

Being a Christian in palliative care

Jeff Stephenson discusses an important speciality

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

Palliative care

Palliative care has been recognised as a specialty for about 15 years and now has its own training pathway, career structure and emerging research base. One succinct 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 that there is nothing more that can be done. It is also 'total' care in that it embraces a holistic approach to the care of both patients and their families, recognising that physical symptoms are only part of the needs of patients with advanced disease who are facing the prospect of dying. It thus integrates physical, emotional, spiritual and social aspects of care, and this of necessity requires a multidisciplinary team approach.

The early hospice movement placed an emphasis on symptom control and quality of care for the dying, and this has had an impact on public perception and expectations. As a result, palliative care provision is now an integral part of the development of oncology services in the UK. Cancer care was the context in which palliative care originally developed, but the general principles apply to non-malignant conditions (such as AIDS and motor neurone disease), many of which impose similar burdens of symptoms, disability and dependence; work in this area is expanding.

Although some areas of the UK have better provision than others, palliative care services are generally well developed, and there is a wide 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 also developed in North America, though the model there is more nurse-led and focuses on home care. There are services in some parts of Europe, but these are much less well developed than in the UK. As a result, 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 ever-present debate on euthanasia, in which other European countries are probably looking to us to take a lead.

How I became involved

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. However, 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 also in coping emotionally themselves. I felt it was important to have some sort of 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 in my career. This was holistic care as I had never encountered it before, and it was very rewarding to be part of a multidisciplinary team. I worked under a Christian consultant who was highly eminent and very 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 tremendous privilege to be able to come alongside those facing death.

I finished my elective with a sense that this was probably the area of medicine to which God was calling me. After finishing house jobs I embarked on a senior house officer (SHO) medical rotation. During this time I found none of the specialties as rewarding as my time at the hospice, and I realised that this was indeed my calling. I therefore went on to complete a specialist registrar rotation in palliative medicine before taking up my present post at St Luke's Hospice.

What my job involves

My job is mainly hospice-based, but I also do some sessions in the community. I share the work with a team of five other doctors, many of whom are part time. Most days begin with a ward meeting at which doctors and nursing staff discuss the management of each patient - effectively a 'sit down' ward round. Once a week this is expanded to become a large multidisciplinary team meeting attended by social workers, occupational therapist, chaplain, day centre staff and complementary therapists. On most days I am involved in the management of patients on the inpatient unit, reviewing symptom control, supervising junior staff, planning discharges and talking to relatives. I also run two outpatient clinics per week, one of which is a pain clinic held jointly with a consultant anaesthetist from the local hospital. We may be asked to review patients attending the day care centre, and I also spend one or two half-day sessions a week working with the community palliative care nurses, discussing cases and visiting patients in their homes. I take part in an on-call rota for the hospice inpatient unit, mainly supporting junior doctors. In addition to these clinical duties I have roles in teaching (including medical students), training juniors, clinical governance and audit, and research.

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 via the phone - 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 very sad and emotionally draining and you need to have ways of coping with this. Staff are faced with their own mortality and issues about suffering and others' distress on a daily basis. The challenge is to be able to engage with patients in a meaningful and therapeutic way, whilst at the same time 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 start to weigh a lot, and it is important to have ways of off-loading this burden.

My faith helps in a number of ways. First, 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 and problems to God in prayer. I can also, when given the opportunity and permission to do so, share my faith with those who are struggling in the face of suffering and despair. It also enables me to set boundaries in terms of what my limitations are: having done all that I can in human terms I am able to 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 that he gives when asked.

Challenges

There are two particular challenges resulting from my Christian beliefs that have to be resolved in the context of that 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 to Christ, and that God in his love will not let anyone be condemned eternally. It is easy to understand the reasons 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 clearly contrary to Scripture, and to suggest otherwise is to give false hope. Although Jesus' death and resurrection open up the possibility of salvation for all,[1] it is only through a living faith in him that salvation becomes actual and effectual.[2] Universalism virtually denies freedom to the human will. It minimises the gravity of sin, invalidates biblical teaching on the final judgment,[3] and completely 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 obviously 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. Thankfully God alone knows those who are truly his, and it is not up to us to know or decide.

The second area of challenge relates to the issue of healing. Sometimes for patients who are Christians there is an inner 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 far more than many of us do. 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 miraculously and deliver from death, we must not forget that this is always only a temporary healing - we will all die. What I do want to emphasise is that we have tremendous 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 firmly 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 or not 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 to the Creator God. As it has expanded and moved back into mainstream healthcare palliative care has become secularised and the dominant ethos is now humanism. The concept of spirituality has been broadened and watered down so that it is now very hard to define, and spiritual care is difficult to provide.

It is essential for more Christians to get involved in this work and to reclaim the ground. We are uniquely equipped to speak truth into the 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 into our suffering, who ultimately has conquered death and who offers eternal life to those who put their trust in him. While the deathbed is not the place for aggressive evangelism, opportunities to share the gospel do arise when situations are approached sensitively and with the Holy Spirit's leading. We can also 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 in this and ultimately in control. We can be empowered to be companions in the 'valley of the shadow of death'[7] for a while, our very presence bringing 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 near future. We need more Christians working in this area and contributing to those debates.

How to get involved

It is important to say that this kind of work is not something that everyone can do. I believe that to do it effectively and survive there has to be a sense of calling. As Christians ministering in this area, we also 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 generally equip a person better to face death than a non-believer - observation and research suggests that this isn't necessarily the case. I think 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] I feel strongly that 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 11:20-38. In this passage we see Jesus' compassion and presence with Mary and Martha in their pain and his attitude to death; later on in the chapter we see a foretaste of his victory over death when he raised Lazarus from the tomb. 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 knew and 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 as believers. We are already a risen people who have died the death that matters,[10] and it is so important for us to grasp that.

If you feel that God is calling you into this work I would suggest that you try to spend some time in palliative care or a hospice. Thankfully, many medical schools now include palliative care in the curriculum, but if yours does not then try to get some exposure, either in an elective or special study module, or as a junior doctor. As regards the practicalities of training, anyone wishing to specialise in this area needs to join a specialist registrar training rotation. The entry requirements for such rotations are usually a postgraduate qualification such as MRCP, MRCGP, MRCS, or equivalent. I think the best preparation is a general medical background such as obtained in medical SHO rotations or general practice training schemes. I would be more than happy to discuss training or any other issues raised by this article; my email address is given at the end.

Working in 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 also tremendously rewarding and full of opportunity - Christians have a huge amount to contribute.

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References

1. 1 Jn 2:1,2
2. Rom 10:9; Eph 2:8,9
3. Mt 7:13,14, 25:41; Lk 13:23-28
4. Mt 28:19,20
5. 1 Pet 3:15
6. Jb 2:21; Ecc 3:1,2
7. Ps 23:4
8. 1 Jn 4:18
9. From a talk by Dr Andrew Fergusson at the 2003 Lee Abbey Hospice Conference
10. Jn 5:24