StChristopher's

Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes

Min Stacpoole

Dr Amanda Thompsell

Dr Jo Hockley

Acknowledgements

The toolkit owes its existence to Professor Joyce Simard who developed the Namaste Care programme and inspired us and many others across the world to work to improve the care of people with advanced dementia at the end of their lives. We owe a great debt to her work which we have used as a basis for this manual.

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Introduction

> ***'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.'***
>
> **Dame Cicely Saunders, founder of the modern hospice and palliative care movement**

This toolkit aims to help you and your care home use the Namaste Care programme to give excellent care to your residents with dementia, especially in the later stages of their illness.

As well as being kept well fed, clean and comfortable, people with advanced dementia need to feel loved and they need to express themselves and be recognized as individuals. They need care that enhances their quality of life. However, an Alzheimer's Society survey found that only 41% of relatives consider that their loved ones with dementia living in care homes enjoy a good quality of life[1].

People with advanced dementia become very frail as the brain shuts down and they often find it difficult to communicate and interact with other people. This means that they are no longer engaging in the conventional group activities of the care home. Care home staff can find it difficult to make the lives of residents with advanced dementia enjoyable and meaningful, despite their good intentions. People with advanced dementia living in care homes sometimes spend long hours alone in their rooms, or asleep in an 'activity' they can no longer take part in. In another Alzheimer's Society study[2] the average interaction between a resident with advanced dementia and care home staff, not including time spent in giving personal care or helping with meals, was observed to last only two minutes.

The Namaste Care programme

Namaste Care is a structured programme, developed by Joyce Simard in the USA[3], that integrates compassionate nursing care with individualised activities for people with advanced dementia in a group setting. 'Namaste' is an Indian greeting which means *'to honour the spirit within'*. The care programme is multi-dimensional, including physical, sensory and emotional elements. The purpose of Namaste Care is to give comfort and pleasure to people with advanced dementia through sensory stimulation, especially the use of touch. Namaste Care increases the length of time that care home staff spend engaging and connecting with residents with advanced dementia and provides a possible solution to meeting the sensory and emotional needs of these residents, and enriching their quality of life.

The programme is conducted seven days a week, for two hours in the morning and two hours in the afternoon, but does not require additional staff, or space, or expensive equipment. Namaste gives a structure to the 'empty time' when residents with advanced dementia are not engaged in personal care or mealtimes. The Namaste sessions are run by a Namaste Care worker who is a member of the care staff team and are delivered in a designated place within the care home, protected from interruptions and made homely and attractive, so that there is a calm atmosphere.

The core elements of the programme are:

- *'Honouring the spirit within'*: the guiding principle of Namaste Care is a respectful and compassionate approach to individuals with advanced dementia.

- *The presence of others:* Namaste residents are brought together as a social group with a dedicated Namaste Care worker, so each resident feels 'included' in their community.

- *Comfort and pain management:* comfortable seating and pain assessment/management are the essential first step towards enabling Namaste residents to relax, engage and express how they feel.

- *Sensory stimulation:* the programme incorporates stimulation of the five senses (touch, hearing, sight, smell, taste). Music, colour, therapeutic touch and massage, aromatherapy oils and food treats are all part of the multi-sensory environment created in the Namaste room.

- *Meaningful activity:* in Namaste, personal care is provided as a meaningful activity, even though the Namaste residents will usually have had their morning wash. The focus is on pleasure rather than personal hygiene. Hands and face are gently washed with a warm flannel and patted dry with a soft towel. Moisturising creams are applied and the Namaste Care worker uses this opportunity to make eye contact, and talk affirmatively with the resident. Hands and face washing is part of everyone's life experience and usually results in a sense of well-being. The Namaste Care worker will explore individual wishes and preferences and adapt activities to meet people's needs.

- *Life story:* knowledge of the resident's life story is key to adapting the programme of activities and interventions so that they are meaningful for each person.

- *Food treats and hydration:* the Namaste Care worker offers drinks and food throughout the session (being mindful of any swallowing difficulties). This creates extra opportunities to improve hydration and nutrition and contribute to the residents' health and well-being

- *Care worker education:* care workers involved in Namaste require education about dementia and all aspects of the care programme. The care workers need support to feel confident.

- *Family meetings:* holding a family meeting when a resident is going to start the Namaste Care programme creates a further bond between the family/friends and the care staff, opening up the conversation about end-of-life care. Families are encouraged to take part in the Namaste sessions when they visit.

- *Care of the dying and after-death care:* the care that residents enjoy in the Namaste Care programme can be transferred to the bedroom when the person is unwell, and when they are dying.

- *After death reflection:* dedicating time to remembering a resident after their death supports the care staff emotionally. Reflecting on what went well, and any difficulties, provides an opportunity for care staff to learn from the experience and improve the care they give to residents when they are dying.

None of these core elements are anything new in dementia care. However, what is different is that Namaste brings people with advanced dementia together in a single care programme that provides company and stimulation on a regular basis.
St Christopher's Hospice and the South London and Maudsley Trust evaluated the effects of Namaste Care on the quality of life of people with advanced dementia in five care homes in South London. We found that Namaste Care reduced the severity of residents' behavioural symptoms, such as agitation and aggression, as well as lethargy[4]. It also led to increased satisfaction among family members who found visiting easier because their loved one was more content. The family appreciated the efforts that they saw care staff making to meet the needs of the person they love. Some family members joined in with Namaste Care alongside the care home staff. Care home staff also found the programme rewarding and felt more satisfied with their work[5].

> *'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.'*
>
> (Email from the daughter of a resident)

Aims of the toolkit

We want to share what we learned from setting up the Namaste Care programme in a variety of UK care home, and support you and other care homes to find new ways of working and providing care for people with advanced dementia that meets their psycho-social and spiritual needs.

We want to provide a practical guide to introducing Namaste Care into UK care homes. The toolkit has been designed to help everyone working within the care home — (from the care home manager to the maintenance staff) — understand and support the Namaste Care programme. The whole team needs to be involved in making the care programme work and everyone can enjoy joining in.

We hope that the toolkit and the accompanying workshop will enable you to:

- Understand the purpose of the Namaste Care programme and its benefits for people with advanced dementia, families and friends, and care home staff
- Communicate the vision to the whole care home team
- Lead change in the way the care home team works with people with dementia and their families
- Introduce and establish the Namaste Care programme in your care home
- Develop a strategy to evaluate and sustain the Namaste Care programme in your care home.

Section One

Advanced dementia

Section aim:

- To describe the advanced stages of dementia in order to help you:
    - Select residents who will benefit from Namaste Care
    - Understand why this group of people needs Namaste Care
    - Recognise the need to plan end-of-life care for residents with advanced dementia

Advanced dementia

Dementia is an umbrella term used to describe a number of different diseases of the brain, including Alzheimer’s disease, vascular dementia, mixed dementia, dementia with Lewy bodies, fronto-temporal dementia and many others. Alzheimer’s disease is the most common type of dementia. It causes abnormal function and eventual death of selected nerve cells in the brain[5].

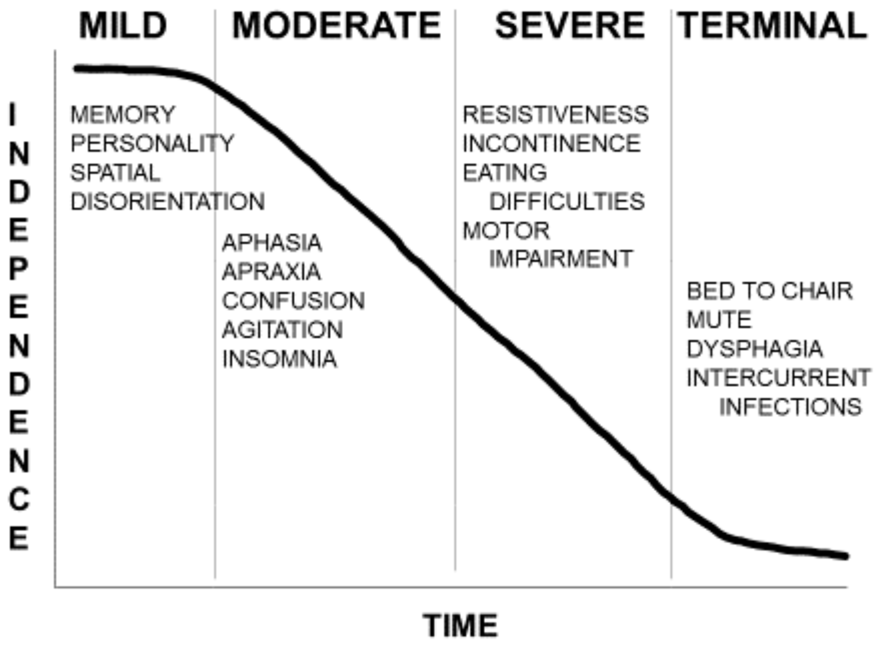
Whilst the progression of symptoms is unique for every person with dementia, as the disease progresses, people generally tend to lose memories, become immobile and completely dependent for all activities of living, and gradually are less able to use meaningful speech. People with advanced dementia can also experience distressing symptoms due to depression, social withdrawal, agitation, resistiveness to care (which sometimes seems like aggression to carers), swallowing difficulties, recurrent infections and pneumonia[6,7,8]. Pain is also common in frail older people with dementia and often goes unrecognized. This is because people with advanced dementia are often unable tell their carers that they are in pain[9,10,11].

In the later stages of the disease, unlike in the earlier stages, people with dementia are not able to participate actively in most group activities, e.g. a quiz or a sing-along. They can therefore become increasingly isolated within the care home environment because staff are unsure how to engage them in meaningful activities[12].

Tracking the progress of dementia

It is useful to try and work out what abilities the person with dementia has so that you can work out how best to engage them in activities and enhance their quality of life. As not everybody with dementia experiences the same symptoms or progresses through the disease at the same rate, there are assessment scales that can be used to help recognise what stage a person has reached in their dementia, for example, the Clinical Dementia Rating Scale[13].

Namaste Care will especially benefit residents who have reached the stage of severe dementia and terminal dementia.



Course of progressive dementias. Reprinted from Mahoney, E.K. et al. (2000) Management of Challenging Behaviors in Dementia with permission from Health Professions Press, Baltimore

People with only moderate dementia may well enjoy Namaste some days, especially if they are not feeling well or if they are anxious or agitated. On other days, these people will need more active activities, like a reminiscence group, cooking, gardening, or a programme such as 'The Club' designed for people with moderate dementia, that provide more opportunity for social interaction and cognitive stimulation.

Dementia is a life-limiting disease

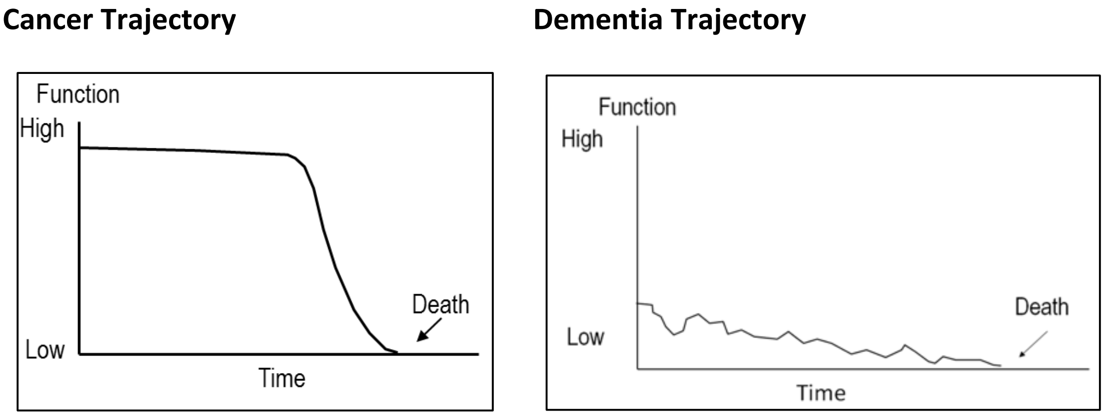
Dementia is a terminal illness[14]. Everybody knows someone who has lived for 10 or even 15 years and more with dementia. However, the median survival time from a diagnosis of dementia until death[15] is only 4.1 years. People diagnosed with dementia aged between 60 and 69 years have a median survival time of 6.7 years, but for people diagnosed with dementia aged 90 years the median survival time is only 1.9 years[16].

At present, there is no cure for dementia. Some people already have an existing health problem when they are diagnosed with dementia, such as heart disease. Some develop another illness alongside the dementia, such as cancer. Therefore, people with dementia often die from other causes before the dementia reaches the end stage[14]. However, others will die because the dementia shortens their life span[17].

The end-of-life course for dementia is different from cancer

People who die from terminal cancer usually follow quite a predictable journey. They remain fairly independent through the illness, until their condition deteriorates quickly and they become very weak a short while before they die (see Figure 1.1). It is therefore quite often the case that health care professionals can predict fairly accurately how long someone with cancer might have left to live. People with dementia are different. They slowly become weaker over many years, both mentally and physically, as the dementia progresses[18].

The diagram below shows how people with dementia can live for years with a very low level of physical function and repeated health crises, which sometimes involve hospital admissions.



Cancer Trajectory

Dementia Trajectory

Figure 1.1: Typical patterns of deteriorating health from cancer and from dementia[18]

This long, slow decline, with ups and downs, explains why it is hard to predict how long someone with dementia will live and when they may die. Even when care staff, doctors and nurses know people with dementia very well, they still find it difficult to predict accurately when the person will die until the last week of life[19].

Predicting the course of the disease

There are various tools we can use to help us predict when someone will die. None of these tools are satisfactory and predicting how long someone with dementia will live is difficult and can be inaccurate. A helpful guide is the 'surprise question' used by the Gold Standards Framework programme[20]. In asking the surprise question, the health care professionals involved in a person's care ask themselves, 'would I be surprised if this person dies in the next year?' If the answer is no, then it is important that end-of-life care planning is set in motion. We need to bear in mind that 56% of all care home residents die within a year of admission to the care home[21].

Prognostic indicators

The Gold Standards Framework (GSF) uses specific factors to predict how long a person with dementia may live[20]. Of course, some of these are exactly the same as the indicators of advanced dementia. Table 1.2 details the triggers from the GSF to remind us that life expectancy may be only a year or less:

Table 1.2: Gold Standards Framework prognostic indicators for people with dementia

- Unable to walk without assistance, *and*
- Urinary and faecal incontinence, *and*
- No consistently meaningful verbal conversation, *and*
- Unable to undertake activities of daily living, such as dressing, independently
- Barthel score <3 (the Barthel Scale measures performance in activities of daily living[22])

Plus any of the following:

- Weight loss
- Recurrent fever
- Urinary tract infection
- Reduced oral intake
- Severe pressure ulcers – stage three or four
- Aspiration pneumonia

Reproduced with permission. Prognostic Indicator Guidance (PIG) 4th Edition Oct 2011 © The Gold Standards Framework Centre In End of Life Care CIC, Thomas. K et al. © used under licence by the Gold Standards Framework Centre C.I.C.

The three most important factors making it likely that the person will die within a year are: problems with eating, especially weight loss and swallowing difficulties; pneumonia; and febrile episodes, especially recurrent urinary and respiratory infections[20,9,23]. People with advanced dementia who suffer a hip fracture or pneumonia are at high risk of dying within six months[24]. However, everyone is different.

