**End-of-life Care: what is important for me and for us. A review of recent UK strategy and policy documents and their implications for chaplains.**

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**Abstract**

This article reviews some recent UK strategy and policy documents about building a “national choice offer” to enable end-of-life care to be delivered at home, and encouraging the formation of supportive communities. Notably, with the implicit assumption that planned choice is sufficient for end-of-life care, the contribution of healthcare chaplaincy is neglected. The article explores the implications for healthcare chaplains, how chaplains can help to build up compassionate communities, and some practical aspects of community support for those of faith and no faith through initiatives for parish support.

**Key words:** Chaplaincy; choice; community; dying; end-of-life; family; holistic; spirituality

***What’s important to me*. Reviewing the review.**

**Reviewing the background**

In February 2015, the UK government published *What’s Important To Me: A Review of Choice in End of Life Care*. This was the culmination of a process to engineer change in the NHS officially begun in 2008 with *End of Life Care Strategy,* a report outlining the government’s central agenda: to tackle the taboo on discussing death. Other initiatives included the Dying Matters Coalition set up by the National Council for Palliative Care in 2009 to promote public awareness of dying, death and bereavement, as well as care plan promotions, surveys on experience of care in the last three months of life, and comment from VOICES, Views of Informal Carers – Evaluation of Services.

Additionally, the UK’s difficult experience of the Liverpool Care Pathway significantly informed the discussion leading up to the 2015 report. An independent review of the Liverpool Care Pathway, tellingly entitled *More Care Less Pathway* (2013)*,* highlighted the inadequacies still blighting end-of-life care despite new strategies. The review’s chair, Baroness Julia Neuberger pointed to cases of poor care and preventable problems of communication between healthcare staff, patients and families that caused many to be suspicious of end-of-life care in hospitals. Notably, she reiterated the call in the 2008 report for the need to have a proper national conversation about dying.

*What’s Important To Me* began in 2014 as a review undertaken by an independently-led programme board of leading experts in end-of-life care, and included perspectives from charities, health and social care, policy making, carers, and those with personal experience.[[2]](#footnote-2) The review collected some 1,000 responses over a two month period.[[3]](#footnote-3) Bowing to the “substantial shift towards the idea of patient choice” (Neuberger 2013: Foreword), the board’s remit was to advise the government on how to improve “the quality and experience of care for adults at the end of life, their carers and others who are important to them *by expanding choice*” (2015: iv, my italics).

The board formulated three general questions, asking first, what kinds of choices should people be able to make at the end of their life and what should be in place for these to be achieved; secondly, it asked for examples of choices made, and what care and support had been offered; thirdly, it elicited some idea of how to measure or evaluate a “national choice offer”. Broadly speaking, the board’s report offered a “blueprint” to the government, the health and care system, and to society: “people have told us what they want”, it said, “Now is the time for action” (2015: 3).

Notably, there is a shift in emphasis from the *End of Life Care Strategy.* In the 2008 strategy, focus on dialogue at all levels, coupled with various strategies and research into people’s experiences, were at the forefront of NHS reform not least because “how we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services” (2008: 6). However, by 2015 choice appears to be the dominant factor.

**Reviewing the findings**

The very title of the report, *What’s Important To Me: A Review of Choice in End of Life Care*, is indicative. End-of-life care may be “everyone’s business and needs to be recognized as such” (2015: 2), but this appears to be a matter of ensuring, or at least maximising the individual’s choices and preferences (2015: 1; 4). Given that dying, death and bereavement are the “point of maximum vulnerability” in life, and perhaps reflecting perceptions of lack of control for patients on the Liverpool Care Pathway, the report claims it is vital to offer people choice and control. The chief fear, it seems, is fear of lack of control in the dying process (2015: 1).

For the majority of respondents, choosing the place of care and death was primary (2015: Annex A). Most respondents considered the best option to be dying at home with the appropriate support,[[4]](#footnote-4) though currently this choice is not realised in practice (2015: 1).[[5]](#footnote-5) Respondents also highlighted the importance of choosing whether or not to be involved in, and have control over, decisions. Having early and sensitive conversations with professionals, “being listened to”, was felt integral to being empowered to make decisions (2015: Annex A, 13). Again, the focus on listening seems to be rather narrowly construed as being heard through having preferences recognized.

