

## **We need to talk about Palliative Care**

**Jan Walker**

### **What has been your experience in terms of access to palliative and end of life care?**

My mother died from lung cancer in February 2015. During her terminal illness my experience was that the care was left solely to the family to provide. I experienced a lack of joined up working between health and social care and conflicting advice. As her carer during this time, along with my brother, I felt the need for some clear advice about my mother's medication and practical support as we could not provide care and nursing support 24 hours a day. I felt that referrals to social work for care support were not followed through and there was no nursing support during my mother's illness at home. The family was left to administer a controlled morphine drug up to two hours every day with no practical guidance and advice. As my mother deteriorated and her needs increased, the family still could not convince health and social care that my mother needed support. This resulted in a crisis of pain for my mother who was finally admitted to St Columba's Hospice – in my view, this was long after she needed more intensive support. At that point her care needs were met by St Columba's Hospice. But I feel it is such a shame that the family were run ragged prior to this point and that with a bit more support and communication from health and social care professionals, we could have spent more time just enjoying the last few weeks we had with my mother rather than chasing services for support while also providing care and trying to manage our work commitments.

### **How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?**

Better communications from the onset of the diagnosis – not just with the patient but with the family who are ultimately going to be expected to provide the majority of the care. Recognition that families cannot provide care 24 hours a day and practical care support. Talk to the families along with the patient.

### **Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?**

More joined up working and communications between health and social care. A referral system that follows through and makes a professional responsible for referrals being met. Better communications with families about what they can realistically provide in terms of support and care.

### **When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?**

I do not recall my mother being offered any options? Important to have the discussion as soon as diagnosis but not just with the patient who is already overwhelmed by the diagnosis. This was my experience with mother who became stressed and confused by the conflicting advice. More effort should be made to involve the family in any options from the start in a realistic way

rather than just assume their constant availability. It doesn't matter where discussions take place as long as the patient is content with the venue and can be supported by family.

**What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?**

To be honest I do not recall any positive experience of end of life discussions before my mother was admitted to St Columba's Hospice. It was just assumed by health and social care that she would remain at home until the near the end. The challenges for me were around how professionals communicate with family members and assume that family members can provide 24 hour care. Families want to be there and provide care and loving support but they cannot be expected to provide 24 hour care.

**What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?**

Nobody talked to my mother or the family about anticipatory care during my mother's illness.

**How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?**

Written guidance should be available to allow patients and families to assimilate the information together. I was surprised at the lack of palliative care in Edinburgh although when I expressed this I was told by health professionals that we could not expect any practical support until the last week or so of my mother's life.

**What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?**

I don't know what is provided but my experience is that the information was conflicting between health and social care and it was left to the family to make sense of what services might be available – during what was already a very stressful time.

**How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?**

Speak to the families who it seems will be the ones providing the care.

**What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?**

I don't think the priorities were communicated between health and social care. I was told at one point that it was up to me to liaise with health and up to me to liaise with social care. I did not get the impression that either communicated with each other.

I also have cut and pasted below this response, the content of a letter I sent to my mother's GP practice on 9 June 2015 seeking clarification on the issues the family experienced. To date, I have not received a response to this letter. I

have removed my mother's and the GP's details as I realise you will not want to deal with individual cases but I think the letter summarises very well the experience my family had.

**Jan Walker**

**Letter to GP**

9 June 2015

*I am writing with regard to some queries I have about my experience of caring for my mother at home following her diagnosis of lung cancer in January this year. I am writing to you as I understand that the GP is the person who has overall responsibility for the patient. I hope that is correct. I am very happy for this to be shared with the other services who were involved in my mother's care if that is helpful.*

*As you will be aware, during her time of illness at home, my mother was pretty much chair bound until she was admitted to hospital and ultimately St Columba's Hospice where she died on 26 February.*

*I am very grateful for the support you provided my mother during her time at home and to St Columba's Hospice for its support. However, I would like to better understand how services liaise and work together in such cases and if some more timely and practical support and advice could have been offered to the family during a very challenging time.*

*My questions are as follows.*

**Pain Relief**

***Is it normal to expect people who are not medically qualified – rather than medical professionals - to administer Oxynorm and Oxymorph as much as every two hours to a terminally ill patient? Who is overall in charge of deciding which pain relief should be prescribed? I ask this because this was the situation with my mother and it felt extremely challenging to manage – particularly during her last two weeks at home when she was asking for pain relief every two hours. As these are controlled drugs, I wonder if we could have expected more guidance from medical professionals to help the family manage my mother's pain medication. I did try to communicate this to you and the Palliative Care Team at St Columba's Hospice at the time and I do appreciate that it was difficult as my mother preferred not to take her pain relief in pill form. But I do feel we did not find a resolution to this issue. My mother was never fully pain free – despite the consultant telling her she did not need to worry about the pain. And the family was left in charge of administering and scheduling – very regularly - controlled medication alongside a range of other medication, with very little guidance. My concerns about this were heightened when the Palliative Care Team criticised the way we were administering the morphine. Yet we were doing our best in very challenging circumstances and we had had no guidance or instruction about the best way to administer it other than the dosage information that the chemist puts on the bottle. Nor was it ever quite clear who was in the lead in making pain relief decisions on behalf of my mother and in the context of what the family could reasonably deliver.***

### **Home care referral**

**What information is included in the referral to social work for home care support? Who is meant to lead on such referrals and who is responsible for ensuring that care services are established in a way that is timely and person-centred?** I ask this because it didn't seem possible for District Nurse to help establish any care support quickly and when my mother needed it most. When I called Social Work Direct myself to chase things up, a senior social worker there informed me that very little information was known about my mother and they did not know that she was terminally ill or that there was any urgency for home care support. Despite the referral having been made. Even when the home care service did finally kick in, the carers had not been aware that my mother was terminally ill and they thought she had just been discharged from hospital. Additionally, the care visits were not at helpful times with the carers visiting too late in the morning to attend to my mother's morning needs and too early in the evening to attend to my mother's bedtime needs. So I do wonder who should have been in the lead in resolving the home care issue and perhaps even discussing with the family, what care they could reasonably provide. So that a more realistic package could have been put in place.

### **Nursing visits**

**What can terminally ill patients expect in relation to statutory nursing and personal care services in the last weeks of their life?** I ask this because I was told by the Palliative Care Team at St Columba's Hospice in the last three weeks of my mother's life that she likely had 'long weeks' rather than 'short weeks' and that no further support could be provided until nearer the end of her life. On reflection, I still do not understand what 'long weeks' meant. I was also told that it was the role of the local authority and in the large part, the family, to provide the care (and I have highlighted above the difficulty getting carers established). At the time, I felt this was unreasonable as my mother's needs were becoming more and more challenging and worrying – even frightening - to the family. During this time, my mother's pain was increasing, especially when she moved. She was becoming increasingly immobile. She had had a fall. Getting to the bathroom was becoming difficult and on a number of occasions I attended to her toilet needs which she was very upset about. I realise that these things are very difficult to predict but 'long weeks' did not fit with my mother's oncology diagnosis and ultimate prognosis. Yet I was told that her needs did not merit any additional nursing support.

*I appreciate the demands on services but is it really the case that families are expected to provide round the clock care in such challenging circumstances with very little practical support from health and social care services?*

*I do hope you find my questions reasonable and feel any response might help me better understand for the future how services liaise with each other and families and what support can be expected in such times. Hopefully this might also help services understand better the challenges that family members who become carers face, some of which I feel could be resolved with just a little*

*more communication and guidance so that the right services are able to kick in at the right time.*

*I look forward to hearing from you.*

*Yours sincerely*