Living with uncertainty

The uncertainty of predicting prognosis for someone with advanced dementia sometimes prevents health care staff from discussing end-of-life care with families. Doctors and nurses are fearful that they may have wrongly assessed the time the person has left to live, and that if they are wrong they will cause distress; as a result, they do not talk with families about death and dying. However, families usually like to have information and need to know what is happening, so it is important to acknowledge this uncertainty with them. They will understand that it is not possible to predict the prognosis of their loved one accurately, but will benefit from having the discussion so that they can plan the end-of-life care of their loved one with the care home staff.

Recognising the need to plan end-of-life care for residents who are part of the Namaste Care group

All the people with dementia who benefit from the Namaste Care programme have reached the stage in their dementia when it is important for the care home to have discussions about end-of-life care with the families.

It is always as well to plan for the worst and hope for the best.

Section Two

End-of-life care for people with dementia

Section aims:

- To describe what is meant by ‘a good death’
- To explain why a palliative care approach is needed to care for someone with advanced dementia

This will help you:

- Understand why preparing for end-of-life care is important for people with dementia
- Provide information about end-of-life care that will be useful in the Namaste Care family meetings

End-of-life care

The Government’s *End of Life Care Strategy*[25] promotes good end-of-life care for everyone in the UK, including people with dementia. The Strategy suggests that, while everyone is different, for most of us ‘a good death’ will involve:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends.

The National Dementia Strategy[6] set a goal that by 2014, anyone diagnosed with dementia would be able to say, ‘I expect a good death. I am confident that my end-of-life wishes will be met’.

End-of-life care for people with dementia

Sadly, people with dementia are more likely to have a poor experience of care at the end of their lives than other people. The present health care system is not meeting the challenge of enabling people with dementia to die well. In 2012, former carers, current carers and people with dementia were interviewed by the Alzheimer’s Society to find out about their experience of end-of-life care for people with dementia. The report[26] found that people with dementia often experience pain and other physical discomforts during the last stages of their illness. Many people with dementia die in hospital despite their own wish to die at home or in their care home.

Treatment in an acute hospital is usually inappropriate for people with advanced dementia because there is no medical treatment that can help at this stage in the illness. Admission to hospital is traumatic and distressing for the person and their families because everything is unfamiliar[27,28]. Families are often asked to make decisions about care in a crisis situation, which can be stressful and traumatic for them[29].

Table 2.1 below details the special challenges of providing good end-of-life care for people with dementia:

Table 2.1: The special challenges of providing good end-of-life care for people with dementia[9,10,27]
Dementia is a long, dwindling disease, and it is hard to predict when someone will die. Therefore, staff tend not to mention death and dying for fear of getting the prognosis wrong and causing distress
Planning future care is difficult because people with dementia are often at the stage when they are unable to understand the choices and decisions that have to be made. Family carers are sometimes overwhelmed by their own emotions and find it hard to articulate what their loved one would want if they were able to make their wishes known.
People with advanced dementia cannot always communicate what they are feeling and experiencing. This makes it hard for professionals to assess pain and other distressing symptoms
As people with advanced dementia cannot always communicate verbally, health care professionals make assumptions about their wishes, needs and symptoms
Staff may be concerned about confidentiality issues with regard to discussing the health of the person with dementia with their relatives

The aims of care for people with advanced dementia are comfort and pleasure, and the ultimate goal is a peaceful, dignified death in familiar surroundings.

End-of-life care planning

Good planning is the key to good care and this is also true of good end-of-life care. It is *very* important for people with dementia to have the opportunity to talk about their future health care choices and preferred place of care and death while the disease is in the early stages. When people reach the advanced stage of dementia they often lack capacity to understand the decisions that need to be made about their health care and their end-of-life care.

Therefore, the opportunity for future health care planning should be offered while people are still able to make decisions and say what they want for themselves. If plans are made early enough the person will be able to be involved in decisions.
If the person is no longer able to make decisions, then the health and social care professionals involved must make any decisions using best interest principles as laid out in the Mental Capacity Act 2005[30], and be guided by the person's family or friends.

The Mental Capacity Act 2005 provides a framework for decisions to be made by others in the person's best interests.

The World Health Organization's definition of palliative care

According to the World Health Organization:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual.' [31]

A number of principles underpin palliative care (see Table 2.2).

Table 2.2: The principles of palliative care[31]
Provides pain relief and symptom management
Affirms life and sees dying as a normal process
Does not intend to hasten death or to postpone it
Takes a holistic approach to care, taking account of psychological, social and spiritual needs as well as physical care
Encourages and supports people to live as actively as possible until they die
Offers support to help the family cope during the patient's illness and in their own bereavement
Uses a team approach to address the needs of patients and their families, including bereavement counselling, if needed
Enhances quality of life, and may have a positive influence on the course of illness
Can be helpful at any stage in the course of illness

A palliative care approach for people with advanced dementia

Palliative care is concerned with looking after people with advanced diseases that cannot be cured, relieving people's suffering and supporting them and their families through difficult times. The modern hospice and palliative care movement started at St Christopher's Hospice, London, in the 1960s. At first, palliative care was focused on cancer, but since then more attention has been given to caring for people with long-term conditions, such as motor neurone disease, multiple sclerosis, heart failure, Parkinson's disease, stroke and end-stage dementia.

People with advanced dementia need a palliative approach to their care from the time they are diagnosed with dementia[32]. Many people think that palliative care is only about looking after someone in the last few days of their life, but in fact it is about relieving suffering and improving quality of life right from the time when a person first finds out that they have an advanced, progressive, incurable disease.

A palliative care approach includes accepting that dementia is a life-limiting illness and making plans to ensure that when the person is ready to die, they die comfortably and peacefully[33].

A palliative care approach to people with advanced dementia is a very important part of the Namaste Care programme.

> *'How people die remains in the memories of those who remain behind'*
> Dame Cicely Saunders, founder of the modern hospice and palliative care movement.

Section Three

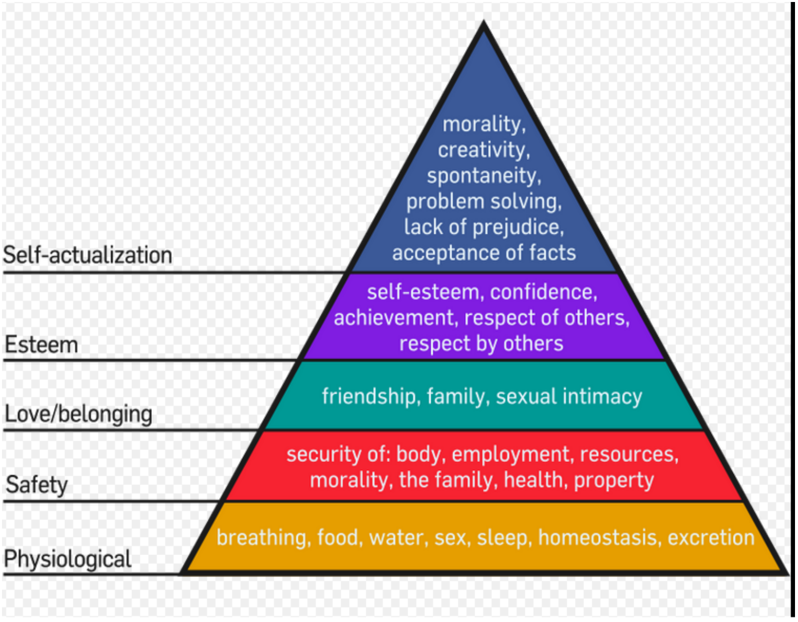
Person-centred care and the Namaste Care programme

Section aims:

- To consider the motivation for human behaviour
- To describe person-centred care
- To outline the most important emotional, spiritual and social needs of people with dementia
- To show how the Namaste Care programme can help incorporate the concept of person-centred care into practice.

The underlying motivation for human behaviour is complex and there are many different explanations and models offered to enable us to understand better why people behave as they do. Maslow[34] (1943) explained human behaviour in terms of fulfilling needs. Maslow described a hierarchy of human needs with the most fundamental physiological needs at the bottom of a pyramid, rising through psychological needs to self-actualization, fulfilment and creativity (see Figure 3.1). When basic needs are met, a person tries to fulfill their psychological needs. Everyone (including people living with dementia) relates to their world according to whether these needs are met[35].

Figure 3.1 Maslow's Hierarchy of Needs



People with dementia will need extra support to meet their emotional, spiritual and social needs, as their condition progresses. The higher needs of Maslow's hierarchy are similar to the psychological and social needs identified by Tom Kitwood[36] in his person-centred philosophy of dementia care.

Person-centred care is a philosophical approach to dementia care, pioneered by Tom Kitwood[36] in 1997, and remains the foundation for excellent dementia care in the UK.

The National Institute for Health and Care Excellence's[32] quality standard for dementia care recognises that a person-centred approach is essential to delivering high-quality care for people with all stages of dementia.

This section of the toolkit sets out the principles of person-centred care on which the Namaste Care programme is based.

Person-centred care

We are all unique and each one of us has individual characteristics, responses, feelings, thoughts, beliefs and experiences. This is what gives us our sense of 'self'. The sense of self is generally equated with the idea of 'personhood'.

Person-centred care seeks to support and maintain 'personhood'[36]. The Namaste Care programme is motivated by the intention to 'honour the spirit within' the person with dementia at the stage when they are no longer able to communicate their thoughts and feelings. 'Honouring the spirit within' mirrors Kitwood's philosophy of person-centred care.

Dementia can undermine a person's sense of self, which in turn can lower their sense of self-worth, and make them feel that they are a burden[37]. Some of the problems with dementia are created by other people and the negative ways in which they perceive the person with dementia.

Kitwood described the negative ways in which other people (however unwittingly) can demoralise a person with dementia and cause them to become socially excluded. The negative elements of this 'malignant social psychology' can be seen in Table 3.1 below

Table 3.1: The elements of 'malignant social psychology'[36]	
Disempowerment	Objectification
Infantilisation	Ignoring
Intimidation	Imposition
Labelling	Withholding
Stigmatisation	Accusation
Outpacing	Disruption
Invalidation	Disparagement
Banishment	Treachery

Joyce Simard, the creator of Namaste Care, wrote:

- *Elizabeth is 84 years old.*
  She has lived with Alzheimer's disease for the past eight years.
  She no longer walks, sometimes she makes sounds but most of her day is spent in bed; she becomes invisible.
- *John has dementia and is 'parked' in front of the nurse's station for hours at a time. He occasionally cries out but no one can understand why.*
  If he cannot be calmed, he is put back in his room; he becomes invisible.
- *Emma, Julia and Harry are unable to participate actively in any of the activity programmes offered. They are taken to a 'day room' where they stare blankly at a television set; they are silent and become invisible as staff rush to help more vocal residents.*

Residents like these are typical of thousands of nursing home residents with advanced dementia who are well cared for medically, given medication, vitals taken, groomed, changed, fed and bathed.

Is this quality of life?
Are we meeting spiritual and social needs?
*Are we providing **meaningful** activities for the person with advanced dementia?*
Who is listening to their silent cries?

Taken from: Simard[38] (2007)

Kitwood[36] outlined approaches that enhance 'personhood', namely 'positive person work' (see Table 3.2). The elements of 'positive person work' are as follows:

Table 3.2: Core element of 'positive person work'	Experience of the person with dementia[36]
Recognition	Experiences a sense of 'belonging'
Negotiation	Feeling of being in control
Collaboration	Feeling of being in partnership with others
Play	Imaginative expression. Recognition of the 'inner child'.
Sensory exploration	Opportunity to explore self-awareness and self-discovery through sensory experiences
Celebration	Celebrating special occasions, but also celebrating every moment, experiencing joy with others
Relaxation	No sense of body tension and a sense of safety and security
Validation	The person's feelings are acknowledged and honoured
Holding	Feeling of being safe, secure and supported
Giving	Experience of value and worth in an environment to which the person is a contributor
Facilitation	Opportunities for personal growth
Creation	Opportunity and ability to express self creatively through actions and emotions

Tom Kitwood's fundamental belief was that people with dementia need to feel a sense of control and purpose, and that when we reach out somebody will be there[36].

According to Tom Kitwood, people with dementia need:

- *Attachment*: to feel loved and safe
- *Comfort*: to be physically and mentally relaxed and not to be in pain
- *Identity*: to be respected as a unique individual and have a sense of self-worth
- *Occupation*: to use their time meaningfully and not to be bored
- *Inclusion*: to have companionship and feel part of the world, not to be lonely or excluded.

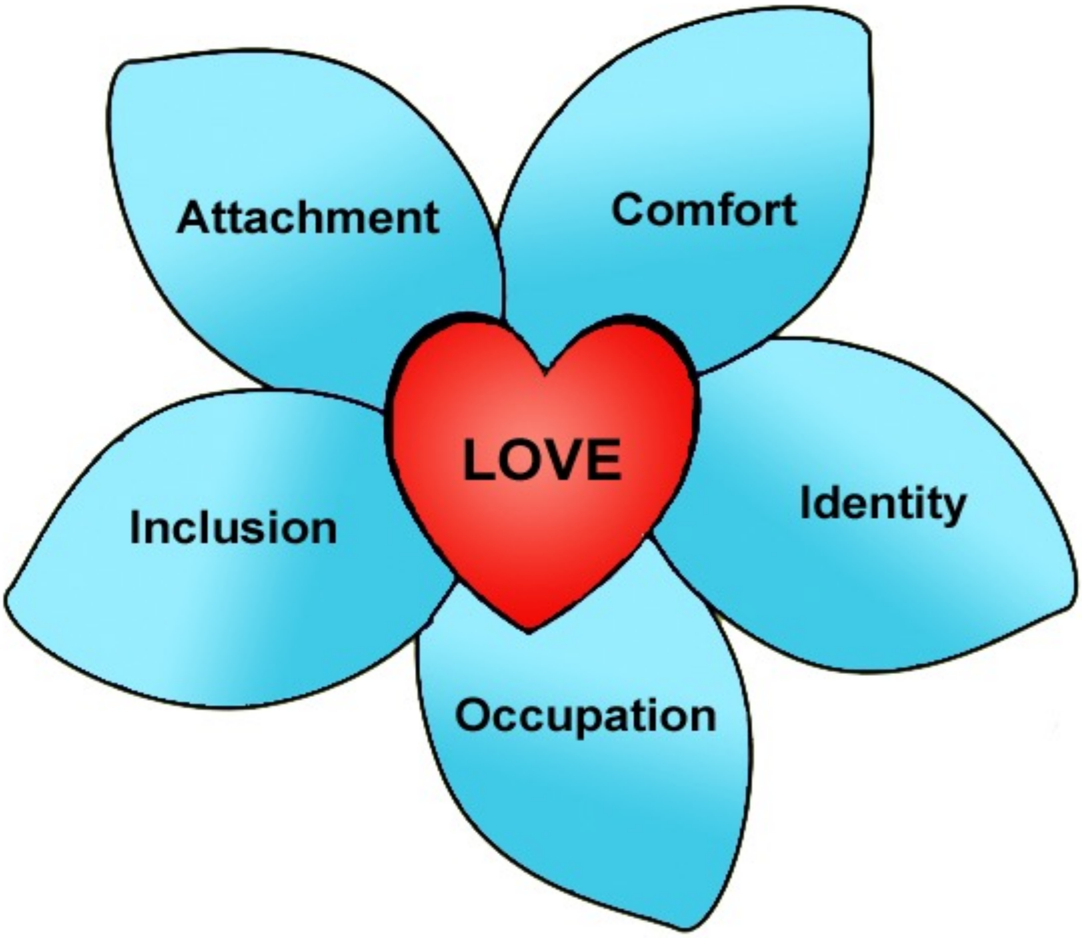
Unless these fundamental needs are met, it is impossible for people with dementia to function as a person.

