

Most Powerful Schwartz Round

'Dementia care matters'

'Dementia care matters' is nominated as the most powerful Schwartz Round by Epsom and St Helier University Hospitals NHS Trust. The Round captured the complexity of caring for people with dementia. The breadth of the impact covered bearing the helplessness and despair both as NHS staff and as daughters and sons of people affected by dementia in addition to celebrating the success of using a model of care enabling the creation of a safe, calm and respectful environment for patients to thrive in.

The diverse panel shared captivating stories and included a nurse lead for the development of the trust's pilot dementia friendly ward, a porter transporting patients with dementia to and from this ward, a nurse both working with older people and supporting her father with dementia and a junior doctor involved in the complex discharge plan for a woman with dementia and at the end of her life.

Enduring despair...

Each panel member acknowledged the difficulty in bearing and witnessing the impact of the disease on both patients and their loved ones. The porter noted how closed up, angry and confused a patient was when he transported her to the dementia friendly ward and relayed his fears for her future welfare. A nurse spoke emotionally about her family's traumatic decision for her father to live in care including the difficulty of witnessing his deterioration and her concern about the protection of his privacy and dignity in the care home. The lead nurse talked passionately about her frustrating experience of witnessing the discrimination her patient faced accessing end of life support to respect her husband's wish for her die at their home. The nurse informed the stunned audience that on this particular occasion, the wife sadly died in hospital. In the same case, the junior doctor admitted feeling an overwhelming responsibility to make a safe clinical decision where she favoured the husband's passion and commitment for wanting to care for his wife at their home despite her concerns about his overbearing caring style.

...creating hope

The hope of finding a way through dementia to care for the person also emerged from the Round. The lead nurse emphasised the importance of facilitating an intimate environment on the dementia friendly ward with lunch clubs, afternoon tea with china tea cups, organised huddled chairs to encourage conversation between patients on the ward, old style TVs and old era music in the ward background. The porter commented on his joy at seeing the same patient he transported to the ward angry and confused several days earlier to now laughing, walking with confidence and looking like a completely different person. He admitted to originally feeling little or no hope for this patient to then being surprised to see the same person transformed into a happier person. The nurse whose father has dementia spoke of the value of the 'This is me' hospital passport containing invaluable information on getting to know her father. She saw this initiative as an example of how 'little things can make a huge difference', such as knowing what her father likes to eat, the importance for him to get dressed every day, and information of his history of escapes from previous care homes.

All attendees were invited to reflect on the personal impact of the Schwartz Round where a number of themes emerged.

Unheard voices

One of the panel members afterwards commented:

"I felt as if we were bringing dementia care out of the shadows and giving permission to speak" (Lead Nurse).

Another panel member said: "I did not anticipate that the majority of the audience were or are affected by this disease" (Matron).

In particular, the impact of hearing the porter's story, a voice often unheard, led an audience member to comment: "It made me realise how important our porters are in a patient's story" (Consultant in Palliative Medicine).

A collective voice of carers in the Round acknowledging the importance and respect for their voices as advocates in the NHS system also emerged as a powerful theme. This was reflected in the comment: “The way in which it [the Round] has influenced my practice the most is understanding the importance of family and carers in the assessment process and decision making in the best interest of the patient where they lack capacity. While I already recognised the value of their input it made me realise just how important it is to family and carers to be involved at every stage” (Macmillan Clinical Nurse Specialist).

Expressing and sharing emotions

The power felt by the emotions that were expressed about dementia in this Round was commented on by a number of attendees:

“I felt a great admiration for my colleagues for the strength they showed in speaking about a very personal and often emotional subject, and for their professionalism” (Communications Officer).

“I thought it was wonderful just how many staff were willing to share their personal stories and it really touched me. I spend a lot of time in my role as a palliative care nurse specialist caring and providing support to patients and families with dementia, so it had a real impact hearing from those people who are affected by it” (Macmillan Clinical Nurse Specialist).

“Despite having experience working with the older population and more recently people living with dementia, it is rare that you hear such gripping and personal information being shared both from fellow colleagues and health care professionals, in a safe and controlled environment” (Advanced Nurse Practitioner).

“The Round stimulated many emotions ranging from tears to fears of the future” (Matron).

Compassion and hope

Despite acknowledging the difficulties, dilemmas and emotional impact of both patients with dementia and their carers, the Round simultaneously inspired hope for how dementia care can be delivered differently.

“It was so hopeful and heartening to hear how a dedicated dementia ward was improving the care of so many of our patients and the possibility that this could be expanded into other wards is progressive of the trust” (Consultant in Palliative Care).

“It was an inspiring and uplifting Round as it showed an example of innovation in the trust that was making a positive and powerful difference. A real morale booster” (Clinical Psychologist).

“I was comforted to hear professionals talk with such care, compassion and commitment about supporting and caring for people living with dementia; comforted because it gave me hope that my grandmother will continue to be cared for by similar people with a similar approach” (Communications Officer).

The power of Schwartz Rounds

The ‘Dementia care matters’ Schwartz Round had a unique intimate quality, none like any other. The tone of the Round may have been influenced by a more unusual panel including a non-clinical staff member and a nurse talking about her father with dementia from a personal perspective rather than a professional one. The Round attracted interest specifically by staff who have a family member living with dementia. It was also noted that staff who had not spoken in previous Rounds, contributed to the discussion for the first time.

As the sixteenth Round in the trust, the Rounds appear to have developed a level of safety to explore feelings and challenges at a deeper level. Professional boundaries faded to allow the distressing feelings associated with witnessing the impact of this disease on patients and loved ones to surface. The compassion that emerged for providing helpful and hopeful care for people living with dementia renewed inspiration for working in the NHS to find ways to alleviate suffering and distress for patients in our care.

To conclude, the powerful impact of the Round bringing people together for a common cause was succinctly summarised by a non-clinical member of staff:

“...we all attended as staff and in sharing our experiences, came together not as professionals, but as people with much more than just our place of work in common” (Communications Officer).

Dr Yasmin Mullick, Clinical Psychologist
Schwartz Round facilitator