

Oral Abstracts

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Supporting Palliative Care Awareness and Delivery in Nursing Homes Through Collaborative Learning: Project ECHO AIIHPC

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Problem Statement: Nursing homes are providing increasingly complex care and support to residents with life limiting conditions. If they are to enable residents to live as well as they can and to have their personal wishes considered then training in the fundamentals of palliative care and an understanding of how and when to access specialist palliative care services is essential.

Approach: Project ECHO AIIHPC: Nursing Homes brought together palliative care professionals (the hub) with nursing home staff in Ireland (the spokes) using the ECHO model™ building participant knowledge through online synchronous teaching sessions, case presentations and discussion. Sessions last 90 minutes, accessed by nursing home facilities using videoconferencing software. Topics chosen by participants include symptom control, managing difficult conversations, advance care planning and accessing specialist palliative care.

Results: Project success has been measured through quantifying gains in staff confidence at managing palliative care issues and assessing the impact on unplanned hospital transfers, advance care planning discussions and patterns of referral to specialist palliative care services. To date 44 nursing homes and over 550 nursing home staff have participated in the project. Phase one saw pre- to post-training session confidence scores increasing in assessed nursing home staff from a range of professional backgrounds by an average of 20 to 34% ($p < 0.005$), which was maintained at six-week follow-up. Evaluation of phase two is ongoing.

Conclusions: Project ECHO AIIHPC: Nursing Homes fosters a spirit of peer-learning and reflection in a safe environment which supports the development of a community of practice. During ECHO sessions there are opportunities to discuss challenging patient scenarios, with participants working together to determine best practice moving forward. The first two phases of Project ECHO AIIHPC: Nursing Homes have seen improvements in nursing home staff confidence in managing palliative and end-of life situations with further evaluation ongoing.

Do the Welsh Have it? Evaluating a Bereavement Service Supporting People Bereaved by Dementia

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Problem statement: The detrimental impact bereavement can have on a person's psychological, physical, social and emotional well-being is well established. Yet, for people with dementia, their family and carers, the provision of appropriate bereavement support is to date, limited.

Approach: Cruse Bereavement Care Cymru and The Alzheimer's Society Cymru embarked on a three-year collaborative project – The Bereaved by Dementia Project. Together they pioneered an innovative and exploratory initiative which aimed to address the bereavement needs of people with dementia, their family and carers.

Utilising the experience and expertise of their combined networks, they have; (1) Recruited 120 new Bereavement support volunteers; (2) Developed and delivered a Bereavement Support and Dementia Awareness training module – delivered to both Cruse Bereavement volunteers and external delegates from public and third sector organisations (n= >300); (3) Developed an informational resource; and (4) Supported over 200 clients bereaved by dementia to date.

Employing a multiple-component and flexible approach, an independent research team have evaluated the project. Through a combination of both quantitative and qualitative methodologies we have generated data that permitted a rich and holistic examination of the project.

Results: At the time of submission, we are still engaged in iterative data analysis, however the final report will be submitted by May 2019. The conference therefore is (inadvertently) synchronously timed for us to showcase our findings in more detail. Findings from our interim report, and our further analyses indicate that not only has the project satisfied its initial targets, it delivered in ways that were both unexpected and significant.

Conclusion: While full implications, recommendations, and suggestions for future research are reserved for our final report, we can nevertheless confidently assert that The Bereaved by Dementia Project has increased access to bereavement support for people who are bereaved by dementia in Wales.

CLEAR Dementia Care ©: Supporting Carers to Understand Behaviour and Reduce Distress

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Problem Statement: People with dementia can present with behaviours that carers find challenging and difficult to understand. These behaviours are often caused by the stress and distress the person experiences as they try to cope with the daily challenges of living with dementia. Failure to understand behaviour and address identified unmet need can result in unnecessary placement breakdown, unnecessary hospital admission and increased distress.

Approach: The innovative CLEAR Dementia Care © model was developed to help carers to understand behaviour from the perspective of the person and find ways to offer support and reduce distress. Successful implementation led to the development of a Level 1 training programme for carers and care staff. Level 2 and 3 programmes have also been developed to enable implementation of CLEAR Dementia Care across other organisations. A handbook on implementation has been published and includes a range of complex case presentations and a comprehensive pack of resources.

Results: CLEAR Dementia Care facilitates greater engagement, ownership and joint accountability between carers and staff. This has led to a reduction in the frequency and intensity of behaviours that carers found difficult to understand. Reduced hospital admissions and increased efficiency have resulted in significant cost savings. Following Level 1 training, 1180 carers and care staff reported an increase in their understanding of behaviour. Following Level 2 and 3 training, over 300 NHS staff from a range of disciplines in trusts across the UK reported that they felt more able to engage with care staff and help them to support people with dementia.

Conclusions: CLEAR Dementia Care can be successfully implemented across organisations. The model helps staff and carers to see the whole person and understand their perspective. This enables them to find ways to reduce distress. The outcome is better care and enhanced quality of life.

Service Innovation: How can Hospices Reach More People with Dementia?

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Problem Statement: Few people with dementia die in hospices and the number of people with dementia accessing hospices is limited unless service design is inclusive and supportive of people with dementia and their family carers with varying needs. St Cuthbert's Hospice, Durham was the first hospice in the UK to appoint an Admiral Nurse 2014 to set up their dementia service. In 2016, it was recognised by NHS England as seeing more people with dementia than any other hospice in the UK.

Approach:

Although initial referral criteria to the Admiral Nurse aimed to reach people in more advanced stages of dementia, potentially at end of life, advanced dementia can be difficult to define and for referrers to understand. So, as people in earlier stages of dementia and their families began to access support from the Admiral Nurse, the service was shaped, based on need rather than limiting to end of life care.

Results:

St Cuthbert's Hospice Dementia Service now delivers Cognitive Stimulation Therapy, Maintenance Cognitive Stimulation, Sporting Memories, art and movement based interventions and a volunteer led Namaste Care Service, providing meaningful engagement for people at home and in hospital with advanced dementia. People with dementia and their families have access to the hospices' Everything in Place' Project and the Admiral Nurse leads on the service, providing a key role in supporting families of those affected by dementia.

Conclusions:

Influencing change, harnessing community kindness and keeping an open mind about where the service could go enabled a thriving dementia service to develop. Encouraging people in earlier stages of dementia and their families to access the hospice promotes opportunities for advance planning and provides a 'link' to the hospice as the dementia progresses, increasing the opportunity for a good end of life care experience.

Evaluating the Feasibility and Acceptability of the Conversation Starter Kit Tool for Residents with Dementia

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PROBLEM STATEMENT: The need for a palliative approach in dementia is widely recognized. However, advance care planning (ACP) is still rare in Canadian long-term care (LTC) homes. Residents and their families view ACP as uncomfortable and difficult to implement which leads them to postpone and avoid these discussions. The purpose of this study was to explore the perceptions of long-term care residents and their families about using an ACP tool called The Conversation Starter Kit, with the goal of facilitating more and improved ACP discussions.

APPROACH: This study utilized a mixed methods approach. Data was collected in four LTC homes in Ontario, Canada from 21 residents and family members during an interview after they had completed the tool. Data was analysed using thematic analysis and descriptive statistics.

FINDINGS: All participants read all sections but only 73% completed all sections of the toolkit. Participants spent an average of 52.3 minutes completing the toolkit and 36.4 minutes discussing it with their family members and/or LTC staff. Participants reported: a better understanding of ACP after using the tool (80%), that the tool helped clarify the available resources and/or choices (53%), and that they felt less apprehensive about ACP after using the tool (60%). Qualitative findings revealed many strengths (e.g., usefulness, ability to start difficult conversations, content and clarification), and weaknesses of the tool (e.g., redundant information, difficulty understanding the content and lack of information regarding medically assisted dying). Family members noted that the toolkit would have been helpful to receive earlier on in their family members' disease trajectory, perhaps before being admitted into LTC.

CONCLUSIONS: These study findings support the feasibility and acceptability of the tool to engage residents and family members in; ACP discussions in LTC. Future work is needed to evaluate the effectiveness of the tool with a larger sample.

Namaste Care Programme: Giving Carers a Confident Voice and Enriching end of Life Experience

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Problem Statement: People with advance dementia lose the ability to communicate, yet they still need the comfort of being engaged with family, friends and carers.

