**Written statement from Councillor Terri Beer:**

Palliative care through to end of Life care

There has been a misrepresentation regarding my motion which is Palliative care through to end of life.

Palliative care doesn't mean end of life and that should be acknowledged. People with palliative care can have years enjoying a reasonable quality of life as in my own experience with a family member.

Palliative care in my experience is a real postcode lottery in Plymouth and it seems those who speak up for loved ones get the care they seek. It's not consistent. Some will contradict my statement, but this is a real fact having spent many months talking to residents in the city and my own ward as well as sharing my own personal experience.

My family member has been in Palliative care for over two years and during treatment he gets the best care because I would speak up for him if he didn't. As a carer I get no support what's so ever just hurdles and obstacles to go through. It shouldn't be like that. Employers in some cases don't recognise the issues around Palliative care and the impact it has on the person supporting the person in Palliative care. The Council don't in my view understand the issues a member faces when dealing with someone living in Palliative care and going through treatment or even recognise bereavement and its impacts.

There needs to be better support and understanding. I tell people and speak up about Palliative care that I am facing with my family member.

Palliative care does mean that in the middle stage of any illness that for example Cancer dictates your life and plans. The very reason I can't be with you today to share my voice.

End of life care is still failing and although partners will sit before you and tell you it's alright it's far from that.

Examples:

A man with terminal cancer who chose to die at home. Nurses came and because he was asleep, he was not washed or changed. He missed medication and pain relief on more than one occasion. Family members then faced the challenge of changing this man who had been in soiled pads most of the day causing soreness and made to feel extremely bad of the situation he had no control over. End of life meds were not available and even I supported this family with a trip to the hospital to get medication and pain relief. This was a personal friend of mine. He died in pain crying out and family could do nothing as nursing staff were not available. His body lay in the house all night and until 11am the next day. The trauma to the family was imminence.

A lady who during Covid had been in hospital for over 11 months and during this time the family found out she had cancer that had gone to her brain, leaving the patient with brain damage. Fed through a tube, non-verbal because of the brain damage. (Paraneoplastic Cerebellar Degeneration) Living in a nursing home in Palliative care. Due to low staff levels often the family would find their loved one unclean and sat in faeces. Medication was hit and miss and at times family had to demand care and attention. Feds were often late and administered quickly. There then came a transfer to another nursing home and within three weeks this patient died. She died not in pain and in the arms of her sister, that was me. No nursing staff present. Its was a good job it was me there as I spoken up, complained until I got the care for this relative. The failing here was the sudden move, lack of staff and again as the close family member no support.

Palliative care through to end of life:

For two years I cared for my family member at my home. No help, no aids until I fought for them. No night-time support. I covered it all. That was my commitment. Then a stay in hospital and within no time the family member got Covid and I was told not to visit. I did visit and used PPE provided which was very poor. My family member accepted that he was approaching end of life and wanted to die at St Luke's. Enquiring about the I was told they have 12 beds at St Luke's and there is a long waiting list. Prompted by experience and knowing who to talk to I was able to carry my family members wishes out and get him transferred to St Luke's in a Ward. He was there for three weeks stabilising his pain relief. He was clean, washed and comfortable but that was because I had spoken up and spoken out to get this for him. Not everyone at this point has a Terri.
My brother died in a private room with my daughter holding his hand one side and me on the other. A nurse was present and was advising us of the final moments. The point is this would not have happened if I didn't know who to talk too. Not everyone has the energy at this time.

The above examples are my experience and because I am the person who speaks up, fights for what is right I did things my way.

These examples show very different points not consistent and like I have stated if I wasn't strong enough to speak up then the above would have been very different.

Palliative care has shown me different stages of an illness and its not the end game by no means but a journey that you shouldn't have to demand care it should be consistent and it's not.

This needs to be reviewed regularly to ensure equal care for all.

Councillor Mrs Terri Beer