Respondents interpreted high quality care as adequate symptom control, timely management of crises and expert medical skill, but also kindness, compassion, listening, honour, dignity and communication. These empathetic skills are highlighted as significant not because they affirm patient dignity but rather because they help professionals identify spoken and unspoken needs and wishes (2015: Annex A, 13-17). Co-ordinated and joined up care was highly valued and quick access to up-to-date information about the person was recognized as a key element, again to enable the person to make choices (2015: Annex A, 20). Issues identified as important included support for carers, family and friends, and the impact of death on these significant others. This co-ordinated care, that also encompasses significant others, is seen as part of “what needs to be in place for people’s choices to be achieved” (2015: Annex A, 19-20).

This highly individualised co-ordinated care requires trained, flexible and adaptable staff and joint working between palliative care specialists and other clinical staff, so that people who “may die in the foreseeable future” and who are outside of the hospital setting, can be identified as early as possible (2015: 4; 6; 7). Each person will have an individual care plan recording choices and preferences, and a named senior clinician with overall responsibility for care and fulfilment of these preferences. The person will then be offered the services of a care co-ordinator as first point of contact (2015: 5).

The report does not hide the fact that implementation requires financial investment and changes in the way in which organisations like the NHS work. For the strategy to be successful, the report calls for additional community care settings. Care planning should be proactive so that unnecessary admissions to hospital, and so presumably the likelihood of dying in hospital, are avoided. Certainly the report recognizes existing challenges, in particular in issues of funding, the current poor identification of needs in conditions other than cancer, and the ongoing problem of access to appropriate palliative care. Noting the demands and pressures already placed on professionals, the report also points to a “culture of reluctance” among professionals. However, and once again highlighting choice, this reluctance is not so much related to discussing dying and death as to honest conversations about patient needs and preferences (2015: 12-13). Still, there is no comment on the anecdotal frequency of the patient asking the professional what he or she would do if he or she were in the patient’s situation. Curiously, the co-ordinated strategy makes no mention of the services of the healthcare chaplain as part of the specialist team, perhaps because this appears to come under private individual preference (2015: Annex A, 17) rather than being part of a holistic package of care. Nevertheless, the report confidently suggests that a national choice offer for end-of-life care should be in place by April 2020 and that it should be supported and publicized as a right within the NHS framework (2015: 7).

**What is important to *US***

Undoubtedly, being able to express preferences, priorities and choices is a significant aspect of end-of-life care. However, this is only one aspect of end-of-life care. If attention is not paid to the conversation that has taken place alongside *What’s Important To Me?* not only may we be excluding those who cannot make choices, but also we may find ourselves unprepared for the full impact of the choice to bring dying and death back home.

Part of the conversation leading up to *What’s Important To Me?* involved an influential public health research initiative originating in the North East of England for end-of-life care that went beyond hospital and hospice based services. The NHS North East Strategic Health Authority produced a short pamphlet in 2009/2010, the *Good Death Charter* to kick-start a society-led response to dying and death. Professor Edwin Pugh, consultant in palliative medicine and chair of the Good Death advisory group, explained that the Charter not only urges right medical services at the right time, but also encourages people to come together in their communities to help and support dying people: the Charter “is about living with dying”.[[6]](#footnote-6) This leaflet was so successful that in 2014 Public Health England[[7]](#footnote-7) asked the National Council for Palliative Care to review and update it through public consultation and pilot schemes, so that it could eventually be used nationwide. This became the new *Dying Well Community Charter,* and in January 2015 eight “Pathfinder communities” pioneered this public health approach to end-of-life care in various regions of England.

The *Dying Well Charter* complements *What’s Important To Me?* by locating people within their relationship networks and community support. This clarifies that what is important is not simply choice of the place of dying or good skilled care that aims to fulfil preferences. What is important is also the belief that dying and death should not be isolated from the rest of life, particularly life in families and communities. Indeed, as much as many fear losing control, many fear dying alone or being abandoned or being disconnected from their communities (*Dying Well Community Charter,* 2014). Through placing emphasis not so much on what a person wants or prefers in a relatively short period before death, but rather on the person and on solidarity with the community, the Charter calls for respect for the person and for carers, for who we are, for how we live, and for our relationships. It reminds us that everyone still has a contribution to make, that people need help with maintaining independence, control and with decision-making, and that everyone should be treated with dignity, respect and compassion. Like *What’s Important To Me?,* the Charter asks for kind, honest and appropriate communication, but it also calls for support mechanisms because it recognizes that the person is not an isolated individual who is always in control. The Charter’s appeal to the community was followed up by the *Public Health Approaches to End-of-Life Care Toolkit* (2014) which details “compassionate communities” as the way forward to accommodate care, dying, death, loss, and bereavement.

