

Sustained from the Inside – Attending to Vision

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Keynote Address at the Annual Conference of the Association of Hospice and Palliative Care Chaplains, The Hayes Centre, Swanwick, 16 May 2011

'Find purpose, the means will follow'. M K Gandhi

'What sustains you from the inside?' That question comes from a poem called *'The Invitation'* by Oriah, Mountaindreamer which I often use to introduce the concept of spirituality and spiritual care to colleagues. I am sure the poem will be familiar to many of you here but, even so, I would like to invite you to hear it as personally addressed to you from the lips of one of your patients. So take a moment to travel back in your mind's eye to your place of work, and let the first patient that comes into your head be the one who says to you:

It doesn't interest me (*chaplain*) what you do for a living.
I want to know what you ache for
and if you dare to dream of meeting your heart's longing.

It doesn't interest me (*professional carer*) how old you are.
I want to know if you will risk looking like a fool
for love, for your dream, for the adventure of being alive.

It doesn't interest me (*friendly person*) what planets are squaring your moon...
I want to know if you have touched the centre of your own sorrow
if you have been opened by life's betrayals or have become shrivelled and closed
from fear of further pain.

I want to know if you can sit with pain, mine or your own,
without moving to hide it or fade it or fix it.
I want to know if you can be with joy, mine or your own
if you can dance with wildness
and let the ecstasy fill you to the tips of your fingers and toes
without cautioning us to be careful, to be realistic
to remember the limitations of being human.

I want to know (*chaplain*) if you can see Beauty even when it is not pretty every day.
And if you can source your own life from its presence.
I want to know if you can live with failure, yours and mine.,
and still stand at the edge of the lake and shout to the silver of the full moon, "Yes."
It doesn't interest me to know where you live or how much money you have.

I want to know if you can get up after the night of grief and despair
weary and bruised to the bone
and do what needs to be done to feed the children.

It doesn't interest me who you know or how you came to be here.
I want to know if you will stand in the centre of the fire with me
and not shrink back.

It doesn't interest me where or what or with whom you have studied.

I want to know (*dear spiritual carer*) what sustains you from the inside when all else
falls away...

'Mountaintreaming', from *The Invitation* published by HarperSanFrancisco, 1999

What sustains you from the inside when all else falls away? What keeps you going as day
after day you sit at bedsides, listening to stories of hopes dashed, dreams shattered and
time running out or as you comfort relatives, support colleagues, teach spiritual care, play
your part in clinical governance or conduct funerals?

For me, the question 'what sustains me from the inside when all else falls away' is an
invitation to grapple with my own personal vision. Who am I and what am I for? What is my
work and vocation in the world and how is that to be expressed?

In '*Open to Judgement*' Rowan Williams asks:

'Are you looking into your vision? Are you letting yourself be changed and shaped by
what you see? I'm asking, in fact, about the precise degree to which your vision is for
you what you live by from day to day, a matter of life and death, sense and
nonsense.'

There is a real urgency in Rowan's understanding of vision as the core from which we live
day by day, the internal wiring which directs our reflexes and impulses, the criteria by which
we determine meaning in our lives. He continues:

I have no right to destroy your vision, nor you, mine. I have no business to devalue
your understanding or make light of your struggles, nor you, mine. But we have the
right – and perhaps the duty – to put the questions to each other and hear them from
each other.

Rowan Williams, 2002, *Open to Judgement*, London: DLT, p. 110

I think what Rowan is saying here is not so very different from the kinds of conversations we
have at bedsides with patients or in the cafe with relatives when we ask:

'How are you doing?
How are you coping?
How are you making sense of what is happening to you?
What keeps you going?
What is getting you through?

Questions we ask, conscious that we have 'no business to devalue their understanding or make light of their struggles'. Questions which have a deep relevance and resonance with our own lives too.

