

## ***Pat's Perspective on Palliative Care***

**“...You're allowed to just be the person you are...”**



As an English Literature student back in the 90's, I was used to reading about the lives of people at various stages throughout their lives. I didn't realise then that nearly 20 years later, as a Palliative Care Social Worker, narrative would continue to be central to my practice. My daily work continues to be dedicated to listening to the personal stories of people, and those important to them, at the end of life.

However, much of my work is done in isolation – I work in a community team where I am regularly visiting people in their own homes. Sometimes I meet with the person individually, or with them and those important to them, but the stories and their experiences usually don't go any further than a discussion with colleagues in a meeting, or at their desk. People's experience of palliative care is often not discussed, captured or shared outside of the palliative care world – which denies us the ability to develop a collective understanding - in both social work and society as a whole - about what people and their families value at this most important of life stages.

With this in mind, I approached Pat – a man in his 70's who I have been visiting at home for the last 18 months. My visits with Pat have been in turn frustrating, funny, sad, and emotional. I have supported Pat and his wife in making the heart-breaking decision for her to move into a nursing home, and have worked alongside Pat to manage the ongoing mental and emotional impact of his deteriorating health. Pat had always said that he wanted his experience to be used to help others, and with this in mind we agreed that I'd interview him, and write this article to highlight his experience of palliative care.

Pat shared – as many people do – how he has always been an independent person, used to any illness being able to be resolved quickly. He feels that palliative care came along at just the right time in his life, as it allowed him to focus on himself at a time when he felt “...any time spent on me would be a denial of my role towards my wife...I hadn't realised I'd worn myself out...”. For Pat, the key was that services were available on a gradual basis, able to be offered responsively as he needed them “I was...surprised how quickly practical help was available”.

Being known to St Christopher's Hospice gave Pat access to a wide range of services not just nursing but also our Anniversary Centre, a social space where he was able to come and enjoy concerts and cake with his wife, as well as music therapy in his own home when the decline in his health meant he became bedbound. Pat spoke of the music therapist being "...a character...she has her own speciality and we can chat and it's unrelated to everyday existence but it's relevant to a side of my life that I enjoyed in the past". Being able to be viewed in this holistic way, as a person with a past, present and future continues to be very important to Pat "I don't like to admit to giving up on any attempt at resolve, I prefer I to do that [try and resolve an issue] even if it's wasted effort. And I've never been encouraged to give up".

What surprised Pat most about the hospice service was not just the range of services available but also the depth of the connection – especially offered by myself as a social worker. He shared his sense that my role had gone beyond "she's obviously got a job to do and it turns out she's pretty good at it", to going "far beyond that into genuine, what appears to be genuine personal concern and that's the footnote throughout everything to do with the hospice. Everything is made to feel as though you are the important one...you're allowed to just be the person you are and that's always been the note with you, Sally".

Pat also commented on the practical support I'd offered "...you've done so much in the practical sense in dealing with officialdom which I've got, quite frankly, bored with dealing with. And I'm very appreciative of these efforts". Most of all Pat spoke passionately about how he felt our meetings had been a good use of his time: "I've thanked you before, but it's really meant. I've had so much other experience of what was basically wasting time. Just because you're ill and dying doesn't mean people have to talk in codes or act in codes...it's absolutely annoying if they're just using time, which I ain't got that much to spare". We discussed the changing nature of Pat's illness, and his wish for people to understand "it's [the hospice team's involvement] been surprisingly beneficial in that I realise I'm at a time in my life when the mental aspect of having disease can take over the physical, and the total care aspect of St Christopher's is helping me with both of those sides – the mental and the physical. And it's certainly made me not resent the physical so much, which probably puts me in a better state to survive and take benefit from the things that the hospice can do in the physical sense". For Pat, it was important that he felt our times together had "...gone far beyond just the physical needs" and that our discussions had recognised "that not just the mental, but total relationship needs of the person, is as important as purely physical health".

Being viewed holistically, as a whole person, helped Pat to continue to build his own personal resilience – in the face of major life changes as well as deteriorating health, with myself and the hospice team contributing to "a reassurance that if another day comes along, you'll deal with it...reminding you of your own resilience". This in turn helped Pat to be able to be "...completely frank, which is a difficult thing I 'spose for many men; to be completely free when opening up my own vulnerabilities". My discussion with Pat also crucially reminded me of how we can forget that sometimes it's as much about what cannot be articulated: "We've held hands a couple of times" said Pat "and there is communication in that simple thing".

Now, at this point you may be thinking what a self-congratulatory article, that I've cherry-picked someone who would have nothing but good things to say. However being able to take risks and have challenging – but necessary – conversations with Pat was pivotal to the

relationship we've developed. This was highlighted by Pat who, in his usual tongue and cheek way, quipped that he always thinks he's right and that he has always expected compliance in both word and deed from 'the ladies'. When I asked if he felt I'd done this he said "oh, by no means! You shot me down in flames and made me question my values particularly about the ladies". Pat explained that he valued our ability to have robust, honest conversations. One example of this was around a discussion Pat and I had regarding the distress he felt at not always being able to see his wife. Her visits were dependent on a relative being able to drive to collect Pat's wife from the nursing home and bring her to the couple's home. In recent times the relative themselves had been unwell so contact between Pat and his wife had been sporadic. Pat was finding this very distressing, and led him to feel despondent as to having any control of the situation for himself. I encouraged Pat to consider practical ways to continue the bond between him and his wife even over distance. Initially Pat found this concept hard to consider or see value in - he just wanted to see his wife. However the more we talked, the more able Pat was able to see the value of trying to communicate with his wife in between visits, with Pat concluding, after receiving glowing praise from his wife for sending her a bunch of flowers and a card, "I will admit that you were correct...". This small gesture gave Pat the opportunity to communicate his love and care – which he missed doing when they didn't meet.

My aim in writing this article, then, has not been to flatter my ego or that of the wider hospice team. It hasn't even been just about exploring what is important to Pat at this time in his life. At root, I also wanted to share some of Pat's story, of how he came to be known to St Christopher's Hospice and to show the man he has been, as well as the man he is now. Illness and death can take so much from us; preconceptions about life-limiting illness can mean that people die – socially – long before they take their last breath. For me the joy of my job is the discussions I have, and relationships I facilitate and form – with Pat as he was when I first met him, with his wife, with the professionals I've joint worked with and with Pat as he is now – much changed but still living.