**Compassionate communities**

The Toolkit expresses more fully than previous initiatives that end-of-life care requires a public health approach rather than being seen as simply a private matter of choice. As Professor Allan Kellehear and Dr Aliki Karapliagkou, the Toolkit authors point out, the ramifications of dying, death, caring and loss reach into the whole of society through the social and psychological issues raised, the burden of bereavement on those left behind, isolation of those who are terminally ill, disabled or aging, stigma associated with certain illnesses leading to depression, as well as issues associated with suicide and sudden death (*Toolkit* 2014: 23-24). Moreover, the Toolkit situates dying, death, care and loss where it is found, “in everyday life”: “living with a life-threatening or life-limiting illness, living with bereavement, and living with long-term care-giving ARE social experiences” (2014: 21; 43).

Responding to “patchy and sporadic” care and the current narrow focus on end-of-life care delivered through palliative and hospice facilities in the last few weeks or months of life, the Toolkit encourages everyone to become knowledgeable and informed about death, dying, loss and care, and to return to compassionate care for the dying as “a community matter” (2014: 7, 18). After all, the needs and experiences involved in end-of-life care are found in a community setting among family and friends (2014: 43). Ideally, this community-wide engagement extends to schools, workplaces, social groups, religious organisations, and includes education through the internet, publications, lectures, discussions, expert panels and support groups (2014: 51, 47).

Although the Toolkit recognises that “supportive environments” [[8]](#footnote-8), care policies and ideas are “mainly motivated” by healthcare services, it also calls for these to be “decided upon” by communities themselves (2014: 5). While not being prescriptive, the Toolkit offers three “community practice models” as ways forward: first, there is provision of services into the patient’s home under the initiative and control of the healthcare service (2014: 52-54). This offers the option of end-of-life care at home in a way very much envisaged by *What’s Important To Me?.* Second, the community engagement model, under the control of the healthcare service and the community, where care services and community workers empower others to problem solve and organise care. In this model, healthcare services work with the community irrespective of the level of community participation (2014: 55-58). Third, the community development model which is under community control. Rather than relying principally on professional direction, the community articulates and delivers its own solutions (2014: 59-62). The Toolkit illustrates this with a hospice that works in partnership with schools, the police and community care organisations, so that volunteers make links with the community, engaging with, in particular, ethnic minorities, initiating educational activities and organising art exhibitions.

**Bringing death home: the implications**

The report *What’s Important To Me?,* the charters on *Good Death* and *Dying Well,* and the *End of Life Care Toolkit* all call for supportive relationships and being open about living with dying. While *What’s Important To Me?* emphasizes identifying and enabling choice, *Good Death* and *Dying Well,* and the *End of Life Care Toolkit* recognise that dying and death are situated in a community context, and that properly supportive end-of-life care can be offered only through communication and action strategies that emerge from within that context. Perhaps acknowledging that beliefs and wishes surrounding death also come out of previous experience of the dying and death of others, the *End of Life Care Strategy* quotes Dame Cicely Saunders, the founder of the modern hospice movement: “How people die remains in the memory of those who live on”.[[9]](#footnote-9)

Nevertheless, the realisation that dying and death are a community issue, that dying and death happen in families and in the experience of living, is not new. The North American theologian and founding father of bioethics, Paul Ramsey, wrote in his highly influential book *The Patient as Person,* “‘the process of dying’ needs to be got out of the hospitals and back into the home and in the midst of family, neighbourhood, and friends” (1970: 135). However, for Ramsey, and unlike *What’s Important To Me?,* this is not primarily a matter of patient choice. Ramsey notes that people tend to die in hospitals because people want to think that everything that could be done for the patient is done; hospitals are seen to be well equipped to “manage death”, and families are ill equipped to do so (1970: 135). Ramsey adds that this tendency to place death in hospital rather than in the community leads to remoteness and unfamiliarity with death itself, and ultimately to isolation of the dying patient. Like the *Good Death* and *Dying Well* charters and the *End of Life Toolkit,* Ramsey sees the significance of living with dying in the community, and, for Ramsey, the family seems to be central.

