THE NAMASTE CARE PROGRAMME - ENABLING QUALITY OF LIFE CARE FOR PEOPLE WITH ADVANCED DEMENTIA

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OVERVIEW OF SESSION

- Discussion in pairs + feedback:
 - □ Your experience of people with advanced dementia
- Background to end-stage dementia & its challenges
- The Namaste Care programme
- Implementing & evaluating the programme

DEMENTIA PROGRESSION: FAST STAGING

- 1 No functional decline
- 2 Personal awareness of some functional decline.
- 3 Noticeable deficits in demanding job situations.
- 4 Requires assistance in complicated tasks eg finances, planning dinner for guests etc
- 5a Cannot recall address, tel no, family members' names etc
- 5b Frequently some disorientation to time and place
- 5c Cannot do serial 4s from 40, or serial 2s from 20.
- 5d Retains many major facts re self
- 5e Knows own name
- 5f No assistance toileting, eating but may need assistance choosing proper attire
- 6a Difficulty putting clothes on properly without assistance
- 6b Unable to bathe properly eg adjusting water temperature.
- 6c Inability to handle mechanics of toileting eg forgets to flush, does not wipe properly.
- 6d Urinary incontinence
- 6 Faecal incontinence
- Ja Speech limited to about 6 words in an average day.
- 7b Intelligible vocabulary limited to single word on average day.
- 7c Cannot walk without assistance
- 7d Cannot sit up without assistance
- Ve Unable to smile

QUALITY OF EOLC FOR PEOPLE WITH DEMENTIA

- Studies in UK & USA suggest:
- end stage dementia patients in acute hospitals, psychiatric wards & nursing homes experience high levels of 'suffering' compared to people with cancer
 - 60%, majority receive sub-optimal end of life care
- [Lloyd-Williams & Payne 2002; Mitchell et al 2009; Aminoff & Adunsky 2004; Sampson et al 2006]

...WHICH INCLUDE...

- More inappropriate interventions
- Less symptom management
- Fewer referrals for specialist palliative care
- Less recognition of their spiritual needs
- Families are asked to make decisions in times of crisis

(Morrison & Siu 2000; Sampson et al 2006)

WHAT ARE THE CHALLENGES IN EOLC FOR PEOPLE WITH ADVANCED DEMENTIA?

- Professionals unskilled at symptom assessment where there is little communication from the resident/patient i.e. pain assessment
- Poor recognition of dementia as a terminal illness, failure to plan while the person has capacity
- Even with a plan, family or care staff may panic and ask for hospitalisation
- Difficulty in recognising the dying phase
- Quality of life? Social and spiritual care?

WHAT IS CURRENTLY OFFERED BY PALLIATIVE CARE FOR PEOPLE WITH END-STAGE DEMENTIA?

- Future planning (including DNACPR and no inappropriate hospitalisation)
- Family support and information
- Pain and symptom management
- Integrated care plan for last days
- Bereavement support

"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







spirit within

Joyce Simard

Health Professions Press

Amazon.com

joycesimard@earthlink.net

Namaste

"To Honor The

Spirit

Within"

namastecare.com

The Power Of Lovin Touch

namastecare.com

SYSTEMATIC REVIEW OF NON-PHARMACOLOGICAL INTERVENTIONS FOR REDUCING AGITATION

The only interventions with moderate efficacy were:

- Sensory interventions
 - Aromatherapy
 - Thermal bath
 - Calming music
 - Hand massage
- (Kong et al 2009)

NAMASTE CARE - KEY ELEMENTS (SIMARD, 2013)

- "Honouring the spirit within"
- Sensory stimulation: using all 5 senses
 - Sight, touch, taste, hearing, smell
- The presence of others
- Meaningful activity
- Life history
- Comfort and pain management
- Care staff education
- Family meetings
- Care of the dying and after death

NAMASTE CARE PROGRAMME "ENTRY CRITERIA"

- MMSE 0-7
- Non-ambulatory
- Sleeps a great deal of the time
- Limited vocalization
- Total care
- Unable to actively participate in activities

CREATING THE RIGHT ENVIRONMENT



- Residents with end-stage dementia not isolated in bedrooms or inappropriately mixed with those residents who are more able to engage
- No TV
- Calm atmosphere
- Green plants

NAMASTE 'DAY': 10.00-12NOON & 15.00-17.00HRS 7 DAYS/WEEK

Preparing the space:

- Carer gathers supplies i.e. individual's bags/fruits/smoothies/juices
- Room lights dimmed & soft music playing
- Lavender sensor opened

Person is welcomed to Namaste room

- each person is touched and greeted by name
- Placed in a comfortable lounge chair
- A quilt or blanket is tucked around them
 - Extra pillows used to position
- Assessed for pain/discomfort/distress

WELCOME TO NAMASTE



HYDRATION & FOOD TREATS



Help with extra nutrition and hydration when awake

APPROPRIATE MUSIC & FILM



NAMASTE 'MORNING' ... CONT/

As appropriate -

- Wash hands/face & apply lotion
- Brush/tidy hair
- Shaving
- Therapeutic touch head or hands or feet
- Manicure nails
- Personal likes, lipstick, hair ornaments etc.