Approach: The purpose of the Namaste Care programme enables carers and those with advanced dementia to engage and connect with each other. It provides a possible solution to meeting sensory and emotional needs to enrich quality of life. The programme includes the stimulation of all five senses, one of which is hearing. The use of song /music therapy has been found to harvest numerous cognitive and behavioural benefits, providing temporary relief from dementia by connecting deeply with emotional processing and memory recall. 'SingTonicity' is a group therapy designed to enable participants to achieve an improvement in self- confidence, physical well -being and can enhance life coping skills. Maria Magee and Siobhan Heaney developed and lead a pilot project, along with Derry Well Women and supported by the Western Health & Social Care Trust. The programme has been completed three times and involved 40 carers of people with advanced dementia. The programme was evaluated using the Self -Assessment Lifestyle Inventory Tool.

Results: The carers evaluated the programme positively and achieved skills which helped them to become more creative, confident and engaged when communicating with their loved ones. They no longer felt isolated in their role as carers.

'it allowed me to participate in improving the quality of care of my husband and gave me a great feeling of inclusiveness and a feeling of worth in his care during a very challenging time'

Conclusions: At the end of life when so much has been lost, the use of sound and music has been used to great advantage by carers and is worth exploring further within the Namaste programme.

The Impact of a Virtual Reality Training Programme on Health Professionals' Knowledge, Understanding and Empathy

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Problem Statement: Dementia is one of the major causes of disability and dependency among older people worldwide. Dementia is a terminal illness, which brings a life expectancy shorter than most cancers (Hospice UK, 2015). Virtual reality programmes offer a new and innovative sensory distortion programme designed to provide participants with a greater understanding of people living with dementia.

Approach: Aim to investigate the impact of the Virtual Dementia Tour (VDT) programme. A mixed method transformative design was used. Two focus groups were used to examine how the VDT training impacted on practice. A quantitative repeated measures research design using a psychometrically acceptable scale was used to measure changes in the knowledge, understanding and empathy levels. A purposive sample of health care professionals (n=133) who participated in the virtual reality training programme completed pre and post experience questionnaires. The programme allowed participants to appreciate the symptoms of moderate dementia.

Results: Full ethical consent gained. The findings demonstrated a positive and statistically significant impact on participant's knowledge and understanding of empathy. Participants also reported that they felt they had overestimated their knowledge regarding dementia prior to training and that the training allowed them to 'walk in the shoes' of the person with dementia. Statistically significant changes were noted across nurses, allied health professionals, health care assistants and medical staff. Almost all (95%) participants recommend the programme as an effective training tool. Participants reported that the VDT training had a significant impact on practice and helped to bring their theoretical understanding of dementia 'to life'. However, the experience distressed some participants' therefore support must be built into the training.

Conclusion: The virtual reality experience is an effective, well received training programme providing a unique opportunity to experience dementia. All training must be embedded in an overarching programme of facilitation and practice development.

When the Marriage of Dementia and Palliative Care Doesn't Work out - it can be Painful!

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Problem Statement: Pain management for the person with dementia within acute care remains a challenge. Therefore, healthcare practitioners must explore ways to provide optimum pain management.

Approach: A Participatory Action Research (PAR) approach was employed as part of a PhD study. This approach provided practitioners in an emergency department, acute medical unit and a surgical ward with the opportunity to examine their practice using a variety of techniques to generate actions that could lead to improvements. The first step was to identify specific problems relating to pain management. A case study of a man diagnosed with dementia and a condition requiring palliative care and the staff who cared for him while in hospital was used to enable staff to consider the challenges encountered regarding his pain management.

Results: Data analysis from the study presented several emerging sub themes including; lack of time, too busy, task oriented, rushed communication, family involvement, inadequate knowledge and understanding. These sub themes were then assembled into four overarching themes; knowledge and understanding of dementia, tick box culture, not knowing the patient and not joining the dots. These themes demonstrate the complexity of marrying pain management practices with optimum care thus highlighting a gap in the way we are caring for patients living with dementia within the acute care settings.

Conclusion: Exploring practice from the micro setting perspective reveals much about the culture of care for older people in hospital. Using rich data obtained in a case study and drawing on emergent themes from the project provides an opportunity to reflect on pain management practices delivered to older people who have both a dementia and palliative diagnosis. Having a raised consciousness of the challenges of caring for people with both a dementia and palliative care diagnosis is required to help practitioners make patients feel better.

The Effectiveness of a Global Positioning System for Someone with Dementia to Maintain Independence

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Problem Statement: During Occupational Therapy visits it was highlighted that service users who walked on a regular basis as part of their daily routine had taken a wrong turn or got lost at some point in their dementia journey. This put them at risk of mortality, injury, dehydration and hypothermia. A further risk was the stress caused to carers as they reported they would worry about their loved one going for a walk and getting lost. Admissions to permanent care are significantly more common with those who get lost.

Approach: A pilot project was developed to issue global positioning systems (GPS) to service users who met the essential criteria. GPS devices can locate a person by satellite and then transmit details of their location to a mobile phone or computer. If the service user goes outside the pre-set boundary their carer will be alerted. Carers can then check the location of their relative by logging onto the system.

Results: Comments from carers regarding use of GPS were "I feel a bit more confident knowing he is going out with it." "It's a little bulky. If it was smaller or lighter it would be better". App is "easy to use." "It has been a God send 'cos I'm on my own". "Gives so much peace of mind and reassurance". Comments from service users regarding the use of GPS were "Better battery life would be good". "Feel reassured when out as I can press the button on it to summon help". "It makes you feel there is something there in case anything did happen".

Conclusion: Overall service users and their carers were happy with the provision of GPS and advised it was beneficial to maintaining service users independence and reducing care giver stress. The Northern Health and Social Care Trust dementia team now provide GPS for anyone who meets the essential criteria.

Advance Care Planning and Lasting Power of Attorney - The race Against Time

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Problem Statement: People with a diagnosis of dementia are no longer able to plan for their future.

Approach: The outlook of this service is recognising the need for advance care planning with individuals who have a diagnosis of dementia. Highlighting the potential issues that families may encounter without vigorous planning in place and educating other professionals to understand that a diagnosis of dementia does not mean the person loses capacity to make decisions. Research of available support for those with dementia to complete ACP and specifically LPA's showed a lack of timely and financially viable options for people within Blaenau Gwent.

Results: Use of social work role to provide advice and information on advance care planning and furthermore assisting individuals to complete advance care planning documentation and lasting powers of attorney. This has resulted in the completion of over 60 lasting power of attorneys with a saving of over £12,000 for individuals within the service. Comparisons will be drawn highlighting the potential issues families may face having not completed plan compared to those who have completed the documentations will be discussed to reinforce the need for these interventions.

Conclusions: The need for education regarding advance care planning and lasting power of attorneys is evident. Encouraging professionals to be proactive and recognise the need for robust planning and refer to relevant agencies has been very effective. Remembering that advance care planning ensures person centred care, reduces conflict between families and professionals and ensures that care and treatment is closely aligned to the individual's preferences and choices.

How to Arrange Dementia-Friendly Funerals

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Problem Statement: There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025 (www.alzheimerssociety.org.uk). Although they may express this differently, people living with dementia grieve too. When a person who is close to them dies it is important to include people living with dementia, where possible, in the funeral arrangements and the funeral service to help them express their grief and pay tribute to the person who has died. Yet, this audience is rarely considered within the context of funeral arrangements and in the lay-out and design of crematorium and burial sites.

Approach: Structured interviews with funeral professionals have been completed to assess to what extent people living with dementia are included in funeral arrangements. In addition, the design and layout of a sample of crematoria sites in London have been analysed to seek how they support bereaved people living with dementia. Literature research and interviews with a selection of dementia professionals have been done to identify what is needed to arrange a dementia-friendly funeral.

Results: Initial advice has been developed for funeral professionals and crematorium and burial site staff to provide tools on how to communicate with bereaved people who are living with dementia and how to include them in funeral arrangements. In addition, suggestions have been made on dementia-friendly design and layout of crematorium and burial sites.

Conclusion: How to have a dementia-friendly funeral is a topic of which little literature is available and of which, as far as we are aware, to date, no evidence-based research has been done. This advice and the suggestions presented are a starting point, aimed at triggering a wider discussion between funeral professionals, staff at crematorium and burial sites, people affected by dementia and their families, Alzheimer's society and academia.

