Being a Christian in palliative care

BY JEFF STEPHENSON

Christians in every generation have been inspired to work with the destitute and dying. Dame Cicely Saunders is regarded as the founder of the modern hospice movement, with the establishment of St. Christopher's Hospice in 1967. She and many of those who pioneered the expansion of hospice services were Christians, setting up facilities with the implicit aims of welcoming all and expressing the love of God in patient care.

PALLIATIVE CARE

One definition of palliative care is 'the active total care of those who have advanced, incurable life-limiting illness'. Active care emphasises that there is much that can be done to control symptoms and maximise quality of life for patients who may otherwise feel there is nothing more that can be done. It is 'total' care in that it embraces a holistic approach to patients and their families, recognising that physical symptoms are only part of the needs of patients with advanced disease who are facing death. It integrates physical, emotional, spiritual, and social aspects of care, and this requires a multidisciplinary team approach.

The early hospice movement emphasised symptom control and quality care for the dying, and this has had an impact on public perception and expectations. As a result, palliative care is now an integral part of healthcare services across the UK. Cancer care was the context in which palliative care developed, but the general principles apply to non-malignant conditions, many of which impose similar burdens of symptoms, disability, and dependence; work in this area has expanded progressively. Although some areas of the UK have better provision than others, palliative care services are generally well developed, with a range of services: hospices, many with day care and outpatient services; hospital teams providing support to patients on acute wards; and community teams providing care and support for patients in their own homes and in residential care. Following the British example, palliative care services have developed in North America, though the model there is more nurse-led and focuses on homecare. There are services in parts of Europe, but these may be less well developed than in the UK. This country is well placed to influence attitudes and approaches to the care of the dying in other parts of the world, and in that respect, there are likely to be challenging opportunities for medical mission in the future. It also gives us an important voice in the debate on euthanasia.

I had my first contact with palliative care as a clinical student. As with most medical courses at the time, we received almost no teaching about issues surrounding the care of the dying. I was profoundly influenced by

the experiences of friends who qualified before me and as junior doctors found themselves confronted by these issues. They had no training, both in terms of providing appropriate care and in coping emotionally. I felt it was important to have some preparation, and I therefore spent some elective time in a hospice. I found the experience extremely moving, and it proved to be a turning-point. This was holistic care as I had never encountered it, and it was very rewarding to be part of a multidisciplinary team. I worked under a Christian consultant who was eminent and experienced, yet whose self-effacing humility, approachability and bedside manner were inspirational. In terms of professional attraction, this was a growing specialty that required the skills and knowledge of a generalist (any organ system can be involved!) and the ability to think laterally, as well as grappling with the ethical challenges that end-of-life care throws up. More importantly, however, as a Christian, I felt it was a privilege to be able to come alongside those facing death. I finished my elective with a sense that this was the area of medicine to which God was calling me. After finishing house jobs, I embarked on a senior house officer (SHO) medical rotation. I found none of the specialties as rewarding as my time at the hospice, and I realised this was my calling. I therefore went on to complete a specialist registrar rotation in palliative medicine before taking up a consultant post at St Luke's Hospice.

My job is mainly hospice-based, but I also have community input. Most days begin with a ward meeting at which doctors and nursing staff discuss the management of each patient, before the doctors head onto the ward. Once a week this is expanded to a large multidisciplinary team meeting that most recently has been attended by specialist nurses from our community team, social care colleagues, and physiotherapist. Most days I am involved in the management of patients on the inpatient unit, reviewing symptom control, seeing new patients, supervising junior staff, planning discharges, and talking to relatives. I run a weekly pain clinic, jointly with a consultant anaesthetist. At any time, I might be asked to give telephone advice to community team specialist nurses and other medical professionals. I take part in an on-call rota for the hospice inpatient unit, supporting junior doctors. In addition to these duties, I have roles in teaching (including students), training juniors, clinical governance and audit, and management of the medical team. I was also medical director of the service for seven years.

