

Kim spreads the word...

“Good end of life care stems from good quality of life.”



When a resident at Meadow View nursing home was taken ill, rushed into hospital and died shortly after, a staff member stayed with him throughout, providing medication and personal care so that he was not just pain-free, but calm because he was with someone he knew till the end.

Team leader Kim Maddison broke news of his death to his friends at Meadow View – an Enable Care and Home Support nursing home for people with learning disabilities – in terms she felt they understood, and took them to his funeral.

“We thought we’d handled it well, but how wrong were we?” says Kim, a registered learning disability nurse, 18 months on. “We didn’t understand their need to grieve properly. The last they saw of him was going off in an ambulance; they didn’t have the chance to visit him and say goodbye.

“That will never happen again. Now we’d tell people what’s going on and involve them at every stage. Disenfranchised grief is now a thing of the past.”

The friends someone leaves behind are given time for remembrance, with a proper celebration of that person’s life, with photos, songs they liked, and an entertainer they enjoyed seeing at the home.

Part of the garden is now a reflective area, featuring a wooden wheel engraved with the names of people who have died.

“There are no dates of birth and death – those would mean nothing to our service users; instead we have favourite sayings or something else that is a real reminder of the person, that opens up conversation and provides happy memories to help their friends in their grief,” says Kim.

It was also about 18 months ago that a

“Disenfranchised grief is now a thing of the past.”

Macmillan care home educator approached Meadow View to see if they wanted to run the life enhancing care home award, which focuses on: use of end of life tools, service user involvement, staff wellbeing, staff education, equal access to health services and maintaining community links.

Kim, who had completed the Open University death and dying course, took the lead as ‘quality of life care champion’ and Meadow View completed the award last April, the first learning disability home to do so. Now Kim’s supporting Enable’s other two nursing homes to achieve the award.

“Enable is a really forward-thinking company that recognises and utilises people’s strengths and passions,” she says.

Kim strongly believes that talking about death, and what choices people have at the end of their life, is all part of the overall quality of life and should happen when they’re still well. And individuals who

“We thought we’d handled it well, but how wrong were we?..we didn’t understand their need to grieve properly.”

find it difficult to communicate verbally should have equal opportunity to make their wishes known and ensure they’re acted upon.

Now everyone at Meadow View has their own advanced care plan, detailing all their personal preferences, like whether they want to be buried or cremated, songs they want at their funeral and who they’d like to be there.

It takes time not just to get this level of information from someone whose capacity may be limited, but to be sure they understand what choices they’re making.

Kim uses knowledge gained over the years – many people have lived at Meadow View since it opened in 1996 and she started work there in 1997 – including facial expressions and body language, and relevant images, like pictures of a church, coffin and hearse.

Meadow View is divided into three bungalows, for older people, individuals whose behaviour may be challenging, and residents with complex and

profound care needs. Other staff have volunteered to become end of life ‘mini champions’ to support service users in their own bungalows in making choices.

Meanwhile Kim is spreading the word that good end of life care must stem from good quality of life. She actively challenged local healthcare providers she felt were seeing the learning disability not the person when treating Meadow View service users.

Initial meetings to address Kim’s complaints have led to regular contact and mutually respectful working relationships between the home and health professionals at nearby hospitals and GP practices. “Now they see us as expert primary care givers, so they listen to us and act on what we have to say.”

Within the home, there are now champions in other key areas – privacy and dignity, autism, epilepsy and health promotion. “These individuals have the passion you need to move the service on, and once they see the impact on service users’ quality of life it drives them to do that bit more,” says Kim.

The right knowledge is crucial. She has worked with Skills for Care to develop appropriate staff training programmes, produced an end of life booklet and pulled together comprehensive files of straightforward guidance any worker at Meadow View can access at any time.

But she is especially proud of her ‘dignity tree’ – a strong visual representation of the six areas of the life enhanced care home award that she uses in training and other events. On the tree’s green leaves are examples of what everyone should be doing, like respecting privacy. The trunk features core legislation, including the Mental Capacity Act. Lying below the tree are brown leaves, reminding people what they should never do, such as not listening to service users. And resting at the foot is a tombstone, with the epitaph ‘I did it my way’.

So what is Kim’s way? “Get it right now, while people are well, and things fall into place at the end.” ■

Vicky Burman