Above all what matters is not to lose the joy of living in the fear of dying

Spirituality is a term being increasingly used in our culture, in healthcare, in education and in business. It is noticeably absent from most current church vocabulary except when it refers to specific traditions such as Franciscan spirituality. This article is an attempt to engage and grapple with the question: How can church communities better understand and participate in the on-going attempts to articulate the nature of spirituality in our society now?

In order to do this I have chosen to look at one sector, that of health, and to take as a case study the growing appearance of Maggie’s Centres in hospital grounds throughout the UK and now also beyond. Maggie’s Centres are interesting in that they do not write about their work in spiritual terms. I hope to show that they both express much of what is now described as spiritual in healthcare. Further I suggest they also give those of us in church communities some vocabulary to enter and contribute more fully to the debate. This, then, is a form of conversation between current attempts to define spirituality, the actual practice of Maggie’s Centres and our Christian heritage.

Briefly, Maggie’s Centres grew out of the life experience of one woman, Maggie Keswick Jencks. She was diagnosed with breast cancer in 1988, received treatment and got on with her life. In 1993 the cancer returned and she spent the last two years of her life in seeking to live as fully as possible, during which ‘She came to believe that this quite deliberate move from passive victim to active participant was the single most important step she took in dealing with her illness. She was living, even if she was dying (as indeed we all are).’ In the
midst of this she wrote a small book called *Empowering the Patient*, yet she soon came to feel that yet another piece of text was not quite enough. What she and others needed was a welcoming place near the hospital with good information available through both staff and a library. The plan for a place had begun to emerge. Maggie had worked as a landscape architect with her husband Charles Jencks, and was convinced of the importance of the physical aspects of creating a welcoming space. Richard Murphy, an Edinburgh architect, provided the plans to convert a small stable building in the grounds of the Western General Hospital in Edinburgh and the first centre was being developed when Maggie died in July 1995.

This story illustrates spirituality as it has been defined within the current NHS Scotland policy documents on spiritual care. There has been a gradual integration of spirituality into healthcare definitions over the last fifty years. In 1948 World Health Organisation discussions defined health as ‘a state of complete physical, mental and social well-being and not more merely the absence of disease or infirmity.’ In 1984 the organisation invited its members to include a ‘spiritual dimension’ in their health service planning. These roots gave rise to the UK and Scottish governments adopting spirituality as part of healthcare and requiring each NHS Trust to provide guidelines on policy for all staff and training. In a recent document – *Spiritual Care Matters* – explaining spirituality to staff, John Swinton is quoted as saying,

> Illnesses are deeply meaningful events within people’s lives, events that often challenge people to think about their lives quite differently. [...] A person’s spirituality, whether religious or non-religious provides belief structures and ways of coping through which people begin to rebuild and make sense of their lives in times of trauma and distress. [...] These experiences are not secondary to the ‘real’ process of clinical diagnosis and technical care. Rather they are crucial to the complex dynamics of a person’s movement towards health and fullness of life [...]”

Maggie’s experience of illness can thus be seen as an outstanding example of an individual who found meaning in her personal situation,
allowing the rebuilding of purpose into her life. She became sure that her active participation in dealing with her illness helped her to live the rest of her life fully, but also, that belief provided inspiration that has taken shape and form in a way which continues to inspire others to embrace and engage with their own experience of cancer in a similar life-giving way. Many people coming to the centres ask about her life and want to hear her story.

It is interesting to note that the word inspiration rarely occurs in the literature regarding definitions of spirituality and this points to a possible aspect that the church could usefully highlight and bring more centrally into the public debate around definitions and the understanding of spirituality.

The word inspiration also links to the central feature of space in Maggie’s Centres. They are places where people can breathe and tell their story. In contrast to the busy environment of the hospital with its own agendas, Maggie’s Centres people find space to ask their questions in an atmosphere that is as relaxed as a home. The buildings are designed to be interesting, to draw people in, to invite them towards the table with a cup of tea. Maggie’s seeks to offer welcome and companionship to any individual. This picks up two features articulated in *Spiritual Care Matters*. Firstly there is an expectation that spiritual care be offered on an individual basis, one-to-one, in a way that is person-centred and, secondly, that spirituality be considered as primarily relational.

At first sight this would appear to correspond to the tradition of pastoral care current in many churches. In this tradition pastoral care is often offered individually and seeks to be tailored to the particular needs of each person. Yet here I detect an element of difference between the heritage of the church and the current use of the word ‘spirituality’. In healthcare, it is clear that the language of psychology is being used. Now pastoral care, it is true, can be offered from such a perspective, but this need not be always the case. Many church approaches still operate from a primarily paternalistic viewpoint where the intention of the giver is to help from a position of power or of knowledge. Often this is associated with providing support in a time of distress by making arrangements and helping people. A person-centred approach, in contrast, works from the assumption that the person being helped is
in charge and with the help of good information can make their own decisions. The role of the person alongside them is to assist them to create space for reflection.

