core team: Champion &amp; 2 Senior Care Workers Mission statement completed</td>
<td>Good co-operation with activities, kitchen, laundry maintenance etc. Some engagement with trained nurses. Change recognised by GP</td>
<td>Alcove in lounge used &amp; area screened off. No natural lights. No sink or fridge</td>
<td>Room painted - new plants/pictures bought. Furniture re-arranged. Basic supplies available - no delay &amp; restocked regularly Environment changed</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>Manager Senior SN Senior CW CW</td>
<td>Manager and Deputy left. Replacement management team fully engaged</td>
<td>Champions: Senior SN Senior CW + CW Core team: Manager + 3 Champions Mission statement completed</td>
<td>Full co-operation with activities, kitchen, laundry maintenance etc. Some engagement with trained nurses Change recognised by GP</td>
<td>3 separate programmes running in lounges on 3 floors. Natural light. Sink just outside door, no fridge.</td>
<td>Lounges de-cluttered &amp; furniture rearranged. Room painted as part of refurbishment. Basic supplies bought – re-stocked regularly Environment changed slightly</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>Manager, Deputy Manager 3 Senior CWs</td>
<td>Manager and Deputy Manager fully engaged</td>
<td>Champions: 2 Senior CWs Core team: Manager &amp; Deputy + 2 Champion Mission statement completed</td>
<td>Good co-operation with kitchen, laundry maintenance etc. Good engagement with trained nurses Change recognised by GP</td>
<td>Manager’s office converted. Natural light. Sink and fridge available</td>
<td>Office cleared &amp; painted. Plants &amp; pictures bought. Basic supplies bought – re-stocked regularly Environment changed</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>2 Deputy Managers 2 Senior CWs (Manager absent)</td>
<td>Manager redeployed and replaced by Clinical Nurse Specialist</td>
<td>Champions: 2 Senior CWs but not always available. No core team Deputy managers supportive Minimal involvement of wider team. Some senior nurses engaging No recognition from GP</td>
<td>Meeting room cleared. Single Namaste room on separate wing for 3 units. Natural light. Fridge &amp; sink.</td>
<td>Room de-cluttered + painted. Plants and furniture moved in. Basic supplies bought – re-stocked regularly Environment changed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CW – care worker

Table 4.1: Introducing the Namaste Care programme to the Care Homes
The other absent manager sent a staff nurse and two care workers to the initial workshop rather than attending himself. This manager was experienced and keen to be part of the research, but what we didn’t know was that he was in the process of changing jobs as the research study began and was now working out his period of notice. He wasn’t ‘on the floor as much as usual’ and explained that he was trying to withdraw and hand over to senior staff. In his turn, this strong and confident leader himself felt unsupported with the study by higher management.

*What has been most difficult is, I, as a home manager in a big company, actually engaged this programme or embraced this programme without actually having that external support from my side. In a company like this, it is much more difficult, even though I should say that information was sent out to the Director of Dementia and various sorts. We never received any response in regards to that.* (Manager’s interview CH B p3)

The two middle tier unit managers at this care home were expected to lead the Namaste Care programme; and one did push ahead, encouraging care workers on the unit to take Namaste to heart and organised the duty roster and allocation to ensure Namaste care workers ran the programme seven days a week. This unit manager at least provided leadership for her own team.

*The difference is explained by the different leadership in the 2 units. Strong leadership on [name of unit] means that Namaste happens whether the leader is there or not. On [the other unit] there is no cohesiveness between the nurses and the leader’s commitment to Namaste has not been demonstrated when he is there, so when he is not there nothing happens.* (Manager’s interview CH B p1)

Unfortunately, neither of the unit managers had sufficient authority to ensure the support and co-operation of the wider care home team (kitchen staff, laundry, activities co-ordinators, maintenance department etc.). As a result, the lounges were never significantly changed to create a different environment; the ugly chiropody couch and screen remained; the supply of food treats was erratic; care staff had to bring drinks from the kitchen themselves; the Namaste rooms ran out of essential supplies; storage arrangements for equipment were haphazard; care workers felt let down. Although the care home manager recognised the need for overall leadership, he remained disengaged.

Managers in the other three care homes believed that leadership was key to implementing change. They saw motivating and engaging the care home team from the top as crucial to the success of Namaste.

*That is the bottom line, it is the leadership. If the leadership is not embracing it, it is going to fail completely..... The leadership has to embrace this programme 24/7. If the manager or the deputy or the clinical lead, if they are not engaged, if they are disengaged it is going to fail. Because, if they are disengaged, then staff are going to sit back, staff are going to relax, and there is no one behind them to encourage them, to support them and to motivate them.* (Manager’s interview CH D p19)
The contrast between the engaged leadership of these care homes and the disengaged leadership was striking. One of the engaged managers described herself as a ‘floor person’, and within weeks of her unexpected appointment as temporary manager, was able to recognise the strengths and weaknesses of her team. She realised the pressures care staff were under and orchestrated the wider care home team to support them.

Yes. Some staff have taken it on-board and are passionate and with other staff I have to push. I have to push when I do walk around in the morning. For example, with the activity coordinators, I really have to push with them. Because it was too much for the staff to come in in the morning, wash and dress the residents, do breakfast and finish breakfast. And then go and set up the Namaste room and do the programme. (Manager’s interview CH D p10)

This manager not only supported the study but actively created new ways of working to make the change happen. She supported the core Namaste team and used her authority to engage the wider care home team in the Namaste study. In another care homes, the owner supplied the necessary leadership and authority when two managers left during the course of the study.

Where there was full support from regional managers, or higher senior management within the NHS units, initial difficulties and resistance to new ways of working were overcome more easily.

There were different styles of leadership and different approaches to making change happen. The owner/manager of Care Home C was actively involved with changing the practice and culture in the care home, but he was less authoritarian in his style of leadership than others. His style was more collaborative and empowering.

.....when we originally started it [Namaste] we involved them [care workers] and so they felt part of it. And that got them involved in it at the beginning, they felt part of what we were trying to do, which has helped in us doing it. (Manager’s interview CH C p1)

This manager valued the input from an outside source, which he saw as lending external authority to the study. He valued the sense of a shared moral purpose and a shared enterprise with the team in which he was part of the learning process too.

.... and it was the outside influence in a way, it wasn’t as if the boss is just telling you what to do and get on with it. It is actually, this is, we are all working and I am learning, you are learning, we are all on a journey. So we are all trying to improve their lives and this is an idea which we are all agreeing on. (Manager’s interview CH C p9)

At the outset there was a feeling in most of the care homes that more staff would be needed to run the Namaste Care programme despite the claim that reorganising the work can create sufficient change. In one care home with uncommitted leadership, and where both researchers judged the units were minimally staffed, it was difficult to get a consistent, regular Namaste Care programme running at first. However, where care home managers were committed, staffing problems were not allowed to obstruct the implementation of the
care programme, and running Namaste was made a priority.

Well I’ve always ... you see somebody would say to me, ‘Oh (name of manager), there’s not enough staff on today to do Namaste’. And you know, ‘We’re under pressures, we’re short staffed,’ etc., etc., and I said, ‘Namaste will happen over my dead body’. (Managers’ interview CH E p7).

4.2 ‘Getting everyone on board’

Care home managers chose core staff to run the Namaste Care programme, and these Namaste ‘champions’ attended the introductory workshop. All the champions were chosen because they were talented individuals who commanded respect within the care team, based on seniority or personality. The champions shared some characteristics: they were experienced and committed to the care of people with advanced dementia; they tended to be tactile and gentle in their approach to people; they had a creative side to their nature. The Namaste ‘champions’ played the key role in taking day to day responsibility for the care programme, and persuading their colleagues to follow their example.

4.2.1 Pressures on the Namaste Care Champions

Pressures of staffing in the care homes affected the ability of the Namaste Care champions to lead change among the care workers. In the two care homes with uncommitted leadership the Namaste champions were not protected or nurtured by the managers. In these care homes, care staff who attended the introductory Namaste workshop were rotated to night duty while the programme was being established, and in one care home a Namaste champion was moved away from her unit. Some champions had long absences from work during the study for personal reasons and no replacement was nominated. This then meant that the rest of the care staff lacked direction. Management input was needed to organise staffing to ensure continuity and ensure Namaste did not become exclusive.

In one care home, where Namaste was being implemented across three floors, a Namaste champion found herself isolated. She worked on a floor specialising in caring for residents with complex behavioural difficulties. There was an acknowledged lack of teamwork on this unit and the Namaste champion became overwhelmed with the tasks she was expected to complete. As well as setting up and running the Namaste Care programme she was under pressure from the rest of the team to ‘pull her weight’ with the normal workload. She often missed breaks trying to organise everything and the nurses gave her no support. Not surprisingly, she began to lose heart. The other champions within the home (working on different floors) had more authority because one was one a senior staff nurse and the other the senior carer on a residential floor; both managed to gain the co-operation of their own teams. However, when the new manager arrived she supported Namaste and nurtured the care worker champion. Once there was support from the top of the team as well as commitment and enthusiasm from the bottom, the Namaste Care programme finally flourished on all three floors.
In two other care homes the Namaste champions were valued and supported by management. In one the manager took positive action to ensure the champions were not rotated to night duty, and when one went on holiday a substitute was formally appointed. In these care homes the Namaste Care champions not only established their role but also guided and mentored other care workers to take on the role: preparing the Namaste room; greeting residents; talking in calm quiet tones; prioritising comfort; and following the Namaste Care Schedule (See Appendix 1).

4.2.2 Core team meetings – developing mission statements
The nurse researcher met monthly with the managers and team to discuss progress and plan the next development. In one home the core team expanded to include two more Namaste champions who then met regularly with the owner/manager to discuss progress and plan the next development. These core team meetings were an important element of the change process and helped staff reflect on the changes taking place, which were then articulated in the mission statements that three of the care homes developed. However, in another more hierarchical care home Namaste progress meetings were always held with senior nurses and not care workers. A core team did not develop as it did in other care homes. Although there was commitment to Namaste from the care workers and floor managers, there were always time pressures which took priority and there was never time to reflect or develop their mission statement.

4.2.3 Engaging the nurses and the wider team
Namaste is essentially an enhanced nursing care programme rather than an activity, but the hardest group to engage across all care homes were the trained nurses. Many trained nurses did not spend more than 10 minutes in the Namaste room throughout the research period. In one care home the manager was not a nurse, but saw that engaging the trained nurses in Namaste would lift their nursing care to a higher level by using the observations made during a Namaste session to inform care plans and treatments, e.g. pain assessment. She was determined to get her nurses on board.

*My focus now, is engaging the nurses, which I am still doing. I am not there yet, 100%, with all the nurses because some are trying to give excuses .... “I have so much work to do here...” [and I say]. “what I want to see is that when the staff are doing the Namaste programme, I want you involved as well. I just want the floor to run very smoothly as well. I do not want to see you in the office doing anything different. Within this period I want to see you engage as well.”...I want them to see what I am seeing, so that they will know the difference that the programme is offering for the residents. And then they will be able to give this feedback to the relatives, because they are the ones in charge.* (Manager’s interview CH D p 13).