Future Care Planning: Insights from People with Dementia and Their family Members

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Problem Statement: Providing information on future care planning is critical, it facilitates decision-making and planning to ensure the person with dementia gets the care and support they need based on their preferences. The aim of this study was to ascertain from those provided with a booklet on future care planning if it met their needs and what if any improvements could be made to the booklet to improve their knowledge and understanding.

Approach: To address this issue, people with dementia and their family members or carers (as appropriate) were asked to review a booklet titled 'I have dementia ... How do I plan for the future'. Ethical approval was sought and provided to conduct this study. The person and/or their carers included in this study were recruited through the medicine for older person's team. Packs were posted to 42 people and 20 questionnaires were returned, a 48% response rate. Descriptive statistical analysis was undertaken with chart data, and thematic analysis applied to the qualitative data.

Results: 95% of respondents found the booklet helpful with 60% of all respondents reporting that the booklet was either 'easy' or 'very easy' (40%) to understand. 65% spoke with someone about the content of the booklet, reporting that it was very beneficial and facilitated important discussions on future care planning. Respondents strongly recommended the provision of this booklet and validated the information contained therein. Significant insights and suggestions about how future editions of the booklet could be enhanced were also provided.

Conclusions: The study has contributed to our understanding of the information needs for future care planning of people with dementia and that of their families. Respondents endorsed the provision of this booklet about future care planning and also suggested minor amendments that will enhance future iterations.

Palliative Care and the Person with Dementia: Is There a Place for Resilience?

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Problem Statement: The concept of resilience is not often associated with the experience of dementia, much less when a person with dementia is in receipt of palliative care.

Approach: A six-year PhD study was undertaken which asked 'Is the concept of resilience applicable to people with dementia?' And if so, 'What are the opportunities and obstacles to using resilience in practice?' This included six dyads of a person with dementia and social worker, and employed narrative analysis to reveal resilience in action.

Results: The preservation of identity is at the heart of the experience of dementia. This is also central to person-centred care practice. Holding on to 'a sense of self' can be re-framed as resilience in action as the person responds and adapts to the changes in their life. This involves the interaction of risk and protective factors. This research has posited the concept of a 'Resilience Reserve'. Each person accumulates resources throughout life. When a person has dementia their experiences and strengths are not always recognised or utilised. The Resilience Reserve helps us to define, visualise and mobilise these resources, and provide targeted, more personalised support.

Conclusions: Despite the adversity faced by people with dementia, as a result of ageing, ill-health and dementia, the possibility of resilience remains. However, resilience is a vague concept not fully understood. It is erringly associated with independence and invulnerability which appear to make it incongruent with the experience of dementia. It is not easy to apply in practice and there are few frameworks to assist carers and staff. This study has developed such a framework, which employs a scale, to help carers identify risk and protective factors, and a Resilience Reserve model. It is argued that such a model will contribute to a more positive experience of care for all parties.

Building Capability, Confidence and Fostering Partnerships in Residential Aged Care: Improving End of Life Care

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Specialist Palliative Care Provider in Australia: HammondCare was commissioned by the Sydney North Primary Health Network to support Quality End of Life Care in Residential Aged Care (RAC) Facilities. This Project commenced in October 2017 and was completed end of June 2018. This Project aimed to provide optimal care and support to patients and their families, enabling residents to die well in their place of choice. The model of care was designed to provide a holistic integrated service. The University of Technology Sydney has been commissioned to participate in project governance and evaluation.

Two Palliative Care 'Liaison' Registered Nurses, a Staff Specialist, and Bereavement Coordinators were recruited. Offsite education was provided, and structured fortnightly visits to the RACFs by the Liaison RNs provided the opportunity for case based learning, mentoring and advice. The goal was to build internal capability and capacity in RAC. Central to the project involved fostering partnerships with GPs and ensuring staff utilized new or existing services.

Expressions of Interest were forwarded to all RACFs in Northern Sydney. 44 applications received, and a selection panel chose 24 RACFs. Each facility nominated two 'Link' RNs and two 'Champion' Care Workers to be upskilled for a train-the-trainer approach. Resources were developed and implemented, focussing on 14 key learning areas.

The presentation will report on the evaluation findings and impact of:

- Knowledge, skills and confidence of staff;
- Identification of deteriorating patients and timely access to Palliative Care;
- Unplanned hospital admissions,
- Choice and control for patients and families,

"How can you Really see me if you Don't get to Know me?"

Mrs Michelle McDuff¹, Mrs Yvonne Martin¹, Dr Damien McMullan^{1,2}

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Problem statement: With the increasing number of patients with a diagnosis of dementia admitted to our hospice, it was identified that our in-depth holistic assessment tool lacked domains to facilitate a better understanding of the individual behind their dementia diagnosis to provide seamless, person centred care.

Approach: A staff nurse was nominated to undertake the Dementia Champion Programme at a higher education college and through this initiated a change project to improve the hospice's holistic assessment tool. Research of literature identified a tool devised by Alzheimer's Scotland: 'Getting to know me'. A phased action plan was developed so that this tool could be adapted/implemented to enhance the existing assessment tool with a short list of questions about the individual encouraging patient, family and staff participation. A small pilot was undertaken following education of staff on the adapted tool. Education was key to the success of this change project encouraging a team effort, hence ensuring communication of patients' needs would be heard, respected and valued.

Results: The pilot was limited to a small number of individuals. It was well received by families and staff. Staff valued the additional information obtained about the person that was vital to understanding and meeting their specific care needs. Families appreciated and felt reassured by staff taking time to get to know their loved one, understanding their personality and having their voice heard. Value's important to them on their palliative journey.

Conclusion: This pilot indicated that the 'Getting to know me' document can be a useful component of holistic assessment in hospices and appears to increase confidence amongst patients/families that the reality of their world is better understood. It helps staff to ask the right questions. The project is still in its infancy, but additional staff education is planned to allow implementation to progress this year.

A Video Library for Unpaid Carers

Ms. Julie Skelton¹

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Problem Statement: Carers often do not recognise themselves as carers, and do not seek support until they reach crisis point or not at all. They sacrifice their own needs for the sake of the person they care for, having a detrimental impact on their long-term health and wellbeing. Carers of people living with a terminal illness are more likely to suffer their own health issues and more likely to struggle financially than other carers.

Approach: In consultation with carers we developed a digital video library to support unpaid carers during their caring journey, providing information to help manage the practical, physical and emotional demands of caring. The library is designed to be used independently by carers in their own homes or facilitated by professionals. It enables carers to browse videos of carers and professional sharing thoughts and experiences on the caring journey. It aims to help people feel less isolated, recognise themselves as carers, understand the impact, and shares ideas of how to overcome the challenges

Results: Carers who used the library said it:

Gave them the knowledge, confidence, motivation and permission to take action to improve their caring situation

Helped them recognise and accept their caring role, and know they are not alone

Reassured them professionals understood and valued carers

Was refreshing to hear from 'the horse's mouth' rather than someone telling you how they think you feel

Helped them realise they are not alone in experiencing the feelings they do

Helped them recognise the impact caring was having on their own health and family relationships

Was easy to access bite-sized pieces of information

Conclusions: The library was originally designed for use in Wales. Based on the feedback we are improving its usability, adding more diverse voices and will be promoting use outside Wales and outside our organisation

“Stand By Me”

Supporting Carers of People with Dementia in a Pilot Therapeutic Group Programme

Miss. Joanna Jones¹, Ms Philomena Murphy¹

¹*Northern Ireland Hospice, Belfast, United Kingdom*

Aim: Facilitate a therapeutic group programme for carers of people with dementia. Our aim was to create a safe, supportive environment for carers to share their worries, stresses together and to gain support/knowledge from each other to empower them in their caring role. Research shows that supporting carers enhances their own quality of life, enabling them to care for longer.

Method: A therapeutic support group was held weekly for two hours during the Dementia Project. Introductions were made at the beginning of each session, and purpose of the group explained. Carers were invited to recap on their week, and share any issues, difficulties and/or positive experiences they encountered since the last session. These “recaps” brought up relevant topics organically which we facilitated discussions around i.e. anticipatory grief and losses, financial strain, future planning and loneliness.

A questionnaire was distributed to the participants to gain feedback and evaluate the benefits of the programme and highlight any gaps present in the programme.