Person-centred care is about seeing the '**ME**' in de**ME**ntia[36]. Good dementia care involves loving-kindness. It is about the person with dementia having an identity and being understood. In order to give 'loving-kindness' you need to get to know the person behind the dementia by finding out about their life story. When the person is known, their behaviour can be understood more easily and the care worker will be able to form relationships with the person more easily[36,39].

Namaste Care has been structured to meet the human needs identified by Kitwood's 'Flower of Need'[36] (see Figure 3.2) - attachment, comfort, identity, occupation and inclusion. It is a way of supporting and stimulating staff to provide person-centred care and engage in 'positive person work' with people with advanced dementia in care homes.

'The main psychological needs of people with dementia'.

People with advanced dementia often feel bored, lonely and helpless as a result of the effects of their illness. They need to feel that they are part of the daily life of the care home and that they have relationships with the care home staff[40]. Namaste can help care homes give residents with advanced dementia, who are socially withdrawn and no longer able to benefit from group activities, a positive experience of care. At the same time, the programme can help build closer relationships with family members, who can also be involved in the Namaste Care sessions[3].



Reproduced with permission from Kitwood T (1997). ‘Dementia Reconsidered the person comes first’. Fig. 5.2 page 82. Open University Press, Maidenhead, UK

‘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 of a care home)

Section Four

Leading the change

Section aims:

- To highlight the importance of managerial support and leadership to the successful implementation of the Namaste Care programme
- To describe the roles of the Namaste Care core team members
- To explain the importance of teamwork for the Namaste Care programme
- To show that Namaste Care does not require extra staff or space, but a new way of working

The Namaste Care programme and this toolkit are based on best practice dementia care and best practice end-of-life care. The Namaste Care programme does not require extra staff, or space or expensive equipment. However, it does mean changing the way in which everybody within the care home works. To make the change happen, there needs to be willingness to change. Change requires good leadership *and* teamwork.

Leadership

The care home manager and senior management (e.g. regional managers, the company directors, or the owners) need to show commitment to introducing Namaste Care and providing the best possible quality of life for residents. Everyone working in the care home needs to know that the organisation is committed to introducing the Namaste Care programme for the benefit of their residents.

The manager/clinical lead needs to be highly involved during both the preparation phase and **the first weeks of setting up** the care programme. It is important to set time aside and make the Namaste Care programme a priority.

Unless there is commitment from everybody at all levels there is a real risk that the Namaste Care programme will not happen twice a day seven days a week. Strong and effective leadership is needed to establish the programme and sustain the change over time.

Choosing the Namaste Care core team

The manager must choose two or three individuals who are enthused by Namaste and experienced and committed to dementia care. These individuals will run the daily Namaste Care programme and provide leadership at ground level for the care staff. The core team members could be nurses or care workers, but they must be people who command the respect of the care staff. Core team members could be called 'Namaste

Champions', and will be involved with planning and organising the care programme at every stage.

The core team needs to be staff members who **WANT** to do this work, as opposed to just being told to do it!

Everybody needs to be 'on board'

For Namaste Care to be introduced successfully, everyone in the care home must understand why the Namaste Care programme is being introduced and see the benefits that Namaste Care can bring to residents and the care home.

In our evaluation, we found that 'top down' decisions made by managers were unlikely to bring about change unless all the members of the team were on board. The energy to make the change happen needed to come from both the top and the bottom of the organisation[4].

This means explaining the Namaste Care programme to *everyone* working in the care home right from the start. Table 4.1 details what ALL staff need to know about Namaste Care.

Table 4.1: What everyone needs to know about the Namaste Care programme
• The overall aim is to provide quality of life to the end of life for residents with advanced dementia • Namaste Care focuses on meeting the emotional and social needs of the people who are most disabled by dementia • Namaste Care is based around sensory experience: music, massage, colour, taste and scents • Dementia is a terminal illness and acute hospital care has little to offer people in the later stages of dementia who are best cared for in the care home • For people with advanced dementia the aims of their treatment are comfort and pleasure and the final goal of care is a peaceful dignified death in the care home • Namaste Care depends upon the involvement and commitment of every member of the care home team.

Communicating the vision

Within the care home

In the first weeks of the programme, the most important goal of the care home manager/clinical lead is to win the 'hearts and minds' of the care staff. It is vital that all members of the care staff *and* the wider care home team understand what is planned and how residents will benefit (see Table 4.2).

Table 4.2: Benefits of Namaste Care for residents[4]
In our research study, we found that residents taking part in the Namaste Care programme:
Experienced an overall reduction in the severity of behavioural symptoms which was sustained over time
Were stimulated to be more alert and responsive, and engaged more actively with others
Were relaxed and became less agitated as they experienced a calmer atmosphere and approach to care
Enjoyed different elements of the care programme, e.g. massage, music, birdsong, life-like dolls or animals, food treats and improved hydration etc.
Had regular, structured, one-to-one time with a care worker and were offered therapeutic touch and the opportunity to connect and communicate and express emotion. Several residents who scarcely spoke became more verbal.

An example of a positive experience is that, in one care home, on the first day of the Namaste Care programme, a daughter sat with her mother and gently rubbed hand cream into her mother’s hand. We turned round and found the daughter in tears. We asked her anxiously why she was upset, and she said, ‘Mum just stroked my hand back, and that’s the first time she has done something motherly for me for ever so many years’.

Reluctance and resistance

Initially, care staff may find it difficult to accept change, or to believe it is possible to implement the Namaste Care programme in the care home. Issues such as not having enough resources, time, staff or space need to be addressed from the start. Be prepared for care staff to say:

- “There is not enough time to do Namaste, we are too busy” – ***the same number of care staff are looking after the same number of people, so this is not more work.***
- “There is already too much work without bringing in anything new” – ***Namaste meets the residents’ needs, and that is our work.***
- “This is nothing new” – ***that is true, but what is new is to focus on people most disabled by dementia, bringing them together as a group and giving them structured engagement/activity***
    - “We are doing all this already” – ***Are you really? Think of one of your own residents reflect on what they do through the day.***
    - “The activity co-ordinators should be doing this” – ***Activity co-ordinators cannot provide individualised activity for everyone in the care home single-handed! Engaging residents in activities is the role of ALL staff. Activity co-ordinators can be a wonderful resource and source of support for the Namaste care workers alongside this other work.***
    - “We give wonderful care anyway” – ***does your wonderful care include this group of residents? What exactly are you doing for them?***

The nurses may say:

- "This is not clinical care" **– but a *Namaste session will provide information about whether an individual is in pain, whether they are eating and drinking normally, an understanding of their mood and behaviour and conscious level. This information is clinically important.***
- "We have too many responsibilities to get involved with Namaste" ***– the residents' well-being is a primary responsibility.***
- "Namaste is the job of the care workers" ***– without support from the nurses Namaste is likely to fail***
- "It will be very expensive" ***– you will see from the pages below that Namaste is affordable.***

None of these negative statements are true and they should be challenged immediately, because active support from everybody in the care home is needed for Namaste Care to flourish. If possible, try and take sceptical staff to see Namaste Care in action in another care home because 'seeing is believing' and they may become powerful champions.

This toolkit aims to provide answers to the common objections of staff to Namaste Care.

An exercise to get people on board

It is useful to reflect on individual residents in your care home, and discuss with staff what they are doing at the moment to enhance these residents' quality of life. Think about whether more could be achieved if Namaste Care is implemented and there is structured time to focus on engagement and pleasurable activity.

Seeing is believing

If you can arrange a visit for the core team and key staff to another home that is already running a Namaste Care programme, you will find that staff will latch onto the idea more quickly. Encouraging staff to contribute ideas will help to engage them with the project. Care homes are full of talented and creative people.

Once you start the programme and staff members see the benefits for residents and feel the benefits for themselves, then many of the difficulties will start to melt away.

Below (see Box 4.1) are comments made by participants having implemented the Namaste Care programme.

Box 4.1: Comments made by participants in our research study[4]

'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.'

(Husband)

'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 seen the palm of this person's hand.'

(Nurse)

'Phyllis 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 "Hee, hee, hee". She's laughing, she's happy.'

(Care worker)

'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.'

(Daughter)

'And they were just sitting there. When you see their eyes, by touching and the five senses, they are lighting up and they look well. To look at them, they really look well. Even very ill patients are looking much better.'

(Nurse)

Winning over the wider care home team

Activity organisers will have a key role in supporting care staff to run the Namaste Care programme, but *everyone* employed by the care home needs to play a role in Namaste. Kitchen, laundry, maintenance and administrative staff often have close relationships with residents. They need to know that they will play a practical part in supporting the Namaste Care programme and bringing a better quality of life to residents with advanced dementia. Everyone in the care home needs to know that their contribution to the Namaste Care programme is valued.

Families and friends

Introducing Namaste Care will inevitably change the way the care home works. It is best practice to involve relatives in any changes which may affect their family member. As the routine of the care home changes it is helpful to have the understanding and co-operation of families and friends. It is therefore important to hold a relatives' meeting to explain the Namaste care programme to *all* relatives, not only those who have a family member likely to benefit from the care programme.

It is also important that when family members come to visit, they know they are welcome to be part of Namaste, and if they feel comfortable combing the hair of the person they care for, or offering a hand massage or a drink they are invited to do those things. If they wish to take their loved one out of the Namaste room and visit away from the group activity they are welcome to do this.

Try to enlist the help and support of relatives from the outset.

The multi-professional team and care home visitors

Everyone who visits the care home professionally needs to understand the changes that are being introduced and the reasons for introducing the Namaste Care programme, e.g. the GP, community mental health team, community palliative care team, local ministers of religion and volunteers. Ideally, it is best to talk about the programme in person. However, it may be that a letter or email is the easiest way to communicate with them all.

It is vital that everyone (care staff, family members, visiting professionals e.g. GP) understands the Namaste Care programme so that they can support your work.

Choosing the right time to start

The care home needs to be ready for change. The manager and care staff members need to feel confident that they are already giving their residents good health and social care. They have to feel ready to take on the challenge of finding new ways of working that will help people with advanced dementia to connect more closely with others and experience comfort and pleasure every day.

When implementing the Namaste Care programme, staffing levels should be at a normal level for the care home. If your care home is under-staffed, or if your staff are in the process of introducing another improvement in care, it will be difficult to bring about the necessary changes in order to implement the Namaste Care programme properly.

It is not a good idea to start Namaste Care while other major organisational changes are going on. It is also not a good idea to start over a holiday period when staff members are likely to be away and there is less time to build up continuity. Management support is crucial, especially in the first few weeks while the programme is established. If care staff are not engaging with the project it is worth delaying and taking time to gain their support, because commitment from everybody is the secret of success.

Make sure care staff know what documentation you have chosen and feel confident using it. In particular care staff need to be confident in actually undertaking a pain assessment and using a pain assessment tool (see Section Eight).

If you have painted a room, make sure the smell of paint has gone before you bring the residents in for Namaste.

Make sure the core team and the key leaders within the home are working all week when you start your Namaste Care programme.

Using time differently

Re-organising staffing to make time for Namaste Care

Within most care homes, on any particular day, care workers have an assignment of 4 – 8 people at different stages of dementia with different needs and levels of dependency. When you are running a Namaste Care programme, the allocation of staff to residents remains the same in the morning until the residents have been helped with their personal care needs and have had breakfast.

All hands on deck – helping residents get to Namaste

Once most residents have had their breakfast and morning wash, then the Namaste Care worker for the shift goes to set up the Namaste room. Once the room is ready she/he tells colleagues that Namaste is open. The next fifteen minutes are very important because every available person, including the manager and the cleaners, is needed to help bring the Namaste residents to the room. The Namaste Care worker will be there to greet residents as they arrive. This ensures that each individual is recognized with respect and affection at the start of the session.

Sharing the work

For the next two hours the Namaste Care worker stays in the Namaste room, engaging with the Namaste residents. The Namaste group consists of at least the same number of residents as the average care worker's allocation, i.e. 4 – 8. The difference from usual care is that the Namaste Care worker is now caring for a group of people who are all in the later stages of dementia. Sometimes the Namaste Care worker looks after *more* residents than the average allocation, because the Namaste Care residents are generally immobile, and some of them will be asleep at times. In most Namaste care homes, the other care workers and nurses enjoy coming into the Namaste room because they find the atmosphere pleasant and relaxing, and they enjoy interacting with residents.

Meanwhile, other care staff remaining on the floor will continue working with the other more able residents, usually engaging them in activities that suit their physical and cognitive abilities....

We have found that care home managers organise staffing in several different ways when implementing the Namaste Care programme. These are detailed in Box 4.2 below.

Box 4.2: Different ways of organising staffing for the Namaste Care programme

- In some care homes the Namaste Champions run the programme every day. This has the advantage of continuity. However, other care workers need to gain experience and skills to take over if the Namaste Champion is on holiday, or working nights or sick. Also, weekends have to be covered because Namaste Care is a seven days a week programme.

7 days a week and 4 hours a day is the optimal schedule for the Namaste Care programme, but if you cannot manage this at first you should not be put off starting. As a care home you have to decide on the frequency you can commit to, and then build towards a full programme.

- In other care homes, care staff take it turns running the programme, one may take the programme in the morning and another in the afternoon.In the USA there is an assisted living organisation where all staff wanted to be a part of the program so they rotate every 30 minutes!
- Each care home must work out what pattern works best for themselves.
- Ideally, a programme of group activities for people with moderate to advanced dementia is running simultaneously with the Namaste Care programme.

Group activities for people with moderate dementia

Ideally, at this time of day, other group activities are provided for people with more moderate dementia, eg reminiscence, or cognitive stimulation, or gardening etc.. These sessions will probably be organised by the activity co-ordinator. In this way there are two supervised groups of residents on the floor, and one or two residents who may be unwell in their rooms and one or two who may choose not to be involved in either group. In homes where Namaste Care is offered each day there are very few residents who are not engaged in meaningful activity.

Lunchtime

When the programme closes before lunch, the care staff are all needed again to bring the Namaste Care residents out of the room to be made ready for lunch. The Namaste Care worker thanks each resident for attending the session and says goodbye, then briefly tidies up and joins the other care workers. *The same numbers of staff are therefore available to help with toileting and lunch.* The Namaste room re-opens after lunch at 2 pm or 3 pm, according to the care home’s routine, and once again the Namaste Champion (this may be another member of staff now) looks after a full assignment of 4 - 8 residents.

Support from the wider care home team

In order to achieve the best possible care for residents with advanced dementia, the care home manager needs to involve *every team in the care home*. Quality of care depends on cleaners, kitchen staff, laundry workers and administration as well as the clinical care staff who are directly involved in care (see Box 4.3). If all the teams contribute to the programme then any extra work involved is spread right across the organisation.

