

day, and he asked me to compile a list of books a 'well-read' person ought to know. When I gave it to him, he seemed pleased; he'd started subscribing to one of those book collections you build up month by month, those ones you see advertised in magazines, and he said most of the classics I'd listed were due to be coming as part of his set. I last saw him a few weeks ago, and he was telling me then about a new series he had started collecting, all about art - each month he'd get a magazine about the life and work of a well-known artist, and a print of one of his works. He said his lounge would look like the National Gallery by the time he'd finished! He was hoping to go to France soon, and see for himself where some of them had found their inspiration.

Now he'll never get to go. He had a dream, but he was never able to make it a reality. In some ways you'd say he's done well. It just seems such a very sad waste of what might have been.

Extra note: For the Sunday service, Bob assumed that Beverley and Laurence had been married in a Methodist Church and that was why a Methodist Minister was conducting the service.

## CHRONIC ILLNESS & THE LOCAL CHURCH

**Chris Skilton**

*In this article I want to chart some of the actors in our society and in our churches that make life hard for those who bear a chronic illness and to outline some of the realities of life for those who suffer them. In a second article to follow I will suggest some ways in which those who are chronically ill can minister to the church and in which the church and its leaders can minister to them.*

In most of our churches, we pray for 'the sick' week by week and for their healing, renewal, restoration and peace. We are encouraged when people are restored to health and, if they have lived to a good age, philosophical, but affirming, when they die.

But what of those who neither recover nor pass away? Our churches are full of people who bear chronic conditions: their illness will not kill them, but neither can they foresee 'getting better'. These are people with all manner of conditions from arthritis to eczema and from diabetes to depression - conditions to

be lived with, not just from day to day, but year to year. How do we minister to these people, who often suffer in silence, but find aspects of life a desperate struggle; people who feel denied the opportunity to live life, let alone offer the Christian service they would like to give because of their illness?

### **Church and society - not places to be chronically ill**

Those with a chronic illness struggle to cope, not just with the illness itself, but with the expectations of the world and church in which we live. Issues arising from the following areas shape and influence how chronic illness is carried and perceived:

#### ***(a) Attitudes to Medicine***

The past hundred years has seen the eradication of many infectious and life-threatening illnesses. Medicine tends to focus on acute and terminal conditions rather than chronic ones. Advances in many areas have been swift and time spent in hospital for surgery is short. People are bemused when I recall how, thirty years ago as an ordinand, I served in the chaplaincy at the Oxford Eye Hospital, where patients having 'routine' operations for the removal of a cataract were in hospital for four days (if all went smoothly)! No wonder today that to be chronically ill is to defy the trend towards improvement, and to let the side down. Ironically, whereas once a chronic illness might have led to early death, it may now lead to longer, but heavily regulated life - a life that will neither improve nor deteriorate, but be simply 'held in check'.

#### ***(b) Attitudes to the body***

The body sells - clothes, cars, perfume, and in fact, anything. Few adverts feature people who are less than physically fit, healthy and preferably young. Never before has so much money been spent on improving, enhancing and relaxing the body. Those who believe they have less than acceptable bodies feel demeaned. Physical weakness, in an echo of some crude Old Testament interpretation, is seen to imply moral weakness. The recorded experience of these women is salutary: "I felt that I was no longer desirable...Society quietly decreed that I need not bother to become 'a woman': my disability precluded such a luxury"<sup>173</sup>

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<sup>173</sup> Jo Campling: *Images of Ourselves* (Routledge & Kegan Paul, London) 34, 53.

In response to this we need to affirm that we should pay attention to the body and care about it - and about everybody's body. Is our vision of heaven still that everyone will be of ideal height and weight and about thirty in perpetuity? Before we become overly critical of this as Christians, let us beware the imbalance on our bookshelves between the number of titles on 'How I was wonderfully healed from...' compared to 'How God's grace sustained me through forty years of living with diabetes'. I have noticed that the former are in a large section called 'Healing', and the latter in a much smaller one on 'The Problem of Pain'. What does this say to people?

### ***(c) Attitudes to "Doing"***

Church and society regularly define personal worth and personhood by activity. The second question asked of people we meet (after their name) is still "What do you do?". The chronically sick are often identified by what they can no longer 'do'. A cry of the elderly in our churches is often "I just can't do what I used to do for the church" as if this diminishes them in the sight of God and of others, let alone themselves. It may be time for churches to revisit (or visit!) W H Vanstone's classic book *Stature of Waiting* which demonstrates how passivity and 'being' are at the heart of the passion of Jesus and disclose to us something fundamental about the character of God.