Results: Evaluations are still being analysed, therefore a final report is not yet available. Initial results indicate positive feedback from the participants and emphasise the value of a therapeutic group for peer support, the opportunity to discuss worries and plan for the future.

Conclusion: Carers of people with dementia are impacted practically and emotionally by the onset and progression of this disease. Dementia being included under the umbrella of palliative care enables carers to benefit from specialised palliative care services such as this carer group. Carers of people with dementia benefit from having the time and space to talk and listen in a therapeutic group, whilst the person with dementia was in the Dementia Project.

References

Daley et al 2018

Volunteering in a Hospice as a Person Living with Dementia: A Personal Story

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Problem Statement: Within palliative care, people living with dementia do not always have the opportunity to engage and have a more direct say in shaping the service.

Approach: In this presentation, CM will describe her personal experience. Following a diagnosis of vascular dementia CM has been volunteering at her local hospice. After her diagnosis, CM reported feeling scared, lonely and useless. In order to improve her circumstances, to feel useful and to enjoy her life again, she was initially supported to get involved and make a difference by a dementia charity. This increased sense of confidence led to her volunteering for a local hospice.

Results: CM has had the opportunity to use her skills and knowledge within the dementia community, including influencing, giving talks, and helping to train staff. When she approached the hospice, she was very open about her diagnosis; she attended training and met with hospice staff about the role. They talked through any support she might need as a result of her condition, and agreed to continue to have open conversations as part of her volunteering. CM has particularly enjoyed talking to the people staying in the hospice and their families, and is participating in work to make the hospice more dementia friendly. She has also been invited to work with the hospice and a dementia charity to run some 'Dementia Friends' sessions for hospice volunteers.

Conclusion: CM has received positive feedback from the hospice staff, and people have noticed the difference in her confidence, independence and sense of humour as a result of her experiences. CM's story is a compelling example of the positive role people living with dementia can have in the working life of a hospice. As people living with dementia are diagnosed earlier, opportunities for volunteering can be a positive and affirming activity.

There's no Place Like Home: Compassionate Neighbours Reach Out Scheme

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Problem Statement: Compassionate Communities is a globally recognised public health approach to end of life care. It is a community-led social movement, inspiring local people to build friendships supporting socially isolated people living with life limiting illnesses, including dementia.

Approach: A pilot Compassionate Neighbours project was established in a Northern Ireland city in 2015 - delivered by a local hospice in collaboration with local community groups and GP practices. Volunteers receive a bespoke training programme (includes optional dementia awareness training) and ongoing support. Each month, a volunteer provides 8-10 hrs of their time to support people with life limiting conditions, such as dementia, by providing social interaction for the person and respite for their family and informal care givers.

Results: The Compassionate Neighbours scheme has received 308 referrals, trained 143 volunteers and established 125 matched relationships. At present there are around 50 active volunteers across the city. In a single week in January 2019, 40% of the 46 home visits were to people living with dementia. Powerful stories of support and re-engagement have emerged. Community engagement is crucial, extending to schools, housing associations, dementia related services and projects and to the local council which has agreed to adopt the Compassionate Cities' Charter.

Conclusions: The Compassionate Communities project has grown despite the challenge of non-recurrent funding. The Compassionate Neighbour volunteers help people living with dementia and other life limiting conditions to stay connected within their local community through contact and by encouraging participation in activities they enjoy such as shopping, music, swimming or trips to community centres. The volunteers themselves find the scheme rewarding and value training/support received. The Compassionate Communities project has also raised awareness locally about death, dying and loss through death cafés, conferences etc, to help foster a shared approach to end of life care into the future.

Poster Abstracts

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Namaste Approaches in 10-60-06 Accredited Dementia Care Homes

Mrs. Caroline Baker¹, Mr Jason Corrigan-Charlesworth

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Problem Statement: Namaste care is a relatively new concept within the UK but has been used for a number of years within the USA where it was first developed. In essence, Namaste Care has been designed to provide sensory components of care for people in the more advanced stages of dementia within a small group for set time periods during the day. Previously staff had often struggled with providing activity for people in the advanced stages of dementia.

Approach: Barchester first introduced the Namaste concept within one of our pilot 10-60-06 homes (a programme to enhance dementia care). The initial home that we worked with were fortunate to have a separate small lounge that was relatively unused and this was transformed to provide a warm, safe and sensory environment for 5-6 residents and a member of staff.

All staff were trained in the Namaste Care approach working in partnership with the local hospice (who also assisted in evaluating the project).

Results: The evaluation found that residents had increased weight and well-being levels and that staff had increased job satisfaction. In addition, relatives really welcomed the opportunity to participate in the Namaste sessions with the person they were caring for.

Conclusions: Following the pilot, Namaste was firmly embedded within the home and we are now working with the University of Worcester (Association of Dementia Studies) to carry out a formal research in two of our other care homes.

The Dementia Team have also published a book about many of the interventions that were trialled as part of the pilot of the 10-60-06 programme (which now has 55 homes accredited) and a chapter on the Namaste approach and subsequent evaluation has been included within this.

We believe that Namaste has been really helpful, not only for residents but staff and relatives too.

Exploration of Decision Making by Nursing Home Staff When a Resident with Advanced Dementia Deteriorates

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Problem Statement: It is estimated that around 70% of the UK care home population either has dementia on admission or, develops dementia during their residency (Prince et al 2014). There are currently in excess of 400,000 people living in care homes in the UK which equates to approximately three times the number of hospital beds (Oliver 2016). It is estimated that 311,730 of those residents have dementia with 180,500 living in residential care homes and 131,230 in nursing homes.

Approach: This session will introduce a PhD proposal and methodology regarding the exploration of decision making by nursing home staff when a resident with advanced dementia deteriorates and, offering a rationale for the need to research this area based on the presenters clinical experience and the current evidence base.

Results: There are no examples of research in the UK relating to this key area, yet Sleeman et al (2014) state that 55.3% of people with dementia die in care homes, 39.6% die in hospital, 4.8% die at home and 0.8% die in hospices. People with dementia also have complex health and social care needs which can make prognostication difficult given the unclear trajectories. The services external services supporting nursing homes are often fragmented and inconsistent. There is evidence that very few care home residents with advanced dementia receive specialist support or care planning (Sampson et al 2018), receiving reactive as opposed to proactive care.

Conclusions: Given the lack of literature and evidence base for this area there is a clear need to better understand the complex decision-making process in relation to health care provision for people with advanced dementia in nursing homes and identification of roles and responsibilities in they area of care.

End of Life Dementia Care: Does Special Palliative Care Services Have a Role?

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Problem Statement: Specialist palliative care (SPC) at the end of life is becoming much more available in recent years to both cancer and non-cancer patients. Evidence however suggests that non-cancer patients, such as dementia sufferers, may have more difficulty accessing this service.

Approach:

- A retrospective case note review was carried out of referrals in 2012 to a Specialist Palliative Care Service.
- Stratified sampling was used to ensure representation of the following groups: those who had a primary diagnosis of dementia and those who had a co-morbidity of dementia.
- Purposeful sampling was used to select ten HCPs (providing care in a variety of settings) and six carers (18-24 months post bereavement). Participants were interviewed to determine their experiences. Interviews were transcribed and thematic analysis was used to generate themes.

Results:

- 409 referrals were received in 2012 and of these, 42% had a non-malignant diagnosis and 58% had a malignant diagnosis.
- Of the non-cancer referrals, 15% (61) had a primary diagnosis or a co-morbidity of dementia.
- The main indication for referral was for symptom control of pain and confusion.
- Three main themes emerged from the interviews: The Challenge of Caring: Experiences of the SPC Service and Management of Care.

Conclusion: Specialist palliative care for people with dementia is under researched. HCPs face numerous challenges in delivering a palliative care approach to this cohort of patients and acknowledged the positive aspects of having SPC advice and support for dementia patients (Kelly & O'Connell, 2018, A).

Taking care of carers is important - both for their own wellbeing and for maximising the quality of life of people with dementia. Key recommendations include better coordination of palliative services for dementia patients and greater support for carers in their role (Kelly & O'Connell, 2018, B).

Severe Persistent Mental Illness and Access to Specialist Palliative Care at end of Life

Mrs Marianne Tinkler¹

¹Northern Health and Social Care Trust, Antrim, United Kingdom

Problem Statement: In patients with a diagnosis of severe persistent mental illness (SPMI), such as paranoid schizophrenia, access to specialist palliative care at end of life may be hampered, potentially resulting in a difficult death.