However, Ramsey made his comments some fifty years ago, and so it may be necessary to re-examine some of his assumptions. Against Ramsey’s expectations of the hospital experience, in the UK people’s experience and perceptions of the Liverpool Care Pathway demonstrate that hospitals did “manage death”, but often not in a way that showed that everything that should be done was done. Although the Liverpool Care Pathway was intended to replicate in a hospital setting the good practices and standards of hospice care for the dying, a growing body of evidence and complaints from families highlighted instances of poor care where patients on the Pathway were being treated with “less than the respect that they deserve”. The Pathway was used at times as a “tick box exercise”, there were often significant communication failures between professionals, patients and families, and many families believed that their loved one’s death was hastened by over-prescription of pain-killing drugs or the apparently unnecessary withdrawal or prohibition of oral fluids (Neuberger 2013: 3-4). Certainly, when used properly by appropriately skilled practitioners the Liverpool Care Pathway worked well. Nevertheless, the catalogue of failures led to a significant erosion of trust in the way in which dying could be managed in hospitals. However, despite this mistrust, in the UK most people do still die in hospital even when there is no clinical need for them to be there (National Council for Palliative Care 2011; *What’s Important to Me?* 2015: 3). The UK policy documents so far considered agree with Ramsey that dying and death have a natural place in the community. The difference is that in the UK deaths happen in hospital not because hospital is perceived to be necessarily the place with most care and expertise, but more often than not because it is difficult to put in place appropriate care packages, or people get lost in the system, or they and their families are unsupported in decisions about where to die (National Council for Palliative Care 2011).

In contrast to Ramsey’s emphasis on the “claims” of love, care and human presence, currently much of the conversation about caring for elderly people, people with chronic illness, and people who are dying, seems to be around terms such as the “burden” of care, the costs and stress (Chambers and Phillips 2009; Brodaty and Donkin 2009; Bevans and Sternberg 2012; Stajduhar 2013; Strömberg and Luttik 2015; MacArtney *et al* 2015). Attention focuses in particular on the pressures on the “sandwich generation”, people who are often now in their sixties and who carry the double burden of care for children or grandchildren at the same time as caring for elderly parents. The “great burden” of care falls especially on women who, at the same time, have more of a role in the workplace, yet are also expected to be primary carers in the family (Ben-Galim and Silim 2013: 7). Rightly, the aim of much of the research into the burdens of care is to highlight injustice, inequality or lack of support for those who do care for others. However, almost incidentally, the same research also speaks of the willingness to care for relatives as well as the “satisfying and rewarding” and “life-enriching” experiences of care giving (Chambers and Phillips 2009: 101; Stajduhar 2013).

Certainly, for Ramsey the family faces the “claims” of the dying not to be deserted. Nevertheless, fifty years on, family fragmentation and the rise in reconstituted households or blended families, and single households, seems to call into question the practicalities of family care-giving at the end of life. Some of the implications of developments in family structure, and the “challenges” of an aging population have been detailed by the mainly Western forum, the Organisation for Economic Co-operation and Development. *The Future of Families to 2030: A Synthesis Report* (2011) the OECD notes that in the OECD area the extended family has “all but disappeared” and the “traditional family” has been transformed through fragmentation, divorce, cohabitation, looser family connections through blended families, single-parenthood, same sex partnerships, changing education and working patterns, and the growing number of elderly people (2011: 1.7). The OECD report also details sharp declines in the birth rate and “extraordinary gains” in longevity that could rise still further, as well as falls in marriage rates and rises in the number of “reconstituted households”, and growing poverty among the divorced and separated (2011:(3.1) 14; (2.1) 8). Inevitably, alongside these changes, there is disruption to the informal support networks for elderly people, increased poverty, isolation and weakened family ties which imply more recourse to professional care (2011: (2.1) 8; (2.2) 13). This “changing family landscape” does not seem to have been factored into existing support systems, such as who is eligible for care leave or schemes that depend on carers not having work commitments (2011: (5.2) 35) or into issues of gender equality and the pressures on women who are traditionally seen as primary carers yet who also have their own aspirations (see 2011: 4.33; 8.38).

Having considered all these changes and pressures, the OECD report suggests opening up discussion on the “re-balancing of responsibilities among individuals, the family and the state” and it offers a number of avenues (2011: (5.2) 35-36). The first avenue is to review what constitutes the family network; the second is to re-visit the question of individual choice so that individuals can decide for themselves “who should bear responsibility in the future for their care”; the third avenue is to encourage greater social engagement to develop family friendly solutions in the local area (2011: (5.3) 36-37).

Seemingly the UK government is following the second avenue through its *What’s Important To Me?* strategy, coupled with the third avenue through the *Good Death* and *Dying Well* charters and the *End of Life Toolkit.* As for the first avenue, according to OECD figures, the UK has one of the highest rates of family breakdown in the West (see Centre for Social Justice 2014: 28) and so for the UK government family care-giving at the end of life may not be a priority even though there is a move to bring dying home.