OPPORTUNITIES

Unlike many specialties, palliative medicine is 'family friendly' with reasonable hours and on-call duties that are not burdensome – much of the on-call work is done from home – so I have time for family and church activities. However, the nature of the work carries its own stresses and challenges. While it can be rewarding and uplifting, it can also be sad and emotionally draining and you need to have ways of coping. Staff are faced with their own mortality and issues about suffering and others'

distress daily. The challenge is to engage with patients in a meaningful and therapeutic way, whilst maintaining your own emotional and spiritual health. I once heard it said that every death we witness lays a feather of grief on our shoulders. Over time many feathers can weigh a lot, and it is important to have ways of off-loading .

My faith helps. It enables me to deal with my own mortality, so that I am not threatened each time I encounter the reality of it in others. I know that I am a temporary resident here in the world, that Jesus has secured my eternal life and that my true home is in heaven. This hope destroys the power of death and the fear it engenders. My faith also gives me another dimension to the care I can offer in that I can lift patients to God in prayer. I can also, when given opportunity and permission, share my faith with those who are struggling. It enables me to set boundaries in terms of my limitations: having done all I can in human terms I commit the situation to the Lord, leave it at the foot of the cross and walk away. Prayer is also a wonderful blessing in dealing with the other professional challenges that make the work so interesting but also demanding. Ethical decisions, such as those around the appropriateness of active treatments, the withdrawal of life-prolonging treatments, conflicts of autonomy between patients and their carers, and sedation for intractable suffering, can all be shared with the Lord and approached with the wisdom and discernment He gives.

CHALLENGES

There are two challenges that result from my Christian beliefs that have to be resolved in the context of faith. The first relates to patients who are not Christians and the second to those who are. Many Christians who work in palliative care may tend towards universalistic beliefs – that after death there will be another chance to respond

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to Christ, and that God will not let anyone be condemned eternally. It is easy to understand the reason for this as it can be distressing to care for (and sometimes get very close to) the dying without believing that there is hope beyond death for all. However, universalism is contrary to Scripture, and to suggest otherwise is to give false hope. Although Jesus' death and resurrection open the possibility of salvation for all, [1] it is only through faith in Him that salvation becomes effectual. [2] Universalism virtually denies freedom to the human will. It minimises the gravity of sin, invalidates Biblical teaching on the final judgement, [3] and undermines the basis for evangelism. [4] Part of my work involves enabling people to find acceptance of what is happening to them and achieve a peaceful death. I build up relationships with some, and it can be hard to see someone die who doesn't appear to have found salvation in Christ. But we can only be obedient, being prepared to give a reason for the hope that is in us, [5] if given the opportunity, and continue to minister the love of Jesus to those in our care. God alone knows those who are truly His, and it is not up to us to know or decide.

The second challenge relates to the issue of healing. Sometimes for patients who are Christians there is an conflict between the knowledge that God can and does cure miraculously, and the realisation that they are deteriorating. There may be disappointment in them and in their believing relatives that 'prophetic words' promising healing don't seem to be being fulfilled. There are also times when the determination to cling on in faith to one's healing can hinder the process of letting go and preparing for death. I believe in and support the ministry of healing, and I am convinced that we all need to be asking God to heal. However, we must acknowledge that it is a mystery. Sometimes we fail to appreciate the difference between 'healing' and 'cure'. Although God sometimes chooses to cure and deliver from death, we must not forget that this is only a temporary healing – we will all die. What I want to emphasise is that we have opportunity for witness in the way we face death as Christians, and we can proclaim to a frightened world that death need not be the ultimate disaster.