Within the context of a Maggie’s Centre there is a hope that physical spaciousness will be reflected in people’s internal reality, bringing an experience of space consistent with a person-centred approach. Talking and reflecting with others is one of the ways that this takes place. Good, accurate and up-to-date information, not only on the medical questions but also about nutrition, exercise, and relaxation, is vital. In other words, those aspects over which the patient has more control can be made a component part of the nurture of their own being. They are given encouragement to live as fully as they can within the limits of their illness. This encouragement can come in a variety of ways: over a cup of tea, in individual sessions, in teaching groups or classes, or in therapy groups. Many of these are open not only to the individual who is ill but also to their families and close friends. Maggie’s Centres thus combine good professional information and expertise with a person-centred approach that begins with the experience of the individual and seeks to support them in integrating current knowledge into their own situation – thus empowering them. Perhaps this offers the church a window of understanding into what aspects of ‘spirituality’ are embedded in our own tradition (the support of people in times of crisis), at the same time as revealing the subtle shifts in the current use of the term. It is important to note that the main focus of attention is on those resources the individual already possesses. The role of the professional is to draw out the competency of the individual through the process of self-awareness rather than offering help externally in guidance given or instruction offered. There is, therefore, a subtle but clear issue here of where authority or knowledge is understood to reside: Within the person seeking help? Or within the institution (or individual representing the institution) that is offering help? Current understandings of ‘spirituality’ are generally tending towards the former.

Much recent writing about spirituality speaks of its life-affirming nature and its roots in the experience of individuals. Paul Heelas and Linda Woodhead from the University of Lancaster, for example, writing from a primarily sociological perspective, argue that since the
Second World War there has been a ‘turn to life’.\textsuperscript{10} The turn to life need not, of course, be religious:

As a rule of thumb one could say that the turn to life has a religious or spiritual dimension when life is understood as something which cannot be reduced to its material and empirical components but is always (albeit mysteriously) something “more” than these. [...] the turn to life seems to represent not only a turn \textit{to} something, but also a turn \textit{from} something – from religions perceived to be anti-life or life-denying.\textsuperscript{11}

The authors argue that this trend explains the growth in participation in small groups. These groups encourage personal growth often associated with spiritual practices or with alternative and complementary therapies. Such groups place an emphasis on experience and the value of sharing in a communal setting. There is also a similar trend within churches across the denominations, from those on the liberal wing such as Creation Spirituality to Alpha Course groups at the more evangelical end of the spectrum. The authors, in other words, would argue that a new understanding of ‘spirituality’ is already present and affecting our church communities.

This raises a question as to whether the increasing use of the word ‘spirituality’ indicates a change in the way people wish to relate to one another as human beings. Does this focus on learning in small groups, in which experiential sharing is a strong component, point to an emerging form of freedom and life? Are we in a time parallel to the Reformation when education was seen as a means to bring a substantial shift of power and the fuller participation of many more people in society? Does this trend indicate that there is a new form of learning and life happening in small groups based less on information and more on a learning which focuses strongly on relationships? I suggest that this is indeed part of what the word spirituality now means.

When we turn to the world of science there is a growing question as to whether spirituality is a normal part of all human behaviour. This question arises both from qualitative work which analyses what people report of their experience and also from the quantitative work
of neuroscience where new techniques are facilitating much more
detailed analysis of the effects of meditation and prayer on the brain.
David Hay, formerly Director of the Religious Experience Research
Unit and now teaching at the University of Aberdeen, has been
a significant contributor to the debate in the UK about spirituality.
With Rebecca Nye\(^1\)\(^2\) he undertook some fascinating research with
children where they were given photos depicting children of their
own age in contexts where awe was expressed or questions of values
raised. Analysis of the recorded conversations allowed articulation of
a common theme which they called ‘relational consciousness’. This
phrase sought to identify two key aspects: that the children had a level
of perceptiveness distinctive from their normal conversation, and that
they expressed this primarily in language of relationship with other
human beings and with God. This becomes significant especially
when it is held alongside some of the quantitative research. The latter
has made leaps forward since it became possible to begin to map the
chemicals underlying our emotional experience. A strong practical
consequence of this is that it is now possible to be sure there is a
correlation between emotions and our immune systems, giving rise to
the new speciality of psychoneuro-immunology. In other words our
feelings do affect our ability to fight infection, so this means it has
become clear that working with feelings has the potential to facilitate
physical health. This begins to give a scientific underpinning of why
telling one’s story has the capacity to support health and healing.
Herbert Benson of Harvard University’s Medical School, a major
researcher in prayer and spirituality writes,