Approach: An integrative extended literature review using an evidence hierarchy was conducted, assessing the following domains: 1) high death rates of people with SPMI; 2) obesity; 3) social isolation; 4) physical illness; 5) use of, and withdrawal from, clozapine; 6) access to Specialist Palliative Care Team (SPCT); 7) multidisciplinary team (MDT): collaborative working between palliative care (PC) and psychiatry; 8) community outreach.

Results: The review identified that patients with a SPMI are marginalised and not being researched or identified as having difficult deaths or end of life care (EOLC) when withdrawing from medication. It further highlighted that patients with a SPMI are not a priority within PC or mental health (MH) services.

Based on the author's work experience and knowledge in this area the results were not unsurprising. The main themes emerging from this review substantiated the results and showed, 1) access and referrals to SPCT; 2) difficulties in symptom management and under reporting of pain; 3) limited MDT collaboration; 4) poor physical health of the patients'; 5) late presentation by the patients'; 6) stigma associated with MH.

Conclusions: This review provides strong evidence there is minimal collaboration between MH and PC MDT and that symptom control and placement at EOL are not adequately addressed. Although it highlights further research is required, a key aim was to raise awareness of the challenges, through publication, presenting at conferences and addressing PC and MH teams.

Recommendations for future practice are outlined as, 1) increase knowledge and skills of PC and MH professionals through training; 2) improved collaboration; 3) introduction of community navigators; 4) establishing palliative psychiatry.

Why are Care Home Patients Admitted to Hospital at end of Life? A Qualitative Study

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Problem Statement: In Wales, over 50% of deaths occur in hospital. With health planners and Governments promoting end of life care at home, why is it that care home patients are sent into hospital to die?

Approach: This is a retrospective, qualitative, thematic analysis of all care home deaths in 6 residential homes, 6 nursing homes and 6 GP surgeries in the South Wales Valleys between 1st September 2016 and 31st August 2017. The resulting 18 interview transcripts were analysed and coded to provide main themes (such as arranged hospital admission) and subsidiary themes (such as lack of reflection by participants).

Results: Patients dying in their care homes usually died expected deaths.

Across all organisations there were 57 hospital deaths.

Admissions to hospital were mainly by care home staff calling emergency ambulances (39%) and arranged admissions by the patients' own GPs (21%). Patients were admitted to hospital for a huge variety of reasons, and within each organisational group there was significant variation in how organisations managed their patients/clients. Within the 57 hospital admissions there are potentially 57 causes.

Subsidiary themes indicated poor communication between homes and GP surgeries, and lack of continuity of care.

Conclusions: Significant changes need to be made to the way care home patients are managed at end of life;

- Care homes need to be of greater importance to politicians and NHS planners,
- Care homes should be registered to provide end of life care, and should be inspected and regulated accordingly.
- Locality groups should be established (e.g. with Ambulance personnel, GPs, care home staff etc) to facilitate improvements, and
- GPs should work closely with intermediate care teams to provide community centred care with physician-led governance.

Such changes would provide improvements in patient care in the community at minimal extra cost.

Supporting People with Dementia to Die at Home

Mrs. Caroline Mogan-Jones¹

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Problem Statement: Given the right support, most people would prefer to die at home. However, very few people with dementia do so and knowledge gaps remain on how best to support this population. To improve care for people with life limiting illness, public health approaches to palliative care known as “Compassionate Communities” have emerged where communities are able to utilise their own strengths and resources to support people living at home until the end of life. However, it is not known how they support families who are providing end of life care for people with dementia.

Approach: This research is using qualitative methods to gain an in-depth understanding of the experiences of informal caregivers who have looked after someone with dementia at home until the end of life and to identify what services and supports were available. A survey is also being conducted to explore how “Compassionate Community” projects are supporting people with dementia to remain at home until the end of life.

Results: A thematic analysis of 26 interviews with bereaved informal caregivers revealed that a network of informal and professional support is crucial to allow people with dementia to remain at home at the end of life. Domiciliary care was especially important but services were often inconsistent and inflexible. In addition, caregivers reported feeling increasingly isolated as the person with dementia reached the end of life and struggled particularly with continence care and reduced mobility.

Conclusions: Whilst families value support from professional health and social care services, there is inequitable access and wide disparities in end of life care at home for people with dementia. However, caregivers are often determined to look after the person with dementia at home until the end and with appropriate support and training more families could be empowered to do so.

Pain Assessment in Dementia in Nursing Home Settings

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Problem Statement: Dementia symptoms such as verbal and physical aggression are problematical and may be caused by unidentified, untreated pain. As older people are known to have more medical co-morbidities the challenge is to improve pain identification, assessment and management in all settings.

Approach: Recognising distress linked to pain can be difficult for staff, particularly in those who are non-communicative. Distress itself may not be easily observable. In residential homes it is often those who are the most demanding that have their needs addressed. Some may express their pain through inactivity, restlessness, aggression or idiosyncratic behaviours the cues of which are often only derived through consistently working with them over a period of time and getting to know them. To develop our practice in residential care of people with dementia, we carried out a small-scale study to compare two observational pain assessment tools.

Results: Thirteen residents were recruited (12 female; 1 male) most were recruited from the statutory residential care sector (n=10; 77%); their average age was 78 years (69-91). All had challenging behaviour and most had more than one painful comorbid condition. A review of the medical records indicated that neither pain histories nor pain assessments were routinely performed, despite being mandated at one of the Private Nursing homes. Nursing staff relied on their own knowledge of the resident in addition to collateral history, communicated by other staff and residents' families in order to recognise the presence of pain.

Conclusions: As a small-scale observational study, our findings warrant further investigation particularly into the constructs which pain tools claim to detect and measure. Pain ratings are designed to inform treatment decisions; therefore, further investigation into these scales is imperative in order to integrate these tools into existing clinical practice.

Collaborative Approach to Developing an Admiral Nurse Service Within a Hospice Setting

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¹Douglas Macmillan Hospice, Stoke-on-trent, United Kingdom

Problem Statement: It is well documented that people with Dementia don't receive the same access to quality End of Life care (Hospice UK, 2015).

Approach: The hospice undertook a piece of work to identify clinical staff concerns, barriers and training needs required to support people with Dementia. Funding was secured from Dementia UK to appoint an Admiral Nurse. A stakeholder group was formed including representatives from hospice, mental health Trust, commissioners, carers and Dementia UK. This steering group meets bi-monthly and has driven the hospice Dementia agenda. It was recognised that the Hospice had end of life care expertise but not Dementia expertise. The hospice seconded an RMN from a mental health Trust with expertise in Dementia Care and an interest in end of life care in 2017.

Results: The percentage of referrals to the Hospice with a primary dementia diagnosis increased from 5.8% to 12.2% during the first year the Admiral Nurse was in post. The Admiral Nurse has supported 195 people living with Dementia and their families in the hospice, community and within care homes. The Admiral Nurse developed hospice bespoke Tier 2 Dementia training to meet the requirements of NHS England core skills education and training framework. The impact of the Tier 2 Dementia training is being evaluated through the use of pre and post confidence questionnaires and will be available at time of conference.

Conclusions: Based on an interim evaluation the hospice secured funding from Dementia UK for a second Admiral Nurse post making the hospice the only one in the UK to have two Admiral Nurses. From April 2019 the Admiral Nurse will be employed and funded by the hospice. Having an Admiral Nurse has strengthened and developed the hospice Dementia strategy and led to a strategic alliance with a local Dementia support charity.

Pain Management in Persons with Dementia: Hospice Healthcare Professionals' Self-Rated Confidence and Training Priorities

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Problem Statement: Pain is a prevalent symptom in Persons with Dementia (PWD) at the end of life. As PWD often have challenges expressing their needs, it is imperative for healthcare professionals (HCP) to be able to assess and manage pain in this group of patients. We evaluated HCP's confidence levels and their learning priorities regarding assessment and management of pain in PWD within a hospice service.

Approach: A learning needs assessment was performed via an online survey (Survey Monkey®) with 110 HCP in September 2018, exploring the learning needs and priorities of doctors and nurses.