Box 4.3: Sharing the load with the wider care home team

- In one care home the activity co-ordinator set up the Namaste room while the Namaste Care worker went for a break before beginning the care programme.
- In another care home the nurse set up the Namaste room after finishing the medication round so that the Namaste Care worker could have a break before starting Namaste.
- The kitchen staff can help by putting together a tray or trolley of drinks, water and a choice of juice, and preparing food treats for the Namaste programme, e.g. orange segments, pieces of banana, or pureed fruits for people with swallowing difficulties. The Namaste core team can talk with the cook and the kitchen staff to create variety and choice, e.g. one day ice cream, another day yoghurt smoothies or cake. The type of food will depend upon each resident's swallowing ability.
- Laundry staff can support staff with washing the extra towels/face cloths used in Namaste, and keeping the room supplied.
- Maintenance staff can help with jobs such as fitting up a blind to diffuse bright daylight, advising about natural lighting, or setting up speakers for the music system.
- Everyone can play a part and everyone should be encouraged to spend at least twenty minutes in a Namaste session so that they understand what is going on.

Finding a Namaste space in your care home

The most important feature of the Namaste room is the constant presence of the Namaste Care worker. Remember, *'If there is no one there, it is not Namaste'*.

Everything that is done in the Namaste Care programme is done *'to honour the spirit within'*. Every decision you make about the environment of the care programme should reflect this fundamental philosophy.

The perfect Namaste room

Ideally, Namaste Care has a designated room, where everything can be left in place, supplies can be locked away after the session and there is no danger of more active residents going into the room and damaging growing plants or fragile ornaments by mistake (see Box 4.4). However, if there is no separate room, then a Namaste space can still be created. It may be a screened-off area in a lounge or the dining room. The environment must be made 'special', i.e. welcoming and homely, with natural or slightly dimmed lighting, attractive scents, such as lavender from an aromatherapy diffuser, and with soft music playing. There should be as little distraction as possible.

Box 4.4: In the *perfect* Namaste room there will be:	
A window looking over a garden	A bird table outside
A door to the outside	A music system and a variety of music
A DVD player and appropriate DVDs	An aromatherapy diffuser
An aroma therapy diffuser Reclining chairs	Beautiful pictures Growing plants
Ornaments from the past	A cupboard that can be locked
A fridge	A sink with running water
A smoothie maker	Curtains or blinds

Creating your Namaste space:

You may need to be quite creative about how you set up the room or space to provide a Namaste Care programme (see Box 4.5).

Box 4.5: Using space creatively

- One care home had just one lounge and most residents had to eat in that. Its only option was to create a Namaste space at one end of the room. The staff rearranged the furniture, painted the walls pink and hung a curtain, which they drew when there was a Namaste session.
- In another care home the manager had a large office. She moved out into a smaller one and the room was transformed into a Namaste room with a lick of paint and some pictures.
- Another home had a large dining room that was empty except at meal times; this was 'dressed' immediately after breakfast with some colourful wall hangings and flowers.
- In the USA, a care home started its Namaste Care programme in an empty resident's room.

However you organise the space, *you will need*:

- A space that can be protected from people walking through and causing a disturbance
- A committed team who will use their imagination to create a homely, welcoming atmosphere
- A music centre
- A means of scenting the room
- To find a way to bring the natural world inside
- Storage.

See Chapter 5 for more detailed information about essential supplies.

Making it happen

If you are only relying on one particular person to run the Namaste session it will not work. One person cannot be around every day of every week. Therefore, it is important to have several staff members who can run Namaste sessions. The Namaste sessions must be 'officially' allocated on the rota. It is also important that you allocate people who are enthusiastic and confident to run the Namaste sessions. We all have unique skills and some of your staff will be better suited to doing Namaste than others. Over time, every member of staff will be able to run the Namaste Care session.

The manager must protect and support the core team members while the Namaste Care programme is being established, e.g. not putting them on night duty, or sending them on escort duty. Ideally, for the best chance of success, during the initial implementation phase, the manager/clinical lead needs to be present at the start of each session, and to engage with every aspect of the programme.

We have found that the Namaste Care programme enables you to use time more productively. In Box 4.6 below we summarise this.

Box 4.6: Using time productively

In many of the care homes we have visited, you can often find a care worker sitting in the lounge, during the morning or afternoon, looking after a group of residents and making sure they are safe. Often the care worker is filling out fluid charts or some other paperwork, but not inter-acting with residents

The Namaste Care programme uses this care worker's time differently. Instead of 'minding' residents, the Namaste Care worker engages with residents with advanced dementia and provides appropriate sensory stimulation and one-to-one time in a group.

The more freedom that the Namaste Care workers have, the more they will develop ideas themselves. Family members often enjoy taking part in Namaste and sometimes supply ideas and skills and material.

Section Five

Getting ready for the Namaste Care programme

Section aims:

- To highlight what needs to be done to get Namaste Care started

Once you have decided to implement the Namaste Care programme in your care home, you need to prepare – making certain decisions and preliminary organisations.

Decisions

- Decide on a **budget** (even if you decide you have nothing to spend — that will then be clear)
- Choose the **core team** (encourage them to read *The End-of-Life Namaste Care™ Program for People with Dementia*[3])
- With the core team **choose a space** for the Namaste Care programme.

Preliminary organising for Namaste by care home manager

- Explain the Namaste Care programme at **staff meetings** and, for example, at handover meetings
- Put up **notices/posters** in the care home announcing the introduction of the Namaste Care programme and a provisional start date.
- Meet with/write to **GPs and other relevant outside professionals and agencies** to inform them that you are commencing the programme
- Set up **a relatives' meeting** to inform them about changes
- With the core team **list the basic equipment** for the Namaste Care room
- **Review residents** with key workers to establish which residents fulfil the Gold Standards Framework criteria[19] for end-stage dementia and would therefore benefit from attending the Namaste Care sessions
- Make sure there are **suitable chairs** (see Box 5.2) – a Namaste Care programme cannot work with residents sitting uncomfortably
- Make sure essential supplies are ready (see Box 5.1). You can always make a 'wish list' (see Box 5.3) that people might donate to
- **Set a *realistic* date to start the Namaste Care programme.**

Box 5.2: Essential equipment and supplies[4]

(N.B. Most of these will be available in the care home already)

- Comfortable chairs
- Music system and CDs (or MP3 player and downloads)
- An aromatherapy diffuser (or a plastic spray bottle with distilled water and a drop of lavender essential oil)
- Attractive coloured rug/blanket for each resident
- A 'wash bag', or zip locked bag for each Namaste resident containing their own brush and comb, face cream and hand cream, nail clippers, emery board, lip balm, etc.
- Drinking cups that can be labeled, or disposable cups and a marker pen
- Face cloths and towels
- A large storage bag for each resident, e.g. a plastic zip bag to keep a rug and/or pillow and perhaps a life-like doll or animal
- A rummage bag with silky, tweedy, velvety scraps of material, bubble wrap, etc.
- Two to three portable (preferably folding) chairs for the Namaste Care worker and for visitors
- Hand sanitizer, rubbish bags
- Box of tissues for runny noses
- Laundry bags and gloves in case of accidents
- Namaste Care worker has a visible name badge with their first name in large font
- Welcome sign (one care home has a notice that says, 'Please come in quietly and gently'.

Box 5.1: Seating

People with advanced dementia often need special chairs because they are usually frail and immobile, and often have contracted limbs.

Having a chair with wheels is particularly helpful because it means the person does not become 'bedbound' and can spend the day in comfort and move around the care home. These chairs are however specialist equipment and very expensive.

It is therefore important for you to assess whether you think the chair the resident is in is the most suitable one for them (often the care home has a variety of chairs); it may well be there is a more suitable one but if not do seek advice. People with dementia in private care homes are entitled to assessment of their seating needs by an NHS occupational therapist.

Requesting an O.T. assessment is the first step towards getting appropriate seating for such a resident.

Sorting out the funding for an appropriate chair can cause delay so below are some possible other solutions:

- Sometimes the NHS supplies a suitable chair

- Sometimes the resident has their own funds
- Sometimes relatives will buy a comfortable chair
- The family and the care home can share the cost on the understanding that the care home keeps the chair when the resident dies
- Sometimes care homes have chairs they have bought or inherited
- There are charitable trusts that will contribute to the cost of specialist equipment for sick people
- If the finances permit, consider including the cost of one new reclining chair in your Namaste budget.
- Consider fund raising for a chair e.g. coffee morning, raffle etc.

Box 5.3: Wish list for Namaste equipment

(N.B. May be available in the care home, or perhaps someone would donate, or raise money for funds)

- A trolley for equipment for the session and to take equipment to a resident's room
- Green plants
- One or two life-like dolls
- Life-like cats and dogs
- Life-like singing birds
- A fridge for food treats
- Picture books
- Poetry books
- A variety of essential oils
- Tambourine and rainmaker
- Pictures and ornaments
- A DVD player and appropriate films with a screen to show them
- Foot spa

Jobs for core team

- Check around the care home for already available equipment and supplies (see Box 5.1)
- Ask colleagues and visitors for scraps of material, etc. for a rummage box.
- Check out your colleagues' skills. For example, does anyone have training in aromatherapy or massage? Does anyone have a beautiful singing voice? Does anyone have a garden from which they could bring flowers?
- Collect supplies for each individual resident (see Box 5.2). Use their own supplies and discuss this with family/friends at the family meeting (see Section Six).
- When you have decided where to run the Namaste Care programme, prepare the space. It may need a lick of paint, or you may need to create a screen. Allocate roles to team members and check your equipment and storage and

that the music player is working before you confirm the starting date for Namaste.

- Make a welcome sign.

Box 5.1: General supplies

- Pillows for positioning
- Blankets/rugs/quilts (colourful)
- Face cloths
- Bowls in which to soak hands
- Towels
- Aqueous cream for moisturising skin
- Cotton buds
- Hypoallergenic oil for massage
- Soap dispenser/hand sanitiser
- Gloves and laundry bags in case of accidents
- Disposable wipes

Box 5.2: Personal supplies for Namaste residents

A clearly named bag containing

- Hairbrush and comb
- Nail clippers
- Emery board
- Face cream
- Lip balm
- Items supplied by the family, e.g. perfume and make up for women, after shave for men

A large bag such as a dry cleaning bag to keep the blanket and, for example, a life-like animal.

Documentation

The manager and the core team must decide how to document the Namaste Care programme.

Suggestions for documentation include:

- A record of attendance
- A personal profile for each resident
- Documenting any risks
- Allergies
- Concerns about infection
- Information about conditions such as diabetes
- Swallowing difficulties
- Sensory impairments, e.g. poor sight, wears glasses, or poor hearing in one ear
- Concerns about behaviour, e.g. may try to eat inedible things
- A ‘sensory’ biography of likes and dislikes
- Favourite music
- Foods/tastes
- Scents
- Does the person like hugs and touch?

- Does the person respond to colour or enjoy looking at pictures?
- A folder containing a record of activities for each of the residents taking part and their responses to different sensory experiences.
- A non-verbal pain assessment scale which staff in the care home understand how to use (see Section Eight)

Once potential residents have been selected for Namaste, it is important that the manager sets up a meeting with individual family/friends to explain why Namaste Care will be suitable for their relative (see Section Six).

Finally, the care home manager should fill out a Namaste Care checklist to be sure that everything is in place to start the Namaste Care programme.

Section Six

The ‘family meeting’: communicating with relatives

Section aims:

- To offer guidance for holding a Namaste family meeting with the resident’s family/close friends
- to inform family about the role of Namaste Care in helping to maintain the quality of life of people with advanced dementia
- To ask the family’s help with creating a ‘sensory biography’, e.g. the person’s favourite music
- To explain the importance of planning end-of-life care at this stage
- To highlight the importance of discussing issues such as advance decisions to refuse treatment and cardiopulmonary resuscitation

When you have assessed that a resident would benefit from Namaste Care you need to set up a ‘family meeting’ to explain the change in care to family/friends. Good communication with relatives is key to the success of Namaste Care.

The family meeting is held to learn from the family and engage with them in finding ways to bring pleasure and trigger memories for their family member. This meeting is also an opportunity to acknowledge the resident’s deterioration from dementia with family/friends in the positive context of offering more appropriate care. The discussion about how to provide quality of life can open up conversations about maintaining quality of life to the end of life and planning end-of-life care.

The main purposes of the ‘family meeting’ are to:

Introduce the concept of Namaste Care

- Discuss with relatives/friends that it is felt the resident’s condition is progressing.
- Explain that the resident is no longer able to take an active part in conventional care home activities.
- Describe the Namaste Care programme and inform relatives/friends that Namaste Care is an intervention that has been shown to benefit residents with advanced dementia e.g. by reducing isolation, agitation, and anxiety and promoting engagement and communication.
- Learn more from relatives/friends about their loved one’s life story, and any meaningful activities and sources of comfort and pleasure that the family feel would benefit them during the care programme, e.g. what music is associated with pleasurable events in the resident’s life, and what perfumes or aftershaves

the resident may like and which may trigger memories. You can think of this as compiling a 'sensory biography'.
- Encourage relatives/friends to participate in the Namaste Care programme and share care staff members' efforts to connect with the person with dementia.

Prepare relatives/friends that their loved one's condition is worsening

- This meeting gives you an opportunity to explain that, even at this late stage in dementia, people have a sense of self and are able to engage emotionally with others. Family/friends and health care professionals should concentrate on maintaining quality of life to the end of life.
- High quality end-of-life care needs planning, and an end-of-life care plan needs to be agreed upon.
- Prepare the relatives/friends for loss.
- Discuss the burdens and benefits of acute medical interventions (discussions may encompass issues such as cardiopulmonary resuscitation and preferred place of care and death), and explain that comfort and pleasure are the aims of care at this stage in the dementia trajectory
- Establish the goal of a peaceful, dignified death in familiar surroundings at the care home.

You may not achieve all the aims set out above in this first meeting. Nevertheless, it is important to start the conversation about end-of-life care while the person with dementia is not imminently dying, because it allows time for the family to adjust to the idea of losing their loved one. Give the family a chance to go away and think, talk with friends and look things up on the internet or speak with their own GP. Then, invite them to come back for another meeting to talk through the steps that need to be taken to ensure the person they love has a peaceful, dignified death cared for by people who know them well.

If you already know the resident's family well and have already explored their thoughts and preferences around end-of-life care for their loved one, then this meeting will be a chance to check that nothing has changed and everything is in place to ensure a peaceful, dignified death in the care home e.g. the signed DNaCPR order and an end-of-life care plan.

Having a face to face meeting rather than a telephone discussion is best practice because when you meet with the family you will be more aware of any distress and you will be able to able to pick up on non-verbal communication which is lost over the phone.

If you feel that a family member is in need of support then you can refer them for a carer's needs assessment which is provided for in the Care Act[41] (2014).

Preparing for the meeting

It is essential to invite to this meeting relatives who are involved in the care of the resident, or friends who may be more involved with the resident than actual family members. Clearly, if there is a Lasting Power of Attorney for Health and Welfare, that person should be invited. The meeting can be arranged when the family/friends visit their loved one, or by telephoning/sending an invitation letter to the relevant person or people involved.

Confirming the meeting with the relatives/friends a few days before it is due to take place is very helpful. In the interests of good communication, it is also best practice to ensure that all staff members are aware that the meeting is happening.

It is important to prepare properly and respectfully for the meeting. For example, there needs to be enough staff on duty, and, if possible, a Namaste Care worker who can attend as well as the manager, or a senior nurse. You should try to arrange a quiet space/room for the meeting where there is no telephone and where there will be no interruptions from people coming in and out. Make sure there are enough chairs and if possible arrange for tea and coffee which helps create a relaxing atmosphere.

Remember to plan sufficient time for the meeting.