> Western medicine still makes serious distinctions between
mental, emotional and physical roots of illness despite
the amassing of research that finds mind and body are so
interwoven that such distinctions are not only artificial, they’re
unscientific.\(^13\)

What this tells us is that old boundaries between disciplines are breaking
down. Science no longer operates in a completely separate frame of
reference from the world of feeling or of spirit. A consequence for those
of us in the church is that areas of human experience that have been
considered our domain, things of the spirit, are now being investigated and named without our initiative and without our control. What does it mean for us that scientists are beginning to define spirituality as a quality of being human that is hard-wired into our biological make-up? How do we respond to this situation? Do we object as if we were fighting for territory? Do we see it as an opportunity? And if the latter is so, what sort of opportunity do we see – one of promoting our position, or one of learning and contributing to a new situation? What would bring health for ourselves and others? Using the language of spirituality as practised in Maggie’s Centres and articulated in *Spiritual Care Matters*, the first step would be to listen. To listen and wait for what is beneath the surface of our questions: to create space and to see what emerges from the relationship of encounter.

So rather than continuing to look at Maggie’s Centres to try to understand current definitions of spirituality, I now want to change the focus and look at what the ‘language’ of Maggie’s Centres might reveal to us about the church. Can we grasp what others might see in us through the terminology of spirituality? What heritage might they see and what guidance might be offered to us about the latent potential within our own tradition?

Looking from this perspective others might draw our attention to the rich heritage of stories that we have in those Scripture narratives that give voice to human dilemmas and struggles down through the centuries. These stories have the potential to offer companionship, to counter the experience of loneliness and fear, and to provide reassurance that people in the past have navigated themselves in and through such difficult territories of human experience. In some ways this an obvious thing to say and people of faith continue to do this, normally facilitated through preaching, through individual and corporate reading of Scripture, and through pastoral care, usually undertaken by the minister. However, the way we articulate and facilitate this process could be made a lot more accessible to a lot more people.

What is often lacking in our churches is a context where people going through similar life experiences can meet together in such a way that they are enabled to support one another. In recent years narrative theology has given voice to the process whereby individuals can find
their personal story mirrored in Scripture and progress their journey of faith. Yet generally we have not integrated into our patterns of church structure small groups in which people can safely explore those inner places where faith and life experience throw up discontinuities, confusions, and painful feelings. We do not have a strong enough understanding that faith and belief grow and change throughout life and that this is to be expected. The experience of Maggie’s Centres shows that strength can be found by making space for that which is vulnerable within us and that strength can come from sharing feelings. There is value in small groups that are not about joining or signing up to a set of beliefs but rather in sharing experience of life. This awareness is, in fact, already clearly articulated within our Christian tradition by such writers as Henri Nouwen and Jean Vanier. It also ties up with trends already present in our church communities – annual bereavement services, for example. This should encourage us to use such opportunities to create space where sharing stories can bring life and hope.

Maggie’s Centres also demonstrate to us the fact that when faced with the crisis of serious illness most people ask deep questions about meaning – people of all faiths and none. This might encourage us to think of ways that we could offer such listening and meaning-making contexts for people beyond the immediate church community. How might we relate to GP surgeries and offer support to people in health crisis or those living with long-term chronic ill health? Anthropologists such as Arthur Kleinman have mapped clearly the meaning families attach to illness as something that needs attention in its own right. Creating space for people to safely explore meaning, allowing them to express their story, is a form of resource. This is the kind of spirituality that Paul Heelas and Linda Woodhead are analysing as culturally appropriate for this period in history. As in Maggie’s Centres they are likely to speak of their common health concerns and what emerges from that: in such contexts the people coming set the agenda, they might speak about God – or they might not. This suggests some clues concerning the practice of narrative theology. In a very straightforward way the kind of practice we have been considering seeks to serve people who are ill, offering them space, time and respect. Now, while much of the ‘text’ here is the nature of the illness, and how
to stay attentive to life in the midst of that, could this be, from our perspective, an example of contextual theology? This might not sound like a conventional way to spread the gospel but it may actually in practice do so. More than that, if we provide a context, a room, and someone to accompany those wanting to tell their story, we promote the search for meaning.

