Sinead's story - Little pastoral care in the period before she died

Background

Anna tells the story of her sister Sinead's life and untimely death. Sinead developed kidney problems which necessitated dialysis treatment for all of her life. Anna became Sinead's primary carer, as their mother had died many year's previously. *'My mother died when I was in my mid-20s and Sinead my (younger) sister had been chronically ill. Sinead was 9 years younger than me. So I took over her care. She came to live with me. I was the mother of young children and we were also a foster family. Sinead fitted right in, and she really blossomed again. She had a joie de vivre and she never embraced the patient role. She really lived her life to the full.*

Shortly before her mother's death, Sinead received a kidney transplant. But, unfortunately, Anna says '...*the transplant failed – this was nothing to do with* [the quality of treatment she received from] *the health services.* . Anna feels that their mother's death may have been involved in the failure of the transplant - *'...she was having difficulties with it, perhaps it was related to our mother's death, and the emotional upheaval of this time.*

Despite her health problems, Sinead was a larger than life, energetic woman who did her best to ensure that her health problems did not take over the rest of her life. For example, she travelled whenever she could, but eventually, Sinead's health had deteriorated to the extent that she was reaching the end of her life.

Long-term care by the renal dialysis team

Anna says that Sinead had very positive experiences during the long period she was receiving dialysis treatment. *'I have to say that the care she got was for the most part exemplary. The kidney dialysis unit in the hospital helped me as a young parent look after her.'* Sinead had very good relationships with the dialysis unit staff, to the extent that they became very attached to her over the years. *She was a 'have bag will travel' kind of person and, she was their poster girl up there (the kidney dialysis unit), supporting new patients facing dialysis. She was a great example of how to live a life with a chronic debilitating illness. We went everywhere; we went to Spain with the ambulatory dialysis system (CAPD). But when she got the MRSA she couldn't have CAPD and she was back on haemodialysis. But even then we went to Florida. She sourced dialysis wherever it was available with the support of the team in the hospital. I'd say that she drove them crazy with her travels, but they were brilliant and supportive to her.'*

Nevertheless there were some problems with Sinead's treatment over the years. After one episode of dialysis in hospital she contracted MRSA. Anna says '*One day we went to get school books for the children and she did a dialysis exchange in the hospital and, after that (I don't know how long, I've forgotten) she was back in hospital – she had MRSA. I think that MRSA is a very complex thing...I am not blaming anybody for that.'*

Gradual decline towards death

Sinead's deteriorating health was not helped by the MRSA, and Anna says the infection hit her sister hard '...a*fter getting the MRSA attack, she was in (hospital) 2 days before her birthday in August and she didn't get out until December....We all do our best with it, but she died steadily between 2003 and 2008. And she died hard. She was going to die anyway* (independent of the MRSA) *and after her post mortem they couldn't figure out how she was still walking, with the damage to her internal organs.'*

Anna feels that much of the care Sinead received during this extended interaction with the general hospital was good, and that the hospital staff worked well with her as Sinead's carer. Anna is a social worker by training and she says '*I had put in place a plan (part of my expertise was de-institutionalisation) and I realised that she was becoming institutionalised...and they worked with me...we had her out of hospital for Christmas.'*

However, Anna knew that Sinead's health was continuing to disimprove - '...*And [though] we worked away with her issues...we didn't think that she was going to survive. But by 2007 I could see she was failing... I was saying to her health care team "what are we looking at here?"'*

But Anna feels that some of the health care team had difficulties in facing up to the deterioration in Sinead's condition – '*They could not talk to us about end of life. I had worked long enough with people in the developing world … I could see death. Anybody who has worked in a palliative care situation can see it. I think that they did just not want to lose her because some of the team had worked with her since she was a child.*'

Care in the Accident and Emergency Department and ITU

By 2008, Sinead was back in hospital and moved to high dependency. Her health had continued to decline and Anna had a confrontation with the consultant over her condition - '*I said to the consultant - in front of a witness (otherwise I would have doubted it) - I said she's dying... The consultant asked "Well you tell me what she is dying of [because it didn't show up on the tests]". But I said "I'm her sister not a doctor. You tell me what she is dying of..."*

Anna says there were other incidents which were also distressing '... *for instance one night a confused old man climbed into her bed – she just laughed and laughed about that, but* (at the same time) *she was terrified because she couldn't move physically... we refused to leave her alone in the hospital then, and I think that maybe we were regarded as being the 'bad (awkward) family', but there was no other way – she was very vulnerable, she couldn't eat. She couldn't move, she couldn't do anything, she vomited all the time. Her organs had all calcified. The fact that she was still alive was a testament to the woman she was and her love of life.'*