Outline of discussion content

Introduction

It is helpful to begin by checking if the relatives have any concerns or queries. Ask them how they feel their family member/friend has been over the past few months. Remind them that if anything is said that they do not understand then they should interrupt and ask for an explanation. Box 6.1 gives some useful suggestions.

Box 6.1: Communication suggestions

- How does [name of resident] seem to you?
- Have you noticed any changes in [name's] condition?
- We feel that [name] is less able to do things than previously? (try to give an example of change in the individual) ……Would you agree?
- Dementia is a progressive disease, in that the person with dementia, over time, gradually becomes less well.
- The signs that the dementia is progressing include loss of appetite and difficulty swallowing, difficulty walking without help, more infections, increasing difficulties with talking and interacting with other people. Again, try to relate this to changes the family may have seen in their family member
- Such symptoms indicate to us that [name] may be entering the final stages of life. It is of course difficult to know just how long someone has left to live, as everyone is different. [Name] may have a few months, or even years. There is also the possibility that [name] has less than a few months. We don't know but we will be monitoring them closely and will of course keep in regular contact with family.

Information about the Namaste Care programme

The family/friends need to be informed (if they do not already know) that the care home offers Namaste Care to residents with advanced dementia, and that Namaste Care will help staff members engage with residents and provide pleasant experiences. Explain that the programme also ensures that their loved one with dementia will be closely monitored for pain and distress, while at the same time their hydration/nutrition will be improved as staff members concentrate on giving fluids and appropriate food during the sessions.

Bringing up the topic of the resident's deterioration

This meeting is a chance to talk with the family/friends about the progression of their relative's dementia and support them to acknowledge that dementia is a life-limiting condition. It is important to explain that it is difficult to predict exactly when somebody will deteriorate and how quickly. This may be the first time the family have spoken about their relative's end-of-life care. It may be the first time they have faced the prospect of the person they love dying.

A relative may ask 'how long has my mother/father got to live?' Be sure to explain that predicting when someone is likely to die is particularly difficult and unreliable for people with dementia. Be careful to talk in terms of months, or weeks, or days, whichever is appropriate; never a particular number. If you are asked to predict say, "we are looking in terms of months/weeks", not 'a month' or 'two weeks'. It is important that you reassure them that you will be monitoring the person closely and if their condition deteriorates you would let them know immediately. This is a useful opportunity to check contact details for the relatives are correct and find out if they would want to be called overnight if there was a sudden deterioration, or if they would prefer to be called in the morning.

This meeting encourages the family to think about the things that matter to their loved one towards the end of life, as well as any personal goals of care and previous wishes that the person may have written down while they were able

The family could be asked to consider what they feel their loved one, if they could express a view, would like to happen at the time of their death, e.g. where they would like to die, whether it is thought they would like certain music to be playing, and who they would like to be present. This is an opportunity to discuss what the family/friends know about their loved one's previous concerns and wishes; whether the person ever spoke with them about what they would wish to happen when they were dying.

Statements of wishes and preferences

The family need to understand that a statement of wishes and preferences is not a legally binding document but will be used by health care professionals to guide decisions. No one can demand a particular treatment if the medical team feel it would not be in the person's best interest to undergo such treatment. An example of this would be if a person with terminal cancer only had a few days or hours left to live and the family requested another trial chemotherapy. The duty of the medical team is to act in the person's best interest. Therefore, if the medical consultant judged the treatment would be futile and would cause the person additional distress then they would refuse the family's request[42]. Below are some information and suggestions that might be helpful when discussing future care (see Box 6.2)

Lasting Power of Attorney for Health and Welfare

A person with capacity to make decisions about their future care may choose to appoint a Lasting Power of Attorney for Health and Welfare and give this person responsibility for making future decisions on their behalf in the event that they lack capacity. This is a legal process and a Lasting Power of Attorney document must be registered with the Office of the Public Guardian. When the person appoints a Lasting Power of Attorney they can choose whether or not to allow that person to have the power to make decisions about life-sustaining treatments. If there is a registered lasting power of attorney for health, then there is a legal requirement for the health and social care team to consult with them about health issues, even if the clinical team see another friend or relative more often than the person who has lasting power of attorney.

Box 6.2: Communication suggestions to help when discussing future care

- Although we cannot be certain how long [name] has left to live, we find that it is good practice to prepare for the end phase of their life while at the same time hoping for the best. For example, it may be useful at this stage to start thinking about where you think [name] would like to be cared for until the end.
- In our experience, it is much better for a person with advanced dementia to remain in familiar surroundings. Hospitals can be very distressing for people with dementia, because they are very noisy and busy places.
- Our main aim is to ensure that [name] is kept comfortable at all times and that we honour any requests they may have made about what they would like to happen when they die. Did they ever talk to you about this?
- Although we all hope that your loved one will be with us for a while yet, it would be very useful to discuss how you would like us to care for [name] when the time comes. For example, it is very important for some families to be present with the person they love when they are dying.

Making decisions when people lack capacity to make decisions for themselves

The Mental Capacity Act 2005[30]

The first principle of the Mental Capacity Act 2005 is that someone should be assumed to have capacity to make their own decisions. When a person has dementia, this assumption needs to be tested.

The Mental Capacity Act requires the judgement about whether a person lacks capacity, and if so what to do about it, to be made at the time the medical decision has to be made. However, often at the point a crisis occurs, it may be difficult to consult everybody who should be consulted. It is best practice, therefore, to plan ahead.

A mental capacity assessment should be undertaken to establish whether the resident is able to understand and retain information for long enough to weigh up the risks and benefits of a decision and communicate the decision they make. Ideally, people with dementia should make provision for their end-of-life care wishes to be met in the early stages of the disease while they have capacity. People in the later stages of dementia will not have the capacity to make the necessary decisions to ensure they have a dignified and peaceful death.

If the resident has not appointed a Lasting Power of Attorney for Health or Welfare, or made an advance decision to refuse treatment, then the responsibility for making decisions about the resident's care lies with health and social care professionals. Health and social care professionals are bound to act in the best interests of a person who lacks capacity to act on their own behalf. Almost invariably the health and social care professionals will be guided in their decision making by the family/friends of the person because the family have the person's best interests at heart, and know what mattered to them, and what the person might have chosen for themselves.

A best interests meeting

In cases of people who are unable to make their own decisions, end-of-life care decisions need to be informed by a best interests meeting. In order to arrive at the best possible outcome for the person and, as far as possible, to act as the person would wish in the circumstances, the best interests meeting must involve the person's family/friends, and any legally required representative as laid out in the Mental Capacity Act, along with the health and social care professionals who know the person best. It is essential that everyone involved has a full understanding of all the issues involved. When decisions about health care are discussed, health care staff must be involved. In a care home it will usually be the GP who takes the lead, but not in all cases.

If a best interests meeting is held, it is important to document who was present, what the decision was, what the arguments were for and against the decision, and then at the end see what decision those present felt would be in the person's best interest.

Advance decisions to refuse treatment

In the meeting, it is important to ask about any advance decision to refuse treatment that the person with dementia may have made. This issue can often be forgotten on admission to the care home.

Although a treatment cannot be demanded, a person may state their wishes to refuse a *specific* medical treatment in advance. For example, in the case of a person wanting to die at home, they could state that they only want comfort measures to be implemented and do not want to be transferred to hospital for active treatment, such as artificial nutrition or respiratory support. The treatments that the person wants to refuse need to be clearly stated in an advance decision to refuse treatment document, and the document should specify the circumstances in which it would be applicable. Such a document is legally binding if signed and witnessed and was written at a time when the person had capacity (The National Council for Palliative Care and National End of Life Care Programme[42], 2009).

Topics to be discussed with the families of people with advanced dementia in order to prepare them for deterioration in the condition of their relative, and guide future decision-making

The following questions can provide useful information to guide decisions relating to the end-of-life care of a person with advanced dementia:

- How can we ensure that any known wishes of this person can be followed?
- Will this person benefit from cardiopulmonary resuscitation?
- Will this person benefit from artificial nutrition or hydration?
- Under what circumstances will this person benefit from hospital admission?

The person's wishes should guide the care they are given. Cardiopulmonary resuscitation, artificial hydration and nutrition and other treatments cannot be demanded by the family, and should be given only if the senior clinician involved (in a care home this is usually the GP) believes that a treatment is in the best interests of the patient.

Helpful facts which you may wish to refer to when answering relatives' questions.

Cardiopulmonary resuscitation

Cardiopulmonary resuscitation is an emergency procedure to restore the heartbeat of a person in the case of a cardiac arrest where there is no heartbeat. It involves inflating the lungs with a mask or tube inserted in to the windpipe, regularly pressing down very firmly on the chest and sometimes using electric shocks to try to correct the rhythm of the heart.

The person conducting the discussion must be sensitive to the fact that when having discussions about cardiopulmonary resuscitation, relatives feel that by saying 'no' to it they are actually letting their loved one die. Therefore, it is important that the relatives are aware of the full facts before giving a view as to what their relative would have wanted. Successful resuscitation (i.e. the person recovers enough to leave hospital), only occurs in one in eight people with all types of illness. Elderly people with chronic illness only have an average survival of less than five percent; for people with advanced illness, survival rates are often less than one per cent[43]. There has never been a successful resuscitation attempt following an unwitnessed cardiac arrest in a care home[44].

For elderly residents with dementia, it is usually not in their best interests to opt for resuscitation as, in the event of a cardiac arrest, it would mean transferring the person to hospital as an emergency with the very high likelihood that they would die in that environment.

When residents with dementia reach the end of their lives, it is better for them to die a natural death, in the surroundings they know, and with the people they love.

Artificial nutrition

For people with advanced dementia, there is no evidence that artificial feeding through a nasogastric tube or a percutaneous endoscopic gastrostomy (PEG) tube (a tube that goes directly into the stomach) has any benefit[45]. It has been found that:

- Length of life is not extended
- Weight loss is not halted
- Complications such as pressure ulcers are not prevented
- The person is likely to pull any tube out
- The person loses the comfort of food and one-to-one contact with the person who feeds them.

Artificial hydration

When people are dying they are not able to maintain hydration. People dying with, for example, cancer, who are able to describe how they feel when they are dying, rarely describe thirst as they become more dehydrated, although they do complain of having a dry mouth. If a person with advanced dementia stops eating, drinking and swallowing because they are dying, there will be no benefit in transferring them to hospital to rehydrate them with intravenous fluids. Giving good regular mouth care relieves the dry mouth just as well[46].

Hospital admission

Hospital admission is distressing for patients and families[24,27,28]. Hospital admission rarely benefits people with advanced dementia:

- They are four times more likely to die during the admission than someone without dementia
- They receive inadequate symptom management, especially of pain
- They are less likely than other terminally ill patients to be referred for specialist palliative care.

Section Seven

The Namaste Care programme

Section aim:
- To outline the practical preparations for Namaste Care
- To describe what is involved in Namaste Care sessions
    - To consider the effects of sensory stimulation on behaviour and communication
    - To provide examples of comfort measures, appropriate sensory stimulation and meaningful activities

The sooner you start Namaste Care the better, so that your residents can enjoy the benefits of the care programme. You will continue to develop your programme as you go along.

Setting up the Namaste room, making a sensory environment for people with advanced dementia

You will find very helpful advice in 'How to Make a Sensory Room for People with Dementia'[47], which is available as a free download from the internet. This guide book offers suggestions for creating an age appropriate multi-sensory environment. You will find evidence based guidance on making the space you choose feel comfortable, safe, meaningful and familiar for people with dementia.

Box 7.1: Understanding the world through our senses, sight, sound, touch, taste, smell and movement

We all need stimulation to understand the world around us. We learn about our surroundings through our senses: sight, touch, smell, taste, sound and movement. Sensory deprivation has deeply negative effects on health and wellbeing. When there is too much stimulation people can become overwhelmed. Most healthy people are able to make adjustments to their environment, or within themselves, in order to get on with life and function well.

People with dementia who have impaired physical and cognitive abilities often have little control over their environment, so they need support to find a level of stimulation that fits their needs. If there is very little stimulation, with nothing much happening and nothing to do, then many people will sleep to pass the time away, but some become anxious and agitated. Some people with dementia become agitated and anxious when the environment is over stimulating, while others may respond to over-stimulation by 'switching off' and withdrawing.

In the multi-sensory environment of the Namaste Care session, the Namaste Care worker tries to help each individual to relax. Namaste Care can help people with dementia who are feeling agitated, anxious and tense to unwind and feel calm. These

people are often exhausted and the release of tension may mean that they fall asleep in Namaste.
Other people with dementia protect themselves from the complexity and over-stimulation of their surroundings by withdrawing into sleep and lethargy.

In Namaste Care the multi-sensory environment reduces distractions and allows these people to set aside some of their defences and to 'wake up' in Namaste sessions. People who are generally unresponsive and lethargic may start to interact more with other people and the environment, perhaps they respond to the music, or perhaps the touch of the Namaste Care worker encourages them to make eye contact or to speak.

Lighting

Lighting in Namaste should be natural. Soft lighting reduces the shadows and makes everyone look better. Wall lamps with soft bulbs create a homely atmosphere. Bright overhead lights could be dimmed with a dimmer switch, or with a special lampshade. You may need a blind to filter bright sunlight. Some care homes have special bubble tube lamps. These are an attractive feature but they are not essential.

Music

Music has the power to unlock memories and emotions in all of us. It is a cornerstone of the Namaste Care programme and the Namaste Care worker should think carefully about the music for the day. During each session she/he needs to observe how individual residents respond to particular pieces of music.

At the start of the day, soft, gentle, classical music may be effective. Even though the music is gentle, you may need to play it quite loudly because many residents have poor hearing. If the music can be heard outside the Namaste space, other residents may walk in to see what is happening and may decide to stay for a while.

If you play music continuously, people stop hearing it. So, after about forty minutes, have ten minutes of silence before starting the music again. Relaxation music, which has a slow rhythm, can slow the heartbeat and help the body to relax. For a change, you can put on a recording of birdsong or waves on the seashore. Always notice if a resident appears to enjoy or be moved by any music you play.

Music triggers memories. The music the residents loved when they were younger may have strong associations for them. When family members have told you what particular music was associated with a positive experience for their relative, which particular singers or songs were played at significant events, you can try playing them in the Namaste session. It is then important to observe whether the resident's quality of attention and engagement changes and to notice the effect of the music on the other residents in the group.

If a piece of music makes someone sad, offer them comfort and support but do not immediately stop playing the music. The person may have been bottling up emotions and the music enables them to be in touch with their feelings and express them. You should think carefully about when/whether to play that piece of music again.

Lively music towards the end of the session prepares the resident for the change from the calm Namaste room to the bustle of the care home and the meal ahead. Dance music, for example, can make the transition easier and helps to ensure Namaste residents feel awake and ready for the meal.

Scenting the room

Scenting the room immediately creates the sense of somewhere 'special'. Lavender and lemon balm have been shown to reduce anxiety, depression and agitation in people with dementia and both essential oils are generally safe to use If you have access to an aroma-therapist you will be able to explore using a range of fragrances.

If you have an electric aromatherapy diffuser, you can put the oil into the container, switch it on and the room will be scented. If you do not have a diffuser, put two to three drops of essential oil into water in an ironing spray bottle and spray the room.

Also, importantly, when using aromatherapy oils, you must be aware of the safety issues involved, particularly for residents and staff. The care home should have a policy for their use and storage. Essential oils are chemically complex and should be used with caution. If there is someone in the care home with aromatherapy training, now is the time to make use of her/his skills and knowledge.