### ***(d) The need to categorise - and stigmatise***

We all label people. Those who bear a chronic illness are no exception. A description of one aspect of life, for instance, "Kate suffers from rheumatoid arthritis" becomes Kate's defining characteristic. To define people in this way is to demean and diminish them and make unfair assumptions about them. Even in the writing of this article I am conscious of the phraseology I am using. It would be easy to write about 'the chronically ill' which creates a category of people about which others will make assumptions. We might look with care about how we speak about and pray about people in church week by week. What does having on our prayer list and saying in our intercessions for several weeks "Harry with Crohn's Disease" say about Harry and do for Harry in his relationships in the church family?

To categorise is also to exercise control. Society (and church is no exception) is still usually ordered by the physically able to suit

themselves. There is a growing body of literature written by those with physical impairments pointing out that for too long the organisation of their care has been undertaken and dictated by able-bodied professionals. The language of illness and its images drawn from war and violence betray our anxiety about the control and health of the body. To describe someone as having 'lost their battle with cancer' implies that they are defeated and shamed. People still speak of 'kidney failure' as if the body was not up to scratch. Notice, too, the way that language about illness is pejorative - "what's wrong with Mary's leg" or "he's got a bad leg". And 'invalid' can be pronounced in two ways!

To act in this way is often a means of denying our common frailty, weakness and vulnerability. We are all impaired, whether in a faculty, limb or organ, repressed emotions, lack of judgement, quick temper, lack of self-esteem ... the list is endless. In our churches we single out others (albeit to offer prayer) from an alleged position of strength, when we need to minister to one another by the grace of God out of our common vulnerability.

### ***(e) Better and better - now!***

Even in an age that has slowly woken up to the limitations of progress, life expectancy, like the A-level pass rate, is assumed to be always on the increase. Health is often seen as a property of life, and as an end in itself and as human right, as freedom from disease and infirmity. For those with a chronic condition, what is 'better' can be difficult to evaluate. In our ministry we must exercise discernment in ensuring that our ministry of healing is about the life of the kingdom and not signing up to 'better now'. Christian faith should be well placed to affirm the inter-connectedness and wholeness of life. Incarnational faith "creates a constant bias towards seeing person as whole beings".<sup>174</sup> Those who are chronically ill do not need the added burden of being told that they are not being healed because they lack faith, have unconfessed sin or a bitter spirit. This will simply be heart-breaking for those who after many years of debilitating pain will long to be free from it.

## **The realities of chronic illness**

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<sup>174</sup> James Woodward, *Encountering Illness* (SCM, London 1995)

A key task in pastoral ministry is to understand and to recognise the implications of where people are. In this section I will outline a series of different and sometimes contradictory feelings and states of being which sum up the effects of chronic illness.

### **(a) Vulnerability**

There is an inevitable vulnerability to the twists and turns of the condition itself and to the increased sense of the fragility of life. The surgeon Oliver Sacks vividly described his own experience of being in hospital: “I had to relinquish all the powers I normally command...I found this humiliating at first”.<sup>175</sup> Some will feel vulnerable at a constant round of medical appointments. The indignity of regularly having to undress or be undressed in front of total strangers is hard to bear. Frequent examinations of parts of the body, especially those not usually on view, or the insertion of instruments into it are signs of a loss of control and of a vulnerability to others. Writing in another context, but pertinent to this discussion, Sara Savage reminds us: “Our embodiment is fraught with risk; hence our desire to control our bodies at all costs. Life would be so much simpler if bodies were objects; our vulnerability could be ‘controlled’.”<sup>176</sup>

### **(b) Uncertainty**

Chronic illness brings home to us that life is uncertain. Our need to plan ahead can be thwarted and there can be embarrassment in having to cancel another event, not turn up at church to read the lesson or phone into work unable to make it again. There may not be reassuring answers to questions like, “What do my symptoms mean? Will I be able to function tomorrow?”. One person wrote in the midst of their own chronic condition that “we cannot help posing questions about values, what a person is, what he is for”.<sup>177</sup>

### **(c) Predictability**

This is an experience that can be felt at the same time as uncertainty! Illness can be predictable. There is no way that diabetes or arthritis can be dealt with by a few days spent quietly at home as one would getting over flu’ or a tummy bug. Michael

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<sup>175</sup> Oliver Sacks, *A Leg to Stand On* (Duckworth, London 1984).