Anna feels that the attitude of some staff left a lot to be desired, and mentions one incident in ITU where she felt they failed to recognise her role as carer. '*I remember an incident with one of the nurses in ITU and this really upset me. I went down to get Sinead some ice because she wasn't allowed fluid, and her mouth was very dry. By the time I was able to get back in to the ward it was just a bag of water, having waited so long outside for readmittance. There was nobody there to let me in (and of course I don't blame them for that), but while I was waiting to be let in, a doctor who knew me asked was I going in to see Sinead. He let me in to the ward (having explained to him that a nurse had told me to wait here and she would come out for me). When I went in, the nurse saw me and came across the ward...and she raised her voice to me and was quite aggressive about coming in without permission* [even though the doctor had invited her in]. *It is this kind of thing that gets to you, even though it was cleared up by another nurse who came over (before I reacted and the situation escalated).'*

Anna also experienced staff attitude problems prior to Sinead entering the ITU. *'One evening one of the nurses called me on the internal line to get over fast that Sinead was very upset.. Sinead was actually bending over in pain - when I told her to 'shush', (trying to comfort her as you would a child), she said 'don't shush me, I can't do this anymore'. (The nurse advised that I shouldn't leave until I spoke to the consultant. She saw how sick Sinead was). Her nurse was trying to support Sinead to cope with another half hour of dialysis as she needed it.'* But Anna knew that this was not the issue. '*It was too late - we were saying she can't take it – we are saying no – what part of no don't you get? ... .'* And Sinead said to Anna *'I can't do this anymore'.*

Anna was very concerned at this lack of listening to Sinead, as well as the failure to recognise the gravity of her condition - '*I was looking at a potential suicide intervention which would have been horrific to us, Sinead was adamant that she did not want to end her days hooked up to machines and that is what happened, but the real issue was that nobody could talk to me about palliative care. Pain management they weren't so bad at, they were good professionals, but they couldn't talk about it. The euphemisms 'when they go there' … What are you talking about - go where? When she is facing end of life and no one is talking to her about it. They were certainly not talking to me about it and I was her carer.*'

The care at end of life in Intensive Care

Eventually, Sinead's health had deteriorated so much that she was transferred to the Intensive Care Unit. Anna also recounts another incident of insensitivity when Jeannette was in the ICU. '*One day one of the nurses saw me making a call on my phone and she came over and said to me "were you on your phone". I said yes, I was calling my Dad… and she said, in a really discourteous manner, that the phone will interfere with the machines. I felt this did not show any understanding of the situation. And that is what makes people complain....A lack of respect or a power trip ….My sister was dying in the bed, and I needed to be in touch with my elderly father. When the consultant came in he had TWO phones. I was in a side ward where no one could hear me - I wasn't interfering with anyone.'*

Eventually, the end was coming close for Sinead - '*She was getting sicker and sicker and then she plateaued for a while. I had to go to abroad for work and I said to the consultant is it OK to go. I was there 4 days and then I was told to get home fast. She had slipped onto a coma by the time I had got home, and we never saw her again – she was gone. I then had to make the decision about withdrawing treatment whether they would switch off* [the noradrenalin] *and this happened without her own consultant being there. He would not talk about Sinead dying.*'

Anna felt that the way they interacted with her at the very end was, at the very least, insensitive. *'When they were turning down the noradrenalin the nurse who was doing it was chewing gum as she spoke across Sinead And then they asked me to step outside the room to discuss a post-mortem while she was still alive. And I was outside the door with the duty consultant, one nurse was discussing what she was doing that night, (which she was entitled to do), but while my sister was still alive and they were talking about a post-mortem in the middle of this busy ward. I feel that, first of all, the discussion about whether to have a post-mortem should have been done after her death. Or with a bit more sensitivity.' And not in an open hospital ward.*

Anna also feels that when Sinead eventually died, there was little sensitivity around the needs of the family. '*It was very, very hard. Lucky it was a Saturday, because there was a 2 day delay in doing the post-mortem and that was the only time we had to come to terms with what happened. Sinead was at the heart of the family and, quite apart from direct family, we had a load of foster kids who had seen Sinead as a key part of their lives. They didn't get to say goodbye.*' But Anna also says that not all staff were insensitive. '*Then again we had the nurses from the dialysis unit coming in who used to be so good to me', and cared so much about Sinead.*

Given her professional background, Anna understands very well the pressures that staff can be under, but she still feels that her treatment was not handled in a professional way. '*What I am trying to get across is that this is their bread and butter every day, but to us it is one of the most traumatic experiences of our lives. I had to pick up the pieces for my family afterwards and no one ever came to ask us how we were.'*

Lessons that could be learned

Anna does recognise that some parts of the system and some people within the system were very helpful. '*Not all of it was awful and the parts that weren't made the rest of it OK at the time. For example, the dialysis nurses that came down to our home for the funeral were wonderful.*

Anna feels that MRSA is a complex issue and she doesn't harbour blame for it. '*The MRSA that Sinead got, I'd say that it was waiting to happen and that it is a global issue, I don't blame the hospital for that because we are all involved in transmitting it - the overuse of antibiotics and so on is to blame and that the hospital did their best against a very big issue. When she went to hospital with the MRSA, looking back, she was starting to physically weaken. The MRSA just finished her off.*'