In another care home, the deputy manager role-modelled the contribution that Namaste could make to nursing, using observations from the Namaste room charts to inform the daily nursing handover.

*Yes because a lot of the times ... after the Namaste group I’ll get, “Oh I noticed during the group” or when I go to handover, “I noticed this in Namaste Group”. So it’s definitely been*
quite good in terms of finding out things that probably wouldn’t find out in a normal shift, if they had not had that one to one time. (CH E post Namaste FG nurse p29-30)

The Namaste core team of another care home involved the nurse researcher to help involve the nurses.

It’s when we start having the meetings with (MS) and the nurses in handover. We tell them about it and then when we start, actually start doing it, and getting them involved in it. So they get involved in it, now they're starting to like it. (CH C post Namaste FG care worker p14)

Once the nurses became interested and understood their role they became more motivated in the programme. In the care homes where the nurses played a part in Namaste, then the GPs took notice and recognised there were benefits for residents that Namaste could offer.

4.3 Seeing is believing

There is a Chinese proverb, ‘Tell me and I’ll forget; show me and I may remember; involve me and I’ll understand.’ Engaging and motivating the care staff and particularly the managers and the designated champions was essential to achieving change. The most powerful element of the initial training was some role-modelling of the Namaste Care programme by Professor Simard with residents and staff. In each care home positive changes were noticed in residents at the very first session:

\text{We had about 15 residents – as many as the room can hold. Activity staff very active and very responsive. Wonderful head massage from the man on the team. One lady who always asks for the toilet every 10 minutes – didn’t! Another who always complains of headaches – didn’t. Several went to sleep – enjoyed having their hair done. One man who ‘wanders’ was easily settled with a newspaper, and the calm atmosphere, and intermittent reassurance and touch to resettle him. (Nurse Researcher’s reflective diary p17)}

Inevitably, several members of staff completely missed any introduction because of being on night duty, annual leave or sickness. During the implementation of the programme, new staff came and some staff left. Even for those chosen to lead the programme, who attended the workshop and the role modelling and had access to Professor Simard’s book, the way forward was not completely clear.

\text{I would say it [Namaste] did not go smoothly at the beginning because I think we still weren’t sure exactly what it was or what the purpose of it was as well.’ (CH D post Namaste FG care worker p21)}

For some care staff and managers a visit organised to a local ‘pioneer’ care home, who had established the Namaste Care programme independently, created a ‘light bulb’ moment of engagement when they realized that Namaste Care lay within their grasp. This pioneer home had been running a successful programme for 18 months prior to the research study. Visits to this home became an extension of the experiential learning through role modelling that helped to kick start the programme in three care homes; neither of the NHS homes took
up the invitation to visit another care home.

For the majority of care home staff, deep learning came from witnessing the effects of Namaste Care on their own residents and relatives, and indeed themselves. The new manager at Care Home D who started the job at very short notice, described how she became inspired.

Seeing the physical evidence myself and how residents who are normally so restless and agitated, when they are put in the Namaste room and given the programme, they are so calm. Since I have observed that, I have taken it on board myself in the home to make sure that this programme is really, really rolled out more, running well and more staff are involved. And that even more residents are taken to the room and given the Namaste programme. (Manager’s interview CH D p2)

4.4 The Namaste Care programme - a structure facilitating change
Implementing the Namaste Care programme meant the routines of the care homes were changed, and they made different use of the space and time available.

4.4.1 Using space differently
At Care Home C the decision to paint the alcove where the Namaste Care programme was running felt like a turning point; painting the room a soft pink and buying new pictures sent a clear signal of commitment to the Namaste Care programme. The picture hanging day felt like a party with the care staff enthused and energised. Each care home experienced some similar excitement. The deputy manager of Care Home D said staff were ringing him on their days off to check that he had bought lavender oil, wash bags, and fluffy blankets. Hidden talents for décor emerged and the enthusiasm and the pride that care staff took in creating a homely atmosphere in the Namaste rooms were good for team building and good for morale.

4.4.2 Using time differently
Sharing the philosophy and vision of Namaste, ‘honouring the spirit within’ was a source of motivation, but the care home managers recognised that the Namaste Care programme also provided a structure, and ways of working, that facilitated change in practice. The deputy manager of Care Home E spoke about the power of the care programme to engage and empower care staff. While she noted that there is nothing new in the Namaste Care programme, she also felt that Namaste is much more than the sum of its parts.

I think Namaste was already happening here on this unit because we have staff who were doing lots of pieces of work already..... you know hand massage, people getting their hair done, quiet time etc. But I think ... Namaste brings it together as a more focussed piece of work and the staff feel much more involved and in control of that. Whereas before it was probably disintegrated, now you can see what you're doing. (Managers’ interview CH E p4)

The process of implementing the Namaste Care programme shifted the focus away from tasks. Namaste created a different routine, with the focus on holistic care; care workers
were no longer ‘doing for’ but ‘being with’ and focussing on quality of life. A care worker spoke about the change in the use of time, and described the difference the Namaste morning schedule made, turning previously ‘empty time’ between episodes of physical care into ‘quality time’ for interaction and engagement.

Because we know we’ve got a slot for Namaste, and rather than doing something else we’re there with our residents, engaging. We get to do massages, we get to give them their little treats, their fruits, their juice at a certain time, you know, their time. Their hair, if we don’t get to shave them during personal hygiene in the morning, we’ve got that time with them, we can do all these, make them nice. It gives them more time to engage back to you rather than, [in the] morning, when we getting them washed and dressed, you rushing. You have no time to spend with them. That slot, Namaste slot is their time to engage with them and to spend more time with them. (CHB post Namaste FG care worker p5)

The manager of Care Home E welcomed the guidance Namaste gives staff for spending time with people with advanced dementia. The difficulty and awkwardness of being with someone with advanced dementia who cannot communicate is rarely acknowledged. Family and care staff struggle to know what to do or say when they sit with someone who is unresponsive or agitated. Namaste offers an approach that helps to make ‘being with’ the person with dementia easier and more enjoyable for everyone concerned.

....it can be very daunting talking to somebody, and very depressing talking to somebody who is not going to necessarily respond back to you. Whereas Namaste has opened people’s eyes to see you don’t necessarily have to have somebody talking back to you. Just being there with them and observing the smiles....communication is not just by verbal, it can be by just somebody smiling, somebody showing appreciation. (Managers’ interview CH E p14)

4.4.3 Family meetings – seeing dementia as a terminal illness

Even in the care homes that had completed the GSFCH training, there was reluctance to set up Namaste family meetings to discuss end of life care. In one care home the manager was asked four times to arrange a meeting with a relative who visited every day and who wanted her mother to die in the care home. In this care home, during the first month of the study, a resident with very advanced dementia collapsed in his chair and was sent by ambulance to hospital where he died. This happened despite the family’s clearly expressed wishes, documented after the Namaste family meeting and agreed with the GP, that they did not want him to go to hospital. Following a reflective debriefing session with care staff (Hockley 2013), many fears and insecurities emerged. The owner/manager started to take a more active part in the end of life care meetings; and since then family meetings were held with the owner/manager and a nurse present and have became part of the care home culture.

Nurses who knew their residents well found that they learned more about them in the Namaste family meetings, and felt that they had a closer relationship with the family afterwards. Families enjoyed sharing the challenge; one son went off to buy Chanel No 5, which had been his mother’s favourite perfume and which he said brought back memories for him too; a daughter brought in old photographs which she had not done in the two years her mother had been in the home. Relatives brought in music to play in the Namaste rooms.
One daughter was very tearful talking about her mother dying, but she was grateful for the opportunity to talk and relieved that a plan was made for when her mother’s condition deteriorated.

When residents were dying, Namaste Care was transferred to their bedside. For residents and staff sitting with the dying was made easier by the Namaste Care programme with its focus on comfort; permission to touch and guidance for ‘being with’; and capacity to build relationships between care staff and relatives.
Chapter 5
The Impact of the Namaste Care programme

I think it has completely changed the way we approach care in the home now. I think it has made my job easier because I had, you know, you have a vision of what you want in the home and what you want for your residents. Namaste has packaged that into a programme which has allowed me to get things across to the staff in a way that they can understand. (Manager’s interview CH C p1)

This chapter details the impact of Namaste Care in the five nursing care homes that undertook to implement the programme. It reports the analyses of both the quantitative and qualitative data.

5.1 Quantitative results

Thirty-seven residents were recruited to the study through the consultee process (see Table 5.1). In undertaking the statistical analysis, three subjects were eliminated from the analysis: one because the baseline information was missing and two because they died before the second assessment. Three further subjects died during the study period and one was discharged to another care home, so only 30 full sets of four research measures were taken.

Table 5.1: Number of residents recruited and relationship to consultee

<table>
<thead>
<tr>
<th>Care Home</th>
<th>No of residents recruited</th>
<th>Personal consultee</th>
<th>Nominated consultee</th>
</tr>
</thead>
<tbody>
<tr>
<td>CH.B</td>
<td>6</td>
<td>Wife, brother, son, daughter, sister-in-law;</td>
<td>1 nominated consultee (Older people’s specialist nurse)</td>
</tr>
<tr>
<td>CH.C</td>
<td>9</td>
<td>Husband x 3, wife, daughter x 3, son, friend</td>
<td></td>
</tr>
<tr>
<td>CH.D</td>
<td>8</td>
<td>Husband x 2, wife, daughter x 3, son</td>
<td>1 – nominated consultee (GP)</td>
</tr>
<tr>
<td>CH.E</td>
<td>7*</td>
<td>Wife x 2, son x 2, daughter, cousin</td>
<td>1 – nominated consultee (GP)</td>
</tr>
<tr>
<td>CH.F</td>
<td>7</td>
<td>Son x 2, daughter x 2, partner, wife</td>
<td>1 – nominated consultee (GP)</td>
</tr>
</tbody>
</table>

*one resident was discharged to another nursing home

The characteristics of the residents recruited to the study are summarised below in Table 5.2. Baseline data was collected:

- before Namaste was implemented, and a set of measures recorded
• subsequently, three sets of measures (Doloplus-2 and NPI-NH) were taken for each participant following the introduction of Namaste, at intervals varying from 1-2 months.

