The Palliative and End of Life Care and Dementia ECHO Knowledge Network

Experience of Service or Practice Development Case Study
(e.g. implementation of new guidance, assessment tools, models of care)

**ECHO ID:** (for administrative use)
**Name of presenter:**

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**Key Theme For Case Presentation**

Decide what the key issues you wish to highlight are and, the objectives of the intervention or change. Consider the ECHO participants and how you may be able to demonstrate value for them.

We share results of the pilot of a new service, and a case study from the service, to highlight the work of Dementia Support UK (DS UK), and suggest that neuropsychiatric symptoms of dementia, specifically agitation, should prompt caregivers to initiate a comprehensive pain assessment.

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**Background information/setting the scene**

What was the case for e.g., change? Introduction of new tools, new referral criteria? Include here key points which will help participants understand the situation.

There are currently no pain management guidelines for UK care home residents with dementia. In a study published in 2017, Rajkumar et al. found that 35% of people living with dementia in the care home cohort lived with pain, and that pain severity was significantly correlated with dementia severity, neuropsychiatric symptoms, and agitation (2017).

Dementia Support UK (DS UK) provides easy, real-time, access to specialist dementia consultancy and non-pharmacological support to those caring for people living with dementia in the UK. DS UK’s differentiation is its expertise in caring for people that experience behaviours and psychological symptoms of dementia (BPSD) through a model that prioritises relationship-based interventions, using an eco-bio-psycho-social approach. DS UK consultants aim to improve understanding of the behaviour(s) exhibited by the person with dementia, help to identify possible triggers and interventions to anticipate, respond, reduce and/or treat/manage the behaviour. DS UK is an innovative model that improves care for the person with dementia by reducing stress and distress, provides expertise and resources for carers, and builds capacity across the sector.
Interventions/ development / change

Interventions/ actions/ activities. Key points e.g., what you did or observed.

In June 2020, DS UK ran a pilot (feasibility study) with a focus on supporting care homes in England during the pandemic, funded by Innovate UK. The evaluation found the most common neuropsychiatric symptoms of dementia reported to the service was agitation, followed by aggression.

Unidentified pain is a significant contributing factor in behaviours reported about people living with dementia. People living with dementia are often unable to self-identify or report pain and may express their discomfort through responses perceived as agitation and aggression. In addition, dementia may affect a person’s experience of pain. Older people can also have co-morbidities such as arthritis which can be overlooked in association with pain where dementia is also a factor.

The case study attached exemplifies the complex nature of pain management for people living with dementia and those living with dementia in care homes. This discussion focuses on Jenny who is an 85 year old woman, with a history of dementia, of unspecified type, living in a care home. Jenny had been living in the home for a year, having previously lived alone.

Staff reported that Jenny was agitated and aggressive, with her behaviours impacting on the care teams’ ability to offer care and support. Jenny would often decline offers of support with personal care, and frequently declined medication. DS UK were able to respond the same day, completing a triage over the phone where initial strategies were suggested, and arranged a video consultation.

Care home records indicated several diagnoses which may have contributed to Jenny’s pain and discomfort, including frequent constipation, a recent urinary tract infection and cancer in the right pelvic wall and the back of the bladder.

It was discussed that she may be declining support with personal care due to pain, and the declined medication may mean she is not receiving adequate analgesia.

Tailored strategies included:
- Delirium screening, including bowel movements and sleep monitoring.
- Close monitoring of pain on and after movement using the Abbey Pain scale, and discussing outcomes with the GP.
- Adjusting the time of morning analgesia and offers of personal care, to optimise pain relief during movement.
- Utilising those staff with the best rapport for intimate care and known distress points.
- Utilising her love of singing and music to create a positive social environment before and during offers of care.

Output

Key points - what it took to achieve the change / intervention. Were there any barriers / constraints?

The care team had not considered pain to be a contributing factor in relation to these behaviours because Jenny was prescribed analgesics. Jenny’s overall health profile including cancer had been taken into account but not prioritised as the issue was thought to be related to dementia. Jenny’s agitation and aggression had been attributed to ‘her dementia’, rather than as a communication of illbeing.
### Outcomes

Any impact on patient/family, you and/or your service, other services or the wider health and social care system. Include here outcomes e.g., the changes that were made because of the interventions either by you or by your service. What might have happened without this intervention?

| The care home manager reported that the team successfully implemented the range of suggested strategies. The process of assessment and problem solving helped the care team to recognise that Jenny’s behaviours were her way of communicating her pain and as a result they were aware of this and could anticipate, monitor, and respond. |

### Reflections and points for discussion.

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<th>The correlation between behaviours and pain is known, yet more needs to be done to raise awareness with care and support staff. DS UK launches its full UK wide service in June 2021. The service is supported by our app which is free to download with access to a wide range of resources and support options. A subscription service is also available offering livechat, dedicated consultation time, and access to resources, e-learning, and the latest research.</th>
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<td>In Australia, we have undertaken the world’s largest population-based study of dementia behaviour. Agitation is a common psycho-social symptom of dementia, and studies suggest that the agitation may be as a result of unmanaged pain. The individual in the case study often declined offers of support with personal care, staff attributed this to another manifestation of her agitation. Intervention enabled the team to rephrase her refusals as a response to pain.</td>
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<td>People living with dementia often have complex health needs, and comorbidities that themselves may indicate pain. Effective pain management requires tailored psychosocial care strategies alongside appropriate analgesia to be effective. PRN medication should be avoided in favour of prescribed times for the routine management of pain. Where PRN is prescribed it should include notes specific to the person concerned to assist staff in deciding when it might be required.</td>
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<td>Adopting an eco-bio-psycho-social approach means that a care team can consider lots of intersecting elements that impact on the experience of pain and dementia as demonstrated in the attached case study.</td>
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<td>Our pilot found that the experience of carer stress experienced by staff in relation to the stress and distress of people in their care can be significant. Effective pain management can also improve carer wellbeing in care settings as it alleviates behaviours in people living with dementia.</td>
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