On Learning from the patient as spiritual teacher

For years now, I have held the view that my patients are my teachers and that I receive daily spiritual guidance and direction from them. That view was born from my very first week at CARA, an agency set up to provide spiritual care for people living with HIV and AIDS. I was as naive as you can get and completely out of my depth when I went to visit Jonathan, a young man living with AIDS, at his home. As he closed the door behind me he asked: 'Whats the deal? You visit me and I die. Whats in it for you?' I had been trained in Biblical Studies and Doctrine. I could decline a Greek verb and pick holes in the Arian heresy, but nothing had trained or prepared me for the question 'what's in it for me?' I was speechless at the time and not particularly articulate in my response now, but what Jonathan taught me, that day, was that from henceforth and forevermore my patients would be my teachers and my spiritual guides if only I would let them. When I recounted that visit with Jonathan to David Randall, my supervisor, he said that there were two commandments in working with people who were staring death in the eye. The first was 'Thou shalt not bullshit'. And the second was like unto the first, 'Thou shalt never bullshit'. Why? Because the dying are great bullshit detectors. Cicely Saunders makes the same point far more politely when she says: 'the dying have shed their masks ... and are all the more open and sensitive because of this'. (cited in the Tibetan Book of Living and Dying, p 211) And in shedding their masks they invite you and I to shed ours too. In moving beyond the superficialities of everyday living they invite me to take a good look at myself and find what is rich, meaningful, lasting and true. In their powerlessness, they invite me to let go of the illusion that I am in control. In their vulnerability they invite me to befriend my sense of inadequacy. In their suffering they show me what compassion looks like. In their search for meaning they ask what makes me tick. In facing up to dying they ask what I live for. In running out of time they ask how I am using mine. In anticipating saying goodbye they ask about the quality of my relationships. In searching for hope they ask 'what sustains me from the inside?'

I pose that question out of the conviction that when we live out of the vision that lies at our very core – the vision that sustains us from the inside - then rather than being depleted, our work energises and refuels us. (cf Renzenbrink viii.) Conversely, when we live divorced from vision, out of touch with our core, then our lives and our work, though mechanically faultless, become corrosive and toxic as we head towards meltdown and die inside. In short Vision sustains – lack of vision haemorrhages.

'Our relationship with our work influences our inner life as well as our experiences with others. It can set in motion a cycle of damage that, if not for our awareness, can overtake our whole lives' *Trauma Stewardship*, 42

As the wise woman said: 'By the time you're thirsty, you're already dehydrated' quoted in *Trauma Stewardship*, 45

In my experience as a psychotherapist and pastoral supervisor working with spiritual leaders and with a good number of healthcare chaplains, what I have seen time and time again is that it is not so much over-working or over-caring which leads to burn out so much as a lack of life giving purpose, a sense of who a person is, what makes them tick and what they are here for that destroys them. We are well used to recognizing that inner hole of purpose and meaning in our patients but would do well to be on the look out for it in ourselves and in our colleagues.

Organizational or Contextual vision

But personal vision, important though it is, is only part of the equation. As employees or volunteers of an agency, our individual or personal vision, what we feel called to do or be, how we feel inclined to express ourselves has to be worked out within the culture, norms, patterns of relating etc 'agreed' in that context otherwise we run the risk of 'doing our own thing'. So taking my own personal vision statement 'I have come that you would have life, life in all its fullness', it is not a matter of me making the job fit what appeals to my temperament and personality but rather of me bringing my personal vision of life and fullness to the tasks and expectations set out in my job description whether I find them life giving or not. In other words personal vision needs to dialogue with organizational vision and expectation. And that can be a real challenge especially when spiritual care is largely provided by a one person band and where post holders are trusted to get on and do with a minimum of oversight. I know for a fact that there are parts of my job which leave me stone cold and some which even clash with my personal vision but I also know that I am NOT self employed and to behave as if I were would be devious and deceitful.

