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Walk with me BGS.pdf [2]



With around 160,000 vacancies in the social care workforce, Professor Deborah Sturdy, chief nurse for adult social care, says that the social care workforce needs a boost [3][1], and that **the solution lies in talking up the praises of the work done by nurses in social care**.

'One of the things I talk a lot about,' says Professor Sturdy, 'is how we have got to **change the narrative**. If you look at nurses just within the four walls of a care home, what they are actually doing is running a nurse-led service.'

**'If you start to use a different narrative around this, it brings a different kind of thinking and a different kind of recognition for what the career is. The sector itself needs to talk up the phenomenal skills that nurses in social care have.'**

Associate lecturer at Oxford Brookes School of Nursing and Midwifery and care home nurse Dr Helen Cowan responds to this call and here gives an insight into the complexities of the role.

**The "cum panis" of care home nursing**

Before my career in care home nursing, I worked in a hospice for terminally ill young people. The nurse and religious sister in charge explained, during my induction, the philosophy behind the care. "Cum panis," she said, two Latin words meaning "bread with", used in Roman times when workers would share, quite literally, the bread of their labours. Derived from "cum panis" is the English word "companion", a fellow journeyer who walks beside us, sharing not bread but life's way, and this idea, she explained, would underpin our work in the hospice.

In any type of palliative nursing, be it in the care home, hospice or family home, the nurse "walks with" the patient

at the end of life, a journey lasting days, months or years. Needs can be acute, chronic, physical, emotional or spiritual, and the nurse knows the patient and family well enough to decide when to walk in front (when they take the lead in clinical decision making) and when to walk behind (when they enable residents, and promote independence). In the final hours, the care home nurse is often found simply at the bedside, walking now "beside".

"Don't walk behind me; I may not lead. Don't walk in front of me; I may not follow. Just walk beside me and be my friend." *

**Walking in front**

Care home nurses are used to making best interest decisions for residents who lack capacity. The resident is at the heart of the decision-making process and involved as far as possible. This means [4] "finding out about the person's past and present wishes, feelings, values and beliefs, using information included in care plans and advance care plans, consulting with the person's family, carers and advocates and seeking to establish the person's wishes, preferences and values"[2].

Clinical decisions are made in the context of frailty, possible futility, and objectives of treatment which may differ from those for younger people, with an increased emphasis on comfort rather than cure. Prescribing needs to take into account the perspectives of patient, pharmacology, and prescriber. Alongside overall appropriateness of the prescription, its acceptability to a resident with dementia is another part of the prescribing puzzle. Will the resident be able and willing to swallow the medication? Will they tolerate monitoring, even blood pressure measurement? Non-adherence to prescribed treatment [5][3] remains a significant feature of care home nursing.

Professor Deborah Sturdy, England's first-ever chief nurse for adult social care, describes the "incredible tenacity, management skills and advanced clinical decision-making skills" required by nurses in care homes (which she prefers to call '**nurse-led units**' [6]), "because often you are the only registered practitioner in there making complex decisions"[4]. The care home nurse needs a grasp of everything from neurology to urology, cardiology, pharmacology, endocrinology, and psychology, to inform wound care, palliative care and symptom control, continence care and management of diabetes and advanced Parkinson's, when symptoms are more complex. Deciding whether or not to call for emergency assistance from an already-overstretched ambulance service can be difficult; acute emergencies such as stroke, sepsis, diabetic ketoacidosis, and "cardiac asthma" can present, as well as more subtle signs such as those associated with delirium or infection, against a background of dementia-associated confusion.

Acting as advocate if expert opinion is needed, the care home nurse helps modify the prescribed plan of care to reflect the individual's specific routines and behaviours - sometimes affected by dementia - and finds ways to aid communication, understanding and acceptance. Before collaborating with the care home nurse, one tissue viability nurse was kicked by the resident as she started to assess a leg ulcer; integration and strong relationships [7] between nursing colleagues in the NHS and social care are essential, as we "work together to deliver the best for some of the most vulnerable in society"[5].

**Walking behind**

Seen and unseen, the care home team enables and empowers the resident, restoring ability and dignity, or reconsidering what remains realistic, and helping those important "little victories" to happen. Sometimes walking quite literally behind the resident with a wheelchair in case they tire and need to sit, staff (including carers and visiting occupational therapists and physiotherapists) skilfully assist mobility and reduce falls risk through a variety of methods, starting with a comprehensive falls risk assessment [8] - which covers cognitive impairment; continence problems; falls history; footwear that is unsuitable or missing; health problems that may increase the risk of falling; medication, postural instability, mobility problems and/or balance problems; syncope syndrome; and visual impairment[6].

Buildings designed with colours, textures and layouts that take dementia into account enable and empower residents to explore and exercise without obvious intervention (though a close eye is kept, and sensor mats provide added safety). When food is made soft and bite-sized, minced and moist, pureed or liquidised, and fluids thickened,

and both are in continual supply, residents claim back some control over their swallow, their intake, and their choice of when they eat (frequently little and often).

Sometimes staff are not needed – and, for residents with dementia, a doll can be an important 'travelling companion', 'walking behind' the resident, restoring them to a place and time when they felt in control[7]. Doll therapy [9] has the potential to preserve dignity by de-escalating agitation or engagement in physical or verbal abuse. A sense of dignity also comes from the person now being able to give care rather than receive it.

Much is written on music – it too can restore a sense of self, and reawaken souls. Neurologist Oliver Sacks showed how music could 'call back the self' in dementia, awakening moods, memories and thoughts – and sometimes even spoken words - that had seemingly been lost. Music [10] can enliven, calm, focus and engage patients long after they have forgotten the music itself[8].

**Walking beside**

Some residents will reach out to hold the hand of a staff member, or accept one that is offered, expressing, non-verbally, a desire for another to truly 'walk beside' and 'be their friend'*. During dying, the being 'beside' happens at the bedside.

Subtle signs that the end is near include reduced or absent oral intake, a change in breathing patterns and blotchy-red purplish marbling of the skin, especially on the legs. Diagnosing dying is though a combination of science and art, and nobody has mastered it.

Do not resuscitate orders are addressed early by the care home nurse, with the process often viewed as invasive and futile, and the order offering some protection from a procedure that is unwanted, unlikely to succeed, and where harm usually outweighs benefit. Advance care planning, focusing on individual wishes for resuscitation and hospital admission, is essential. Far from being a tick-box exercise, it gives families the chance to share what matters most to their loved one with dementia. Having the time to listen and co-create a shared narrative [11] helps form a truly person-centred plan[9].

In the final hours, or days, anticipatory medicines are available, in small doses, to reduce pain or agitation. Mostly though, care home nurses are trained to simply be at the bedside, "walking beside". Feeling as if they are "doing nothing", they need to remember, as other trained professionals do, **that sometimes,** doing nothing **[12] is the bravest decision of all**[10] – and that the act of stepping back from invasive intervention, when all involved are in agreement, allows attention to turn to the small things, the details of daily living, which are so easily overlooked when the focus is fixed on fighting for life at all costs. Walking beside the resident, and behind the family (as appropriate), allows the 'fundamentals of nursing care [13]' such as oral hygiene, pressure relief and continence care to take centre-stage[11]. Comfort and compassion are key, as well as connection to those who really matter, and at moments like these Kitwood's emphasis [14][12] on love as the "one all-encompassing need" is entirely right – and actually underpins all that we do in care homes, where, in the misting of memory, feelings become very much more important than facts.

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*A saying attributed to French writer and philosopher Albert Camus, though there is no accurate reference.

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