# AHPCC Conference 2015

# “Daring to be real”

Our Day Hospice: trialling a patient self-assessment tool, called “The Distress thermometer”. But they’ve decided to rename it “the *well-being”* thermometer. When I asked why, I was told that it was because distress sounds so negative (which is as good a place as any to start thinking about “daring to be real”).

My first day as chaplain in a SPCU – 1994. Although I’d had an interview for the post, nobody seemed to imagine I needed any training or particular preparation for the role. Though they did give me a badge. I walked to the nurses’ station and introduced myself; and one of the senior nurses said: “I’m so glad you’re here. The husband of one of our patients, who died earlier this morning, has locked himself in the viewing room, with a bottle of whisky from the drinks cabinet… Can you do something?” It introduced me, right from the off, to the yawning gap that so often exists between theory and practice – between how we talk about palliative care & about chaplaincy, sometimes in very elevated (almost romantic) terms, and the raw, painful stuff of *what actually goes on.*

And I’ve called this session *daring* to be real because I don’t believe that “real” is something any of us finds easy. (TS Eliot: “Humankind cannot bear very much reality.”)

One of the first books I was given to read was “Introducing Palliative Care” by Robert Twycross – classic text book, clear, informative. The word *palliative* derived from Latin “pallium” – cloak, cover; so (in palliative care) symptoms are “cloaked” with treatments, with the aim of providing comfort. But cloaks can also mask – they hide from view all the scars, wounds lurking beneath the surface. I’ve come to feel that it is all too easy in speaking about palliative care to collude with a fantasy – no-one need die in pain; unfinished business is resolved; peace at the last. Variations on this fantasy embrace the people who work within (palliative care): an extract from a thank you letter: This was “heaven on earth;” and “you’re all angels;” ”whatever the difficulties and stresses of your job, you are never stressed”.

#### Q: What is the emotional/psychological/spiritual cost to us of giving people that impression – of enabling them to feel that way about us?

Work in a hospice for any length of time and you cannot fail to be aware of the way that staff who will expend seemingly endless reserves of empathy and compassion on patients and their families can be pretty nasty to one another. (It sometimes feels as if our degree of inner chaos is directly proportional to the perfection of the soft furnishings.) And I don’t think we should be too surprised at this, or too hard on ourselves. We are, after all, dealing day in, day out, with suffering, fear, pain, death & dying… As well as what we absorb from those we care for, there is also what we bring, from our lives and our own vulnerable selves.

So what does it mean for us to be real in this context?

Perhaps some of you saw about a fortnight ago the remarkable TV drama ‘The C Word’ about a young woman, Lisa Lynch, who died in 2013. She wrote a blog which became a best-selling book as she was living with cancer.

*The opening words of her blog were: “I’m going to write my way through the bullshit – counteract some of the utter crap that’s out there. Where are the people telling it like it really is…?*

Later (after treatment): *“After six hideous weeks of chemo I want to pick myself up, dust myself down and write something uplifting. God knows, that’s what everyone around me expected, and deserved. But more than wanting it to be uplifting, I want it to be honest; and the honest truth is that at the end of treatment it feels like there’s as much to mourn as there is to celebrate… “I want it to be honest”.*

So in response to Lisa’s heartfelt, angry demand…

In the quest to be real:

## Most important thing to be: ourselves

*“The greatest asset which any of us offers to another in caring relationships is ourselves, or to be more precise, our reflexive selves – the self which we have reflected upon. In the fullness of our humanity, including our vulnerabilities and wounds, we have the capacity to create grace-filled relationships with others who seek our care”.*

*Ewan Kelly: Personhood & Presence.*

(We could have another whole session on what is involved in being self-reflective…)

And I think we should be helped in this by the fact that, in one sense, we have *nothing* *else* to do. Sometimes, I long to have something clearly defined and practical to fall back on: oh, for a bed to make, a leg to bandage, an injection to give! Fundamentally, though, chaplaincy is not primarily about having a requisite set of skills (though of course we can learn to be better at what we do), still less is it about the right assessment tool with which to evaluate a person’s needs. It is about being ourselves with the people we encounter… (which is why reflecting on who we are, what we’re bringing… is so important.)

What makes this more complicated is how people see *us.*

Two encounters, both disconcertingly on the same day:

* a woman with painfully swollen legs: “I don’t need to see the lymphoedema nurse, I need you to lay your hands on my leg and pray for the swelling to go down”:

and a little later on:

* a gentleman with a brain tumour, elegant and somewhat disinhibited, who kissed my hand and said: My dear, I have always thought that people like you talk absolute bollocks”.

So I was assigned the role of miracle-worker *and* charlatan in the same morning.

But, if we can gently resist the projections that people foist upon us, relationships can open up in a remarkable way….

*“By being themselves, ‘being me’ and so contradicting the person’s expectation of what the chaplain will be… the chaplain can demonstrate a preparedness to be in human contact with a suffering person no-matter-what, and at this point their relationship can become creatively therapeutic.”*

*Steve Nolan: Spiritual Care at the end of Life*

### Invitation: to reflect on an occasion when you have been able to be yourself in a pastoral encounter with another, and this has opened things up between you; or maybe when you have been unable to get past the way someone else sees you, the role, and that has been frustrating…

## Most important thing to do: be present/listen

In the Christian gospels, Jesus, when he is contemplating his crucifixion, goes to pray in the garden of Gethsemane and takes his closest friends with him. He asks them to stay, and to watch with him. When he comes back from his anguished prayers, he finds them asleep.

It has always felt to me that their sleeping is about not being able to stay with the pain. “Could you not watch with me one hour?” No they couldn’t: they escape into sleep, or violence (anything to *do* something!), or they run away.