The following two statements relevant to pain were: 'I am confident in assessing and managing pain in non-dementia patients' (non-PWD) and 'I am confident in assessing and managing pain in dementia patients. Self-rated confidence and their priority for training and development were ranked on 6-point Likert scales with a lowest score of 1 and highest score of 6. Statistical analysis was done (results pending).

Results: One hundred and six of the 110 HCP (96.4%) responded. Of the respondents, 12.3% were doctors, and 87.7% were nurses. Majority were females (87.8%). Over half of the respondents were between the ages of 25 to 34 years (52.8%).

In all groups of respondents, the mean 'confidence in assessing and managing pain' were 4.51(SD0.94) for non-PWD and 3.89(SD1.03) for PWD. The mean scores for 'priority for training and development' needs were 4.38(SD 1.39) for non-PWD and 4.57(SD1.24) for PWD.

Based on job designations, the mean self-rated score of 'confidence in assessing and managing pain' in PWD were as follows: Senior Doctors (Mean=4.83); Junior Doctors (Mean=4.57); Nurse Clinicians or above (Mean=4.0); Registered Nurses (Mean=3.82); and Enrolled Nurses (Mean=3.52). Priority in training and development: Senior Doctors (Mean=3.5); Junior Doctors (Mean=5.0); Nurse Clinicians or above (Mean=4.09); Registered Nurses (Mean=4.56); and Enrolled Nurses (Mean=5.0).

Conclusion: Pain management in PWD remains a priority for training, especially amongst junior staff.

Occupational Therapy: Creating Dementia Friendly Homes

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Problem Statement: Individuals living with dementia having difficulty remaining safe and independent within the home environment due to poor design; which also resulted in increased carer stress.

Approach: To address this need, a service improvement project was implemented in the form of an information leaflet with the aim to:

1. Empower service users to make simple, low cost changes to their own home.
2. Promote independence and safety by focusing on increasing orientation, falls prevention and improving daily function.
3. Provide a written resource as a "back up" to the information provided by the OT during assessment.
4. Ensure service development within the department.

Methods of research included a review of current best practice, Service user feedback and focus groups to obtain peer professional feedback.

Service user feedback regarding common difficulties experienced at home guided the leaflet content:

- Orientation: Use of orientation clocks, calendars, signage to increase orientation, labelling of cupboard doors.
- Memory: Use of a memory book, whiteboards, daily diary, life story work, memory box.
- Perception: Colour contrasting, floor coverings, visibility strips on edges of steps.
- Safety: Visual prompt aids, assistive technologies, Global positioning systems (GPS), lighting.
- Well-being: Structured routine and activity, tips for nutrition and dietary intake, importance of natural light for sleep pattern.
- Falls reduction: Sufficient space, walking aids, removal of tripping hazards, assistive technologies - sensor alert mats and falls pendants, terrain of outdoor spaces, rails and equipment aids.

Results: Service users who implemented the Dementia specific advice provided, reported an improved level of function; increased orientation, safety and independence; a reduction of falls and reduced caregiver stress.

Conclusions: The leaflet has been approved by the Professional Head of Occupational Therapy services and is currently being distributed by Occupational Therapists throughout the Northern Health and Social Care Trust.

A Novel Four-Stage Process for Refining the Namaste Care Intervention for People with Advanced Dementia

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Background: Palliative care can be important for people with advanced dementia, but there are few effective interventions. Namaste Care is a multi-component sensory intervention for people with advanced dementia, delivered in care home, community and hospice settings. Implementation into practice has started, in a number of countries worldwide, but to date there is minimal evidence of effect being determined.

Aims: To describe the development of an intervention description, manual and training package to support implementation of Namaste Care within the context of a feasibility trial.

Methods: A four stage approach was followed: i) Collation of existing intervention materials and drawing from programme theory developed from a realist review to draft an intervention description. ii) Exploration of readability, comprehensibility and utility with Namaste Care naïve staff. iii) Use of a modified nominal group technique with people with Namaste Care experience (staff, family carers and volunteers) to refine and prioritise the intervention implementation materials. iv) Final refinement with a patient and public involvement panel.

Results: 18 nursing home staff, 1 family carer, 1 volunteer and 5 members of our public involvement panel participated in three groups. A 16 page A4 booklet was produced, with flow charts, graphics and colour coded information to ease navigation through the document. This was supplemented by infographics, and a training package. The guide describes the boundaries of the intervention and how to implement it, whilst retaining the person-centred focus of the Namaste Care intervention.

Conclusions: Interventions in palliative care can be rapidly developed, poorly specified, or implemented without evidence. This four-stage process may have utility for others to adapt or fully specify interventions before testing. This should enhance fidelity, and facilitate practice implementation. TRIAL REGISTRATION: ISRCTN14948133 FUNDER NIHR HTA

The Model for Dementia Palliative Care Project: Key Messages From Initial Stages of Model Development

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Problem Statement: While it is increasingly recognised that people with dementia have needs that can be addressed by a palliative care approach, no model for dementia palliative care exists in the Irish Healthcare System.

Approach: The Model for Dementia Palliative Care Project addresses this gap. The main aim is to develop a service-delivery model to support people with dementia to live well at home in the community for as long as possible. This is a significant 3-year project involving multiple research phases. Results are available from Phase I: Scoping Review and Phase II: Stakeholder Survey. The scoping review appraised the published evidence for various potential components of a dementia palliative care model. The international, web-based survey had two aims: i) to explore key stakeholders' preferences for a model; ii) to identify existing services in the Republic of Ireland, Northern Ireland, England, Wales, and Scotland.

Results: Published research evidence for dementia palliative care models, or individual components, for the community is limited. However, common areas include: advance care planning, education on the disease process, 24-hour nurse phone support, improved care co-ordination and family support. Echoing this, survey respondents rated the three most essential aspects of a model as: "Care for People at all Stages of Illness" (77% considered 'essential'), "Information Continuity" (75% 'essential') and "Defined Pathways for Specialist Service Input" (58% 'essential'). In addition, good communication between palliative care and dementia care teams was perceived to be core to a successful model, with a key worker needed to facilitate this communication, and to support families e.g. around care transitions.

Conclusions: Notable components of an effective dementia palliative care model for the community have been identified. This will inform our development of a service-delivery model, which will improve the palliative care of people with dementia, and their families.

A Hospital Liaison Pilot to Assist Delirium Discharge Planning to a Specialist Community Delirium Unit

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Problem Statement: A diagnosis of delirium can increase the length of stay in hospital and make it difficult to find an appropriate community placement. A person experiencing a delirium can be challenging for hospital staff to care for and the potential delayed discharge can impact on availability of beds for new admissions. It can also negatively impact on the wellbeing and recovery of the person with delirium.

Approach: In response to these challenges a hospital liaison pilot service was established. A CPN from a specialist community-based delirium unit makes weekly visits to two acute hospitals to liaise with staff to identify individuals who may be suitable for discharge to the specialist unit. The goals were to identify appropriate admissions, offer advice to staff about when discharge to the specialist unit is appropriate, work with discharge co-ordinators to increase speed of transfer to the specialist unit and improve the admission process by meeting the person and their family prior to admission. It was also expected that accessing qualitative information about the person prior to their admission would enable better therapeutic planning for the transfer, for example, if listening to classical music helped reduce levels of distress, the unit could arrange for this to be available prior to transfer.

Results: To date the pilot has been successful with increases in appropriate referrals and admission numbers. Qualitative information gathered from hospital staff about the person has also enhanced the admission experience for the person. As the pilot progressed, demand for the service to assist discharge planning for people with complex delirium has increased.

Conclusion: The findings have a number of implications regarding discharge planning and placement options for those who no longer need acute hospital care but still require support for an ongoing or resolving delirium.

A New Model to Support Delirium Resolution in Community Care Beds

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Problem Statement: Delirium is a common serious medical condition developing over hours or days which can present challenges for staff in a hospital environment and significantly delay hospital discharges.

Approach: In response to these challenges, an innovative new service was set up to support individuals with a diagnosis of delirium who no longer require hospital care but who are unable to return home due to the ongoing symptoms of delirium. These symptoms often include increased confusion and disorientation, agitation, hallucinations and delusions. Service users who may previously have had a prolonged stay in hospital are enabled to discharge to a community bed for up to six weeks specialist assessment and delirium intervention. Since its commencement the service has developed a new model, CLEAR Delirium Care with a strong emphasis on biopsychosocial formulation driven by research in the areas of dementia and neuropsychology. A training programme for staff has also been developed.