Getting the balance right between treatment and palliative care

The key issues for Anna were around acknowledging that Sinead's illness was terminal. This was slow to happen and was handled badly, with negative consequences for Sinead, Anna and her extended family. '*When she died do you know what the books next to her bed were? They were brochures for ocean cruises with dialysis services available on them! She was a beautiful and vibrant woman who loved life and it seems that, no one actually thought that she might die. What did they think, that someone with an illness like Sinead's was going to live forever?*

Anna feels strongly that palliative care should have been made available – Sinead was dying in a more difficult way than needed to be the case because it was not made available. Sinead didn't say anything about this except to Anna*. 'She said to me that 'I can't go on'.* Anna says '*First of all it should have been in a palliative care setting. When she died, there was pain on her face – there was no peace. And when she died and they took out the tubes, she went back to herself. But the difficult conversation had to be had and no one recognised it except me that she was dying. And we missed the last few weeks of her life as a result*.'

Anna didn't feel able at the time to make a complaint, so there was no longer term learning or response from the system. She says '*The dialysis services were A1. There was nothing to address there. They knew her very well and all of her ways. But when she went down to ICU, they didn't know her, it was different. There was one nurse from India and she was so gentle, and she stayed with me when she was dying. There were others who were much less empathic. That nurse was so supportive – she let me lay out Sinead with her.'*

Anna feels that there is a failure to acknowledge and deal with issues relating to dying, and death demands more open attitudes to these issues. '*There needs to be a more open attitude about chronically and terminally ill patients. There comes a time when we can no longer fix all the bits. We are surviving all the things that killed us all years ago, so we are going to have to face up to this issue. We have to have openness to it, and not have a fear of failure, or whatever it was. Around death there has to be more sensitivity. After Sinead died I got her stuff back in a yellow bag. I know that this has changed since then.'*

More sensitivity - towards the patient and the family

For Anna, insensitivity was at the heart of the negative experiences that she had. *'They need to have awareness all the time of the patient and family.'*

Anna also notes the failure of services to listen to her about the severity and nature of Sinead's illness. '*I wasn't listened to, I think because they are so busy. I don't think they are unkind people, I think they would have sat down if they had the time to do it. But if you have 10 people doing 20 people's work this is what you are going to get.'*

Clinician's need to be able to face up to patients' death and dying

Another point Anna raises is that many individual clinicians did not seem to be able to face up to the issues of death and dying. '*The consultant did not want to see that she was dying. He thought that he should do everything to keep her alive, that this was his role. He did a very good job treating her medically for years, but now it was time to let go.'*

Structural problems need to be addressed

Despite all that had happened, Anna recognises that many of the apparently 'human' failures were, in fact, due to structural problems in the health service. '*In ICU, we have to be very careful of burnout. We have high octane situations with high octane workers. I see this with some of my own students. Some of them have to be in on the drama. We do need people like that, dynamic people who will not collapse under the pressure and we need those workers.'*

Need to have a pastoral role and perspective in the care team

However, there is also a need to have a balance in the health care teams between more technologically-oriented staff and those who appreciate the need to interact in a supportive way with patients and family. '*But we need to have someone else on the team, not just a social worker who comes in in the morning, but someone who is involved all of the time; someone who can stand back and soften the situation. We do need someone there to oversee the pastoral care.*'

Anna sees this problem in structural terms rather than as being specific to one profession. '*I know everyone works very hard, but there is a disjointed system there. It is not a social work problem – their role has changed, maybe it is a patient advocate, maybe it is someone who has been through it, maybe we need a completely new role. It is not a problem with existing disciplines, but an issue of the balance of the clinical team. It needs someone who is able to come into the room and slow it all down and make the situation more human - acknowledging that the patient is dying, but being human about it.'*

Anna thinks that the emphasis on technological approaches to medicine and health care, while understandable, is getting in the way of dealing with the issues surrounding end of life care. '*There are problems with the basic ethos of technological medicine. Every hospital should have a hospice ward for a start. Politeness and courtesy are not an add-on. It is a part of the culture that we are supposed to care. You know, 'tell me what is wrong with you, tell me why you are upset', rather than 'you are upset now, what we are going to do now is …. And treat you like a child.*'

For Anna, the root causes of these problems are understaffing and overwork. '*They are totally understaffed …. You can't do gallon sized work in pint sized time…. The HSE has to resource their services properly – how can you be compassionate all the time when you are exhausted.*'

How the system deals with mistakes

Anna also feels there is a need to improve how the system deals with mistakes. '*The system doesn't learn from its mistakes, because they are afraid. There is a fear of negative consequences if they admit mistakes. I don't blame them for that… Mistakes do happen and we make a judgement which isn't always right, and I accept that it is not an exact science.*'

More holistic approaches taking into account families and carers as well as the patient

Another issue for Anna is the almost exclusive emphasis on the patient. While it is obviously appropriate to provide treatment to the patient, she also feels that '*the treatment is focused mainly on the person who is ill, not on the family or carers or significant others. However, it is not holistic and the person who is ill is relying on the family or the carer to take them where they need to go, whether it is out of hospital or to let go…. It is a very medical model and the social model isn't taken into account enough.*'