I don’t think we should underestimate how costly it can be to stay, to keep awake and attentive, silent when we long to jump in, to remain with all that cannot easily be resolved – resisting the temptation to try to fix things. And we have to be conscious of how even ritual, prayer can be problematic if we use it to evade discomfort, offer ‘resolution’ too soon…

#### \* story from my family history (prayer offered at the wrong time…)

When I started in healthcare chaplaincy 20 years ago I was fortunate enough to hear an interview with the late Dennis Potter, the TV playwright, just weeks before he died of cancer. He spoke unforgettably about his experience of hospital chaplaincy. I’ve kept his words ever since and I look at them when I’m feeling brave:

*“There is something trivial and empty about too facile an optimism when you are in the dark. The simpering fool who asserts that everything will turn out all right in the end is too often the man who wants to sprinkle sugar on a festering wound or stuff his ears with cotton-wool in order to cut out the cry of the innocent.*

*There is in religion quite a bit of this morally indefensible evasion, expressed in what may fairly be called the Sunday School response to the world. One of the funniest and saddest things I saw in the hospital where I was a patient was the young chaplain, doing a swift, head-bobbing round of the infirm: an amiable fellow, with a pink countenance, his nerves nevertheless stretched to the full, scurrying up and down between the beds, nodding and grinning helplessly with a ‘gobble-gobble’ that eventually articulated itself into “Is everything all right?” And equal panic came back from the bed. “Yes, yes”, we would say, terrified that he might linger, and perhaps even more alarmed about the prospect of answering honestly and thus giving too unguarded a voice to the anxiety or even despair kept for much later in the night”.*

 *Dennis Potter (interview 1994)*

The punchline for me is when he talks about the alarm at the prospect of *answering honestly*…

The contrasting picture is provided by these words of Jim Cotter:

*“I sit by your side.*

*I have nothing to say.*

*There is nothing I can do.*

*I am anxious.*

*I am afraid.*

*But I stay”.*

 *Jim Cotter: Healing - more or less*

And when we can stay, and listen, then often those whom we listen *to* are able to hear themselves, their own stories and their own deepest longings...

*“My basic ministry with the dying and bereaved is to listen – to listen attentively and with such care that people can listen comfortably to themselves, with a confidence that comes from being valued”.*

 *Bill Kirkpatrick: “Going Forth” (1997)*

This asks for patience, refusing the temptation to rush, and recognising that sometimes there are no answers…

*“I beg you, as much as I can, dear sir, to be patient toward all that is unsolved in your heart and to try to love the* ***questions themselves*** *like locked rooms and like books that are written in a very foreign tongue. Do not seek the answers, which cannot be given you because you would not be able to live them. And the point is, to live everything.* ***Live*** *the questions now. Perhaps you will then gradually, without noticing it, live along some distant day into the answer”.*

 *Rilke R.M. Letters to a young poet*

### Invitation: to reflect on an occasion when you have really been present/listened to someone and it’s made a difference; or maybe when someone has really listened to you…

I would suggest that in being ourselves, and in truly being present / listening to the other without judgement in our pastoral encounters, there is something intrinsically healing. I believe this promotes well-being, precisely because we are not shying away from the messy, complicated realities of our humanness – the pains as well as the joys, the things that can’t be resolved as well as those that can. I believe that, when we do this, we are in effect saying: you are loved.

## The most important thing to say: You are loved

This, for me, is linked to notions of hospitality: hospitality, which welcomes and accepts the other person as he/she is:

*“Hospitality… wants to create a friendly emptiness where strangers can enter and are free; free to sing their own songs, speak their own languages, dance their own dances. Hospitality is not the subtle invitation to adopt the life style of the host, but the gift of a chance for the guest to find his/her own”.*

 *Henri Nouwen: Reaching Out*

There is a mutuality about this, too, an awareness of our shared humanity… not about doing *for,* or *to:*

#### The Bodies of Grownups

“The bodies of grownups

come with stretchmarks and scars,

faces that have been lived in,

relaxed breasts and bellies,

backs that give trouble,

and well-worn feet:

flesh that is particular,

and obviously mortal.

They also come

with bruises on their hearts,

wounds they can't forget,

and each of them

a company of lovers in their soul

who will not return

and cannot be erased.

And yet I think there is a flood of beauty

beyond the smoothness of youth;

and my heart aches for that grace of longing

that flows through bodies

no longer straining to be innocent,

but yearning for redemption”*.*

 *Janet Morley: All Desires Known*

Some while ago, in our Day Unit – when it was *Day Care* before it became *Day Therapy* before it became *Day Hospice –* there was a lovely luminous summer day, with a lot of creativity and laughter. All the men were painting bird-boxes (their choice!), the women were making jewellery, everyone was mucking in – and I wrote this about how it felt:

#### Day Care

We are day carers.

Some of us have badges;

but we all have names –

We wear our history on our sleeves

in frail flesh and bone,

accents and memories.

We are day carers

Some of us are patients;

but we all need help –

We build bird boxes and friendships,

splash colour onto vases

and grey Monday mornings.

We are day carers.

Some of us are paid;

but we are all professionals –

We work on raw materials together,

threading our time

with beads of hope and laughter.

.The necklace shines;

it belongs to us all.

 *Judy Davies*

So, in the quest *to be real*, the most important thing to be is ourselves, the most important thing to do is be present and listen, the most important thing to say: you are loved.

This is not an easy stance to maintain: particularly as we work in a healthcare environment that will always be more comfortable with things that can be evidenced and measured. But I believe that this is the heart and soul of good palliative care – and what we as chaplains always need to be about.

Judy Davies

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