Results: To date outcomes from the service have been very promising and include an average stay in the specialist unit until ready for discharge of 2-3 weeks with 45% of people returning to their usual place of residence. Service users and family feedback questionnaires have elicited extremely positive feedback and a high level of acceptability of the service.

Conclusion: This service makes a significant contribution to our understanding of how best to support the safe discharge of people with delirium from hospital. This, in turn, reduces the pressures and demands on hospital beds and improves quality of care for the person. Further, we can potentially reduce hospital admissions with delirium through the training of care staff in the community.

The Power of Partnership

Mrs Sarah Harries¹, Mrs Elizabeth Ellis¹, Mrs Alison Jones¹

¹*Hospice of the Valleys, Blaenau Gwent, United Kingdom*

Problem Statement: Barriers to partnership working across organisations jeopardises effective person-centred approaches by professionals for those with dementia at end of life.

Approach: Joint partnership approach to palliative care for those with a dementia diagnosis. Utilising two organisations; one who specialises in palliative care and the other in dementia care. Thus creating a multi-disciplinary service that bridges the gap, removes/reduces barriers and creates a holistic and specialist service for those individuals facing complex issues with their dementia diagnosis at end of life.

Results: Specialist multi-disciplinary service that includes clinical nurse specialists, social worker and dementia support worker. Team works holistically to ensure needs are assessed and support is tailored to the individual. Support includes; medication reviews, symptom management, financial support, planning for the future, lasting power of attorneys, advice and information and an activity group that supports individuals through their dementia journey.

Conclusions: The creation of a model of good practice for professionals working with dementia patients and their family at end of life or during crisis. Ensuring that this model can be replicated by others to ensure professionals maintain a person-centred approach despite potential issues whilst working across organisations.

The Purpose of Activity Groups and how do we Ensure They Meet Individual Needs

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¹*Hospice of the Valleys, Blaenau Gwent, United Kingdom*

Problem Statement: Can activities within an activity group be purposeful and meaningful to all.

Approach: Consultation between organisations, professionals and individuals who access the service (both person with diagnosis and carer) to discuss a “programme” of purposeful and meaningful activities that meets the needs of all individuals attending whilst managing dependencies.

Results: The creation of a generic, rolling activity group that meets the needs of individuals and carers attending in a purposeful and meaningful manner. Research into the needs of individuals and carers, the legislation that guides practice and the ideas and concepts of those leading the way in dementia care has been utilised within the consultation process. The outcome has been the creation of a 12 week rolling programme that aims to holistically meet the needs of those attending. The group covers topics such as advance care planning, advice and information regarding power of attorney and assistance with completion of paperwork, emotional support for carer, music therapy, complimentary therapies, advice and information about disease progression and medication.

Conclusions: It is felt that the group will have a positive and beneficial impact upon those who attend. It is designed to equip individuals and their carers with the information, guidance and practical support necessary to navigate their dementia journey from point of diagnosis. Along with this they are able to utilise peer support and knowledge, using others experiences to expand their own knowledge base.

Creating a Person-Centred Care Environment for Patients with Dementia Within an Acute Care Ward

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Problem Statement: 42% medically admitted patients in acute hospitals have dementia as a secondary diagnosis. Distress associated with hospital admission may worsen their physical and psychological outcomes. Often care and treatment of the acute illness takes priority and hospital environments are not conducive to meeting the needs of patients with dementia.

Approach: An innovation underpinned by the Institute of Healthcare Improvement (IHI) triple aim; the companion role was developed to provide: a safe environment, therapeutic, compassionate support to patients' living with dementia, delirium/acute confusion, based on collaboration with internal stakeholders and external statutory and voluntary organisation. An induction programme developed and evaluated according to level 2 of the Dementia Learning and Development Framework, included integrated and reflective learning from education partners, palliative care services and other clinical practice area.

Quantitative data on rates of patient falls and episodes of distressing behaviour was evaluated. Qualitative data on patient/carer, staff experiences and Companion reflections was obtained through semi-structured interviews, focus groups and recording of reflective journals.

Results: Analysis demonstrated decrease of 71 falls during the evaluation, equating to approximately 7% reduction for the year. Significant reduction in distressing behaviours was observed. Qualitative data themes emerging from patients', carers' and staff were reassurance on patient safety, promoting nutrition and hydration for patients, a calm environment and releasing nurses' time to deliver safe, effective care. In reviewing the companions' reflective journals significant information suggested that this role promotes and facilitates "personhood", which is fundamental to person-centred dementia care.

Conclusions: This innovation demonstrates improved patient outcomes and potential savings to healthcare, reflective of reduced patient falls and distressed behaviours.

The validated service model encompasses addressing the clinical needs whilst contemporaneously preserving the identity and dignity of the patient. Scalability across other care environments is evident and permanent funding has been secured for regional roll out.

“We can do so Much More”: Recognising Needs of People with Dementia in Palliative Care

Ms Monica Reardon¹

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Problem Statement: With dementia on the rise, palliative care services are supporting increasing numbers of people with dementia, either as a primary or secondary diagnosis. Providing high-quality care can be challenging for palliative care staff who may have limited experience and knowledge of supporting people with dementia.

Approach: Healthcare staff delivering both hospice and community palliative care services completed a survey assessing their confidence and competence in supporting people with dementia, and what training they felt would improve this. Only 10% of hospice healthcare staff had received any formal dementia training. Based on areas of need identified in the survey, we worked with a training provider to develop a bespoke training course on supporting people with dementia in palliative care. The course was delivered to 41 staff within a hospice, and the impact assessed using a post-training evaluation.

Results: Prior to training, 30% of staff reported they were “not at all confident” in caring for a person with dementia. Post-training all staff reported feeling “fairly” or “very” confident.

Staff reported that the training:

- Helped them recognise that dementia is a terminal condition and how palliative care can support people with dementia
- Improved understanding of “challenging” behaviours and how they can manage these
- Taught them practical approaches to providing care in an enabling way which they felt were relevant and would improve their practice.

Conclusions: Staff trainers across both inpatient and community settings are integrating this into core curriculum. Response was incredibly positive and represents a culture change in which staff better understand the value of palliative care for people with dementia. Staff are motivated to explore how care practices can be improved for people with dementia. The organisation recognises this work as best practice and are exploring its potential as a national training standard.

Facilitating Quality End of Life Care in Nursing Homes

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¹*Belfast Health and Social Care Trust, Belfast, United Kingdom*

Problem Statement: Changing demographics mean that people are living longer. Nursing Home residents now have multiple co-morbidities, complex needs and are often in the palliative or terminal phase of illnesses on admission.

Approach: Two Palliative Care Facilitators employed by Belfast HSC Trust to facilitate Nursing Home staff to become independent in the clinical care of their residents, thus, providing high quality, coordinated care, preventing unnecessary hospital admissions during their care and at the end of life.

Role Outline:

- Clinical consultancy – assessment and review of residents
- Provision of advice, guidance and support to empower and enable staff
- Provision of training to establish a sound knowledge base
- Competency based learning to promote staff independence
- Audit to identify themes and trends
- Establishing palliative care link nurse system to coordinate care provision and to act as a resource for colleagues
- Facilitating reflective practice and analysis of complex cases or incidents
- Challenging poor practice
- Enabling staff to undertake advance care planning and family discussions

Results:

- Despite increasing complexity, 70% of residents remain within the Nursing Homes at the end of their lives
- Staff report and display increased confidence, knowledge and competency
- More appropriate use of Trust services
- Equity of care provision for residents with cancer and all end stage conditions
- Positive resident and family satisfaction outcomes

Conclusion: The approach of providing clinical consultancy and leadership with training and staff development has increased staff knowledge, skills, competency, confidence and empowerment, facilitating delivery of high quality palliative and end of life care within their Nursing Homes. Sharing learning from this model can help to inform such development and make recommendations for service improvement. This work is currently being enhanced through Regional work strand on Transformation of Care Homes.

How do we Develop Knowledge and Understanding of Dementia: A Hospice's Approach

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¹*St Helena Hospice, Colchester, United Kingdom*

Problem Statement: The purpose of the hospice is to help local people with incurable illness to live well and die with dignity and choice. One of the strategic priorities is to reach out based on need, regardless of diagnosis or circumstance. One of our ambitions was to invest in education in conditions that traditionally have received less palliative care support, such as dementia.

