We need to talk about Palliative Care

Glynis Billimore

Feedback from our recent experience of Hospital Based Palliative care.

We have had recent experience of palliative care with my mum who died following a complex admission with a chest infection to IRH and who had moderate stage Alzheimer's.

Our overall experience was not good. My mum was transferred into ward 1 in Larkfield unit in Inverclyde for what was called palliative care ward.

My mum did get a single room but the care received is not what you would expect at end of life. The following are the issues I had with my mum’s care, which I can expand on if necessary.

Good Basic nursing care is so important to ensure comfort, safety dignity and respect at end of life.

- Basic care was at times not adequate or to a standard expected.
- No oral hygiene carried out despite mum not being able to take oral fluids or diet and her mouth was not clean and very dry.
- We had to request this and carry out myself on several occasions.
- Basic care carried out mainly by students and care assistants during day. Night staff care was from Staff nurse and care assistant working together.
- I feel Staff do not have sufficient skills, training or knowledge in palliative care.
- What training have care assistants had in palliative care in this area?
- Poor positioning for assisting with breathing often seen. Mum distressed on several occasions when I arrived for visiting.
- Communication with family very limited at this very painful time.
- No support for relatives offered.
- Mum had painful ear infection and could not get anyone to deal with this.
- Mum could not swallow due to pain and no supportive feeding offered.
- Fluids had to be requested and only option they would consider was via sub cutaneous which was not effective due to pooling of fluid.
- Poor listening skills and frustration in getting staff to listen and act to concerns we had of some of her symptoms.

I tried to get my mum moved out of hospital “palliative care” to get a more hospice type care but was unsuccessful due to need to get subcutaneous fluid support in care home. I had managed to source a nursing home who would
support this but the GP service would not prescribe SC fluids therefore was unable to get mum to more appropriate end of life care.

My mum had care at home prior to her admission by Inverclyde council carers who delivered an excellent standard of care who seemed to have the appropriate training and right attitudes to care.

**Conclusion**

I think the hospital staff training and attitudes are a main issue that needs to be addressed. Staff need to get training from areas of excellence like Ardgowan Hospice if they are going to call themselves palliative care ward.

Ideally we need hospice type area and care that can provide the best of care for all people at end of life or provide enough support to have people die at home with 24 hour care and support.

To do this we need to invest in good training of all nurses working in this area in palliative care and not just a tick box type on line training that seems to be the way now and not always appropriate.

I would be happy to assist with any meetings you have regarding this if necessary. I am a senior nurse with 39 years experience so have some knowledge of what should happen.

I hope this feedback is helpful for your very much needed review of this type of care for all people who are at end of life in Scotland.

**Glynis Billimore**