Certainly, *What’s Important To Me?, Good Death* and *Dying Well,* and the *End of Life Care Toolkit* speak of the importance of involving family in decision-making even if not care-giving at the end of life. Moreover, the apparent loosening of family ties and the challenges facing the family may indicate why there is particular emphasis on creating compassionate communities and supportive environments to help in end-of-life care. However, the conversation about dying and death in these documents is framed not only in terms of choice and control but also in the rather generalised comfort terms of the provision of educational, emotional, cultural and spiritual support. In contrast, for Ramsey, bringing dying and death back home and into the community is more than simply a means to address further public health issues or a method of opening up a conversation about dying or a way of providing more information and education about death or even a pathway to more choice. Rather it is to do with the reality of dying. And the passage of fifty years makes no difference to this reality.

Ramsey pulls no punches about the experience of dying: it leaves behind “shattered” people. Families and carers are “shattered by confrontation with reality, by the claims of the dying not to be deserted, not to be pushed from the circle that specially owes them love and care, not to be denied human presence with them” (1970: 135). An end-of-life strategy that is all about preferences or public education seems to assume that dying and death can be managed simply by careful planning. A strategy that focuses on choice seems to forget that while each death is deeply personal, it is my death, at the same time I cannot fully imagine my death (Gordon 2016: 2). Certainly we can prepare for death, but when the reality takes place it “has the quality of ‘shock’” (Catholic Bishops’ Conference of England and Wales 2010: 3.1) and it challenges even the best laid plans.

The reality of dying brings into sharp focus many powerful and profound questions that are usually found in the domain of religion and spirituality: questions about life and death, the finite and infinite, whether suffering has meaning, how to heal broken relationships, what happens next? These questions touch on aspects of our common humanity and so they are asked by people of faith and by people of no particular religious affiliation. Moreover, research highlights that people who are dying share some common end-of-life experiences that seem to occur in all cultures, whether religious or not (Brayne and Fenwick 2008; Kerr *et al* 2014; Grant *et al* 2014). Many people feel an overwhelming need to face and resolve issues from the past, to seek reconciliation with others. People often speak about journeying to another reality, they have visions, talk of being visited or being called by people who are long dead. Such end of life experiences have deep significance and offer comfort to dying people. Brayne and Fenwick explain that these experiences seem to help in the dying process. However, it appears that busy professionals frequently miss these experiences or they think that they are being unprofessional if they call attention to them, and relatives and carers fear ridicule if they mention them (2008).

While good spiritual care is recognised as integral to dying well for all people, whether they see themselves as religious or not, many healthcare professionals lack confidence or are cautious about delivering this care (Wynne 2013). This may be because the term spirituality is itself unclear, or professionals may feel that they do not have appropriate training or skills or spiritual awareness, or they are worried about causing undue distress (Wynne 2013). As a result, in end-of-life care spiritual needs risk being unrecognised and unmet. To fill this gap is in part why, in the UK, healthcare chaplaincy is “a service and profession” working within the NHS to ensure that everyone has access to pastoral, spiritual and religious support, and this includes provision in the community setting (NHS Chaplaincy Guidelines 2015: 1.1; 13).

End-of-life care, then, requires preparation, time, and listening well to dying people, their relatives and carers. This listening is not merely to identify needs and wishes. Instead, a major part of this listening involves acknowledging the importance of the spiritual aspects of meaning and spiritual well-being for both the dying and their significant others (Gordon 2016: 53-55). Indeed, it would seem that any planning for dying well should include the recognition of these aspects and the means for addressing them. And for Ramsey, the people who have these shattered families and relatives “on their hands” are “ministers, priests and rabbis” (1970: 135). So, we may wish to ask where the chaplain is in *What’s Important To Me?,* the charters on *Good Death* and *Dying Well,* and the *End of Life Care Toolkit.*

**And chaplains?**

Surprisingly, perhaps, given the recognition of the community aspect of dying and death, chaplaincy and spiritual care does not figure highly in governmental reports. The model offered by *What’s Important To Me?* does not include bereavement services and chaplaincy costs apparently because it is merely a matter of personal choice, and the report quotes pilot data given by the Palliative Care Funding Review suggesting that less than 0.3% of people use hospital chaplaincy services in hospital settings. In quoting this data the report does not seem to have recognised that there are problems in providing full and accurate data for chaplaincy activity (2015: Annex B. 52; NHS Chaplaincy Guidelines 2015: 7.1). Not only are there formal and informal activities, there are also chance encounters, unplanned work, and pastoral care that extends for as long as the person requires it (Caring for the Spirit Strategy 2004: 10). Anecdotally, people who would never normally think of accessing chaplaincy services see a chaplain visiting another patient and ask for a visit, even if they have long since considered themselves out of touch with either religion or spirituality. In part, this seeming indifference to chaplaincy services stems from the fact that many people appear to be reluctant to talk about dying and death, as recognised by the initiatives leading up to *What’s Important To Me?,* or they simply do not know how to talk about spirituality or they are uncomfortable with feelings of spiritual distress or associate spirituality with particular religious ritual (Catholic Bishops’ Conference of England and Wales 2010: 1.3.3).