Do **NOT** use scented candles!

Nursing supplies

You will need face cloths, towels and wash bowls at hand. You will also need supplies of aqueous cream and Q-tips, disposable wipes, hand sanitiser and gloves (in case of accidents, not for routine care!).

Drinks and food treats

Drinks

Try and arrange for the kitchen to bring a trolley with a jug of water and a choice of juices, e.g. orange and cranberry. Each Namaste resident must have an individually marked cup. It may be easiest to use paper cups and a marker pen. You will also need straws. There should be 'thickener' on the trolley for anyone with swallowing difficulties. The needs of residents with swallowing difficulties must be identified in their Namaste Care personal profiles, and the right amount of thickener for a quantity of fluid must be known by the Namaste Care worker

Food treats

People with dementia often have a sweet tooth, which is a good way to increase their calorie intake. Fruit is usually well-received, especially orange slices, pineapple chunks, banana slices or strawberries in the summer. A bowl of pureed fruit for people with swallowing difficulties is important. A smoothie maker would be very beneficial. Other examples of food treats are small pieces of bread and butter and honey, marshmallows, cake and ice cream.

It is very helpful if the care home manager ensures the unit is generously staffed for the first two weeks of the Namaste Care programme. As highlighted previously, if at all possible, the manager/most senior member of staff should aim to be present at the start of the first few sessions. This sends out a message of commitment and ensures that the crucial time when residents are brought to Namaste runs smoothly. Care staff will soon adjust to the change and get the hang of the new routine.

The staff allocation for Namaste needs to be clearly marked on the duty rota so that everyone knows who will be responsible for the Namaste sessions on each shift, *including* the weekends.

The timing of your care home session will depend upon your routine, e.g. what time breakfast is served and what time lunch is ready. You should aim for the Namaste morning session to run for two hours in the morning and two hours in the afternoon.

Preparing for the Namaste Care session

The Namaste Care worker should have a break as soon as she/he has finished helping residents with breakfasts, especially if she has been working since 07.00hrs. She then prepares the Namaste space or room: this involves putting on music, scenting the room, adjusting the lighting, preparing a trolley with supplies such as face flannels, towels, massage oil and hand sanitizer, ensuring the drinks and food treats are ready. It helps the care team if the activity co-ordinator can assist with setting up the room. If Namaste is to take place in an area of the dining room, it should be screened off during the preparation so as not to disturb residents while they are eating their breakfast.

Before each session commences, it is important that the Namaste Care worker becomes familiar with the documentation and is aware of any risks associated with the residents who will be part of the programme, e.g. swallowing difficulties or the need for a diabetic diet.

When the Namaste space is ready, the Namaste Care worker will hang up the 'Welcome to Namaste Care' sign, and tell her/his colleagues that Namaste is opening.

Bringing, greeting and settling residents

Once the room is ready, *all* available staff should spend the next fifteen minutes taking all the Namaste Care residents to the Namaste room and helping to settle them comfortably.

A vital part of the care programme is for the Namaste Care worker to greet each resident by name and welcome them to the Namaste room/space. Each resident must be recognised with respect as an individual person, and a touch or hug will usually be appreciated. The person with dementia will recognise that something different is happening.

Name badge

The Namaste Care worker should introduce her/himself *every* session and should be wearing a name badge in a large font that residents can read.

Comfort

The Namaste Care worker and the care worker who brings the resident to the room make the resident comfortable in an easy chair. It often takes two people to get somebody comfortable, so the escort stays until the resident they have brought is settled. If there is no reclining chair the resident may need small pillows and perhaps a footstool for support. No one should sit in a wheelchair unless it has been individually designed for the person. After positioning the resident, the Namaste Care worker tucks the resident up with the resident's own blanket/quilt.

The blankets/quilts

Tucking a blanket over the knees often seems to be comforting and helps people feel safe. Also, for residents who are able to get up, having a blanket tucked around their knees is a cue for them to stay in the chair. Immobile residents often feel the cold and are glad of extra warmth, even in summer, but be careful the person doesn't get too hot

The blanket/quilt and pillows should be reserved for the individual, labelled and kept in a named storage bag so that there is no 'sharing' and cross-infection. The blankets should only be washed when necessary so they keep fluffy and soft.

Pain assessment

Settling the residents is the ideal time to assess them for discomfort and pain. Signs of discomfort include whether the resident flinched or moaned when they moved, whether it was difficult to position them comfortably and whether they look comfortable.

There is no point in working to engage the resident in activity if they are in pain. See Section Eight for information re pain assessment tools. If the Namaste Care worker assesses that the resident is in pain, she/he should involve the nurse to ensure the resident's pain is appropriately managed.

Food treats and drinks

Almost all residents with advanced dementia are at risk of malnutrition and dehydration. Good hydration is a key factor in keeping a person with advanced dementia healthy and enabling them to fight infection. When people are relaxed they are more inclined to eat and drink. Snacking is a good way to put on weight.

As soon as a resident has been settled, the Namaste Care worker should offer them a drink. People are more likely to eat and drink well when they are relaxed and enjoying themselves. Therefore, offering frequent drinks and tempting people with food treats throughout the session is a priority. Labelling the cups is a good way to prevent giving one person someone else's drink.

In Namaste, the care worker can take advantage of spending long periods with residents with advanced dementia by helping them to take sips and swigs of a drink and to eat the food treats whenever they are awake and receptive. People with advanced dementia tend to sleep a lot. The care worker should touch them gently and the person will usually wake up. If they do not, the care worker moves to the next person, but then may come back in 15 minutes to see if the first resident is ready for care.

Meaningful activity

Personal care

Every one of us, almost every day of our lives, washes our hands and face and brushes our hair. We usually feel better once it is done and, if we have time to notice, we enjoy the process. For people whose memory has receded far into the past, personal care will still be a constant feature of their life experience.

Going to be pampered at a spa has always been a luxury and the aim of the Namaste session is to capture that enjoyable experience. The personal care that is given in Namaste Care is different from the care that is given to residents when care workers help them with their morning hygiene needs.

Individualised care - an example from our experience[5]

One man started to pray aloud the first time he came into the Namaste room and had his feet washed. He had never prayed like this before though he had been at the care home for months, indeed he communicated very little and was often resistive to care. When the care workers told his daughter what had happened, she thought hard and remembered that foot washing had been part of the church ritual in his home country.

This resident had clean feet and well cared for nails; however, Namaste created a special atmosphere. The Namaste care worker was washing his feet gently and her intention was to soothe and comfort him rather than make him clean. The gentle foot washing without gloves triggered reminiscence and opened a spiritual window for this man.

Whenever possible the Namaste Care worker would spend time washing this resident's feet in Namaste sessions.

No gloves in Namaste

No gloves are worn during Namaste Care. There is no need to wear gloves for personal care unless there is a risk of infection or the care worker has to come into contact with body fluids. Taking gloves off allows for closer skin to skin contact between residents and care workers.

Hands and face wash with a warm face cloth

This should be a luxurious experience for the resident and enjoyed by the care worker. The aim is pleasure not cleanliness. The flannel should be hot/warm and ideally the towel should be warmed on the radiator (or with a hairdryer). If a resident has hand contractures, then soaking their hands, and making a gentle waterfall over them will often allow the muscles to relax and the hand to open up like a flower. The resident's hands and face must then be patted dry with a warm, fluffy towel.

While the Namaste Care worker is giving personal care she/he should consciously make eye contact with the resident and talk appreciatively and affirmingly, e.g. thanking the resident for the pleasure of their company, praising bright eyes, fine skin, or a lovely smile. This is also a chance to talk about the resident's past, using examples from the life story supplied by the family.

Touch

Touch is a fundamental means of human communication and is probably the most important element of the Namaste Care programme. We all need touch as part of our lifelong need to be cared for, nurtured, valued, and, most importantly, loved. However, when people are elderly or sick, they can become starved of touch.

One-to-one contact with other people is known to be the most powerful stimulus to engagement for people in the late stages of dementia[48]. Touch may involve just stroking someone's hand or hair or it may be a hand rub or massage (see therapeutic touch handout). Even something as simple as gently brushing someone's hair can be a pleasurable and meaningful experience. In our evaluation study, we found that many of our Namaste residents responded to touch by giving the care worker a hand rub in return or reaching out to them[5]. The experience of touch was mutual in that the care workers were engaging in therapeutic touch 'with' the residents not just 'for' them, and both enjoyed the experience.

Nurses and carers touch the people they care for every day, but usually while doing a task, e.g. washing and dressing. In Namaste Care touch is used purposefully to connect and communicate with the resident and to express affection and reassurance. Therapeutic touch has been shown to *improve nutritional intake*, relieve anxiety and agitation and promote calming and cherishing effects on people with dementia[49].

If a resident does not like touch then this must be respected. However, it is important to try and find other ways to communicate with that person.

So, when everyone has been greeted and settled and has had a 'Namaste wash', a hand massage may be the best form of meaningful activity for many people.

Life-like dolls

After a living person, baby or animal, the next most powerful stimulus with which to engage a person with dementia is a simulated person, baby or animal. This explains the power of life-like dolls to transform the life of people with dementia. If a woman or a man forms an attachment with a life-like doll, then this may allay their anxieties and give them a focus for their love and longing to give care rather than just receive care; it may also give them a sense of control.

As with every activity, knowing the person's life story is crucial. For example, a person may not have had children, may have lost a baby or never been able to have a child, and therefore a baby might have negative associations.

Giving a doll to an adult is potentially problematic. It can be seen as infantilising or patronising the person. It would be unwise to try 'doll therapy' without discussing it first with the family. It may also help to give the family written information about doll therapy[50].

If the family chooses to explore whether their relative will benefit from a doll (or a dog or cat if that seems more appropriate), then a doll should be introduced to the resident. There should be no attempt to trick the person into believing it is a real baby. The doll should NOT be one that cries or wets itself! Ideally, the doll should have a slight smile, and eyes that close when it is laid flat and open when it sits up. The doll should be introduced as a doll, or perhaps left beside the resident so they can choose to interact with it or not. If the person chooses to believe the doll is life-like, then this comes from their own imagination, or perhaps their need.

N.B. It is important to handle the doll respectfully, e.g. not holding it by the feet and swinging it onto the top of the cupboard, as this can cause distress to the person who is engaging with it

Similarly, life-like cats and dogs can be a great source of comfort and pleasure to people who have enjoyed animals all their lives. The same precautions should be followed for life-like animals as for life-like dolls. Introducing a life-like pet should be discussed with relatives and there should be no attempt to deceive the resident.

If a resident has a doll or life-like animal they enjoy, this should be given to them as soon as they arrive in the Namaste session. It may be that they get so much pleasure from the doll/animal that it stays with them and is not just used in the Namaste session. If however the doll or animal does not accompany them at all times, it should be stored in their own bag with their blanket/pillows.

Other activities to stimulate Namaste Care residents

After personal care and a hand massage residents with advanced dementia may doze off. The morning rush, being washed and dressed and having breakfast can be tiring for all the residents. Therefore, a nap is natural and beneficial. Residents who are agitated and find Namaste Care relaxing may sleep, which will provide them with relief and respite from their agitation.

However, a room full of sleeping residents is *not* the aim of Namaste Care. The Namaste Care worker should aim to engage people's interest and attention with stimulating activities. For some this will just be enabling them to experience a pleasant/interesting sensation.

When introducing any activity, taking time to explain and demonstrate to the resident what the activity is about, is more likely to result in a positive response from the resident.

Rummage box

Rummage boxes containing a collection of materials of different textures (e.g. silk, velvet, tweed, bubble wrap) can be brought to the resident who can explore and experience the various textures. If the resident is enjoying touching the materials, they may like to stroke their face and hands with them. If the resident is not interested, the rummage box should be taken elsewhere.

Musical instruments

The Namaste Care worker can show the resident a tambourine or rainmaker instrument, demonstrate how it works and use smiles and nods to show appreciation and enjoyment when it is played. Try to help them focus their attention on the instrument. If they are not interested give up, but if they like it leave it with them. You may be able to support them to use the instrument by moving your hands with their hands.

Memory box

A resident's personal memory box provides an opportunity for the Namaste Care worker to sit with the resident and talk about what is contained within it, reminiscing about the pas. Handling familiar objects can sometimes trigger reminiscence.

Reading aloud

Poetry is like music; it lingers in the brain and is often a powerful emotional experience. Reading aloud may have been a familiar activity for the resident in the past, and many older people learned poems by heart at school, and nursery rhymes at home. Sometimes it can be hard to keep up a flow of conversation when the person with dementia is unable to answer. Reading aloud enables the care worker to keep up a flow of language which may be stimulating or soothing for the person.

Range of movement

Gentle movement to music is fun (dancing!), and creates a connection between the resident and the care worker. It is also good for the resident's circulation, suppleness and mobility.

Getting active before lunch

Twenty minutes before residents have to leave Namaste Care in order to be made ready for lunch, the Namaste Care worker needs to make sure that everyone is awake and alert for their meal.

Play lighter, brighter music

This is a good time to play residents' favourite tunes, such as dance music or show tunes from the 1940s and 1950s. Choose something rousing and cheerful.

Initiate 'fun' activities

Blow bubbles, toss a balloon, wear a silly hat, sing and dance.

Bring the world into the room

Seasonal flowers are a perfect way to try and orientate people to the time of year. For example, a basin of grass that has been recently mown or autumn leaves or snow can all help to orientate the person to the time of year. Passing around a small soft toy bird that chirps when pressed can bring pleasure (from the Royal Society for the Protection of Birds www.rspb.org.uk).

Closing the session

At the close of the session other care workers will come to take residents away. The Namaste Care worker must say goodbye to each resident in turn, using their name, and thanking them for coming to the Namaste session.

The Namaste Care worker must then complete the attendance form and the Namaste activities record for each resident at the session. Anything remarkable may be written in the diary, or in the resident's notes. The Namaste Care worker will tidy up and get ready for the afternoon session before joining the rest of the care staff to help with lunch.

The afternoon session

The timing of the afternoon session depends upon the care home routine. Some care homes reopen the Namaste room at 2 pm, while others like to start the afternoon session at 3 pm. Some residents need to rest on the bed after lunch whereas others need to lie on the bed rather than sit because of skin problems. If residents are sleepy in the afternoon, then at least in Namaste, when they wake, there are people around them.

The afternoon session follows a similar pattern to the morning session, but with different activities. For example, foot soaking and foot rubs can replace the hand massage and, if there is time, nail care and/or hair care can be performed.

The afternoon may also be a time for a nature DVD or an old musical. The session will close with a lively goodbye to each individual. A summary of the Namaste Care day is outlined below.

Visitors

Other residents may 'drop in' and visit the Namaste session. All should be welcomed and if they are willing given a Namaste experience. Any resident may benefit from the peaceful atmosphere and the sensory approach, especially if they are anxious.

Family visitors/friends are always welcome in the Namaste room, but if they prefer to visit their relative somewhere else in the care home, then that should be arranged. Family visitors usually enjoy the care programme and meeting other relatives, and they should all be encouraged to join in with the activities. They will quickly sense that the atmosphere in Namaste is peaceful and calm and will understand the need to talk quietly.

Other members of the care staff are also welcome in the Namaste room and should be encouraged to participate in the programme's activities. They must respect the atmosphere in the room and the intention 'to honour the spirit within' each person in the room, i.e. resident, staff or relative.