Christians need to be involved: I believe that the hospice movement has been God's gift to this country. Jesus has always moved among the marginalised and it was the love of Him that drove a small number of dedicated people to take up the cause of the dying in this way. They were not only driven to act, but they also believed that God is in our dying, just as He is in our being born; [6] that the time and manner of our dying is appointed by God and that when we are with the dying (whether they are in Christ) we are on holy ground. Hospices are open to people of all faiths and none, but the term 'spiritual care' in the context of the hospice movement was originally defined in terms of our relationship with the Creator God. As it has expanded and moved into mainstream healthcare, palliative care has become secularised and the dominant ethos is now humanism. The concept of spirituality has been watered down so that it is now hard to define, and spiritual care is difficult to provide. It is essential for more Christians to get involved in this work. We are uniquely equipped to speak truth into issues surrounding end-of-life care. We are called to follow Jesus into the dark places of suffering and minister where others fear to go. We have the ultimate hope in Christ: the truth that there is a God who loves us, who will come alongside us and enter our suffering, who has conquered death and offers eternal life. While the deathbed is not the place for aggressive evangelism, opportunities to share the gospel arise when situations are approached sensitively, with the Holy Spirit's leading. We can minister in many ways without explicitly sharing our faith, and thereby demonstrate the love of Jesus. A fear of powerlessness often makes people shrink back from engaging with those who are suffering, but we have the assurance that God is with us and is in control. We can be empowered to be companions in the 'valley of the shadow of death' [7] for a while, our presence bringing

References

1 John 2:1,2. Romans 10:9. Ephesians 2:8,9. Matthew 7:13,14; 25:41. Luke 13:23-28. Matthew 28:19,20. 1 Peter 3:15. Job 2:21. Ecclesiastes 3:1,2. Psalm 23:4. 1 John 4:18. From a talk by Dr Andrew Fergusson at the 2003 Lee Abbey Hospice Conference. John 5:24

healing and hope. And if the 'shadow of death' that falls on us as we minister becomes too dark and cold, we have the love that casts out all fear, [8] and the prayerful support and fellowship of the Church to encourage and empower us. At a societal level, palliative care has much to contribute to the debates on euthanasia, life and health, and attitudes to dependency and disability, all of which pose major challenges now and in the future. We need more Christians working in this area and contributing to those debates.

HOW TO GET INVOLVED

This kind of work is not something everyone can do. There must be a sense of calling. As Christians ministering in this area, we need to be secure in our hope. Death and dying engender fear. Hebrews 2:15 talks of 'those who all their lives were held in slavery by their fear of death'. The world believes that physical death is the worst thing that can happen to a person. With such an outlook the inevitability of death destroys hope. Christians are not immune to this fear. One might think that having a Christian faith would equip a person better to face death than a non-believer – observation and research suggests that this isn't necessarily so. There is great truth in the observation that although most Christians believe in heaven in their heads it is not often a reality to us in our hearts. [9] If we are to offer this hope credibly, we must own it ourselves.

I would encourage anyone thinking of becoming involved in this work to meditate on John 11:1-38. In this passage we see Jesus' compassion and presence with Mary and Martha in their pain and his attitude to death; later in this chapter we see a foretaste of his victory over death when he raised Lazarus. But Lazarus would die again, and we need to look at the exchange between Jesus and Martha to find the real message of hope. Martha loved Jesus, called Jesus 'friend' and served Him – much like most of us who call ourselves Christians. But had she really grasped the significance of who Jesus was? 'I am the resurrection and the life' (v25), said Jesus as He put her on the spot and challenged her: 'Do you believe this?' (v26). Do we need to be challenged in the same way? Death need hold no fear for us. We are a risen people who have died the death that matters, [10] and it is important for us to grasp that.

Anyone who feels God is calling them into this work should try to spend some time with a palliative care team or in a hospice. Most medical schools include palliative care in the curriculum. Anyone wishing to specialise in this area needs to join a specialist registrar training rotation. The entry requirements for such rotations used to be broad, but recent changes linking training to joint accreditation with internal medicine mean that the only feasible entry route is through general medical training and Membership of the Royal College of Physicians. Palliative care can be challenging and demanding. People die only once, and as carers we only get one chance to get it right. But it is rewarding and full of opportunity – Christians have a huge amount to contribute.

This article first appeared on the website of the Christian Medical Fellowship, and is reproduced with the kind permission of Steve Fouch, Head of Communications.

About the author

Jeff Stephenson has recently retired. He was previously Consultant in Palliative Medicine at St Luke's Hospice in Plymouth. Jeff is keen to point out that as he first wrote this piece in 2004, some points may no longer be relevant.