In spite of its apparently limited understanding of the data, *What’s Important To Me?* appears to recognize some value in chaplaincy, since it thinks that hospital chaplaincy services “may still be important” to ensure that the spiritual needs of individuals are taken into account in the last days of life (2015: Annex B.52). Still, it may be interesting to consider this add on approach to spiritual care alongside the *End of Life Care Strategy* that recognizes the importance of spiritual care and chaplaincy services as an integral part of the multidisciplinary NHS team (2008: 3.98; 3.101; 3.105). Since spiritual care addresses many needs from religious and spiritual needs to physical needs expressed by, for instance holding hands, and emotional, psychological and social needs (Puchalski 2001), and the NHS has to address all healthcare requirements (McCarthy 2010), spiritual care is not merely an addition to NHS care. There is clear evidence that chaplaincy services help to reduce stress and anxiety in patients, families, carers and staff, and that these services address depression and isolation associated with serious illness (Koenig 2005: 205-207; Mowat 2008: 4.2.2; NHS Chaplaincy Guidelines 2015: 10). Albeit some see the term spirituality as a “weasel word” that has simply filled the vacuum left by psychology and psychiatry, as these two disciplines have confined themselves to mental health (Holmes 2010). A survey by the Royal College of Nursing found that the majority of UK nurses felt that the provision of spiritual care is fundamental and the joint responsibility of “nurses, patients, chaplains, families and other health professions working together”. Furthermore, the overwhelming majority of nurses thought that spiritual care should be applied to non-religious patients, atheists and agnostics, even though the same research admitted that many patients miss out (RCN 2010). Although patients may be missing out in the acute setting of the hospital, and spiritual care appears to be undervalued in government end of life strategies, compassionate communities themselves may offer a way forward with ministers, priests, rabbis and in particular healthcare chaplains taking on significant roles.

**Building up compassionate communities**

Certainly healthcare chaplaincy in the acute hospital setting is a particular form of ministry and it may be that a different form of chaplaincy will emerge from the community setting. Indeed, the *Toolkit* looks primarily to individual communities to articulate and deliver their own solutions for end-of-life care of their members. It encourages everyone to be involved in these compassionate communities (2014: 7) and calls upon churches to have at least one group dedicated to end-of-life care (2014: 62). However, through its wariness of being seen to dictate to individual communities, alongside possibly the view that religion and spirituality are essentially private matters, it seems that little more than this is made of faith communities.

Veronica Barry and Manjula Patel offer a description of the wide variety of compassionate communities operating in England.[[10]](#footnote-10) Among these communities they list various hospices, hospitals, university departments, consultancies, and forums. Activities range from engaging people in conversations about death to holding creative exhibitions to do with dying, and the communities usually depend on volunteers. However, these communities often work in isolation and are unaware of wider networks (2013: 7); moreover, they appear to be discrete and transient. Furthermore, it is unclear how successful these communities are in reaching the community at large.

In contrast, FaithAction, a strategic partner working with the Department of Health, NHS England and Public Health England, argues that “faith based organisations” are uniquely positioned to make a positive difference in , even if their potential is not always recognized (November 2014: 6). FaithAction research, collated in *The Impact of Faith Organisations on Public Health and Social Capital,* looks primarily to the role of faith communities in improving health and reducing health inequalities. Still, its message seems pertinent to end-of-life care giving within families and communities. The National Executive Director of FaithAction, Daniel Singleton, says that “faith is too significant to ignore”, it “reaches people and places that nothing else can” especially when it comes to marginalized communities. FaithAction research urges public bodies to see faith communities as assets with expertise that can be shared since not only do they already have accessible buildings, a “culture of volunteering” and a network of trusted relationships, they also have “nuanced insight” (2014: 8-10). On a practical level, by looking to faith communities that are already providing an increased sense of coherence or meaning to people’s lives, public bodies may find that they do not have to “reinvent the wheel” (2014: 8).

**The healthcare chaplain and the compassionate community**

The healthcare chaplain is well positioned to help in the building up of compassionate communities. Healthcare chaplains already come out of particular communities, yet they also serve the whole healthcare community, patients, families and healthcare staff, through sharing in a commitment to healthcare with other healthcare professionals (Cobb 2004). So, as professionals within the healthcare system and as representatives of faith traditions, they can bridge the gap between health providers and community. Trained in pastoral theology, they have also learned how to cope with the emotional and spiritual demands placed upon them (Newitt: 2011.110-111). In addition, chaplains can act as critical friends to other professionals who may not be as comfortable in a community setting. Moreover, and often unlike other healthcare personnel, they meet the patient and the family as equals and are often engaged with the unspoken rather than with medical interventions.