NAMASTE 'MORNING'....contd/

- 1 to 2 staff at any one time depending on residents needs and numbers
- Give them a friend! As life-like as possible, not "childish"
- Use the SENSES
 - Relate them to life story work
- Flowers and seasonal reminders
- Waking up for lunch & supper (20 minutes beforehand)

APRON - WITH DIFFERENT TEXTURES



FRIENDS: DOLLS AND LIFE LIKE ANIMALS



HAND MASSAGE



CASE STUDIES



namastecare.com

STIMULATION WITH APPROPRIATE DVDS



NATURE AND THE SEASONS THROUGH THE SENSES



NAMASTE FAMILY MEETINGS (I)

- Entry to Namaste triggers family meeting to open conversation about future plans around end of life
- Seeks help of family "to honour the spirit within"
- Life story especially sensory triggers for reminiscence
 Person's likes & dislikes
 - □e.g. favourite music



NAMASTE FAMILY MEETINGS ...

- Acknowledges disease progression early and in a positive context
- Establishes GOALS OF CARE as comfort and pleasure
- Opens conversation around DNaCPR, hospitalisation, preferred place of death
- ULTIMATE GOAL is a peaceful, dignified death in the care home



RESPONSIBILITIES OF NAMASTE CARE WORKER ALLOCATED ON EACH SHIFT

Report any change in individuals
 Assess symptoms - especially pain
 Immediately treat any response to agitation
 Recognise deterioration and dying

NAMASTE AND CARE IN LAST DAYS OF LIFE

- Namaste care continues at the bedside as part of end of life care when a resident is imminently dying
- Comfort, mouth care, loving touch, 'presence'
- Supporting family

UK RESEARCH

An action research study to implement the Namaste Care programme in 6 care homes with nursing

Min Stacpoole & Jo Hockley (2013)

AIM OF STUDY

To implement and evaluate Namaste Care and find out if it improves:

- Quality of life for residents
- Quality of life for their families
- Staff job satisfaction

THE IMPLEMENTATION

- Nurse managers & chosen Namaste Care workers from six nursing homes attended a full-day workshop
 - Given a pack on the project
 - Overview of advanced dementia and the fact it is a terminal disease
 - Introduction to the Namaste Care programme
 - Outline of implementation & evaluation
- Each NH was then visited by MS & JS
 - Teaching 'huddles' (20 mins) about Namaste Care all staff encouraged to attend incl kitchen staff etc
 - Tour of NH with manager to find 'space' for Namaste
- Each NH had 2nd visit to role model Namaste Care

QUANTITATIVE MEASURES

- CDR Clinical Dementia Rating Scale
- Charlson Index Measure of co-morbidities
- NPI-NH Neuro psychiatric Inventory for Nursing Homes
 primary outcome measure
- SM-EoLD Symptom management in end of life dementia
- CAD-EoLD Comfort around dying in end of life dementia
- SWC-EoLD Satisfaction with care in end of life care dementia
- JHNA-JSQ Nursing Home Nurse Aide Job Satisfaction Questionnaire
QUALITATIVE MEASURES

Pre-Namaste:

- Staff focus group
- Staff satisfaction questionnaire

Post-Namaste:

- Staff focus group
- Family focus group
- Managers interview

Care	No of	Personal consultee	Nominated			
Home	residents		consultee			
	recruited					
CH.B	6	Wife; brother; son;	1 nominated			
		daughter; sister-in-law.	consultee (Older			
			people's specialist			
			nurse)			
CH.C	9	Husband x 3; wife;				
		daughter x 3; son; friend.				
CH.D	8	Husband x 2; wife;	1 – nominated			
		daughter x 3; son.	consultee (GP)			
CH.E	7*	Wife x 2; son x 2;	1 – nominated			
		daughter; cousin.	consultee (GP)			
CH.F	7	Son x 2; daughter x 2;	1 – nominated			
		partner; wife.	consultee (GP)			
*one resident was discharged to another nursing home						

СН	No. Beds	Management structure	Manager	Namaste Care Programme
А	60/30	Corporate	Manager & regional manager left	Dropped out on Day 1 of study
В	85/38	Corporate	Manager left mid project	Still working towards achieving Namaste (mornings)
С	41	Family owned	2 managers left, owner took over	Flourishing Namaste
D	60	Corporate	Manager & deputy left - replaced mid project	Flourishing Namaste
E	30	NHS	Manager on development course 4/52 during study	Flourishing Namaste
F	27	NHS	Manager replaced mid project	Stopped Namaste when research ended

WHAT WE FOUND IN THE CARE HOMES 'PRE' IMPLEMENTATION...