One of the graces of working in palliative care is that although the work is intense, difficult and often very sad, the experience of pulling together with truly inspiring colleagues to do something really worthwhile can energise, support and refresh us. But lets not be fooled by the language we hear others use of us everyday. Palliative care teams are not made up of angels and hospices are not all goodness and light. As Michael Carroll writes:

'Organisations are amazing places to work: they are full of idealism and despair, they desperately seek change and they hate change, they create health and support amazing regression, they ask for feedback and kill when they are told what they do not want to hear, they are filled with great cooperation and incredible collusion. They are never dull. And they need supervision – badly!' (in Benefiel & Holton, 2010:114)

I have certainly had dealings with a hospice which left me feeling very uneasy. The only way to describe it was that it felt like the hospice as an organization had been put on the Liverpool Care Pathway but that no-one had remembered to attend to organizational hygiene, symptom control or pain relief. Each day 'I left desperate to take a shower and rid myself of the feeling I had experienced just being there. It wasn't about the condition of the carpet or the decor' but the 'absence of light and hope and possibility' that emanated from the place. In short, the organizational culture felt negative, exclusive and hopeless and that negativity spilled over into relationships between the staff. (This is a paraphrase of Dernoot Lipsky, (2009:24-25)

Towards a vision for our work

In '*Meetings at the Edge*', Stephen Levine describes the work we do in caring for the dying and the bereaved as 'a high wire act' in which 'the heart is kept open in hell' as it tries to maintain 'some loving balance in the face of all our pain and confusion'. In similar vein, in the *Eight Stages of Man*, Erik Erikson posits that in the last stage of our lives we live the creative stress between Integrity and Despair. The fruit of this time, says Erikson, is Wisdom. In the second part of this presentation I want to share with you some of the wisdom I have learnt from patients which I believe, goes some way towards creating a sustainable vision for our work.

Reclaim Role Confidence

Being part of an MDT can be one of the most appealing aspects of our work. The professionalism, skill and competence of our colleagues is impressive. They talk knowledgeably about differential diagnosis, symptom control, lymphoedema. They have sophisticated equipment and state of the art medications. Little wonder, I often hear chaplains describing themselves as charlatans who spend so much time saying what chaplaincy is NOT that they struggle to convey with appropriate confidence what it is. If we are to sustain ourselves for the long haul then we need to hear that in our patients' view, spiritual care matters and confidently reclaim our role within the team.

Re-appropriate Professionalism

Conscious to break with the past, what chaplains sometimes do is overcompensate in an attempt to look professional. On goes the shirt and tie or the power suit as we talk ourselves into believing that the more we don't look or talk or think as chaplains the more 'they' might accept us. We get up to speed with protocols and guidelines, research and spiritual assessment tools and rightly so but neglect the balance between mind and heart, intuition and intellect, mastery and mystery, and accumulate facts rather than cultivate wisdom (cf Benefiel & Holton, 2010:13) Patient wisdom says: Be yourself, there's plenty of them but only one of you!

Don't try to look busy

One of the great gifts of our role is that we *have* time, we can *make* time, we can *find* time to walk mindfully from bed to bed, room to room, to walk slowly enough that colleagues or relatives don't think they are stopping us in our tracks on our way to see someone more important than them. 'In a world gone mad with speed, potential and choice, we continually overestimate what we can do, build, fix, care for or make happen in one day' Muller 2010:5 cited in Renzenbrink, I., (2011) Colleagues don't need to see their own speed and drivenness mirrored back to them by the very people whose presence in the organization needs to point to a horizon far beyond the next deadline or staff handover. The voice of patient wisdom says: when you rush past my room at the speed of lightning you don't even see me.

