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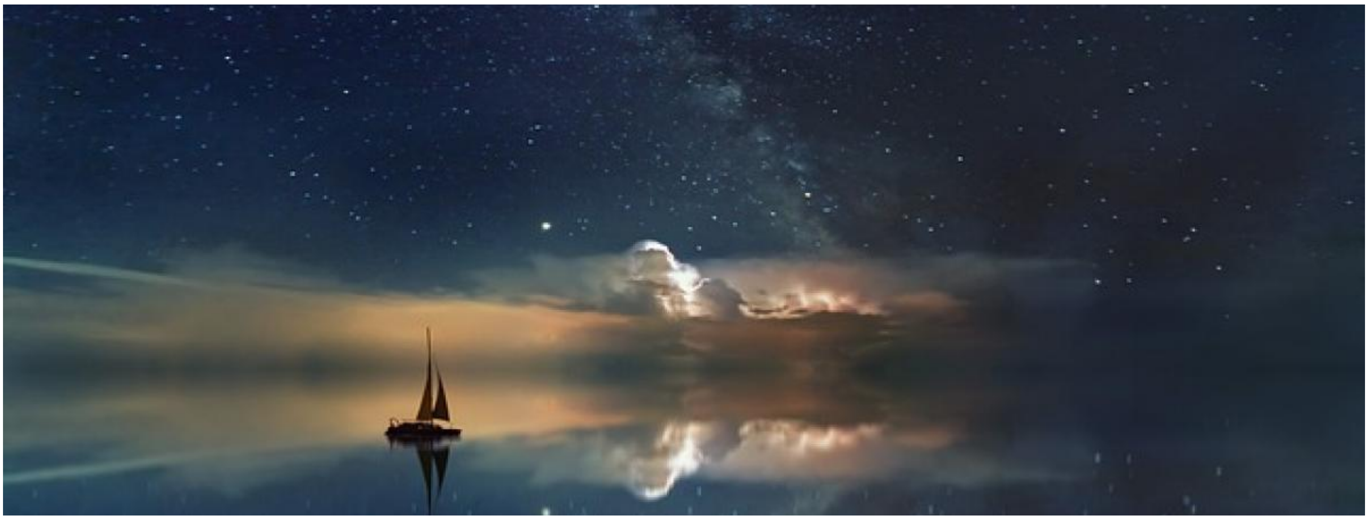

Advance care planning is an important part of community nursing, and community nurses can facilitate ongoing conversations as part of a trusted therapeutic relationship.

Care home Nurse Helen Cowan reflects on her experience of sometimes difficult conversations when making advance care plans, and their lasting impact, allowing patients to speak into current and future decisions about their care.

“Dad spent two of the last days of his life alone and distressed in A&E – for no good reason. […] He was sent there by himself, without his hearing aids, in the middle of the night, simply as a precaution. It was awful for him, and a dreadful waste of resources.” Broadcaster and columnist Adrian Chiles writes in [the Guardian](#) [2].

Chiles’ account of his father’s experience of being hospitalised in the last three weeks of his life conveys a sense of powerlessness, both from himself, his father, as well as the various doctors and nurses involved. Everyone deserves compassionate palliative care, which involves individuals and respects their voice. Creating an advance care plan is a way to facilitate this and help prevent stories like Giles’ from happening.

[NHS England](#) [3] describes advance care planning as “a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care”. It goes beyond decisions around resuscitation, to include thoughts on antibiotic therapy, hospital admissions and, in the broadest possible terms, “what matters most” to the resident in their ongoing, and final, care.

There are also benefits from the sense of empowerment gained from the process of planning itself. Life, and advance decisions, are rarely black and white, but have a million shades of grey in-between. At the crossing between life and death, a last-minute change of plan is possible. The advance care plan is not legally-binding; decisions can be made in response to an unforeseen change of circumstances, acting always in the person’s best interests. Much more than a set of tick boxes where choices are mechanically made, advance care planning is the compassionate, collaborative, co-creation of a shared narrative.

During the Covid pandemic, I worked with health and welfare attorneys, advocates, families, and significant others, to shape stories for care home residents who lacked capacity, making best-interest shared decisions in line with the Mental Capacity Act. My ‘gathered gleanings’ were both simple and profound; they helped create shared meaning and strengthened relationships and enabled holistic care.

Sometimes what matters most is the way that make-up is applied, hair is styled, a hand is held (or not) and when the lights are turned out (or not) at bedtime. I’ve made notes of favourite football teams and foods, who craves company and who seeks solitude, and whether a visit from a vicar might bring comfort or alarm.

Discussing decline and deepening understanding

My experience has shown how people have different levels of preparedness to discuss preferences for future health needs. Some call for care at all costs; others want to delay discussions to a later date or discuss with a doctor. It can take a while to voice concerns; much easier are the things that make someone happy. It needs several conversations, done sensitively, to gain trust over time, dig deeper and uncover the undercurrent of emotions and fears beneath the surface. Community nurses are well-placed to have this ongoing dialogue.

Whether for physical, emotional, or spiritual reasons, strong feelings are often shared against admission to hospital, which is shown in the various voices of people I’ve worked with:

“Keep him comfortable in the care home, let him pass peacefully in a place that knows him well.” “Don’t send him to hospital – you can catch anything there. When he went last time he lost weight and became agitated.” “Don’t subject her to trauma. She believes that ‘absent from the body is present with the Lord’.”

Some fears have simple fixes and bring a sense for the patient, or family member, that some control remains. Other concerns have no easy answers, but what may be achievable is a feeling of being heard and the starting of a shared final journey with the healthcare team.

“Will mum starve to death when she can’t swallow anymore?” can begin a discussion about foods that are minced and moist or small and bite-sized, thickened fluids, or ‘jelly drops [4]’ – award-winning bite-sized sweets, supported in development by the Alzheimer’s Society and designed to increase water intake.

Delivering daily care

Some anxieties are easier to address. For example, that hearing aids, walking aids, dentures, glasses, inhalers, and sometimes a religious book, will be at hand, residents checked and well-cared for (though this is more powerfully role-modelled in real life than put in a paper plan), loved ones kept up to date (or not), channels tuned to favourite programmes, dopamine drugs delivered on time and choices given – even to “dad, who’s deaf as a post but thinks he’s heard”. Extracting essential information like this is the essence of good advance care planning.

What happens in the everyday is important. An overfocus on the future risks forgetting what really matters today, where a difference might be more easily made. Starting with compassionate communication, grounded in empathy, kindness and understanding, advance care planning should also address the incredibly important non-medical things that make a life worth living.

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No decision about me, without me

In its 2010 White Paper, ‘Equity and Excellence: Liberating the NHS’ [5], the Government set forward a vision of an NHS that puts patients and public first, where “no decision about me, without me” is the norm. An advance care plan can help this happen by giving voice to individual choices – painting a portrait of the person, and what matters most – such that the patient is heard, even when they can no longer speak.

At the heart of the NMC Code [6] is a requirement for nurses to treat people as individuals, recognising diversity and individual choice; to listen to people and respond to their preferences and concerns, and to encourage and empower people to share in decisions about their treatment and care. Advance care planning conversations can capture individual concern, convictions and choice, guiding truly person-centred nursing care at the end of life –

and long before.

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