- Noise and confusion
- 'rushing about'
- Compassionate staff but burdened by care
- 'dementia is an isolating disease'
- Family carer's burden
- Lack of trust & poor communications across teams, family, GP
- Dementia not seen as a terminal illness -'unexpected deaths'!

NOISE AND CONFUSION

'We had a scenario yesterday. We had the music playing, yes? So the music is playing and we have got a person out in the garden who is looking at his reflection in the glass and dancing. And he's really happy with the music. So we have got another person who hears the music and hates it and wants it off. So we have all these mixtures of people's emotions in one room. It becomes quite chaotic and confusing.' (pre Namaste FG, CHF - HCA F1)

⁶⁶RUSHING AROUND⁹⁹

'In the morning you just rush.... The nurse will be doing medication, the carers will be rushing, to wash them and clean them, or at least wash their faces so at least they can eat breakfast. So you see them rushing and you see every body sweating.' (pre Namaste focus group RMN B1)

WHAT NEEDED TO CHANGE....

Barriers & Challenges

Space

- Time understaffing/shift patterns
- Disengaged leadership and staff
 - Distracted leadership, sceptical staff
- Perceptions of dementia
 - Little attention to life story or psycho-social needs
- Focus on routines and tasks
 - organisational demands; institutional care

Relationships

nurses/carers; staff/management; families/staff; GPs/care home

WHAT HELPED CHANGE....

Facilitators

- Leadership & authority
- Getting everyone on board/making it happen
 - Finding Champions engaging the wider team
 - Changing the environment; providing the resources
 - rota; allocation; Namaste checklist; progress meetings; mission statement
- 'Seeing is believing'
 - Visiting a Namaste CH
 - Seeing change in their own residents
- Education/role modelling

SEEING IS BELIEVING ...

'Seeing the physical evidence myself and how residents who are normally so restless and agitated, when they are in the Namaste room and given the programme, they are so calm..... just sitting down with the residents relaxing, enjoying it. I mean it really touches my heart. So in one way, yes, it has changed my way of working'

(Manager's interview CH D)

Physical benefits for residents

- Better hydration
- Better monitoring of symptoms especially pain
- Fewer infections
- Fewer falls
- Fewer incidents

WHAT HAPPENED....(II)

'Namaste is a feeling'

- changed atmosphere in CH
- changed environment
- Slows down pace no rushing

Residents calmer & more "alive"

- Fewer distressed reactions
- More responsive, more communicative, happier
- Improved hydration, relaxed muscles, better pain management

CALMER ENVIRONMENT

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

PHYSICAL BENEFITS ... 'MORE ALIVE'

'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'

[Family focus group CH C]

WHAT HAPPENED (III)

Connecting and re-connecting

- Seeing the 'person'
 - breaking down barriers between people
 - □life story
- 'Taking off the gloves'
 - touch releasing 'feelings'
 - compassion
 - recovered intimacy
- Spending time

TAKING OFF THE GLOVES - 'RELEASING FEELINGS'

- PD The very important things is that we are doing it without gloves, so they feel our body, our warm body. So the experience and feeling is totally different...
- FM ...you know, because the gloves is between our skin and their skin. But now we touching them.... we have to feel their own warmness ...they will know someone is touching them.
 [post Namaste FG - CHB: CA5, CA3]

TAKING OFF THE GLOVES-'RECOVERED INTIMACY'

We have one [relative] come in and she says to us that [Namaste] helped. She sat down and she did her husband's hand, and she said that really felt...what's the word for it.. closeness?..... Yes, intimate. She hasn't felt that for years and that was really good and she really liked that. Yes, she did! [CH E: CW]



RESULTS OF NPI SCORES (I)



RESULTS OF NPI SCORES (II)



WHERE NAMASTE DIDN'T WORK ...

- Disengaged leadership
- Staff lacked authority
- Understaffing
- Lack of teamwork
 - nurses didn't get involved
- Namaste seen as another task
- Staff's work not valued by management
 - staff not reimbursed for small expenditure e.g. oils/fruit

THE NAMASTE CARE PROGRAMME AND ITS POTENTIAL FOR CHANGE

- Vision focuses on values 'honouring the spirit'
- Offers an alternative structure to care
- Offers guidance for 'being with'
- Gives permission for intuitive care
- Encourages new skills and creativity
- Fosters relationship centred care
- Opportunities for closer relationships between families
- Creates a positive framework for end of life care conversations and care

'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...at times she appeared to barely realise that 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 am making more of a connection with her and a difference in her life.'

[CH D: relative]



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