Table 5.2: Demographics of residents

<table>
<thead>
<tr>
<th></th>
<th>All research participants</th>
<th>Participants with 4 sets of research measures</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=37 100%</td>
<td>n=30 100%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>22  59.4</td>
<td>16  53</td>
</tr>
<tr>
<td>Male</td>
<td>15  40.5</td>
<td>14  47</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55-95 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Mean: 78.5yrs)</td>
<td>30  100%</td>
<td>16  53</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital state</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>12  32.4</td>
<td>10  33</td>
</tr>
<tr>
<td>Widowed</td>
<td>17  45.9</td>
<td>15  50</td>
</tr>
<tr>
<td>Single</td>
<td>8   21.6</td>
<td>5   17</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>26  70.3</td>
<td>20  67</td>
</tr>
<tr>
<td>White Irish</td>
<td>3   8.1</td>
<td>2   6.6</td>
</tr>
<tr>
<td>White European</td>
<td>2   5.4</td>
<td>2   6.6</td>
</tr>
<tr>
<td>Afro Caribbean</td>
<td>4   10.8</td>
<td>4   13.2</td>
</tr>
<tr>
<td>African</td>
<td>2   5.4</td>
<td>2   6.6</td>
</tr>
<tr>
<td>Dementia diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>17  46</td>
<td>12  40</td>
</tr>
<tr>
<td>Vascular dementia</td>
<td>7   19</td>
<td>6   20</td>
</tr>
<tr>
<td>Mixed dementia</td>
<td>2   5.3</td>
<td>2   6.6</td>
</tr>
<tr>
<td>Fronto-temporal dementia</td>
<td>1  2.7</td>
<td>1   3.4</td>
</tr>
<tr>
<td>Unspecified dementia</td>
<td>10  27</td>
<td>9   30</td>
</tr>
<tr>
<td>Bedfords Alzheimer’s Nursing Severity Scale (BANS-S) [17-28]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17-19</td>
<td>11  29.7</td>
<td>8   26.7</td>
</tr>
<tr>
<td>20-22</td>
<td>19  51.3</td>
<td>16  53.3</td>
</tr>
<tr>
<td>23-25</td>
<td>7   18.9</td>
<td>6   20</td>
</tr>
<tr>
<td>Charlson Co-morbidity Index (age adjusted)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-3</td>
<td>5   13.5</td>
<td>4   13.3</td>
</tr>
<tr>
<td>4-6</td>
<td>28  75.5</td>
<td>23  76.7</td>
</tr>
<tr>
<td>7-11</td>
<td>4   11</td>
<td>3   10</td>
</tr>
</tbody>
</table>

5.1.2 Psychotropic medications

Medication changes were tracked during the study; only 3 residents had psycho-tropic medication reduced, none were increased. All changes to psychotropic medications were made in the care homes which had input from an old age psychiatrist.
5.1.3 Data collected after a resident’s death.

One participant died in hospital in the first month of the study; and, four more participants died in their care homes during the study. Another four participants died in their care homes within a month after the final measures and three further participants had died by April 2013. Twelve research participants died within the year of undertaking the study.

Table 5.3 Residents who died during the study or within 4 months of completion

<table>
<thead>
<tr>
<th>Care Home</th>
<th>No of residents recruited</th>
<th>Deaths during the study</th>
<th>Deaths in the month following the study</th>
<th>Deaths within four months of completing the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>CH.B</td>
<td>6</td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>CH.C</td>
<td>9</td>
<td>3</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>CH.D</td>
<td>8</td>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>CH.E</td>
<td>7*</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CH.F</td>
<td>7</td>
<td></td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

*one resident was discharged to another nursing home

- CAD-EOLD questionnaires were completed by care staff after each of the six care home deaths in the study, and all showed that the residents died peacefully with good symptom control.

- The only SWC-EOLD questionnaire returned by a family member came from the daughter of the resident who had died in hospital. The manager in another care home judged that for the son who had learning disabilities a questionnaire might be burdensome in bereavement, so it was not sent out. Because of the changes of management in two care homes, it was impossible to be certain that questionnaires had been sent. The ethics committee specifically asked that no reminder letters be sent to bereaved relatives, so this could not be followed up.

5.2 Statistical analysis

To determine the effectiveness of the Namaste Care programme, the first analysis compared NPI-NH scores before and after initiation of the programme by paired t-test. The second analysis investigated whether changes of Namaste Care continued during the next few months, and used General Linear Model Repeated Measures analysis. Pearson correlation coefficient was used to analyse the relationship between severity of behavioural symptoms and pain severity.
Severity of behavioural symptoms measured by NPI – NH was significantly lower after initiation of Namaste Care than before (13.94 ± 2.63 (mean ± S.E) vs. 14.85 ± 2.52, n = 34, p < .001). Similarly, occupational disruptiveness was also lower after initiation of Namaste Care (3.74 ± .95 vs. 4.85 ± .94, n = 34, p < .001). To determine the duration of the Namaste Care effect, we analysed changes during the follow-up period in patients who had all 4 measurements (n = 30) (see Table 5.3). General Linear Model Repeated Measures analysis that included all care homes showed non-significant changes in behavioural symptom severity but significant interaction between symptoms and care homes indicating that effects of Namaste Care differed between care homes (Table 5.4). As shown on Figure 5.1, there was a decrease in symptom severity in four care homes but an increase in one care home.

### Table 5.4 Linear Model Repeated Measures Analysis of Longitudinal Namaste Care data

<table>
<thead>
<tr>
<th></th>
<th>Analysis of all care homes</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Wilks' Lambda</td>
<td>F</td>
<td>Hypothesis df</td>
<td>Error df</td>
<td>Sig</td>
<td></td>
</tr>
<tr>
<td><strong>Symptom severity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms</td>
<td>.82</td>
<td>1.685</td>
<td>3</td>
<td>23.00</td>
<td>.198</td>
<td></td>
</tr>
<tr>
<td>Symptoms/facility</td>
<td>.394</td>
<td>2.152</td>
<td>12</td>
<td>61.14</td>
<td>.026</td>
<td></td>
</tr>
<tr>
<td><strong>Occupational disruptiveness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disruptiveness</td>
<td>.713</td>
<td>3.089</td>
<td>3</td>
<td>23</td>
<td>.047</td>
<td></td>
</tr>
<tr>
<td>Disruptiveness/facility</td>
<td>.477</td>
<td>1.646</td>
<td>12</td>
<td>61.14</td>
<td>.102</td>
<td></td>
</tr>
</tbody>
</table>

### Analysis of four care homes with good pain control

<table>
<thead>
<tr>
<th></th>
<th>Analysis of all care homes</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Wilks' Lambda</td>
<td>F</td>
<td>Hypothesis df</td>
<td>Error df</td>
<td>Sig</td>
<td></td>
</tr>
<tr>
<td><strong>Symptom severity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptoms</td>
<td>.653</td>
<td>3.537</td>
<td>3</td>
<td>20.00</td>
<td>.033</td>
<td></td>
</tr>
<tr>
<td>Symptoms/facility</td>
<td>.730</td>
<td>.748</td>
<td>9</td>
<td>48.82</td>
<td>.664</td>
<td></td>
</tr>
<tr>
<td><strong>Occupational disruptiveness</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disruptiveness</td>
<td>.676</td>
<td>3.19</td>
<td>3</td>
<td>20</td>
<td>.044</td>
<td></td>
</tr>
<tr>
<td>Disruptiveness/facility</td>
<td>6.54</td>
<td>1.03</td>
<td>9</td>
<td>48.82</td>
<td>.427</td>
<td></td>
</tr>
</tbody>
</table>
Therefore, we performed another analysis in which we included only the four care homes where symptom severity decreased. We found significant decrease in both symptom severity and occupational disruptiveness (see Table 5.4). Symptom severity was decreasing predominantly in a linear fashion ($F=9.92, p = .005$), whereas the quadratic modeling of the change was not significant ($F=3.53, p=.074$). Longitudinal changes in occupational disruptiveness were represented by significant linear ($F=9.46, p = .006$) and quadratic ($F=4.41, p = .047$) components, suggesting a curvilinear trend.
The reason for an increase in symptom severity in one care home was most likely inadequate pain control. In the care home where symptom severity increased there was not only the highest average pain score but the pain score gradually increased during the study (see Figure 5.2). The pain score in this care home was significantly different from two other scores at baseline and at time 2, and all other scores at time 3 and 4. There was also significant correlation between the pain score and symptom severity score at all assessments (baseline $r = .605$, $p < .001$, time 2 $r = .793$, $p < .001$, time 3 $r = .605$, $p = .001$, time 4 $r = .814$, $p < .001$).

![Figure 5.2 Pain levels determined by the Doloplus-2 scale in five care homes](image)

The decrease of behavioural symptoms during Namaste Care was not due to an increase of analgesic medications. Of the 30 residents who had four measurements, 20 did not have any change in analgesic administration while 10 received additional analgesics or increased dosages. Residents whose analgesic medications were increased had higher severity of behavioural symptoms than residents with a stable level of analgesic medication (Figure 5.3). This indicates that the analgesic regime might not have been effective even with an increase.

When only residents who did not have any analgesic change were included in the General Linear Model Analysis, there was still significant linear decrease of behavioural symptoms prevalence ($F = 5.697$, $p = .028$) while change of occupational disruption had both linear ($F = 4.588$, $p = .045$) and quadratic components ($F = 6.373$, $p = .021$). The quadratic component indicates that the last measurement was significantly higher than the previous measurement and may suggest that the effectiveness of Namaste Care decreased somewhat over time.
Figures 5.3

Severity of behavioural symptoms in subjects whose analgesic medications were increased or unchanged

5.2 Qualitative Data:

In this section, the qualitative data relating to the effects of the Namaste Care programme on residents, care workers, and family members is presented. The over-arching and interconnecting themes emerging from analysis of the post Namaste staff focus groups, the family focus groups, the managers’ interviews and the ‘Namaste’ books are: ‘calmness’; ‘seeing the person’; ‘reaching out to each other’; and well-being. At the end of the evaluation period three of the care homes were achieving a full Namaste Care programme, another home worked more slowly and continued to run the programme every morning with only occasional afternoon sessions. Each of these managers and their staff remain committed to Namaste, but the last care home, although they ran the programme regularly, chose to discontinue Namaste almost as soon as the research involvement was ended. The incoming manager of this care home noted that the Namaste study left very little trace.

Four of the five managers spoke about ‘embracing’ Namaste. This is an emotive response, but reflects the value managers set on the care programme and the emotional nature of the changes brought about by Namaste in these committed care homes.
In one of the committed homes the manager announced, ‘Namaste is like lunch’, meaning something that happens whatever else is going on, and takes priority over other activities and interruptions. This manager felt more confident that staff were now spending quality of time with the residents.

As a manager, I go home happier now the Namaste is in place than I was before, because I know that we are trying to spend that quality time with the resident. (CH C Manager’s interview p19)

In another committed home the manager conceptualised Namaste as ‘a treatment’, as fundamental as food and as important as medication.

It’s the very same..............as giving them their medication, their breakfast, their dinner. It’s part of their treatment plan. Namaste is now part and package of the whole care that we give our patients. There’s nothing separate. (CH E Managers’ interview p8)

5.2.1 Calmness – ‘Namaste is a feeling’

Many of the staff and relatives taking part in the action research study spoke about the calmness that the Namaste Care programme brought to the home. The first impression of walking into a Namaste room was captured by a relative after her first visit to the care home for over a month.