We recognise that hospice staff appear to lack confidence when supporting patients or families affected by dementia. We acknowledge that we need to provide education opportunities for staff and volunteers to increase their knowledge and understanding of dementia.

Approach:

The hospice is committed to providing a number of education opportunities, including:

1. Joining the Regional Dementia Action Alliance.
2. Initiating The Alzheimer's Society's Dementia Friends Information Session for all staff.
3. Organising a 'Caring for those Dying with Dementia at the End of Life' study morning.
4. Promoting dementia awareness tier 1 training offered via E- Learning for Health.
5. Providing in-house dementia awareness tier 2 training.
6. Encouraging staff to complete a Certificate in Principles of Dementia Care delivered via The Skills Network.

Results: The feedback from the varying education opportunities has been overwhelmingly positive. We now have 90 Dementia Friends, 35 staff have attended tier 2 dementia awareness, 70 people registered for the 'Caring for those Dying with Dementia at the End of Life' study event.

Conclusions: The hospice has encouraged all staff to engage with education opportunities to help increase their knowledge and understanding of dementia. We are making a positive impact which is leading to increased confidence.

We recognise the scale of this global issue and are continuing to proactively preparing staff to ensure that we can confidentially support those affected by dementia who access the hospice services.

PrepareDem. Helping People with Dementia and Carers Prepare for Advanced Illness and end of Life

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Problem Statement: To improve end of life care for people with dementia, early advance care planning (ACP) is recommended. ACP can help people with dementia have a say in their future care and has been associated in research with improved end of life outcomes for people with dementia and carers. Other ways of being well-prepared, including being well-informed about the condition and its prognosis and ongoing involvement clinical decision-making, may provide similar benefits. In a new study, PrepareDem, we will explore if and how people living with dementia and their carers prepare for future care in practice, how they can be better supported and impacts on end of life outcomes and experiences.

Approach: We will draw on two English cohorts of people with dementia and their carers; the ESRC/Alzheimer's Society-funded IDEAL cohort (n=approx. 900) and the ESRC-funded DETERMIND cohort (n= approx. 900). We will conduct secondary analysis of survey data from IDEAL and DETERMIND to explore factors associated with if and how people prepare. We will conduct qualitative interviews with people with dementia and carers from the DETERMIND cohort to better understand their experiences. We will also conduct a survey with DETERMIND carers who become bereaved during our study.

Results: The study is in its early stages so there are currently no results available. We will present what is known already and explain why we believe this study is needed, identify current knowledge gaps and set out the specific questions that our study will address, and discuss the theoretical ideas and hypotheses that underpin our research.

Conclusions: Findings from the study will be used to improve the ways in which people with dementia and their carers are supported to prepare for advanced illness and end of life.

Involvement in Hospice Care: An Example from the Torbay Dementia Leadership Group

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Problem Statement: In recent years opportunities for people living with dementia to have a more direct say in shaping health and social care have been increasing. Within the context of palliative care however, finding ways to involve people with dementia can be seen as more complex.

Approach: This work champions the involvement of people with lived experience and highlights the work of a small group of people with dementia who meet together regularly. The group is supported by a dementia charity and works to make a difference in their community. A local hospice approached the group and invited them to visit the hospice, meet with staff and conduct an environmental audit. The group were asked to draw on their lived experience and comment not only the surroundings, but also the atmosphere and staff engagement. Further, the group completed a questionnaire as part of their visit, commenting on the hospice environment.

Results: The group was impressed by the warmth and friendliness of the staff and found the visit both fascinating and reassuring in equal measure. Example feedback from the group included, "such a lovely group of staff whose clear focus is on the patient". Following the initial visit the group returned as an expert panel at an event, 'My Life with Dementia'. This gave attendees an opportunity to speak to people at various stages of their diagnosis about what life is like, their hopes, aspirations, and their fears and expectations of care.

Conclusions: The partnership between the members of the group, the dementia charity and the hospice highlights the value of working together and serves as a good-practice example of involvement and engagement. This work champions people living with dementia as experts by experience, and illustrates how people with dementia want to plan for the future and influence services.

Complex Seating for Persons with Advanced Dementia.

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Problem Statement: Occupational Therapy Dementia Team receive many referrals each month to address the complex postural needs of persons with dementia living in nursing homes. Often the referral states that the person with dementia is nursed in bed and they are unable to sit out. The OT service invest significant money and time to enable persons with dementia get out of bed and participate in meaningful activities each day.

Holistic complex seating assessments are completed and significant OT time is spent devising seating regimes to share with nursing staff to ensure that service users are able to have an improved quality of life by using the seating system as prescribed and demonstrated by the OT. The OT would be concerned that all staff are not using the regime fully which has implications for the person with dementia's quality of life,

Approach: A face to face interview was completed to evaluate with nursing staff if they were aware of the seating regime and its contents.

This was important as the regime contains lots of information pertinent to the care of the person with dementia and we wanted to ensure that it was being used effectively

Results: Results showed most nurses knew a regime had been prescribed, full content was sometimes unclear and all recommendations were not implemented. A poster displaying key points of the regime was developed and shared with staff and families. Feedback informed us that a poster would be a useful educational tool for staff and families, ensuring all staff know there is a regime in place and key points to improve the quality of life for the person with dementia. Staff will know they can then refer to the full regime for more detail.

Conclusion the poster will be distributed to all nursing homes in the Northern Trust.

Nurses' Knowledge and Attitudes Towards Pain Assessment for People with Dementia in a Nursing Home Setting

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Aim: The aim of this study was to determine nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting.

Background: Pain is highly prevalent among older people, yet is often under-recognised and undertreated in people with dementia. People with dementia can lose the ability to report pain and it is the role of the nurse to identify and appropriately assess pain, to provide effective treatment. This requires nurses to have sufficient knowledge and training in the assessment and management of pain in residents with dementia; however, research suggests deficits in this area.

Methods: A cross-sectional survey design was used to determine nurses' knowledge and attitudes to pain assessment in dementia. A questionnaire comprising three sections was distributed to 96 registered nurses across 17 nursing homes in a health-care trust in a UK region.

Results: A total of 32 responses were obtained (response rate 33%). The majority of nurses had a good knowledge in relation to the assessment and management of pain in residents with dementia. There was, however, some uncertainty among nurses over analgesic choice, the safety of opioid use in dementia, and the use of dementia-specific pain assessment tools for residents with no cognitive impairment. The main barriers to effective pain assessment for older people with dementia were workload pressures, poor staffing and lack of medical support.

Conclusion: This study highlights the need to develop pain education programmes and clear guidance specifically designed for nurses caring for older people with dementia. It also emphasises the need for better communication and co-ordination of pain treatment for nursing home residents with dementia.

Keywords:

Dementia; Nursing home; Older people and attitudes; Pain assessment

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Improving the Experience of end of Life Care for People with Dementia

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¹*Southern Health and Social Care Trust*

Problem Statement: A lack of partnership working across Specialist Palliative Care, the Memory Service and the Integrated Care Teams is contributing to a poor end of life care experience for people with dementia.

Approach:

To address the problem the following steps were followed:

- In February 2018 a Working Group was established to drive forward an agreed action plan to address the problem.
- Initially the Working Group engaged with staff across the three service areas to raise awareness of the project and to gain an understanding of the concerns staff have in relation to the care of people with dementia who are at end of life.
- In September 2018, an interface workshop was hosted for the three service areas involved. The agenda included: an overview of Specialist Palliative Care Services and the Memory Service; a service user experience; group work to identify the barriers and challenges when caring for this client group.

Results: The challenges and barriers reported included: lack of awareness of the range and role of relevant services (Trust and Voluntary); lack of knowledge and skills; inadequate resources and a lack of public awareness. Solutions suggested included: improved awareness of the role, referral pathway and contact details of relevant services (Trust and Voluntary); improved collaborative working across the three Teams and appropriate training.

Conclusion: The workshop outcomes are informing the next step in the improvement process. A survey will be undertaken to ascertain staff perceptions of their confidence in relation to caring for this client group and to identify priority training needs. Using the findings a joint training programme will be developed. Apart from improving knowledge, joint training will increase connectivity across Teams. The long term goal is effective collaborative working and better awareness of the needs and management of people with dementia who are at end of life.