What is unbearable?

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Assisted Suicide is a scary subject. As I headed out to an evening on this topic, organized as part of the impressive Kicking the Bucket Festival, I felt slightly nauseous. I wondered who would be there. Perhaps no one! Or, my black humour suggested, only people who had come with a friend. One person I was sure would be there was Nigel Biggar, the Regius Professor of Moral and Pastoral Theology at Oxford University. He was going to open the evening with a talk.

I arrived to find about thirty people in an oak paneled lecture room. Professor Biggar spoke with due seriousness, and then in question time filtered each contribution through his rigorously thought-through criteria for ethical behaviour. The discussion deepened and widened, with one contribution cross fertilizing another. I began to relax. It felt surprisingly heartening to explore this so carefully.

Professor Biggar spoke about the legal criteria for euthanasia in the Netherlands: unbearable suffering with no prospect of improvement; and for physician-assisted suicide in Oregon, US: 6 months to live - plus of course many refining criteria in both cases.

On balance, he is against legalizing assisted suicide in the UK – a different position to many of those present that evening. For one thing, he doubts that the relevant institutions are functioning to a standard that would ensure compassionate application of the legal criteria. For example, Age UK estimate that half a million elderly people suffer abuse in care homes or in their families. In this ugly social context legalizing assisted suicide could mean pressure on vulnerable people to end their life.

However, he commented, not to legalize assisted suicide brings with it an ethical imperative to consider those who are suffering unbearably. What can be done? He had some suggestions, e.g. that medical training needs to be changed, as doctors are focused towards saving lives, and patients can feel pressurized to continue treatment, instead of supported in re-orienting their care towards a peaceful death.

I see other needs in medical education, as well. A friend of mine who has suffered her entire life with a distorted skeleton requiring continual surgical reconstruction told me that after appointments with her specialist with no mention of her lived experience, she often came out wondering if she was mad. Did she really have pain? Not only did she suffer her inevitable suffering, she also suffered from the way the doctors did not acknowledge her daily experience of pain, perhaps because they were so helpless to solve it.

When others deny or avoid what is so, that denial in itself can make a person's pain unbearable. It is a harsh kind of loneliness. Yet when well accompanied the same moment can become bearable - still horribly painful, yet with a sustaining energy that breathes inner strength into a person, and helps them bear their suffering.

Nowadays some medical educators are bringing this awareness to doctors, but to greatly decrease suffering it is not just doctors who need a different kind of education, we all do. Very few of us know how to be alongside someone in intense physical, emotional or mental pain, in a way which sustains that person and our own capacity to care. We feel awkward and scared. We cling to our cultural training to 'fix' things, cheer them up, turn attention away, watch TV, have a cup of tea, make it about me, and in other ways deny or ignore the experience of the person suffering. We do this not because we are nasty people, but because we don't know how else to be.

Yet some people do know. I'll always remember the eyes of the man who held me in a moment of intense suffering, when I was on a train home from visiting my father who was very ill in hospital. During that visit I had realized he was going to die. Something in me was undone and I could not stop crying. I had to get home to pick up my young son, so there was nothing for it but to board the train for the one-hour journey.

Crying with intense grief on a train is not fun, especially in this type of train with seats in groups of four, facing each other. I could just about keep it private until the train stopped in the middle of nowhere. It stayed there for twenty minutes. Without the movement and noise of the train my crying was exposed and audible. Still I could not stop it. Everyone seemed intent on looking away, which was OK with me as I felt embarrassed – but then I saw that one man, seated diagonally from me in the next group of seats was looking directly at me, with a great deal of stillness and presence.

His look was in no way an intruding one. He was just there, seeing, not avoiding, not trying to change anything. He did not try to show sympathy or say something kind. He simply sat and held me in his eyes. I'll never forget his eyes. I was accompanied. My grief was seen, and in being seen a strange sweetness joined in the mix of my feelings and my grief became bearable.

Over the twenty five years since then I have witnessed this kind of accompaniment of another's pain many, many times, and I have seen, heard and felt the beauty of the sustaining quality this brings. My work in this period has been focused around learning and teaching empathic connection with others, and with ourselves.

Sometimes I accompany people in deep distress. This has also enhanced my capacity to be with friends and family in their suffering, for which I will be forever grateful. This way of being is not therapy – it is being human. It is an important aspect of love, compassion and care, yet it is sadly missing from many people's lives.

People come to know this way of being through different journeys. Some through their religion or spiritual practice, some through terrible life experiences of their own, and some through learning principles and skills of compassionate connection. Amazingly, it is quite easy to develop our ability to offer this presence.

What is tragic is that harm in care settings is mostly unintended, and can happen simply through not knowing this. For the carer or family member, overwhelmed by the other person's suffering and unequipped to bear witness to their pain, the only behaviour they may be able to access is denial, avoidance, and even harm.

As some people experience such unbearable suffering that they long for the end of their lives, don't we have a responsibility to educate ourselves and our society into this ability of compassionate presence, to become people who know how to live from the wise saying, 'Don't just do something, be there!'