And I felt a sense of “oh, where am I..... this is lovely!” You know what I mean? It really hit me as I walked through the door – that is how quick it hit me. The feeling of relaxation and everyone is quiet....these are the people who are usually outside and usually standing up shouting – there’s one singing. They were all quiet’. (CH E family FG p31)

The atmosphere had been transformed. In contrast to the ‘chaos and confusion’ this family member now found relaxation and quiet. In another home a relative who visited regularly for years also appreciated the change. She said the care home felt less institutional and more homely.

I have always loved this place.... but I do feel, coming in now and going into that lounge, is a whole different ball game. You go in, it is homely..........It is like going into a home, it is not like going into an institution...You come in and people are grouped. It is the sense of it being a living room, I think it is important. (CH C family FG p21)

Interestingly, the root word ‘relax’ appears 97 times, and ‘calm’ 95 times, across the post Namaste focus groups for staff and family, and the managers’ interviews.

The organisation of the Namaste Care programme meant that care staff used time they spent with residents differently.

I think it is changing in the manner in which we all work. Because at least we have more time to spend with them. Before it was always rushing around, doing this, doing that but at least you have more time to spend with the client, we have more time to sit with them...So I find it’s just spend your focus on them, more time is spent, you spend more time (CH C post FG p10)

The pace of work was changed by Namaste, with residents receiving ‘one to one time’ in a group: more time was spent ‘being with’ residents, giving them attention, interacting with
them, observing and learning more about them

*I think it’s where we dedicate that time to them rather than going off doing something else. You know this is their time; you spend that time with them, so you know more about them. Normally, if it wasn’t a Namaste, we wouldn’t have been spending so much one to one time.*

(CH B post FG p7)

The changed routine meant that the care worker who had previously been ‘just minding’ residents in the lounge, was now busy with the Namaste schedule of gentle hands and face washing, massage, repeatedly offering drinks. Paradoxically, giving more time to residents seemed to create more time and energy for staff too.

*You know, sometimes when you’re sitting and doing nothing, you are more tired than doing something isn’t it?* (CH B post FG p15)

The calmer atmosphere in the care home, and the calmer approach to work were partly the cause and partly the result of changes in care home residents’ behaviour and mood. All four committed care homes noticed the reduction in agitated behaviour in their residents, which were sometimes dramatic. In four care homes, but not in the one where the Namaste room was in a separate location, care staff reported that residents who ‘wandered’, often rested in the Namaste rooms, soothed by the music, or distracted by the attention of the Namaste Care Worker offering massage or perhaps a doll or life-like animal. For example, in a focus group:

- JH:  *How was he before?*
- CWa:  *Very, very restless.*
- CWb:  *Disruptive.*
- CWa:  *Yes. Constantly pacing around the entire unit. He constantly talks to himself, but when he goes into that room, he sits down, he is quiet, he is calm……he was on a lot of Lorazepam in the beginning and he is not now. He has very little now. The family have seen a great improvement……He is much more relaxed.* (CH D post FG p8)

In another care home:

*Like (name of resident), likes wandering around the unit all the time… When it’s Namaste going on, we usually, because she likes babies, we usually giving her a doll. We painting her nails or doing some other things because she can talk a lot. When she’s [in]Namaste, she’s not going; she doesn’t want to go anywhere. She just sitting on there and for her, it’s really, really impressing because she must be everywhere. And when Namaste is on, she’s sitting there…..* (CH B Post FG p23)

A man who cried continuously was comforted and became less tearful and agitated; there was a marked reduction in the disinhibited behaviour of another man; people who usually refused to sit with others joined the groups in the Namaste rooms.

Where the Namaste room was separate from the dementia care units and residents had no independent access, the effect of the programme did not extend beyond the research participants. In the one unit where the geography prevented this free flow, the separateness of the Namaste room prevented any spreading of the calm atmosphere created in the Namaste room.
In two of the care homes the managers set up ‘The Club’ alongside the Namaste Care programme. The result of separating those with moderate dementia and those with advanced dementia and tailoring activities to the different needs created a greater calmness in the homes with two groups of residents being supervised and engaged. A manager explains the difference made by re-structuring where both groups were more appropriately occupied and engaged than before, and also under constant supervision.

... before we used to do activities or we would approach care, and it would be for everyone. But people are at different levels, so what we give for one person was not good for somebody else. Whereas this now, people that benefit from the Namaste go into the Namaste room. People that benefit from the club, can go to the club. (CH C Manager’s interview p3)

Interestingly, many residents with less advanced dementia chose the peaceful Namaste room over more stimulating occupation. These who often ‘wandered’ were guided into the Namaste rooms and either rested a while or went to sleep. Relatives, visitors and the nurse researcher were all conscious of quieter corridors and shared spaces where before there had often been residents walking restlessly and aimlessly.

... before [they] were pacing around and would not even sit down for a second... the fact that they are sitting down now. And even those who were maybe a few who were prone to fall, for example, now they are actually more, they are sitting down. And I, myself, am not constantly checking to see when they are going to stand up.......it is not as hectic as it was before.

(CH D post FG p18)

Another manager specifically attributed an overall reduction in falls, and ‘incidents’ in the care home to the introduction of the Namaste Care programme and ‘The Club’.

5.2.2 ‘Seeing the person’ – a shift from task-orientated care to person-centred care

In four care homes, the Namaste Care programme reshaped the routine to focus on residents, and care staff developed increased attention to respect and dignity.

...you can very easily get caught up in toileting and helping to eat and all of those things and not see the person sometimes. I think this has brought that out.

(CH C Manager’s interview p2)

The care workers were aware of the change from their previous task of ‘just minding’ residents in the lounge to the interactive, engaged role of the Namaste Care Worker.

At first, when we are not doing the Namaste, we take the resident into the lounge then one person would sit down with them without interaction, without hand massage. The resident would be there, the staff would be there just looking after them. But with Namaste, the staff involve themselves; they interact with the resident like, one to one. The resident will talk to you, [you] will talk to the resident, before wasn’t like that.

(CH B Post Namaste staff focus group CW6 p12)
The managers of the committed CHs recognised that the programme raised the quality of care given by their staff to a new level and created a ‘short cut’ to person-centred care, with care staff focussing attention on the people for whom they care.

*I think it’s made them open their eyes and just see that person beyond just that patient that they see in front of them. They see our patients at a much different level. They’re aware of their emotional needs and their psychological needs.* (Managers’ interview, CH E p12)

Even outside the Namaste room the shift to a more person-centred approach changed the experience of residents and released the care workers to respond to them more naturally, as people.

- **CW:** *I think I’ve learned to be a bit more patient and just speak a bit more slow and calm when I’m speaking to them. Sitting down holding their hands, not even in Namaste, just sitting outside, you might just automatically, just you know hold onto a patient’s hand and just...*

- **JH:** *And you wouldn’t have done that before?*

- **CW:** *I would have probably thought but not actually just sit and just ... you know it just come so easy now, just holding their hand.*

(CH E post FG p31)

Namaste seemed to extend the care workers’ self-awareness and communication skills, and support more instinctive, compassionate care. Staff were empowered to develop new skills, or use skills they already had more effectively.

*... We had the skills but wasn’t using it......we had skills to soak their feet and give them a good, nice rub with oils and something. But unless we, you know, had - apart from bath time, we wouldn’t have thought about doing it. It was there but...*

(CHB post Namaste FG CW B8 p26)

The deputy manager from CH E recognised that staff were learning to work at another level.

*It [Namaste] brings people together and gives them knowingness of something they can do. And like I said earlier, it’s not just about washing and dressing somebody. It’s about delivering that standard of care at a much deeper level.*

(Managers’ interview CH E p6)

Staff were encouraged by the responses they saw in their residents and became more imaginative and ingenious; looking for new ways to engage residents and vary the care they gave.

*And we trying to find out something new [about the resident] that we doesn’t want to give them, all the time, the same care. Maybe it’s not very easy to find this thing what the person will like but we are trying.* (CH B post FG CW6 p28)

Sensory stimulation can trigger reminiscence and cut through cultural barriers; one resident who rarely left his room was brought into the Namaste room where the care worker bathed and massaged his feet. He started to pray and prayed for half an hour, which he had never done before. When his daughter visited she explained that foot washing had been part of his church ritual in Jamaica. Through Namaste, staff became more interested in life story and this built closer relationships with families.
We found that Namaste could change how staff felt about their work. Managers found that staff developed a greater sense of self-esteem. One spoke about a care worker who came to her the week before the programme started and spoke about handing in her notice because she was not enjoying her job.

.....And I said, “No[name of care worker], you cannot leave”.....we were talking about [her] being the Namaste lead and everything. Well, within a week and a half she came back a different woman. She said, ‘You know what [manager’s name] thank you so much for that... for to do the Namaste. It gives me a sense of worth.” She said, “I feel as if my work here has more meaning, and I don’t care about what other people think now.” (Managers’ interview CH E p5).

Being chosen to work as a Namaste Care champion is an obvious cause for raised self-esteem, but the care worker’s change of attitude also seemed to come from finding meaning and putting a new value on her work. A relative commented on the effects of Namaste on care workers’ self-esteem.

.... a lot of them have grown in confidence and in their ability to do their job. I think they, within themselves, feel more confident and more positive. (CH C family FG p22)

In the four committed CHs family members started to involve themselves with other residents in the Namaste group. It seemed that Namaste facilitated closer relationships with residents for relatives as well as staff.

I talk to all the residents in here, the ones that I can. I am not a bit afraid now of taking hold of someone’s hand and conversing to them one to one....because I might have been rather frightened of touching somebody. But seeing how the carers respond to the residents here, I think... maybe we could communicate with each other with the feel of my hand.

(CH B family interview p.10)

Respect and dignity

In the committed homes the Namaste Care programme generated an enhanced sense of respect for residents’ privacy, and respect for the interactions between the Namaste care workers and the Namaste residents. Two care workers compared the activities previously organised in the home with the new way of working.

CWa: Now ...... we close the door, we set the scene, we made it nice rather than everybody coming in and out and disturbing them. It makes it more therapeutical rather than just open, the doors open, anybody passing by disturbing.

CWb: We got more privacy now because with all the door closed and the residents, you know.

CWa: And everybody knows we are doing something with the residents, to not disturb.

(CH B post FG p13)

Changing the environment, creating a calm atmosphere and focussing on giving the residents attention, fosters the core message of the Namaste Care programme, ‘to honour the spirit within’.
What I find as well, there is respect and dignity.....when doing Namaste. Because before you used to walk through them,....but now they [care staff] realize there is a quiet area and one tends to walk, even [name of resident], he walks around, he doesn’t walk through. (CH C post FG RN 1 p34)

This enhanced respect and dignity extended into end of life care; with a sharper focus on quality of life to the end. Namaste gave guidance for ‘being with’ residents which supported care workers to ‘be with’ the dying. A care worker spoke about a resident she cared for who died during the study.