Barbara Glasson has lived such a ministry in central Liverpool where she set up what became known as the Bread Church in a flat in the city centre. She records her own learning from listening to those who came twice a week to bake bread in her book *I Am Somewhere Else*. More recently she has worked with survivors of sexual abuse and written of what they have taught her. She writes, ‘Through Christ we are called to hear, to bear witness to those who groan and travail, to the silenced among us [...] This is not simply a piece of therapy, but an act of redemption. It is the work of God in the world.’

This approach of listening both affirms life and actively combats fear. Fear reduces the immune system’s ability and prevents the body’s natural healing capacity. One of Maggie Keswick Jencks’ greatest concerns, therefore, was that people’s fear be addressed. She said, ‘[...] fear, compounded by ignorance and false knowledge – is a paralysing attack in its own right. The myth of cancer kills as surely as the tumours.’ This resonates well with that most frequently repeated phrase in the Bible, ‘Do not be afraid’. To facilitate people in the telling of their story is to allow the naming of fears, it is about being heard and valued, it is about working with human longing, and looking for ways to embody life and love. This is very much in tune with Jesus’ teaching – best expressed in John 10:10 where he says ‘I have come that you might have life, and that abundantly’. Jesus told parables drawn from everyday life, he responded to questions of the disciples as they arose. He understood the power of story. In our day we have heard and seen the power of story-telling in extreme circumstances such as in the work of the Truth and Reconciliation Commission in South Africa. It may be less obvious to us that such strategies could be embodied in local churches helping to make peace in people’s hearts.

Maggie’s Centres also provide a place for meditation. This is normally offered in a guided meditation format, where the person
leading takes people on an imaginary journey that usually includes sensual aspects of taste, touch, smell and awareness of the beauty and value of life. The advantage of this way of working is that it is open to all, accessible to people whether they hold religious beliefs or not. People describe these times as relaxing and life-affirming. Is it possible to learn from this? That worship services with space in them might offer deeper richness? Consider – there are many liturgies available to us now from both the Taizé community and the Iona Community where our heritage is upheld and there is room for people to reflect on their own. The Ignatian tradition, which is now networked across Scotland by the ecumenical Epiphany group, offers people and resources to encourage prayer, meditation and inner reflection. There is a greater readiness among people to talk in small groups – there is a greater willingness to engage in questions about meaning than we might often suppose. Maybe this is, in the end, a product of the Reformation, which placed such great emphasis on people learning to pray for themselves without priests doing it for them. Perhaps this lies behind those movements in our current culture where people express a desire to make meaning for themselves starting with their own experience. Rather than assuming that people are rejecting traditional faith, maybe this move by people to work things out from inside their own experience is a natural product of the freedom our tradition literally fought for.

In conclusion, Maggie’s Centres have been designed by world famous architects, who have created stunning, striking and interesting buildings. Their experience might cause us to reflect again on the many wonderful buildings in which we worship and the fact that people can be deeply affected by spaciousness. Maggie’s Centres call our attention to the resource our sanctuaries can be in enabling the creation of an inner space that encourages reflection. The sanctuaries we worship in remind us that beauty is a part of our heritage and that it can be very sustaining and affirming in times of suffering.

The language of spirituality is here to stay whether we like it or not. I suggest that it offers us space for reflection, not so much about the content of our message, but more about how that message is to be communicated in our current world. This raises the question of
how people learn when so many have access to good education and information. Questions of value and the making of meaning are now moving centre stage in our cultural awareness of what brings people life and health, and the practices of prayer and meditation are currently points of connection with the scientific community.

What, then, does this mean? This means that the church has much to contribute. There is much that still continues to be debated, in particular there are unresolved questions about the overlap between spirituality and religion. Such questions, however, are being integrated into the standard training for our doctors and nurses. I suggest that at every level of our church community it is in our interest to actively engage with this new description of what it means to be human. Our heritage is rich, and if we offer our perspective in a spirit of reciprocity we can take part in the building of a bridge between disciplines that have held themselves separate for many centuries. The word ‘spirituality’ has the potential to enable wider communication – a reconnecting of some forgotten but essential elements in the common human search for meaning and truth in our society.

Notes

1 Maggie Keswick Jencks, A View From the Front Line (London: Maggie’s Cancer Caring Centre, 1995), 23.
2 For more details about Maggie’s life see www.maggiescentres.org.uk
3 Marcia Blakenham, “Foreword” to Keswick Jencks, A View From the Front Line, 2.
8 Ibid., 21.
9 Ibid., 31–34.
12 David Hay, “The Biological Basis of Spiritual Awareness”, in King, Spirituality and Society, 124–35.
16 Barbara Glasson, A Spirituality of Survival: Enabling a Response to Trauma and Abuse (London: Continuum, 2009), 18.
17 Keswick Jencks, A View From the Front Line, 9.

**Bibliography**


