

We need to talk about Palliative Care

Carole McGregor

I am grateful for the opportunity to contribute to the Committee's inquiry on Palliative Care. My husband Clive died of pancreatic cancer on 16th October 2013, a year after his initial diagnosis. We had known since May 2013 that his condition was terminal and that he would probably have only a few months to live.

Personal experience

In our case, palliative or end of life care was never really offered or discussed during my husband's year long illness. Clive's deterioration occurred very quickly over the course of a weekend after admission to a general hospital for a blood transfusion. No palliative care was available nor access to anyone with the skill or confidence to deal with what had clearly become an end of life situation. Communication was appalling; the actions of some staff insensitive, his care seemed to me to be disjointed and perfunctory and my repeated pleas to help me get my husband home were ignored. I kept being told that nothing could be done over the weekend. I eventually arranged his transfer home by private ambulance on the Monday morning. He received the best care possible from our District nurses and died two days later in his own bed with our 13-year-old twins and me by his side. His death has had a devastating effect on our family but what haunts me most are the memories of that weekend, the fear and panic, the sense of abandonment and the utter desperation of our situation.

Access to Palliative Care

I do not know enough about the structure for the provision of palliative and end of life care in Scotland to add anything useful to the debate on how this can be made more equitable. It is clear however, that the best palliative care is provided by hospices and that there are insufficient hospice places available to accommodate everyone who would wish to end their days there. In the absence of significant additional funding becoming available in the near future, it strikes me that the limited places currently available should be primarily for people with complex medical needs, particularly as regards pain control. I know this will be controversial, but I also believe priority should be given to younger terminally ill patients where their premature death will have a much deeper impact. Hospices have the necessary resources and expertise to help people come to terms with the death of a loved one in such difficult circumstances.

There can be little doubt that one of the biggest priorities must be out of hours and weekend provision of palliative and end of life care. I do not understand why this is not a 24/7 service in the same way as A&E. The precise timing of the deterioration and death of a person with a terminal illness is unpredictable. As things currently stand, a palliative care specialist in NHSGGC will only see you if you are 'lucky' enough to need this during the hours of 9am to 5pm, Monday to Friday. It cannot be right that in a supposedly civilized society, people close to death are denied appropriate care simply because it happens to be a weekend. The other area of focus must be the provision of such

services in general hospitals. From my experience, most staff in general hospitals do not have the skills, experience or confidence to deal with such situations. I think a much more robust approach needs to be taken to ensuring that NHS Boards make adequate provision for out of hours palliative care services and in general hospitals. Whilst the Living and Dying Well initiative produced some admirable objectives, it seems to have achieved little in the way of real change with some Boards clearly paying lip service to meeting the required standards of care.

Communication

Despite Clive's diagnosis of terminal pancreatic cancer, there always seemed to be reluctance on the part of healthcare professionals generally to discuss the inevitable or help prepare you for what was to come. For example, when I was told by Clive's surgeon that the attempt to remove his tumour had failed and my husband had only a few months to live, I asked him how I would know when things were getting worse and the end near. In response he simply shrugged and said 'You'll know'. We did have one meeting at the local hospice but only because I specifically requested it as Clive's GP seemed to think it unnecessary. At the meeting we mainly discussed medication and symptom control and there didn't seem an opportunity to widen this out to palliative care generally. When I asked to speak privately with one of the consultants on duty at the general hospital when Clive was declining rapidly the weekend before he died, it was clearly an uncomfortable experience for him. He could not look me in the eye or give any clear indication of timescales other than mumbling that it was possibly weeks not months. I tried to make things easier for him by making it clear that we had known for some time that Clive would die but this made no difference.

I recognize the difficulties in determining when this kind of conversation should take place but nothing can be worse than having no discussion at all. I would have liked someone, soon after Clive's terminal prognosis, to have found a way to speak to me privately and not in Clive's presence. I would have liked the opportunity to discuss how I thought Clive wanted to handle

this and get advice on supporting him and our children. Clive did not want to discuss death in any detail but had said that he wanted to be at home at the end. I could have communicated that on his behalf and assisted with the planning for his end of life care. In the meantime, as his carer, I also needed to know what was likely to happen over the next few months. Preferably this would be from someone who understood his condition and could explain to me how the disease was likely to progress. I would have liked an open and honest conversation about what to expect at the end so that I didn't have to resort to Google and Pancreatic Cancer charities for this information. I would have liked to know what options were available for palliative care, how to access them and be given an honest account of the possible limitations, particularly as regards the availability of out of hours support.

Anticipatory Care Plans

I do not know what these are and their existence was never mentioned to my husband or me.

Information

Please do not waste valuable resources producing more useless leaflets outlining in general terms, what the NHS aims to provide as regards Palliative Care. Talk to the patient and/or family. Help them understand the roles of hospices, hospitals, GPs, District Nurses, Macmillan Nurses, Marie Curie Nurses etc. Help them work out what would be best in their particular circumstances and how this could be achieved. In terms of reference material, all I would have wanted was an accurate, honest and up to date summary of what support is available 24/7 with telephone numbers and operating hours of the people and organisations you may need to contact.

Training and Support

None of the Health professionals that we came into contact with throughout Clive's illness showed any evidence of having had the necessary training and support to enable them to discuss Palliative Care with patients and families. Some had a natural ability to handle difficult conversations in a sensitive and caring way yet I suspect none considered the instigation of a discussion on Palliative Care to be their responsibility and so it never happened. I appreciate that it is not feasible to equip all staff in general hospitals with the skills required to deal with an end of life situation but perhaps it could be possible for there to be at least one senior member of the nursing staff on duty at any given time with the necessary specialist training who could be called upon to facilitate. There are also a number of basic behaviours that all staff should be capable of adopting e.g. find a way to have a conversation with family members out of earshot of the patient, look the patient/family member in the eye when talking to them, don't talk about the patient in his/her presence as though he/she were already dead ('Bet he was a good looking man' said one nurse to me), remember you are dealing with a patient with a terminal illness – their death is not unexpected so do not shirk from talking about it. The manner of a loved ones death has an ever lasting affect on those closest to him and your handling of it can ease their pain and grief immeasurably.

I hope that at least some of my comments are helpful to you and that you are able to bring about some real and meaningful changes to the provision of palliative and end of life care in Scotland. Please don't let this be another navel gazing exercise that ultimately has no bearing on the patient experience.

Carole McGregor (Mrs)