....when she was near to the end, you know, we took her to her room and [brought] the music box into the room. I remember she used to like Nat King Cole. And I had put that music on .... she was very near to the end.....and she held up her head, opened her eyes and smiled.... It was very touching. She was like, something she heard that she wanted to hear, you know. It brings back some memory. Something had happened, something strange. When she give that big smile for that last... that was her last smile. (CH C post FG CW 7 p12)

Respect was a theme that went beyond death to the care of residents after death. When Lucy passed away, Hayley, our Assistant Manager had phoned me up in the night ....and she said to me, “Remember Namaste and we should think about her dignity.” And we both, she picked me up at my house and we both came down to see that her body was OK. (CH C post FG CW 6 p11)

Task focussed care
In the care home where it was difficult to get full commitment to Namaste, the incoming manager observed that the task oriented culture still held sway, and affected the ability of the care staff to adapt to new ways of working.

...they were concerned, often, about what they weren’t doing elsewhere. For example, one occasion a staff member was so anxious that she hadn’t made a bed downstairs on the wing, and that sort of perhaps, didn’t help her... (CH F Manager’s interview p3)

In this care home Namaste was seen as an additional and burdensome task. Residents were brought to the Namaste Care room from the different wings so care workers were not always familiar with those who came. The incoming manager, who had been a regular visitor in another role, observed some Namaste sessions and reported that sometimes staff seemed oblivious to positive responses from residents. It would appear that anxiety and distraction about the routine work of the units that still needed to be completed may sometimes have blinded care workers to the effects of the programme for residents.

....residents have responded very positively to the music or the aromatherapy that’s been used, or the use of touch, yes. And some of those responses have been quite subtle, but not actually observed by staff undertaking those interventions. (CHF Manager’s interview p2)

The emphasis on tasks and ‘getting things done’ was one aspect of a wider dysfunctional culture that militated against the more relationship-based care that Namaste advocates.
I suppose there was a sense of chaos really. That’s the best way that I can put it. There was a sense of chaos, and people rushing around and, you know, priorities were perhaps misplaced. And that didn’t really help Namaste in any way. (CH F Manager’s interview p7)

5.2.3 ‘Reaching out to each other’

While the mission statement was being compiled the Namaste care workers in CH C were asked what the purpose of Namaste is. One wrote, ‘to enable us to reach out to each other’. This theme of connection, re-connection and shared humanity is the foundation of the relationship-based care that Namaste fosters.

Touch as a catalyst for change

Touch is at the heart of Namaste and seemed to be a catalyst for change. When we look, we see and have sight or vision; when we touch, we feel and have feelings or emotions. Again and again, care staff and families talked about the emotional significance and power of touch. The structure of the Namaste Care programme requires those doing the session each day to use therapeutic touch deliberately and repeatedly: gently washing and drying hands and faces; moisturising skin; brushing hair; massaging hands and feet; stroking heads. A relative commented that the programme seems to give people (care staff and families) ‘permission’ to touch the residents.

It creates an environment that’s very different than a care home and that’s not their fault. But there’s health and safety, you can’t do this, you can’t do that. In fact, if you walked into a lounge would you feel quite so at ease if somebody was sitting stroking my husband’s arm? I don’t know. That’s my problem. But by putting them in this room and being straightforward and saying, “This is what we’re doing.” Immediately it’s got a legitimacy. And if they didn’t have that, kind as the people are, there would be no tactile touching and stroking, because should they be doing that? (Family focus group CHE p28)

An important principle of Namaste Care is that gloves should not be worn for skin to skin contact unless there is a medical indication, such as infection. Wearing gloves is embedded in the routine of many care homes, to the extent that care workers routinely wear gloves to wash residents, even when washing someone’s face. The care workers instinctively understood that taking off the gloves when touching residents skin to skin was symbolic of a changed way of working as well as being a physical change that removes a barrier between them and the person they are caring for.

CW1: The very important thing that we are doing it without gloves so they feel our body, our warm body. So the experience and feeling is totally different. So it’s not that you are touching them with the gloves and they just feel, you know...

CW2: Rubber.

CW1: Yes. That someone is touching you with glove or something like that. They just feel your warm body and... We feel them as well, isn’t it?

CW2: They feel wanted now......

CW1: Yes, because it’s more private than...

CW2: Intimate. Intimate rather than with gloves, you know, because the gloves is between
our skin and their skin. But now we touching them, body contact together, you know, they feel our warmness, we have to feel their own warmness like when you rub them, like this. They will know someone is touching them.

(CH B post FG care workers p27-28)

The care worker above talks of the physical closeness that necessarily results from skin to skin contact, and acknowledges that the enhanced awareness of each other as ‘warm bodies’, fellow beings, is a shared awareness and a shared intimacy between the care worker and the person with dementia.

A manager observed deepening relationships between care staff and residents through touch in Namaste.

And you get that relationship... touch builds a relationship between people doesn’t it? ...
The people that do the Namaste, I see them doing it and enjoying it, and you see the expression. They are very calm. So in that moment there is a really good bond between the staff and the resident. (Manager’s interview CH C p15)

Re-connecting and communicating:
Connections were not all one way; a lady whose daughter was rubbing moisturising cream into her hand began to massage her daughter’s hand back. Her daughter became tearful and explained that her mother had not been able to do anything motherly for her for many years.

Many residents with whom there had been minimal communication became more responsive with Namaste. Several tried to use language more than they had before, and if their efforts were not understood, they were appreciated and acknowledged.

CW: ..and she’s communicating a lot more.
JH: When you say communicating, in her way or...?
CW: When you talk to her, she answers back.
JH: Right. Which didn’t happen before?
MS: She wasn’t using words, really?
CW: Never happened, no. It’s a big step for (name of resident). And she, when you start the music in the morning, she tries to turn her ear to it, where the direction from where the music is coming from.

(CH C post Namaste FG care worker p4)

In every care home there were reports of increased communication with residents; another resident who ‘started talking in her own way’; and for those beyond language, a connection nevertheless.

We have a resident here, (name of resident), she doesn’t talk. But once we started with Namaste, there was a big smile. That is because there is a connection.

(CH D post Namaste FG care worker p28)

Intimacy

The awkwardness of ‘being with’ a person with advanced dementia is not dissolved by an existing, loving relationship. Family and friends sometimes start to visit less frequently as communication becomes harder. With the programme, staff were able to help guide
families towards new ways of connecting and communicating with their relative with advanced dementia.

When they come in, because sometimes especially with someone who has dementia, the family would sit there and not know what to do really. They can’t understand if they read a book..... Whereas now we say, do you want to give a hand rub or do you want to do this? Or do you want to comb the person’s hair? Before they wouldn’t see that as an activity..... I am sure it builds up a relationship between them and their loved ones. They are actually combing their hair and you feel that connection. So that has really helped. (Manager’s interview CH C p4)

Family carers were enthusiastic to learn new skills from the care workers and used them to connect and communicate with the person they loved.

Well, I have taken on board the massage of the hands. If my relative is, in any way, on edge shall we say for whatever reason, I do tend to sit down and take his hands and apply what I have seen the carers do in the Namaste. (CH B family interview p7)

Like the care staff, relatives found that Namaste, and specifically touch, created a significant connection; even helping one wife to recover a sense of intimacy with her husband.

We have one carer came in and she says to us that, that helped. She sat down and she did her husband's hand and she said that really felt ... what’s the word for it ... that closeness...
Yes, intimate, yes. She hasn’t felt that for years and that was really good and she really like that. Yes she did. (CH E post Namaste FG care worker p15)

Relatives and care staff both said they felt they had closer relationships with each other through Namaste. Part of this came from spending time together in the same room with a shared purpose, but there was also a greater appreciation of each other’s strengths and qualities. Relatives recognised the compassion of the staff and appreciated the difficulties of caring for people with advanced dementia.

So, it is nice for the staff to have that compassionate moment with them, even though they have got a lot of people to look after. It must make them feel that they are doing something really worthwhile, apart from the normal jobs, as awful as they are, this is something... because you know the personal hygiene things is not all that pleasant. But the Namaste kind of levels it out a little bit.....to the ordinary things they have to do. (CH B family interview p9)

This relative recognised that care workers are people and are inevitably affected by the nature of their work and the difficulties of caring for people with advanced dementia. Another relative felt that the therapeutic touch in Namaste encouraged emotional engagement from staff, which benefitted both staff and residents.

They are doing what they have to do for the patients. But suddenly this is another dimension isn’t it? ..... It appeals to their inner kindness too. If you see that you are giving someone pleasure, you have to be a very cold human being not to be touched by that. (CH D Family FG p20)

**5.2.4 Well-being**

There were several aspects of greater well-being that highlighted Namaste Care was having an effect on the quality of life of residents, their relatives and indeed the staff.
‘More alive’ – benefits for residents

Residents who were lethargic and unresponsive demonstrated changes in response to Namaste Care that were as remarkable as the changes from agitation to calmness in others.

From my mother’s point of view, and people at that level, I think it has been wonderful. She is much more healthy now. I don’t know why, but she is different. She is more alive even though she can’t do anything for herself at all. (CH C Family FG p4)

Interestingly, another relative, from a different care home also described his wife as, more ‘alive’.

I think it does make a difference, especially when you rub the cream into their hands and that. They seem to, Heather seems to come alive, kind of, she wakes up. (CH D family focus group p2)

Nurses also noticed physical benefits for residents as well as the changes in mood, communication and behaviour with Namaste. Before Namaste some residents were apathetic and withdrawn; the stimulation, attention, and additional hydration were healthier than the previous regime.

And they were just sitting there. When you see their eyes, by touching and the five sense, they are lighting up and they look well. To look at them, they really look well. Even very ill patients are looking much better. (CH D post Namaste FG nurse p32)

More commonly the care staff described greater alertness in the more inert residents; more eye contact; more wakefulness; more attempts to communicate; more smiling and more happiness.

(Name of resident) has never smiled, I work here for 16 years and she had never smiled. She’s always been a serious person, never get smile from Phyllis. Now everything you say to Phyllis, is “He, he, he.” She’s laughing, she’s happy. (CH C post Namaste FG care worker p4)

Even one of the quietest residents who seemed to sleep through most Namaste sessions was noticed to be more alert afterwards by his partner. In residents with very advanced dementia, even barely perceptible changes for the better are rare and valued by those who care for them.

…but since the Namaste, even though he seems to be sleeping throughout the whole thing, he is sort of taking in what’s going on. And then when she came in, she could actually see that, well, he is looking at her again, and so forth. So she did see the benefits for him. (CH F post Namaste FG nurse p15)

Sensory stimulation seemed to create a new sense of self awareness in some residents with advanced dementia. One lady stroked her own face after facial hair had been shaved and moisturiser gently applied. The care worker who knew her best had never seen this before. A gentleman who was deeply resistive to personal care began washing his hair while sitting in the bath, which seemed a recognition of his immediate situation and a re-awakened awareness of his own body. His daughter and key worker related his new co-operation with washing to the Namaste sessions.
Another resident, whose dementia was only moderate but whose sight and hearing were significantly impaired, was very withdrawn before Namaste, having to be coaxed to eat and drink, and talking very little. Within two weeks of sensory stimulation with Namaste she was eating and drinking well, smiling and talking much more. On one occasion when having her feet massaged, she remarked, ‘I’m in paradise’.