<sup>176</sup> Sara Savage: “Through Dance” in Jeremy Begbie (ed) *Beholding his Glory* (DLT, London 2000) 71.

<sup>177</sup> Jessie van Dongen-Gerrard, *Invisible Barriers* (SPCK, London 1989) 43.

Mayne, the former Dean of Westminster in the midst of his time suffering from ME wrote that “one of the dispiriting things about my long illness is that you become so boring”.<sup>178</sup> character in Salman Rushdie’s novel, *The Ground Beneath Her Feet*, says: “Our tolerance for the truly hopeless, for those who are irredeemably broken by life, is strictly limited. The sob stories we like are the ones that end before we’re bored”.<sup>179</sup>

Chronic pain and illness are ‘boring’ and others can get bored with it as quickly as the sufferer can. Some are asked by well-meaning friends and ministers, “Are you feeling better?” out of sheer desperate hope that things might be different. I suspect that we all find it hard to minister well in these situations where there seems to be no closure, either by recovery or death. How will we minister to someone in this position when we visit them each month?

#### ***(d) Meaninglessness***

When chronic illness has disabled someone from exercising specific gifts or treasured pursuits and interests, cut short a career or working life, made intimacy with a partner difficult, it is not surprising they feel robbed of purpose or meaning. Victor Frankel, a holocaust survivor, wrote that “man is not destroyed by suffering; he is destroyed by suffering without meaning”.<sup>180</sup>

Pain can be alienating and isolating and thereby compound the struggle for meaning, as can being treated as an ‘invalid’. It is a challenge to discover meaning and an equal challenge for those in ministry not to try and impose meaning on peoples’ lives for them. Mary Craig, who experienced significant heartache in her life wrote: “Two persons can go through the same anguish; one of them may be destroyed by it, the other may achieve an extra dimension. The real tragedy...is the wasted opportunity.”<sup>181</sup>

The issues raised and questions asked in this article are not meant to add to the guilt of the minister or present an unnecessarily depressing picture! However, to offer appropriate and good pastoral care can only be done in the light of a better understanding of the context in which people live, and of the pressures and expectations which are placed upon them. We must

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<sup>178</sup> Michael Mayne, *A Year Lost and Found* (DLT, London 1987) 60.

<sup>179</sup> Salman Rushdie, *The Ground Beneath Her Feet* (Jonathan Cape, London 1999) 489.

<sup>180</sup> Quoted in Vanessa Herrick & Ivan Mann, *Jesus Wept* (DLT, London 1998) 162.

<sup>181</sup> Quoted in Herrick & Mann, 167.

recognise that some of these pressures and emotions arise out of the nature of the illness itself, but often they derive from the construction and interpretation that the wider society (including alas the church) places upon them. To acknowledge these factors in the conduct of ministry and to act sensitively in the face of them is itself a significant act of pastoral care.

## CREATING SAFE COMMUNITY

### Nigel Copsey

*Team Leader for spiritual care in the East London and City Mental Health Trust*

The church is central to any community. It is one of the few places which is an 'open door' to those living within the area. Most Christian communities have been given the stewardship of a set of buildings which can be used to serve the community. Our Father, through Isaiah (see chapter 58), provides us with a vision as to how we should respond to the needs of those in our community. So often we only provide support to those who attend our churches. I believe that the Lord demands us to serve all who are need.

In our society a high percentage of our local community will be trying to cope with emotional distress, mental health problems or mental illness. For more information on these issues, the best resource is the MIND website which provides all the basic information which it is necessary to be aware of. The organisation also publishes a comprehensive range of booklets all related to this area which are a perfect resource for any church.

Any Christian community has the opportunity to establish a 'drop in' which could take the form of a lunch club, coffee time, community evening or a week-long café. The point to make is that such activity should be open to anyone. It is not helpful to name an activity as being for those with mental illness! All this achieves is an increase in stigma. The ideal is to open a 'drop in' to the whole community for anyone who is alone and needs friendship.

There are a number of important principles in establishing such a place.