Protecting the Namaste space

The manager's authority is needed to protect the Namaste space. Namaste needs a calm and peaceful atmosphere, very different from the rest of the care home where everyone is rushing around trying to get things done. There should be no avoidable interruptions to Namaste, care workers and nurses should be respectful of the care programme and try not to disturb the group unnecessarily. If staff need to go in without staying to join the group, they should try to keep their voices down and not to disrupt the atmosphere.

Box 6.1 gives an overview of a morning and an afternoon Namaste session. These are suggestions for a typical day. It is always important to individualise the schedule and be flexible. Seasonal changes, staff changes and resident changes must be respected and the schedule reorganised.

Box 7.2: Morning Namaste Care session

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
- Set up aromatherapy diffuser with lavender
- Play soft music & show nature videos

Welcome to Namaste

- Each person is touched as they come into the room
- Each person is placed in a comfortable lounge chair
- A quilt or blanket is tucked around them
- Extra pillows or towels can be used to help with positioning
- Each person is assessed for pain/discomfort

Morning activities

- Hands are washed and lotion applied to hands and arms
- Face is washed and face cream is applied
- Hair is brushed
- Take into account personal likes, e.g. lipstick, hair ornaments, etc.
- Hands are massaged

Give them a friend! As life-like as possible, not ‘childish’

- Dolls, large dogs, kittens, rabbits, etc.

Nutrition/Hydration

- Constantly offer drinks such as water/juices
- Offer ice cream, yoghurt, smoothies, fruits, chocolate – things you would like to eat!

As time permits

- Shaving the men
- Offering ice cream, puddings, etc.

Waking up for lunch (twenty minutes before lunch)

- Turn up the lights
- Change to lively music
- Fun activity such as blowing bubbles, tossing a ball/balloon, etc.
- Talk about the day
- Use bird sounds
- Take scents to each person to remind them of the weather, i.e. grass, flowers

Afternoon session

Activities

- 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 or nail care

Namaste closes

- Residents thanked for coming to Namaste
- Room tidied and prepared for the next day

Namaste in the resident’s room

When a resident is unwell

Namaste can be taken to people in their own rooms when they are unable to come to the Namaste session, e.g. if they are unwell. A trolley can go from room to room with a portable CD player, some moisturising cream and, for example, a singing bird to engage the resident or whatever is known to please them.

If a resident is distressed

Namaste Care will often soothe someone who is agitated or distressed. If a person is not coping with being with other people in the Namaste session, then trying music, fragrance and therapeutic touch in their own room may enable them to relax and become calm. It may be possible to accustom the person to Namaste Care and gradually introduce them to the group.

When a resident is dying

When a resident is dying, the Namaste Care worker can bring the music and fragrance they enjoyed in Namaste to their room and all personal care can be given as a gentle, pleasurable experience. Family can be shown how to do hand massage and mouth care, if that is appropriate, because involvement in physical care is often beneficial to family/friends. Religious items may be comforting to the resident as well as the families. Religious music that was part of whatever church they belonged to might be appropriate. When someone is dying, ‘honouring the spirit within’ is the guiding principle of their care

After-death care

‘Honouring the spirit within’ continues beyond the moment of death. Care workers will provide the same respectful, loving care for the body of the person who has died as they did for the living person. Ideally, when the person’s body is finally taken from the care home, a care worker will walk with them out of the home to the funeral director’s vehicle, so that the person is accompanied until they finally leave the care home.

Communicating news of the death

Placing a framed photograph of the person who has dies in the hallway is a respectful way of communicating news of the death to visitors and staff who have been off duty. Of course, you must seek the permission of the family for this.

After death reflection

The death of a care home resident is often felt deeply by the care staff, and following the death of a Namaste resident there should be an after death meeting/debrief. This is an opportunity to reflect on the life of the person who has died and the feelings of loss staff may be experiencing. It is also an opportunity to reflect on how the death was managed. What went well? What didn’t go so well? What could be done differently another time? What could be learned? And what could be changed to improve practice?

Section Eight

Achieving comfort and pleasure

Section aims:

- To explain the role of pain recognition and management in the Namaste Care programme
    - To describe the use of a scale for assessing pain in people who are unable to communicate their pain
- To highlight the need for awareness of depression in people with advanced dementia
- To describe the use of a scale for assessing depression in people with advanced dementia who are unable to communicate clearly.

If someone is in pain then they cannot be comfortable! Quality of life is almost impossible to achieve if someone is in distress. Therefore, assessing and managing pain and distress is a necessary part of the Namaste Care programme.

This section deals with pain and depression, which are two common reasons for people with dementia to feel uncomfortable and to be unable to enjoy pleasurable activities. However, if someone with dementia appears distressed and agitated, it is also important to remember other simple causes of physical distress such as being too hot or constipated.

Pain

Untreated pain can have a major impact on the quality of life of people with dementia[51]. Common causes of pain in people with dementia include arthritis, neuropathies and pressure ulcers[52].

Assessing symptoms is particularly difficult in people with advanced dementia who are unable to communicate their distress verbally. There is evidence[24] that pain is often neglected in people with dementia because the person often does not ask for pain relief, and because they may express their pain in unusual ways, e.g. through agitation or withdrawal. As well as these challenges, there is a misconception that people with dementia do not experience pain in the same way as people without dementia[9,11,24,53,55.].

Effective management of pain can lead to significant improvement in symptoms of agitation and/or aggression in residents with dementia. It should not be assumed that the behavioural and psychological symptoms of agitated residents are related exclusively to their dementia[55].

The Namaste Care workers, who spend hours at a time with residents with advanced dementia, are in the perfect position to observe for signs and symptoms indicating pain and distress.

Assessment of pain

It has been found that many care workers do not know how to assess pain in someone with advanced dementia[55,56]. It is best practice to use pain-assessment scales as part of an overall pain-management strategy for residents within the care home. Using a pain assessment scale has been shown to help care workers detect pain and increases recognition of pain compared with not using a pain assessment scale.

There are several pain-assessment scales that can be used for people with advanced dementia who are unable to communicate their pain. No pain-assessment scale is perfect. You should introduce the one that you feel would work best for your care workers. Including staff in the decision-making process will help to ensure that they are committed to its use.

Examples of well-constructed, reliable pain-assessment scales include the Pain Assessment in Advanced Dementia Scale (PAINAD)[57], the Doloplus-2[58], and the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)[59] , and the Abbey Pain Scale[60]. The assessment scales usually require care workers to assess residents during movement and when carrying out personal care or procedures, because these are the times when residents tend to experience more pain.

An overview of the Pain Assessment in Advanced Dementia Scale (PAINAD) is provided below.

Pain Assessment in Advanced Dementia Scale (PAINAD)[57]
PAINAD is quick and simple to use and helps to educate staff about the types of behaviour that may indicate that residents are in pain.

PAINAD has been developed for use with people who are unable to use self-report methods to describe pain, e.g. people who are cognitively impaired and unable to communicate. It covers five behavioural items (see Box 8.1), which are each assessed and scored during periods of activity, e.g. when repositioning, walking or transferring. The behavioural items are scored from 0–3 and scores for each of the five items are added together for a total numerical score.

Box 8.1: The five behavioural indicators of pain in PAINAD[57]
Breathing (e.g. breathing normally, occasional laboured breathing or short periods of hyperventilation, noisy laboured breathing or long periods of hyperventilation)
Negative vocalisation (e.g. none, occasional moans/groans, speech with a negative or disapproving quality, repeated troubled calling out, loud moaning or groaning, crying)
Facial expression (e.g. smiling or inexpressive, sad, frightened, frowning, facial grimace)
Body language (e.g. relaxed, tense, distressed, pacing, fidgeting, rigid, fists clenched, knees pulled up, striking out, pulling or pushing away)
Consolability (e.g. no need to console, distracted by voice or touch, unable to console, distract or reassure)

Pain scales need to be used as part of an ongoing assessment. If a resident is identified as having pain they need to have a care plan drawn up to manage the pain. The care plan must include re-assessment with the pain scale after any intervention to determine whether the pain has responded. If the intervention is not effective then the resident, and the management plan, need to be reviewed. Further assessment and intervention is needed until the resident appears comfortable; this may involve referral to the GP, the specialist palliative care team, or the chronic pain team.

Non drug treatments of pain should be considered first, e.g. warmth or cold to reduce pain in the joints. The administration of a simple drug, such as paracetamol, is often all that is required to reduce the pain-related distress of people with dementia[52,54].

Using the pain-assessment scale is useful for tracking changes in the resident's behaviour and in enabling the care staff and other health care professionals to communicate meaningfully about the pain.

The Namaste Care worker must be alert for signs of pain and discomfort in residents while they are made comfortable at the beginning of the session, and remain watchful for pain-related behaviours during the session. Using the pain scale regularly will help all care workers become familiar with signs of pain.

N.B. If pain persists, despite the use of analgesia and comfort measures, a comprehensive assessment of all aspects of the resident's condition and treatment needs to be undertaken. The resident should be monitored closely over a 24-hour period and, if there is no improvement, the GP should be told about the pain scores and asked to assess the resident[55,61].

Depression

Depression is a common condition in people with dementia, particularly vascular dementia[62,63]. According to the Alzheimer's Society[26], people with dementia living in care homes are at particular risk of depression as a result of unmet needs, including lack of daytime activities and company.

Depression can be difficult to assess, especially if residents have moderate to advanced dementia and have difficulties communicating[63]. Therefore, carers need to become more aware of the causes and signs and symptoms of depression. There are many possible causes of depression in both people with and without dementia[63]. These include:

- Genetic predisposition to depression
- Past history of depression.
- Effects of certain illnesses (i.e. there is an increased risk of dementia in Parkinson's Disease)
- Side-effects of medication
- Bereavement
- Lack of activities, leading to feelings of boredom and aimlessness
- Lack of social support or social isolation
- Traumatic or upsetting events

Depression affects people in different ways and to different degrees. Some of the more common signs and symptoms of depression seen in older people include the following[62,63]:

- Loss of appetite and weight loss
- Tiredness or loss of energy
- Aches and pains that appear to have no physical cause
- Sleep disturbance (e.g. early morning wakening)
- Difficulty concentrating, understanding, remembering or making simple decisions
- Loss of engagement, interest or pleasure in activities that were once enjoyed
- Feelings of isolation
- Deterioration in function
- A change in mood (i.e. more irritable or distressed)
- Increased anxiety, restlessness and agitation
- Feelings of low self-esteem, worthlessness or undue guilt
- Thoughts of death and suicide
- Agitation.

Some of these symptoms are very similar to some of the symptoms experienced by people with dementia, which increases the difficulty care staff can find in recognising clinical depression in their residents with dementia.

However, if care staff observe that a person with dementia seems to find it even harder than usual to remember things, or is even more withdrawn, or becomes more anxious or irritable particularly in the morning, then they should consider the possibility of depression, once they have ruled out a physical cause such as infection or the side effects of drugs. Depression may also worsen behavioural symptoms in people with dementia, presenting as irritability, problems sleeping or refusal to eat. In the later stages of dementia, depression tends to show itself in the form of depressive 'signs', such as early morning waking, reduced social engagement and weight loss[62,63,65].

If such signs and symptoms are observed, then the care home needs to seek advice from an appropriate health care professional. For residents with advanced dementia, completing a depression-assessment tool can help care home staff conduct a more formal assessment and provide tangible evidence on which to base discussion about their concerns with GPs or other health care professionals[56].

The Cornell Scale for Depression in Dementia (CSDD)[64] screens for signs and symptoms of depression in people with advanced dementia (see Box 8.2). The assessment relates to possible symptoms of depression over the previous week and should be completed by carers/nurses who know the resident well. The scale takes approximately twenty minutes to administer. The possible indicators of depression in people with dementia, as assessed by the CSDD, are as follows:

Box 8.2: Possible indicators of depression in people with dementia as assessed by the Cornell Scale for Depression in Dementia[64]

Mood-related signs

- Anxiety (e.g. anxious expression, ruminations, worrying)
- Sadness (e.g. sad expression, sad voice, tearfulness)
- Lack of reactivity to pleasant events (e.g. inability to enjoy, or lack of interest in, pleasant events or interactions with family/friends)
- Irritability (e.g. easily annoyed, short tempered)

Behavioural disturbance

- Agitation (e.g. restlessness, hand wringing, hair pulling, lip biting)
- Retardation (e.g. slow movements, slow speech, slow reactions)
- Acute loss of interest (e.g. less involved in, or stopped doing, usual activities and hobbies during the previous week)

Physical signs

- Appetite loss (e.g. eating less than usual)
- Weight loss (e.g. in the past month)
- Lack of energy unrelated to physical problems (e.g. tires easily, unable to sustain activities)
- Multiple physical complaints (e.g. indigestion, constipation, diarrhoea, stomach cramps, belching, joint pain, backaches, muscle aches, frequent urination, sweating, headaches, heart palpitations, hyperventilation. N.B. These symptoms should be in excess of what is normal for the person and not be side-effects of medications or related to a gastrointestinal condition)

Cyclic functions

- Diurnal variation of mood (e.g. symptoms are worse in the morning).
- Difficulty falling asleep (e.g. problems falling asleep at night)
- Multiple awakenings during sleep (e.g. waking up in the middle of the night not related to going to the bathroom and then going back to sleep)
- Early-morning awakenings (e.g. earlier than usual pattern)

Ideational disturbance

- Suicide (e.g. feels life is not worth living, has suicidal wishes or makes suicide attempt)

- Self-depreciation (e.g. self-blame, poor self-esteem, feelings of failure)
- Pessimism (e.g. anticipates the worst)
- Mood congruent delusions (e.g. delusions of poverty, illness, or loss, perceives illness as punishment)

The usual treatment for depression is psychological therapies in combination with antidepressants.

Taking part in psychological therapies may be difficult for people with more advanced dementia. However, other strategies include increasing the amount of time spent participating in activities that the person enjoys and planning regular activities with other people, because social isolation can make depression worse. It has been found that residents with dementia express happiness over seven times more often during structured recreational time than during unstructured time[66].

The Namaste Care programme can help to both reduce the risk of residents with advanced dementia developing depression and manage depression in residents who have depression.

Section Nine

Developing, evaluating and sustaining Namaste Care

Section aims:

- To suggest ways to develop and sustain the Namaste Care programme within your care home
- To describe the challenges to the Namaste Care programme you may meet in your care home and some ways of overcoming them
- To suggest how best to evaluate the effects of the Namaste Care programme on your residents with advanced dementia.

‘Growing’ the Namaste Care programme within your care home

Daily support and supervision

The overall aim of this toolkit is to help you make Namaste Care a key part of daily routine at the care home. The manager or lead nurse should visit the Namaste sessions daily to ensure that residents are enjoying the session and to offer the Namaste Care worker support. The manager/nurse should ensure that residents are comfortably seated, the Namaste Care worker is wearing the large font name badge, music is playing, and the room looks attractive and colourful and is scented. The Namaste Care Checklist will help you.

The manager/nurse should also check that the Namaste Care worker is busy and occupied with residents, there is hand sanitiser in the room, residents have their possessions stored individually to prevent cross-infection, and the food treats are covered when they are not being used.

Weekly meetings

While the Namaste Care programme is being introduced, weekly meetings with the Namaste core team will help the manager and the Namaste Champions succeed. In these meetings, everybody needs to report on progress and any problems that have arisen. The meeting should focus on what is working well, what is not working well and how things can be improved. These meetings are encouraging and motivating for staff. It is especially important to tackle any concerns from care home team members who are opposed to changing practice and introducing Namaste.