*Improved hydration and muscle tone*
Residents appeared more relaxed, calmer, and happier in the Namaste room, and with this change in mood they were more receptive to drinking and eating. Whereas previously drinks were given at set times, in Namaste drinks are repeatedly offered and frequent sips are more effective.

> The thing I like about Namaste, they get extra foods and they drink more. I really like that. I am not saying they were not drinking before, but it is a top up, they get extra. So it is really good, the foods and stuff like that. (CH D post Namaste FG nurse p20)

Nurses in the four committed homes believed that urinary tract infection rates were reduced in the Namaste residents because of improved hydration. Better hydration and increased intake of fruit had a positive effect on residents suffering from constipation; one Namaste resident no longer required the twice weekly enema he previously needed.

Before the study began, the manager of the uncommitted home told the nurse researcher that residents with swallowing difficulties could not eat fruit, but once Namaste was established they had pureed fruit regularly. However, some nurses in this care home saw Namaste as an obstacle resulting in residents having less to drink because the care workers from one unit were not trusted to give drinks to residents with swallowing difficulties from another unit.

Hand massage is a core element of Namaste, calming and connecting, but also relaxing muscles, and for people with hands twisted by contractures this was especially beneficial.

> You wash and bath them, dress them. But being in Namaste, you’re actually, once you do the massage on their hands and feet, the patient opening their hands and you can actually see the palm of their hands; it makes you feel, “God, it’s the first time I’ve actually saw the palm of this person’s hand”. I don’t [know] if everybody feel that way, but I do. And especially when you do it in Namaste and they actually open their hands because most of the time they’re clenched... (CH E post Namaste FG care worker p19)

One resident started to use his hands more, picking up cups and food.

*Closer observation*
Comfort is fundamental to Namaste. As a result of the different structure in day to day care, care workers spent more time interacting with residents and concentrating on well-being. As a consequence, staff observed more closely and became more alert to changes in their physical well-being, for example, noticing residents’ pain.
One manager considered change in pain awareness and assessment as one of the most important changes with Namaste. He attributed these improvement to the closer contact between care workers and residents. Most of the research participants in this home were assessed as experiencing pain at the outset, and started on analgesia or had their analgesia increased during the research period.

Like pain, that is a big thing we notice now, more. The care staff will come now and say, “So and so is in pain,” which they might not have done before. They notice it more because they are with them on a daily basis more often. (Manager’s interview CH C p2)

‘Refreshed’ – benefits for care staff

Care staff enjoyed working with Namaste and looked forward to the sessions. The enjoyment of one to one time with residents was mutual, and care staff said they found seeing the residents’ pleasure rewarding and satisfying.

To be honest, I find it interesting in a way that, you know, you look forward to that hour to go when you going to have a nice calm atmosphere, you relax. You do things with the residents, you know, you enjoy the way they look, the happiness on their face, the smile when they get their one to one. So in a way it gives you satisfaction knowing that you’re doing something they enjoy as well. (CH B post Namaste FG care worker p10)

Just as residents appeared calmer; staff also found that slowing down, listening to music, the scent of lavender, and skin to skin contact affected their own mood and behaviour. Care workers felt that Namaste relieved some of the stresses of their work.

You are altogether in one room and on top of that, maybe because of the music or the sound effects, you relax as well. I would say that is does for me as well, even for 10 minutes, it can actually just keep me at a calmer level. Even if I was stressed earlier on in the morning, or something, it does actually help. (CH D post Namaste FG care worker p18)

Not only was the Namaste environment calming and restful for care staff at all levels, the care programme felt restorative and invigorating. A manager noticed that care staff seemed ‘refreshed’ by Namaste, and a relative described staff as ‘more animated’. In all the committed homes, the managers and some senior nurses said they wished they were able to spend more time in the Namaste rooms for themselves.

And as a nurse, if I’m stressed out with lots of people and phone calls and other things. I see that Namaste is going on……I sit down with them, listen to their music, have one to one with the resident. Sometimes about 5 - 10 minutes, I have revived myself and then I go back to my work here, whilst other staff continue doing Namaste. (CH B post Namaste FG nurse p11)

However in the care home that did not commit to Namaste there was an underlying resistance to the change that was necessary if the care programme was to be achieved. For some Namaste was described as frustrating; it was often seen as an additional, burdensome
task; it was felt to be too demanding without additional staff. The layout of this home, a lack of organisation and poor teamwork added to the difficulties. Some staff felt that there was no significant change in practice and at every level Namaste was felt as a pressure.

And feel that it’s my duty that I supervise Namaste... Namaste, Namaste and I’m the only person, I’m running down ... up and down to the unit. And I said, ‘Hang on, you know, I mean yes it’s good for patient[s] but how about for the staff as well?’ I’d be running to the units but because they say it has to be Namaste morning, afternoon. (CH F post Namaste FG care worker p16)

Interestingly, the incoming manager identified problems with the culture of care within this home. In the judgement of the new manager, the priority of care had been the interest of staff rather than the residents’ and relatives’ best interest. No wonder therefore that implementing Namaste Care was burdensome.

I think there’s been a culture of... there has been a culture that’s, where the service has been run for the benefit of the staff and not the benefit of the residents. (CH F Manager’s interview p16)

Well-being – benefits of Namaste for relatives
The relatives and friends who came to the focus groups, and those who sent letters of appreciation to the care homes and the nurse researcher, were grateful for the Namaste Care programme which they felt improved the situation of their own family member and fellow residents.

None of us like what’s happened, do we? But I think, in the circumstances I feel quite a peace. I know that everything that is being for (name of husband), can be done and is being done. I feel blessed that he is so close to home. This programme is wonderful because... and it is of tactile nature. They must get something out of it even though they can’t articulate that or even possibly display an emotion. They must get something out of it. (CH D family FG p16)

A husband summed up feelings expressed by many,

...anything that appeals to the senses and gives them pleasure has got to be a bonus.

(CH D family FG p9)

A daughter wrote to explain how Namaste had made her visits easier; helped her re-connect with her mother; and helped her to play an important role in her mother’s life again. These changes were important for her own well-being.

The biggest thing Namaste has given me is a different focus when visiting mum. For many years now mum hasn't been able to communicate with us and conversation has been one sided which is difficult and at times she appeared to barely realise I was there. I now know to do other things as well as talk to mum like show her old photos, brush her hair, feed her treats, and moisturise her face and hands. This makes spending time with her easier and I feel I'm making more of a connection with her and a difference in her life.

(CH D email from family member)

The knowledge that their relative was part of the Namaste Care programme brought peace of mind for relatives. For a wife the sense that her husband was contented, and receiving
appropriate care, lifted some of the guilt she felt for placing him in the care home, and for leaving him each day when she visited.

......there’s a little sort of light when I take myself off to the [Name of cinema] to watch a film on my own, there’s something that he is doing that’s appropriate to him. .....I am sure that has helped that guilt feeling. (CH E family focus group p39)

In each focus group relatives expressed the hope that the Namaste Care programme would be widely adopted because they felt it offers hope for better care and a better quality of life for people with advanced dementia and all who care for them.

Staff found talking about dying easier following the introduction of Namaste and feeling they were able to offer quality of life despite a resident’s deteriorating health. Care home relatives inevitably see many residents deteriorate and die with their dementia. One relative hoped that Namaste care would be there for her husband when he dies. She found some comfort in the hope that there would be good quality care for her husband at the end of his life.

Well, in the situation we are now faced with, I feel we have got to take one day at a time. Because I have seen so many different people here ....this illness progresses at very different rates .... it is nice to think that, if this programme is carried on, the loved one that you are most concerned with won’t just be left to lie in a bed just slipping away...but has someone to sit there with them and hold their hands. Even if you don’t think they can hear you or understand you, but just to talk in every day way to give them comfort really. (CH B Family interview p7)

There was only one negative response to Namaste from a family, who felt that their mother was too tired to attend two sessions per day. Whenever the nurse researcher was able to observe, the resident seemed to be asleep most of the time, so perhaps she needed to rest in the afternoons. The key worker for this patient spoke the same language and was the channel of communication with the family. She felt that the Namaste was culturally inappropriate and that the resident should spend the majority of the day in her own room watching DVDs from her homeland. The key worker (who wasn’t an advocate of having to bring her residents outside the unit and up a floor to the Namaste room) felt that Namaste was too much for the resident.

The final word on the value of the Namaste Care programme goes to a wife.

But I would hate to think that [Namaste] was stopping because his day would be ... barren. Television means nothing to him... I’ve spent the last 8 years interpreting things. So my interpretation is valid now and I believe for my [name of husband], this is like a salvation, nothing else. (CH E, family FG p23)
Discussion

This study is the first to evaluate the Namaste Care programme in the UK, and shows that the programme can be implemented in care homes with nursing in the UK with only modest expenditure and without a change in staffing levels. The qualitative and the quantitative findings from this study show benefits for residents, care staff and family members, and build upon the positive results from Simard & Volicer’s (2010) exploratory study. There was no evidence that Namaste caused any harm of any sort.

The qualitative evidence shows that care staff, managers and relatives judged that Namaste had a beneficial effect on the quality of life of residents with advanced dementia; and, recognised that the Namaste Care programme fostered dignified and compassionate care. The structure of the care programme, especially therapeutic touch, supported greater interaction between care staff and residents, helping staff to develop closer relationships and better communication with the people for whom they cared. Care staff felt they had learned new skills and were better able to meet the needs of their residents; they found Namaste rewarding and felt their own quality of work life was improved. Families also welcomed Namaste; some experienced better communication with their family member; some felt the overall atmosphere of the care home changed for the better; and some felt the care programme had a positive impact on their own quality of life. Relationships between care staff and relatives also became easier; with managers and relatives reporting increased confidence and self-esteem in care staff. Nurses and managers said they found end of life care conversations with families easier in the positive context of the Namaste Care programme, and care staff described using the skills they developed in Namaste to enhance care given to dying residents. We compared our qualitative findings with a taxonomy of findings pertaining to the implementation of psychosocial interventions to improve quality of life for people with dementia in care homes, derived from a meta-synthesis by Lawrence et al (2012) (see Appendix 6), and found a meaningful congruence between our findings and the domains/categories of the taxonomy, which strengthens the credibility of our data analysis.

