Patient views offer ‘important messages’ for nurses on end of life care

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Nurses have a “huge role” to play in helping patients broach the issue of dying and their final wishes, but it is also vital they have the support to do so, a leading palliative care expert has said.

According to the survey of 2,000 adults published this week by the Dying Matters Coalition, most patients regularly thought about death and believed it should be talked about more often, but many admitted they found it uncomfortable to discuss.

Claire Henry, chief executive of the coalition and a nurse by background, told Nursing Times that the survey findings contained important messages for healthcare professionals.

“We need to have these conversations when people are well and that’s everyone’s responsibility, but health professionals should be encouraging them,” she said.

“Nurses, healthcare assistants and their social care colleagues have a huge role to play, because they often have really good relationships with patients and their families.”

She said it was not about asking blunt questions such as “where do you want to die?”, but initiating discussions at the right time.

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Ensuring people recorded their wishes would greatly help nurses provide the right care when patients no longer had the capacity to make decisions, she noted.

The survey also found most patients considered quality of life more important than how long they lived. The most important factor in a “good death” was being pain free, followed by being with family and friends, and retaining dignity.

Ms Henry, who is also chief executive of the National Council for Palliative Care and chaired a recent review into choice at end of life, said it was vital nurses had the right support to discuss care options and deal with practical issues like providing pain relief.
“It’s really important for specialist palliative care teams to work with more generalist nurses,” she said.

She added that a culture shift was needed towards tailoring services to the needs of individuals, which could see nurses taking on new cross-sector roles.

“For nurses it could be quite exciting,” she said. “It’s about focusing on the person and using nursing skills to enable people to deal with symptoms and get on with living.”

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The survey of more than 2,000 adults found about a third think about dying and death at least once a week yet 72% said people in Britain felt uncomfortable talking about death and bereavement.

Just 35% had written a will, 32% had registered as an organ donor, 27% had talked to someone about their funeral and only 7% had written down their care preferences in case they were unable to make decisions for themselves.

Meanwhile, just 18% had asked a family member about their end of life wishes.

However, the majority – 71% – felt being more open would help ensure final wishes were understood and fulfilled.

The research – conducted by ComRes and released to coincide with Dying Matters Awareness Week – also revealed a lack of knowledge about end of life options or the relevant terminology. More than half of survey participants said they did not know what advanced care planning was, with a nearly a third saying they had never heard of it.

Thirty-one per cent did not know the meaning of palliative care, a quarter did not know what end of life care was, while 12% were unsure about what hospice care meant.

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Jane Cummings

The survey findings follow recent controversies over how the NHS deals with death, including the demise of the Liverpool Care Pathway and the use of “do not resuscitate” questionnaires.

Jane Cummings, chief nursing officer for England, said: “Many of us will know from personal experience that these can be difficult issues for anyone to think or talk about, whether it’s patients, their loved ones or the professionals caring for them.”

She said NHS England had “made it clear” in its Actions for End of Life Care guidance, published in November, how much importance it placed on individuals and their loved ones being engaged, supported and empowered to make decisions about their own care.

“Importantly, we signal a shift in focus from just the ‘place of death’ to the broader ‘experience’ of end of life care,” she said. “Wherever people are, we want to enable them to live well and die according to their wishes.”