For people who are in or moving from the hospital setting, and for people who are dying at home, one pressing concern is that out of sight may also mean out of mind. Anecdotally, if relatives no longer attend church their dependent elderly or dying loved one may also drop off the church community radar even though for many the church community is the source of their spiritual life (Matthews: 2010). The healthcare chaplain is well placed to negotiate often difficult conversations with relatives and the dying person with sensitivity and to ensure that links with the church community are maintained. In particular the healthcare chaplain can support the whole family through prayer, sacrament and ritual, including arranging the funeral, when all too often non-church going relatives are either uncertain how to proceed and who to approach, or take the first available option. And for the growing number of elderly bereaved people, the chaplain can be both the source of ongoing care if needed and a conduit for further community care.

The faith community is crucial for dependent people, people who are dying, and their relatives because people of no faith often become open to profound human questions in unexpected ways, and conversely people of faith may discover that their faith is challenged or even deserts them (Catholic Bishops’ Conference of England and Wales 2010: 3.6). At such surprising and personal moments, the healthcare chaplain who is already present and re-presenting God in faithfulness can become that vital connection point to bring a hope. This is hope that goes beyond optimism. For those of no faith and of faith, it is a sure and certain hope that the person will not be abandoned or seen as redundant or as a burden. And for people of faith it is also an eschatological hope.

**And practical hope?**

In order to bring together in a practical way individual, family and community aspects of end-of-life care, the Catholic Bishops’ Conference of England and Wales report *Supporting Families: Celebrating Family Projects 2008-2011* (2012) may help*.* This report recognizes the significance of marriage and family life that applies across the generations. In full recognition of the problems of fractured relationships, the report is interested in strengthening the bonds of marriage and family life through the community, not only by encouraging commitment to family friendly parishes but also by developing a family ministry that reaches out in service to others. Solidarity and families working alongside each other to support parents and grandparents is the way forward, and this can apply to both child and elderly care. The emphasis here is on relationship building rather than simply the acquisition of skills. Here the contribution of all the participants is valued and this can be applied also to those who are nearing the end of their lives since, in the tradition, everyone has a part to play in building up the community and the Kingdom (Matthews 2013: chapter 6).

On the specifics of end-of-life care, the Bishops’ report recommends that at local diocesan level and at parish level adequate training, including training of volunteers, is put in place in particular for bereavement support. It comments on the need for good leadership and the desirability of building on and disseminating good practice. However, since the emphasis is on raising the awareness of the importance of family life as a spiritual journey that looks outwards as well as inwards, it seeks to go beyond immediate practicalities, and indeed go beyond the needs of the insular family. In its role of hospitality and welcome to all, the Christian family, known in the tradition as the domestic Church, is an important witness to the dignity of all human beings, especially people with disabilities, long term conditions and those nearing the end of life (Matthews 2013:163-165). As Pope Francis explained, caring for those who are sick, those who need help in basic tasks, giving time to those who need it, and “a sharing which does not judge, which does not demand the conversion of others”, is part of the missionary nature of the Church (2014). Pastoral outreach to the sick and dying, visiting them in their own homes and in hospitals, supporting their families, and uniting them with their community through prayer and the physical presence of ordained and lay people, has its roots in the New Testament and is seen as carrying on the mission of Jesus Christ who had a special love for the sick and those in need. Initiatives to train and support people who offer care to elderly frail people in their own homes or in care homes or even through telephone calls, healing masses and social occasions where people who are housebound can join the community, are becoming more and more common. The Church’s pastoral care also follows through the sick and dying process to death, funeral arrangements and bereavement, and special consideration is given to more delicate situations such as the death of an infant or death through suicide.

Although *Supporting Families* calls for adequate training, much may also be gained through learning from healthcare chaplaincy. Considerable discernment is required to determine the suitability of a person for the role of healthcare chaplain and the growing literature addressing hospital chaplaincy indicates clearly the need for ongoing professional development and reflective practice in spiritual care and supportive skills in order to build up expertise (Newitt 2011:109-112). However, chaplains also require support and while Newitt indicates a role for spiritual direction and the involvement of church hierarchy (2011: 111), there is also a role to be played by the community as a whole.