The trustworthiness of the qualitative analysis is supported by the improvement in NPI-NH scores for participants. In four out of the five care homes neuro-psychiatric symptoms (as measured by the NPI-NH) improved significantly and maintained the improvement over time. However, when the fifth home was included in the analysis of NPI-NH scores, the effectiveness of Namaste Care no longer achieved significance over time. Reduction in NPI
scores have been found to correlate with improved quality of life in people with dementia who are able to self-rate their quality of life (Samus et al. 2005); so for those unable to rate their own quality of life a reduction in neuro-psychiatric symptoms may be taken to represent an improvement in quality of life. Cohen-Mansfield et al (2012) found that engagement with activity is positively associated with a positive affect and that there is a negative relationship between agitated behaviour and pleasure. Spector et al (2013) found the success of interventions was very dependent on organisational factors such as management, care culture and rifts between staff groups. The care staff in the pre Namaste focus group from the fifth home (where the severity of neuro-psychiatric symptoms rose) spoke openly of ‘bullying’ and highlighted conflict within the team. Pain was assessed to be present in 100% of research participants in the initial measures in this home and remained present in some, because despite increased analgesia, good pain management was not achieved. Inadequately managed pain inhibits engagement in activity in nursing home residents with moderate-to-severe dementia (Chibnall et al 2005).

The action research methodology enabled further insights into the culture and practice of the atypical home which offer some explanation of its status as an ‘outlier’ in the overall NPI-NH data. This home had recently failed to complete an end of life care programme (Gold Standards Framework in Care Homes); the clinical lead left at the beginning of the study and both nursing and carers were unsupported by nursing expertise; symptoms were sometimes not properly identified and when they were, medical management was sometimes delayed; there seemed to be a lack of trust between the care home and the GP practice; furthermore, the converted building was a difficult environment for optimal dementia care. Interestingly, relatives, staff, the regulatory bodies and the research team all perceived a marked improvement in the home as a result of implementing the Namaste Care programme. From this we deduced that the Namaste Care programme may have had a positive effect on the social interactions and the atmosphere of the care home, but cannot be a substitute for good nursing care and medical attention. Not surprisingly, the care home with the best NPI-NH results had all of these attributes: good nursing and dementia care; an excellent relationship with both GP and psychiatrist attached to the unit; well managed pain; and, an environment appropriate for dementia care.

The NPI-NH scores for all the care homes show a slight reduction in the effectiveness of the intervention towards the end of the research period. We considered whether the reduction in effectiveness was related to the deteriorating health of participants, but since there is no correlation between BANS-S and /or Charlson Index with NPI-NH scores at the outset of the study, we thought the decrease may instead relate to staff investing less energy in the programme after the initial interest settled. In their study of Montessori based activities for people with dementia in care homes, Orsulic-Jeras et al (2000), also found a reduction in pleasure over time and were uncertain of the reason for this. A further suggestion is that it may be the dying process that influenced quality of life independently of disease severity or
the burden of co-morbidities; five resident participants died during the study; five died within two months of its completion; and two more died in the following two months.

It is important to look for an explanation for the effectiveness of the Namaste Care programme. Cohen-Mansfield et al. (2011) postulate a model of engagement – ‘The Comprehensive Process Model of Engagement’ – which links the contribution of environmental factors, personal characteristics, and the attributes of stimuli, with different levels of engagement in people with dementia. Their research identifies that one-to-one social interaction with another person is the most potent stimulus for engagement, with stimuli based on the individual’s past and present roles and preferences being the next most powerful. Cohen-Mansfield et al (2011) looked at environmental factors and found that engagement was optimised by: a long introduction for the stimulus; a moderate level of sound; and being in a group of 2-24 people. This model casts light on the effectiveness of the Namaste Care programme: one-to-one interaction within a social group; soft music supplies a moderate level of background sound; residents are encouraged and supported to engage with a variety of stimuli, including many of those found most effective in Cohen-Mansfield’s extensive study (2010). Further work by Cohen-Mansfield et al (2012) suggests that for people with dementia the ability to express pleasure is related to function rather than cognition: like other functions the ability to express pleasure may be lost through lack of use, or strengthened through practice. The Namaste Care programme provides daily opportunities for practice in expressing and experiencing pleasure.

Further explanation for the effectiveness of Namaste Care comes from Kong et al’s (2009) systematic review of non-pharmacological interventions for agitation which found that sensory interventions have moderate efficacy for agitation in people with advanced dementia. There is good evidence that many psychosocial and sensory interventions are effective in reducing agitation for people with dementia, but the evidence is for short term effect during the intervention with little or no longer term effect (Cohen-Mansfield et al 2010, Cohen-Mansfield 2004). The Namaste Care programme overcomes the short-lived effectiveness of sensory interventions by time-tabling: seven days a week, two hours in the morning and two hours in the afternoon. It seems likely that the calmness and contentment achieved through Namaste lasts for at most an hour after a session; however, the calmness staff feel probably lasts longer, and the change in their approach may be long term. Namaste, therefore, has a positive impact on a significant portion of a resident’s day. Schreiner et al (2005) report that residents with dementia expressed happiness over seven times more often during structured recreational time than during unstructured time. Namaste imposes structure on the “empty time” when residents with advanced dementia are not engaged in personal care or mealtimes and empowers care staff to connect with residents and engage in meaningful activity with them.

The qualitative evidence from our study suggests that touch was the most powerful element of the programme, which accords with Cohen-Mansfield’s (2010) findings regarding the potency of one-to-one interaction. Similar findings are reported from a Namaste Care
programme in Australia on the power of touch to reach people with advanced dementia, and help them to reach out (Nicholls et al 2013). The researchers describe the mutuality of the experience of touch and the benefits shared with care staff and family. Their ‘interconnectedness’, and our echoing theme of ‘reaching out to each other’, highlight the potential that Namaste has to develop relationship-based care (Brown-Wilson & Davies, 2009; Koloroutis 2004; Nolan et al 2003), and imbue every day care with significance.

Kontos (2004) addresses the concept of selfhood in relation to advanced dementia, arguing that it is an ‘embodied dimension of human existence’, and recognising smiles, frowns and gestures as subtle forms of self-expression that rest on a lifetime of social interaction and carry meaning. Watson (2012:6) reflects on this work and suggests that care for people with advanced dementia should re-focus on physical care, not as a task completed in a ‘perfunctory manner’, but as ‘a way of valuing and respecting the person, an opportunity to recognise and support their embodied self and a means of forming or maintaining a relationship’. In the Namaste Care programme meaningful activity is provided in the form of personal care, and there is a shared experience which can create connections between the two people involved. Lawrence et al (2012) found that some psychosocial interventions have potential to transform care workers’ perceptions of people with dementia and help them ‘see beyond the symptoms of dementia and to broaden their conceptualisation of the care giving role’ (p.348).

Relationship-based care needs to be set within a person-centred care culture (Nolan et al 2003). Person-centred care (Kitwood 1992) is recommended by national guidelines (DoH 2009; NICE Quality Standards 2010; The Commission on Dignity in Care for Older People, 2012), and is overwhelmingly accepted as fundamental to achieving good quality of life for people with dementia. The staff of the two NHS specialist care units had all received training in person-centred care, and both units achieved sustained improvement in NPI-NH scores for their residents. However, while one unit embraced Namaste and relationship-based care; while the care staff on the other unit remained focussed on tasks and discontinued the care programme as soon as the research was completed. Namaste is not proof against organisational disruption; and, even person-centred care cannot withstand organisational disturbance (Spector et al (2013). Education alone is known to be ineffectual in changing care home culture (Froggatt 2000), and having person-centred care training was not sufficient to create a person-centred culture where the Namaste Care programme could flourish. It also takes confident leadership within care homes to embed the Namaste Care programme and change the culture of care (Wenborn et al 2013).

We are compiling a manual (‘toolkit’) based on our learning from this study.

Limitations and Considerations

Action research is small scale and unashamedly participative. The interviews and focus groups were conducted by the research team and it could be argued that this may have
influenced the evidence collected. However, where there were negative perceptions of Namaste, staff were open in their criticism. Moreover, involvement in the research provided insights, supplied context and amplified the learning from the focus groups and interviews which was why an action research methodology was chosen. The nurse researcher’s reflective diary served to create critical awareness of preconceptions and assumptions brought to the research, and provided some confirmation of the relevance of the themes that emerged from the qualitative findings.

Proxy measures were unavoidable within the population we studied. The NPI-NH was chosen because it was the NHS Specialist Care Units routine measure of the effectiveness of treatments; none of the other care homes had any measure of neuropsychiatric symptoms or quality of life. Despite trying to achieve consistency and trying to use experienced carers when a nurse was not available, we were aware of inconsistencies in the proxy scores of the NPI-NH. Woods et al (2000) advise that the NPI-NH should be used with caution by any untrained rater in care homes to track outcomes of a behavioural intervention. However, within the limits of the study, our NPI-NH results demonstrated significant change resulting from the Namaste Care programme in four out of the five care homes. ‘Talking Mats’ was included in the research protocol in order to try and support direct communication with research participants but in practice we found we could not engage people with a BANS-S score of 17+.

Defining quality of life negatively through a reduction in neuro-psychiatric symptoms may not be ideal. Measures of quality of life for people with dementia are conceptually complex (Alzheimer’s Society 2010) and for people with advanced dementia are necessarily proxy measures. Goyder et al (2012) add a further level of complexity by suggesting that an intervention in a care home may create greater awareness in care workers of deficiencies in residents’ quality of life and this awareness may then influence the scores care staff provide. It seems not impossible that a similar process may affect the answers care staff give to the scripted questions of the NPI-NH. Families and care staff were sensitive to changes in residents’ well-being that were not always reflected by changes in the NPI-NH scores. More sensitive measures of psycho-social well-being in people with advanced dementia would be useful for evaluating psycho-social interventions in care homes.

A further limitation, but also a learning, from our study is the value of precisely defining the intervention prior to implementation. We made judgements about the extent to which a full Namaste Care programme was achieved in each care home. Lack of clear definition undermines accurate assessment of the intervention’s effectiveness. It would have been helpful to have pre-defined a ‘minimum standard’ for the Namaste Care programme. Wenborn et al (2013) found that variability in care homes’ level of compliance with their intervention precluded a per protocol analysis.

In this study, we used a cut-off point of 17+ on the BANS scale as measure of severe dementia (van der Steen et al 2006) and an inclusion criterion for the study. However, in
the homes which had open access to the Namaste room, many of those who benefited most conspicuously had less advanced dementia and were therefore excluded from the study. A different study with wider inclusion criteria would provide a more comprehensive assessment of the effectiveness of the Namaste Care programme.

Care homes reported that residents gained weight with Namaste; that infection rates fell; and there were fewer falls and ‘incidents’. Future research should collect evidence to verify such claims.

**Conclusion**

This study has shown that where there is strong leadership, adequate staffing, and good nursing and medical care, the Namaste Care programme can improve the quality of life of people with advanced dementia in UK care homes with nursing. Care staff, relatives and managers recognised that Namaste Care fostered compassionate and respectful care; they welcomed the changes in the culture of care that Namaste Care brought about, and perceived benefits for themselves as well as residents. The Namaste Care programme can play a part in enabling care homes to meet the UK national agenda for greater dignity and compassion in the care of older people with dementia, without requiring significant investment or additional staff.

The study underlines the importance of engagement for people with advanced dementia in care homes. The understanding of this fundamental construct, and the concepts underlying it, is currently advancing through exciting research which desperately needs to be translated into practice that can benefit people with advanced dementia. The Namaste Care programme is a model of care that can operationalize some of these concepts in care homes, in a form that is acceptable, practical and enjoyable for residents, families and care staff.