Take off your armour

The repeated experience of inadequacy, of having nothing to say or do that would appear to make a difference has driven some of our chaplaincy colleagues to disengage with patients and instead forge deeper and less demanding relationships with their computers and email accounts. In the newly published, *Caregiver stress and staff support in illness, dying and bereavement* one honest contributor writes

'For many of us, the elaborate architecture we build around our hearts begins to resemble a fortress. We build up our defences .. we add a moat, we throw in some crocodiles, we forge more weapons, we build higher and higher walls. Sooner or later, we find ourselves locked in by the very defences we have constructed for our own protection. We will find the key to our liberation only when we accept that what we once did to survive is now destroying us. And thus we begin the work of dismantling our fortress, releasing the crocodiles back to their habitat, and melting down the weapons to recycle into ploughshares. Renzenbrink 43/4

Patient wisdom: On the commode or in my pyjamas I live an unprotected life. Your armour does neither of us any good!

Don't be paralyzed by helplessness

Dissatisfaction in our work and in our lives often starts from the sense that we can never do enough. 'When our personal belief that *we* are not enough collides with our professional belief that *we're* not *doing* enough, we can feel like *we're* coming apart at the seams ... and the haunting questions 'am I good enough etc... can confuse our ability to be honest about how *we're* actually doing, day to day'. Trauma Stewardship p 63 Patient wisdom: Do what you can and accept your limitations.

Get off your high horse

We all need strokes and in our work it can be very affirming to make a deep connection with patients, relatives or staff members. The sense of validation and purpose can assuage the more common feelings of impotence in the face of death. But this needs kept in check especially when we hear ourselves ask 'How will my colleagues manage this week while I am at this conference or in the summer when I go on holiday?' or find ourselves thinking at the end of a day's work 'we couldn't possibly go home yet since such and such a family need me to be here'. Self awareness and appropriate accountability are invaluable here to assure that what passes as 'availability' and flexibility is just that and not a need be needed or an appeal for brownie points. Patient wisdom says: I am more resilient than you think. Get your ego needs met elsewhere.

Ditch the Guilt

For a long time I found it hard to tell patients that I was going off for a long weekend or on holiday and played down the good things that *my* health and freedom allowed me. I felt that telling them would only rub salt into their wounds and reinforce their confined state but what I have found is that, on the whole, patients are genuinely interested in the lives of the staff and love to hear what we get up to when we are off duty or how our children and families are doing. Patient wisdom – Just because I am dying I don't need you to feel guilty about living.

Look after yourself

The final piece of patient wisdom that I have heard time and time again on the lips of those I have accompanied is 'Look after yourself'. One carer writes:

'After years .. of bearing witness to others' suffering, I finally came to understand that my exposure had changed me on a fundamental level. There had been an osmosis: I had absorbed and accumulated [distress] to the point that it had become a part of me, and my view of the world had changed. I realized eventually that I had come into my work armed with a burning passion and a tremendous commitment but few other internal resources. As you know, there is a time for fire, but what sustains the heat – for the long haul – is the coals. And coals I had none of. I did the work for a long time with very little ability to integrate my experiences emotionally, cognitively, spiritually or physically.'

Trauma Stewardship 3-4.

Patient wisdom is clear: Look after yourself for without replenishing the coals the fire will burn out and if that happens, everyone loses.

Conclusion

Seamus Heaney describes our lives as

'a hurry through which known and strange things pass ... and catch the heart off guard and blow it open' (Heaney, *Opened Ground: Poems 1966-1996*, 444)

The cumulative effect of our work can catch our hearts off guard and blow them open. But this itself can be a gift if it propels us back to reconsider our vision and to wrestle once again with that most haunting of questions - 'what sustains you from the inside?' For lost for words and adrift from our core, the very people from whom we want to run when the work overwhelms us – our patients – turn out to be our healers and gurus who, from their deathbeds, nurse us back to life – life in all its fullness – and in so doing remind us that

'The question is not how to survive, but how to thrive with passion, compassion, humour and style.' Maya Angelou

In the privileged positions we hold and in the humbling work we do let's not short-change our patients by scraping by or settling for some half-existence in the name of 'care'. But rather take Howard Thurman's words to heart:

'Don't ask yourself what the world needs. Ask yourself what makes you come alive. And go do that. Because the world needs people who've come alive.'

References

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