Along with Ramsey, many people with or without faith regard death and dying as shattering experiences. However, many faith communities have resources for those who follow a ministry to the sick and dying because those with a spiritual outlook are only too aware that dying and death are meaning-laden experiences. Certainly, each dying and death is unique and, in improving a dying person’s experience of care, there is only one chance of getting it right (Leadership Alliance for the Care of Dying People[[11]](#footnote-11) 2014). Nevertheless, there are insights and emotional, spiritual, and mental experiences that people can share. Research into the dying experience by practitioner experts such as Elisabeth Kübler-Ross and Cicely Saunders, and the extensive reflective literature on healthcare chaplaincy can work alongside knowledge of the development of faith and family structure, to become invaluable resources (Bowman 1998).

**Concluding thoughts**

With its emphasis on choice, government documents seem to rely uncritically on certain assumptions about the centrality of the autonomous person who rationally plans ahead for the future and where faith tradition and the transcendent are relegated to the sphere of the private.

However, the draw of people towards forming compassionate communities suggests that these assumptions are far from accurate, even where policy documents focus on communities as choice enablers. When people are fit and well they may think they know what is important and what choices they would make at the end of life. But when people become seriously ill, and especially when they are dying, spiritual questions tend to surface, whether people are religious or not. People from faith communities will always volunteer to care for those in need. However, if spiritual care is an integral part of NHS holistic care then this should be factored into the provision of every person’s end of life care wherever it takes place.

Whether it is being able to handle the why me question of the suffering person from a religious or even atheistic point of view (Dein *et al* 2013) or the what now and what next questions, be they practical, emotional, mental, physical or spiritual, care of people who are sick and dying is more than a social call and people do want to get it right. Nevertheless, if the shattering effect of dying and death is overshadowed by a focus on education and information as if dying and death are readily grasped, then families and carers, even within compassionate communities, may find themselves unprepared. How this impacts on healthcare chaplaincy remains to be seen, and as healthcare services rapidly evolve, chaplaincy itself must respond to the growing challenges of that evolution. But faith communities, with the correct support, and chaplains as authorised representatives of their faith communities, are in a good position to offer support to families and to people dying at home and in the community.

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2. Given moves for assisted dying legislation, the remit added that the advice offered should be confined to the existing legal framework. [↑](#footnote-ref-2)
3. Respondents were members of the public and professionals. Some 60% of the respondents were female and 75% were white, the majority in the 55-65 age bracket. Notably, this relatively small sample does not appear to be representative of the UK population; 64% of the respondents did not describe themselves as having any disability; there is no indication that actually nearing the end of life was a criterion for participation (Annex A). [↑](#footnote-ref-3)
4. Although the place of care and death was significant, the experience of care was also thought to be important so few described the home unreservedly as the best, (Annex A). [↑](#footnote-ref-4)
5. 75% of people wished to die at home with the proper support, (p.3). However, the report notes that in 2013 in England 48% of people died in hospital, 21% in care homes, 5% in hospices and 22% died at home, (pp.16-17). [↑](#footnote-ref-5)
6. Professor Edwin Pugh, http://www.phine.org.uk/a-good-death/charter/why [↑](#footnote-ref-6)
7. Public Health England is an operationally autonomous executive agency of the UK Department of Health. [↑](#footnote-ref-7)
8. The term “supportive environments” references the World Health Organisation’s First International Conference on Health Promotion and its resulting document, the *Ottawa Charter for Health Promotion*, 1986 (Barry and Patel, 2013, 9). In the *Charter* supportive environments sit within a broad context of health as a “resource for everyday life” and “a positive concept”, and health promotion as going beyond healthy life-styles to well-being. The *Charter* declares that health promotion is not just the responsibility of the health sector, but rather should be on the agenda of policy makers at all levels including the global. As part of this co-ordinated action policy, supportive environments address “the need to encourage reciprocal maintenance – to take care of each other, our communities and our natural environment” and this includes the conservation of natural resources. At the same time, the *Charter* defines health promotion as “the process of enabling people to increase control over, and to improve, their health”. In place of the *Charter’s* more global vision, yet at the same time in keeping with the *Charter’s* commitment to individual choice and control, it would seem that the *Toolkit* takes a more localised and choice driven view of supportive environments. [↑](#footnote-ref-8)
9. *End of Life Care Strategy* title page; see, C. Saunders. (1989). Pain and impending death. In: P.D. Wall and R. Melzak (eds.). *Textbook of Pain.* Edinburgh: Churchill Livingstone. Pp. 624-631. [↑](#footnote-ref-9)
10. The report was compiled on behalf of the Murray Hall Community Trust and the National Council for Palliative Care Dying Matters. [↑](#footnote-ref-10)
11. A coalition of 21 UK national organisations set up after the review of the Liverpool Care Pathway [↑](#footnote-ref-11)