This study shows that it is possible to do meaningful research with people with very advanced dementia in care homes. Developing more sensitive measures of psycho-social well-being would enable better evaluation of the effectiveness of psycho-social interventions. More interventional research studies should be undertaken with this population and those who care for them so that practice can be developed and improved and people with dementia can experience quality of life to the end of life.
RECOMMENDATIONS

Recommendations for policy and practice, and for future research, including research with the Namaste Care programme are set out below.

Recommendations for policy and practice

- **Meaningful activities** should be provided seven days a week, morning and afternoon, for people with advanced dementia to meet their need for engagement and stimulation.
  - The Namaste Care programme promotes compassionate, respectful care, and is practical and enjoyable.
- **Pain and symptom assessment/management** must be a priority for care home nurses, GPs and all health care professionals involved in the care of this population. An appropriate pain assessment scale should be used in all care homes.
- **Appropriate seating** is a fundamental requirement for comfortable, dignified care and funding should be available to provide suitable chairs for care home residents.
- **End of life care**: Planning and co-ordination are key to achieving good end of life care for people with dementia. The Namaste Care programme presents an opportunity to discuss end of life care with families in a positive context, earlier in the disease trajectory.

Specific recommendations for implementing the Namaste Care programme

- Management commitment is key.
- More likely to get buy in if staff have visited care home where Namaste is working well. This helps them to understand the vision and harnesses enthusiasm.
- Regular update on progress and time for reflection needs to be built into the implementation process for care staff.
- Every member of staff should spend at least one session in the Namaste room so they know what it is about and what happens.

Recommendations for research with people with advanced dementia living in care homes and those who care for them

General recommendations

- Further research should be undertaken that explores the experience and the needs of people with advanced dementia at the end of their lives.
- Further research, especially interventional research, should be undertaken in care homes to develop models for practice which deliver meaningful engagement, relationship-based care and quality of life to the end of life for people with advanced dementia.
A better understanding of quality of life in this population is needed. This would enable more appropriate tools to be developed for assessing quality of life that would support both research and practice.

The Namaste Care programme deserves further attention and a cluster randomised controlled trial would establish its effectiveness.

**Recommendations specific to further research with the Namaste Care Programme**

- The intervention (i.e. the Namaste Care programme) should be defined in such a way that researchers and care staff are clear when they are implementing the programme properly.
- Future studies of the effectiveness of the Namaste Care programme should use wider inclusion criteria, including people with less advanced dementia in studies.
- Staffing levels and the level of staff training in dementia care should be included as part of base-line information gathering when undertaking similar research interventions in care homes. Staff numbers and the level of staff training are probably important factors for success or failure in implementing the Namaste Care programme.
- Further research to evaluate the Namaste Care programme should include data on falls, incidents, weight, infection rates.
- A longer period of time is needed to evaluate the impact of Namaste on inappropriate hospital admissions and psychotropic medications.


accessed 22/10/2013


http://www.jrf.org.uk/search/site/Talking%20mats
(accessed 22.10.2013)


(accessed 22.10.2013)


Appendix 1 – The Namaste Care ‘Day’

Namaste:

“to honour the spirit within”

After breakfast and morning care:

Creating the environment
Gather supplies for the morning including face cloths, basins, towels, beverages, pillows for positioning, individual resident supplies, etc.
Tidy the room and dim the lighting
Open lavender room diffuser
Play soft music
Nature videos

Welcome To Namaste
Each person is touched as they come into the room
A quilt or blanket is tucked around them
Extra pillows or towels used to position
Placed in a comfortable lounge chair
Assessed for pain/discomfort

Morning Activities
Wash hands & apply lotion to hands and arms
Wash face and apply face cream
Hair brushed
Personal likes, lipstick, hair ornaments etc.

Give them a friend! As life-like as possible, not “childish”
Dolls, large dogs, kittens, rabbits etc.

Nutrition/Hydration
Constantly offering drinks
Water/juice
Lollypops for residents at risk of choking
Ice cream, Yogurt smoothies
Fruits. Chocolate

As time permits
Shaving the men
Offering ice cream, puddings, etc.

Waking up for lunch (20 minutes prior to lunch)
Turn up the lights
Change to lively music
Fun activity like blowing bubbles, tossing a ball etc.
Talk about the day
Use bird sounds
Take scents to each person to remind them of the weather i.e. rain, grass, flowers, fir trees
Afternoon Session
Individual reminiscence with Life Stories, old pictures and items from the past
Foot soaks
Lotion feet and legs
Range of motion to music (dancing)
Fancy hair arrangements
Nail care

Namaste Closes
Residents thanked for coming to Namaste
Room tidied & prepared for the next day
Paperwork completed

These are suggestions for a typical day. It is always important to individualize the schedule and be flexible. Seasonal changes, staff changes, resident changes all are to be respected and the schedule reorganized.
Appendix 2

Focus group for care staff before starting the Namaste Care programme

The focus group will start with the facilitators asking whether there are any questions and the signing of consent forms.

*Ice breaker: What is your favourite day of the week?*

Q.1) How do you feel about looking after residents with advanced dementia?

Q.2) How would you describe their quality of life?

Q.3) What do you find rewarding?

Q.4) What do you find hard?

Q.5) How well do you get to know a resident’s visitors?

Q.6) What experience do you have in caring for dying residents?

Q.7) How comfortable do you feel talking with relatives about end of life care?

Q.8) What sort of training or information have you had with regard to helping you manage end of life care for people with advanced dementia? What has helped? What else would you find helpful?
Appendix 3 – Interview schedule for managers

Semi-structured interview for care home managers

1. How has the Namaste care programme worked out in your care home?
2. How does this compare with your original expectations of Namaste Care?
3. What do you feel have been the most significant changes as a result of Namaste Care for residents?
4. What do you feel have been the most significant changes as a result of Namaste Care for families?
5. How do you feel care home staff have responded to the Namaste Care programme?
6. What changes have you noticed in the way care home staff work?
7. Has Namaste Care affected the way you feel about your job, or the way you manage your work?
8. What difference has the Namaste Care programme made to you and your staff when discussing end of life care with families?
9. What has been the best aspect of the Namaste care programme for you?
10. What have you found difficult?
11. What have you learned?
12. Are there any changes you would like to make to the Namaste Care programme?
13. What would help you sustain it?
Appendix 4 – Focus group schedules

Focus group for care staff post evaluation of Namaste Care programme

Please could we go round the room, and each person say your name, how long you have worked at [name of care home] and how much you have been involved with Namaste.

Q.1) Do you feel there have been any changes with residents since implementing Namaste?

Q.2) What effect do you think the Namaste Care programme has had for relatives and friends?

Q.3) What effect has the Namaste Care programme had on your relationships with residents and relatives?

Q.4) What difference has the Namaste programme made for you and your work?

Q.5) What have you found difficult about introducing the Namaste Care programme?

Q.6) What have you learned from the Namaste Care programme about caring for people with advanced dementia?

Q.7) What have you learned from the Namaste Care programme about end of life care?

Q.8) Would you make any changes to the Namaste Care programme?
Appendix 5

Focus group for families/friends following implementation of the Namaste Care programme

The focus group will start with the facilitators asking whether there are any questions and the signing of consent forms.

Introduction: Please can you tell us your name and who you visit and how long you have been visiting the care home.

Q.1) How would you describe the changes you have seen with the introduction of the Namaste Care programme?
   • In your relative
   • In the care home

Q.2) What do you feel is good about the Namaste Care programme?

Q.3) What aspects of Namaste Care have you found difficult?

Q.5) How do you find visiting your relative since the Namaste Care programme started?

Q.6) How has the Namaste care programme affected your concerns for the future care of your relative?
   • Entry to programme/end of life conference

Q.7) How has Namaste Care influenced your communication with staff?

Q.6) How has Namaste Care affected your own quality of life?
Appendix 6: A comparison of the Namaste Care programme with Lawrence et al’s (2012) taxonomy of findings pertaining to implementation of psychosocial interventions in care homes

**Taxonomy of findings pertaining to implementation of psychosocial interventions in care homes**  
(Lawrence V, Fossey J, Ballard C, Moniz Cook E, Murray J. 2012)  

<table>
<thead>
<tr>
<th>The Namaste Care programme (a psycho-social intervention for people with advanced dementia implemented in care homes)</th>
</tr>
</thead>
</table>

### Beneficial elements of a psychosocial intervention

#### a) Focus on people with dementia

i. Connecting with others:
- line of communication
- bringing the world in
- mutual understanding
- social inclusiveness

- ‘Reaching out to each other’ was a theme
- Namaste improved communication
- ‘Greetings/farewells’ at sessions recognised individuality
- Being in the presence of others is core to Namaste

ii Meaningful contribution
- Severity of dementia (BANS 17+) meant residents contributed differently e.g. singing, or returning therapeutic touch in response
- Meaningful activity through enhanced personal care

iii Opportunity to reminisce
- Sensory work provided triggers for reminiscence

#### b) Focus on staff

i Seeing beyond the illness:
- learning personal histories
- seeing the person in a family context
- dismantling ‘us’ and ‘them’

- ‘Seeing the person’ was a theme
- Namaste provided an opportunity to revisit personal histories in family meetings
- ‘Reaching out to each other’ – therapeutic touch promoted an equality between staff & residents

ii Examining approaches to care:
- awareness of approach to care
- opportunities for reflection

- Staff were aware of change in residents [‘calmer’, ‘more alive’] and developed new skills
- Staff reflected on new empathetic responses through Namaste & consequential change in practice

### Conditions required for successful implementation

#### a) Reliance on staff

i Providing access
- ‘top down/bottom up’ collaboration worked in 4/5 CHs

ii Knowing the person:
- providing appropriate encouragement
- provide appropriate reassurance
- tailor the intervention to preferences
- tailor the intervention to abilities

- Staff were able to identify residents responding at a sensory and reflex level - appropriate for Namaste
- Staff were able to find out more about sensory preferences and unmet needs through observation & learning in Namaste sessions in 4/5 CHs

#### b) Active involvement of family

- Through family meetings and day to day engagement during visits in 4/5 CHs

#### c) Flexibility

- Namaste looks different in each CH
- Scope to adapt programme to individual ‘life story’ preferences

### Challenges to successful implementation

#### a) Pressures of time and staffing

- Pressure of time + staffing in all CHs. ‘Rushing about’ summed up how care staff felt about their jobs before intervention and identified was an obstacle

#### b) Institutional Philosophy:

- focus on ‘priority needs’
- avoidance of risk

- Task orientation was present in CHs, but Namaste impacted on care home culture in 4/5 CHs
- Risk avoidance less restrictive with residents who are immobile and very frail

#### c) attitudes of staff:

- uncomfortable with intervention
- general resistance

- One home reacted negatively to Namaste
- Slow engagement with wider care home team everywhere
- Individual resistance to intervention but overcome in 4/5 CHs

CH = Care Home