Plans need to be made for the following week. Responsibilities for different aspects of the care programme should be shared out and reviewed at the next week’s meeting. The team needs to work out strategies for managing some of the challenges (see below) that arise in the early days of introducing the care programme. The meetings are also a time to reflect on the impact of the Namaste Care programme on individual residents and the care home as a whole. It is worthwhile asking family and visiting professionals for feedback.

The weekly meetings should continue for as long as the team finds them useful; then they can become fortnightly and then monthly.

Monthly Namaste checklists and monthly Namaste meetings

Before the monthly meeting, the nurse manager should go through the Namaste checklist, to ensure that the care programme is on course. The boxes that are not ticked need to be discussed at the monthly meeting, sorted out and prioritised. For example, if electric equipment needs to be checked, that must be a priority, but if there is no DVD player, that is something for long-term planning.

After the programme has started, it may be helpful to focus on different elements of Namaste (see the introduction to this toolkit) one at a time. For example, you could focus on comfort and look at how comfortable you can make each resident. This might involve looking at seating, or finding suitable cushions to support a person's head, or a contractured limb. You might think about loosening tight clothing or removing shoes during Namaste. Warming towels can enhance the sense of comfort after a wash or a massage. Pain assessment will also be considered under this topic, and this may involve a teaching session for care workers on using a pain assessment scale.

Once Namaste is well established, monthly meetings will primarily be about developing the care programme for individual residents, extending the range of activities undertaken and making the programme more flexible.

Reflecting with the care staff

The manager needs to keep the Namaste Care programme at the top of the agenda for all team meetings in the first few months and must support staff to reflect on changes in practice. Reflecting on changes in practice is an important part of creating change. It is important for staff to see and feel the benefits for their residents. Therefore, every member of staff should spend at least twenty minutes in a Namaste session during the first month of implementation.

It is important to address any concerns raised by staff as soon as possible before misconceptions and rumours arise. Sceptical staff are often those who have the least understanding of Namaste Care, so it is especially important to ensure they attend a session and learn from experience.

It is *essential* to make sure the success stories about change in individual residents are passed on to all members of staff within the care home.

Writing a mission statement

Writing a mission statement for the Namaste Care programme (see Boxes 9.1; 9.2) involves asking staff to put their observations, ideas and beliefs about the benefits of Namaste Care into words. The exercise builds on reflective work and helps to embed the change. The process of recognizing and articulating the positive changes seen with

Namaste helps everyone to value the care programme. The mission statement should capture what staff value in the Namaste Care programme.

At a team meeting it is important to inform all the staff that you are planning to write a mission statement for the Namaste Care programme in your care home. You could show them the example of a Namaste Care mission statement in Joyce Simard's book[3], as well as the two examples below that were written by UK care homes that have already implemented Namaste Care.

You could start by asking everyone for their impressions of Namaste Care and writing down what they say on a flip chart. Copy down the words they use and keep them. Put up a notice in the office and ask everyone to write down what they like and value about Namaste.

Sit down with the Namaste core team and start to put together a mission statement using the thoughts and words of your own team. Take this draft back to the whole team for their comments and further contributions. Then go back to the core team and repeat the process until you have a mission statement that everyone can sign up to and of which they feel proud.

The mission statement is especially useful for informing new staff, relatives and visitors about the Namaste Care programme and explaining the benefits for residents, staff and relatives.

You could frame the mission statement and hang it in the Namaste room.

Box 9.1: Mission statement for the Namaste Care programme at Amberley Lodge Nursing Home

At Amberley Lodge we embrace Namaste and what it stands for
Namaste Care is a deep expression of respect and dignity that recognises the quality of people with advance dementia
It is a glowing light of compassion that honours the spirit within
We believe that the spirit in each individual lives regardless of physical and cognitive status
Our aim is to:

- Treat every individual in a unique way, recognising their individual differences, and
- Nurture each person through loving touch and meaningful activities in the presence of others

We focus on comfort, wellbeing and quality of life
We believe Namaste Care can be given anywhere in the home
We do everything in our power to make their passing gentle and peaceful at the time of end of life and surrounded by people who care

Box 9.2: Mission statement for the Namaste Care programme at Lakeside Nursing Home

At Lakeside Nursing Home we recognise that our residents with advanced dementia are all people like ourselves, and we want to give them the care we would want in their situation. The Namaste Care programme enables us to reach out to each other through loving touch, meaningful activities and the presence of others. We want our residents to feel at home and to feel that they are loved and respected. We want them to be comfortable, calm and peaceful and we will try to make pleasure and enjoyment part of their everyday experience.

Working together as a team means that residents in the Namaste Care programme receive excellent health care with a holistic approach focusing on comfort and quality of life. We also believe that last days are precious and the team will make every effort to ensure that when our residents die their passing is peaceful and dignified and that they are surrounded by people who care.

Challenges

Staff shortages

Staff shortages are the most common challenge to the Namaste Care programme. When somebody is off sick or has had to go on escort duty unexpectedly, staff may say, ‘We can’t do Namaste because of the staff shortage’. Nobody says, ‘We won’t have lunch because there’s a staff shortage’, or ‘We won’t give out medications because there’s a staff shortage’. People with advanced dementia need emotional interaction and sensory stimulation *every* day – Namaste meets social, emotional and sensory needs.

The situation can be overcome by the determination of the staff to involve themselves in the Namaste sessions. However, staff have to believe in the value of the sessions. If there is lack of commitment then Namaste is not going to happen.

Strategy for coping with staff shortages

- Ask members of the wider care home team (e.g. the manager or administrative staff) to step in for short periods, e.g. twenty minutes at a time, to release the Namaste Care worker if she/he is desperately needed somewhere else for a short time
- If the person who is filling in is not a member of the care team they can provide a presence in the Namaste room and there is no reason why they cannot put hand lotion on someone’s hand, brush hair, change the music and chat with residents
- Consider *increasing* the number of residents in the Namaste session so that more people are looked after in the group.

The psycho-social and spiritual needs of residents with advanced dementia are as important as their physical needs, and keeping the Namaste Care programme going should be seen as a priority.

Challenge

Residents with advanced dementia who don't settle in a Namaste Care session

Inevitably there will be the occasional resident who does not settle when they are first taken to the Namaste sessions. Some people are too agitated, distressed or anxious to sit down, even for a moment, others may be noisy and disruptive so that they destroy everyone else's peace.

Strategy

- Try to bring these residents to Namaste sessions. You will be surprised at the response of those residents who your staff will tell you will cause issues in the Namaste room, or who staff feel will not like it.
- The Namaste Champion should try to find activities with which to engage the person by referring to their life story and asking advice from the family and care workers.
- If someone is disruptive for ten minutes then they should be taken out of the Namaste room so the session is not ruined for the others.
- The Namaste Champion should find a time to do one-to-one work with this person in their own room.
- Just because someone did not appear to like Namaste the first time, does not mean they should not try it again.
- Often people become gradually accustomed to Namaste and build up the length of time they spend in the care programme.

Challenge

Involving families from the outset

Families and friends can be a great source of support for Namaste. Family visitors usually enjoy coming in to the Namaste room, and the praise they give to staff when they realize what they are doing is beneficial for staff morale. However, if families/friends are not involved with the care programme from the outset then they may not let their loved ones go into the Namaste sessions. This is a waste of this invaluable resource.

Challenge

Using Namaste family meetings to the full

In the family meetings, sometimes staff only explain about the Namaste sessions and do not use the opportunity to help family/friends understand that the person they love has advanced dementia, and therefore has limited life expectancy. Failure to understand that a person with advanced dementia is in the last stages of their life can lead to a series of crisis decisions for the family when the person's condition inevitably deteriorates. Family misunderstanding of the situation often leads to the person being admitted inappropriately to hospital.

When family members have had time to reflect, they are often unhappy that they did not fully understand the situation and wish they had been given the relevant information about end of life care

Challenge

Not individualising activities

The aim of Namaste is always to enrich quality of life for residents with advanced dementia. However, if the care given is not based on the individual's own specific needs and does not reflect their unique life history, then it is not based in a truly person-centred approach and is less likely to improve the person's quality of life. For example, someone might respond with great pleasure to the perfume she used as a young woman, but have a very limited response to other fragrances.

Challenge

Afternoon Namaste sessions

Care homes appear to have more difficulty establishing the Namaste Care programme in the afternoons than in the mornings. The reasons for this are varied. For example, staff are more tired after the morning work, lunch breaks need to be covered in the afternoon, a number of residents may need to rest on the bed for a period in the afternoon because they have skin problems or because they are unwell or very frail, and often residents are sleepy in the afternoons.

However, to be fully effective for residents with advanced dementia, the gentle relaxation and stimulation of Namaste must occupy a substantial part of their day. Residents with dementia are more likely to be agitated towards evening, and the Namaste session creates a welcome calm.

Strategy

- Adapt the timing of the afternoon Namaste session to suit your care home routine
- For those who are unable to come to the Namaste session, take Namaste (music, touch, scents, tastes, colour) to the residents' rooms
- The manager/shift leader needs to visit each session in the afternoon until the routine embeds. Once Namaste is embedded in the afternoon routine, care staff will enjoy the afternoon sessions as much as the morning sessions. Also, as residents are grouped together and are relaxed, the afternoon sessions do not increase the workload
- Remember that even if residents are sleepy, if they fall asleep in Namaste there will be someone with them when they wake
- Challenge staff to create a different experience in the afternoons, perhaps working on life stories and/or reading aloud to the whole group. Creating a

different experience of personal care from the morning, e.g. manicures, or foot washing and moisturizing feet and legs.

Evaluating the Namaste Care programme in your care home

How do you know that you are 'doing' Namaste properly? And how do you know whether the Namaste Care programme has improved the care you give to people with advanced dementia?

Standards for Namaste Care

Joyce Simard has developed standards for the Namaste Care programme so that you can check the quality of your care programme[3] (see Box 9.3).

Box 9.3: Standards for Namaste Care[3]

- Namaste care is offered seven days a week
- Namaste Care is offered at least four hours a day
- Namaste Care takes place in a special environment: music, scent of lavender or other appropriate scent, attractive, homely space
- Namaste residents are assessed for comfort/pain using a recognised scale and a means of communication between the Namaste Care workers and nurses must be established
- Residents who receive psycho-active medication are assessed by nursing staff for changes in behaviour at least twice a month and medication is reviewed with the doctor
- Activities of daily living are offered as meaningful activity
- After-death care
- After-death reflection: a reflective debrief is held within a week of a Namaste resident's death

Measurable outcomes

If you are meeting the above standards it is very likely that your care home is now achieving a higher quality of care, and providing a higher quality of life for your residents with advanced dementia.

It is important that you can demonstrate the improvement and 'show case' your achievement to all concerned:

- Senior management, the company directors, the owner
- Relatives at the care home
- Care Quality Commission and other regulators
- Social services
- Professional visitors
- Prospective clients/families.

It is also important not to make extra work. Much of the information you collect already (see Box 9.4) can be useful and you could easily use this to audit some of the effects of Namaste. Remember that when you start an audit you must have baseline data, so you will need to start collecting information before you begin the Namaste Care programme, in order to detect any changes when you next collect the data.

You could also audit changes in medication, e.g. decreases in anti-psychotics and sedatives such as benzodiazepines and hypnotics.

Box 9.4: Examples of information you may already collect
Regular weight measurements: Look for whether the weight of Namaste residents stabilises or even improves, but remember that unsustainable weight loss is a feature of end-stage dementia
Information about infections in the care home: Look for a reduction in chest infections and urinary tract infections among Namaste residents. This may be a result of increased fluid intake and because happier people are often healthier
Records of falls: This may not relate directly to Namaste residents, but there may be a reduction in falls because the care home is calmer, especially if you have continuous group activities for people with moderate to severe dementia
Record of 'incidents' involving residents: This again may reflect a calmer atmosphere rippling out from the Namaste Care programme
Pain-assessment record: If you are assessing pain regularly you will probably pick up and treat more pain than previously
Pressure ulcers: may be reduced with increased hydration and nutrition.

Quality of life

You may want to measure quality of life specifically. This is especially difficult to measure in people who are unable to describe their own quality of life. There are a number of scales for assessing quality of life in people with advanced dementia. Examples include: DEMQOL (Dementia Quality of Life)[67]; QOL-AD (Quality of Life-AD)[68,69]; QUALID (The Quality of Life in Late-Stage Dementia Scale)[70]; and Dementia Care Mapping (DCM)[71].

None of these tools are perfect. They all have advantages and disadvantages. However, one local care home has reported to us that it finds QUALID[70] very user-friendly and useful. The QUALID has eleven items to score.

Sustaining the Namaste Care programme

If you can demonstrate that Namaste Care has a positive impact on the quality of care and the quality of life of your residents with advanced dementia, then you will have strong reasons to work hard to sustain the Namaste Care programme in your care home.

Work is needed to sustain any initiative in the care home setting because of the pressures associated with working in a care home. The monthly meetings of the core team must address continued motivation. Staff should be praised for their Namaste work. There should also be encouragement to keep improving the care given in the Namaste sessions, and it is important that the changes and discoveries from the session are fed back to the GP and to the relatives.

Presenting your Namaste Care programme

Staff turnover is an important obstacle to sustaining the Namaste Care programme. Therefore, it is important that all new staff, especially care workers and nurses, receive education with regard to Namaste. The Namaste core team needs to create a teaching session, which could use a PowerPoint presentation or be based around a book of photographs, for new staff, volunteers and visitors or for showing off your work at a conference.

Just like writing the mission statement, creating the presentation helps the team to reflect on what is most important in the care programme, and why it is valuable for residents, care staff and families.

Volunteers

If the care home has any volunteers, the Namaste Care programme offers a great opportunity for them to contribute to a rewarding aspect of care home life. Harnessing the creative skills and energies of your volunteers will improve the quality of life of residents and care workers, and support the continuation of the Namaste Care programme.

Fundraising for your Namaste room

It can be fun to have more money to spend on the Namaste room. One way of doing this is through fundraising. Visitors are usually happy to buy a raffle ticket for a good cause. Relatives are often only too glad to learn of something useful, e.g. essential oils, that they can give their relative for Christmas and birthdays. One son rushed out after a family meeting and bought his mother a bottle of her favourite perfume!

Namaste

The main aim of the Namaste Care programme is to provide meaningful activity, comfort and pleasurable experiences for people with advanced dementia. However, it is also important to remember that the guiding principle of Namaste Care is *to honour the spirit within* each person. This means everyone — your residents with advanced dementia and yourself, and everyone who lives and works in the care home.

Feel proud of what you are trying to do and what you have achieved. Encourage all members of the team to value and respect colleagues who are working to the same ends. When people are doing a good job, praise them. Namaste should bring fun and energy into the work environment. However, it can only be successful if teamwork is good and every team member is respectful of one another.

Once care staff have learnt from their experiences in the Namaste sessions, they will take new skills into their work outside Namaste. Care staff and nurses will find that using loving touch and a slow gentle approach to every contact with residents makes life much easier for everyone. Families will appreciate the efforts made for their loved ones. The calm of the Namaste room should start to flow under the door and into every part of the care home.

In the downloadable resources listed below the toolkit you will find ‘tools’, e.g. the Namaste Care Programme Checklist, suggestions for documentation which you can adapt, template letters etc., which can help you set up the Namaste Care programme in your care home.

You can read accounts of care homes that have successfully set up a Namaste Care programme in the articles referenced below.

Namaste!

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