

## **The Spirituality of Imperfection**

Fred's journey and the practice of pastoral care  
in a Liver Transplant Unit

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During my chaplaincy internship in a Liver Transplant Unit (LTU) I was privileged to meet Fred [not his real name] and his family. Fred had been referred to the LTU for an assessment for a liver transplant. As with all patients entering the LTU, he was required to undertake a full multidisciplinary assessment by each healthcare professional on the team – for example, the dietician, physiotherapist, occupational therapist, physician, surgeons, psychiatrist, nurse co-ordinator, social worker *and* the chaplain. This assessment was necessary in order for patients to be offered a place on the transplant waiting list. Not all patients were successful in being offered a place on this waiting list. It was always a very nerve-wracking time for patients, their families and carers.

When I first met Fred, he was filled with suspicion and expressed to me how tired he was of constantly being questioned by people in the hospital. The chaplain was often the last person to complete a multidisciplinary assessment with a patient (possible reasons: the team gave priority to physical needs first; the chaplain's role was the only part-time position in the unit; it was a challenging role for staff to introduce to the patient, and so on.). As part of an initial pastoral assessment a chaplain might consider the following issues with a very ill person:

- Where that person finds the 'sacred' in their life.
- Their need, if any, for wholeness and healing.
- Whether the person has an awareness of, or is contemplating, their own mortality,
- Whether the person, if aware of his/her own mortality, has reflected on/is reflecting on a desire to live or has an awareness that he/she may be seriously ill with a liver disease and if left untreated, may eventually die.

There is a need to explore these difficult questions because of the importance of the level of commitment that each person brings to the decision about whether they believe they are a suitable candidate for a liver transplant or not. A patient's attitude of 'not wishing to die' has been found to be unhelpful when receiving a liver transplant. A commitment to life – to 'wanting to live' rather than just 'not wishing to die' – has been observed and noted anecdotally to be essential to a patient's health and well-being. This is because the medical work-up, treatment, surgery and recovery are both rigorous and very challenging for patients to manage. Life has, in most cases, been very hard for liver transplant candidates, and it takes enormous courage to say 'yes' to engaging the transplant process, while trusting and hoping that life will be kinder to them after the transplant.

The lead-up to a liver transplant can be a profoundly scary and sacred time as each person comes to terms with their own mortality and the possibility of a second (or third) chance at life. The recovery period can be stressful for patients, families and their carers, as relationships become realigned to a new reality, and to a much deeper appreciation that their loved one had the potential to receive 'the gift of life'. What to do with the remainder

of that new life offered to them, and how to 'be' in the world, becomes the focus. Many 'tide changes' (not just 'sea changes') to a person's life can be made during this period. It can be a time of deep mystery, wonder and awe.

As I journeyed through this encounter in the 'pin of life and death' with Fred, I discovered that he was a person with extraordinary resilience and that, as he was maturing, he was becoming a person of great courage in the face of overwhelming odds. Fred shared his story with me (as chaplain) while simultaneously testing my trustworthiness and respect time and time again, as he searched for a way *through* this momentous health challenge. Up to this time, Fred had dealt with his life and death situations the only way he knew how – on his own, keeping his own counsel – and with great willness and caution. Fred told me that, in the past, he had been labelled by many professionals and people in positions of authority as 'extremely difficult', 'dodgy', 'an alcoholic', 'irresponsible', 'dumb', 'a nutter'; just to name a few. Naturally he was waiting for me to label him too. I didn't.

Instead, I let Fred know that I admired his courage for coming into the LTU. I also let him know that some people left the unit after seeing only the doctors and nurses. I affirmed that he had chosen to stay and how honoured I felt that he was willing to meet with me. I also mentioned to Fred that I was the final person who would be meeting with him before a decision was made as to whether he would or wouldn't go on the transplant waiting list. I explained to Fred that if he went onto the waiting list, I would be available to him at all stages during the process leading up to the surgery, including being present during the transplant surgery and throughout his recovery period.

I sat in silence with Fred whilst he made a choice about whether to trust me or not...and whether to decide to accept the possibility of being placed on the waiting list or not. It was a moment of great vulnerability for Fred. He was being invited to trust another person. And more importantly he was being invited to trust himself and the choices he could make about his own health and/or death.

Fred knew the stakes were high. He was very ill – terminally ill - and whatever had worked for him in the past would not work for him now. He knew that he was being offered a choice...an opportunity...without judgement...the possibility of receiving another person's liver...as a gift of life to him. No-one had ever offered this possibility to Fred before. Never. I bore witness to Fred integrating an understanding about the enormity of this gift – that he was seen to be a person of worth, that he mattered, that he existed. We sat in silence together for some time. It was indeed a sacred moment. I found myself in the presence of a man embracing the profound responsibility he had to his own life. It was deeply humbling and moving to bear witness to Fred honouring himself in this way. Eventually Fred began to nod, and then the tears gently flowed. In nodding to me Fred accepted the invitation to the possibility of another chance at life: to the possibility of a liver transplant.

During that initial assessment Fred entrusted some of his life story to me. As a child Fred and his two younger sisters had lived in public housing with their mother. Fred remembered his mother telling him one day, when he was nine years old, that she was going to leave him at home with his two sisters over the following weekend so she could visit their uncle in Sydney. His mother left Fred and his two sisters on the next Friday and never returned home again. Fred was left to raise himself and his two sisters without any adult family and friends to support him. The full weight of adult responsibility had been handed over to a nine-year-old.

Fred told me that he managed to keep himself and his two sisters together until his youngest sister turned eighteen, although he never did tell me how he managed to do so. He did tell me however, that there had been some ‘run-ins’ with different authorities and people along the way. At the time of this initial liver transplant assessment, Fred was in his forties, was married, had two teenage daughters and was still in regular contact with his sisters.

Fred left school at fifteen. School had felt meaningless to him and he needed to find work to survive financially. Fred worked hard in the construction industry, saved his money and became financially secure. Fred also played hard, and drank hard. He became an alcoholic, developed liver disease, and eventually found himself facing the decision about whether to choose liver transplant surgery or not.

Fred was accepted onto the transplant waiting list and, after waiting for approximately three months, he had a liver transplant. I attended the operation. During my time working in the liver transplant unit, patients were often in surgery for up to nine hours, commencing at any hour of the day or night. The enormity of what is actually going on – that is, that one person has died and another person is to receive another chance at life – is truly breathtaking. The sacred nature of this work was *always* palpable in the theatre.

Fred received a liver, lying on the operating table with arms outstretched as if on a cross. His own liver was removed, creating a deep space within his body to make way for another liver; only possible because another person had died. I observed the surgeons skillfully, gently and reverently placing the new liver into Fred’s body, where they silently worked their medical miracle. The surgeons literally stroked Fred’s new liver into life, to encourage the blood to enter the liver: to bring new life to Fred. With each stroke, the liver changed colour – from white and pale to pink and warm, pulsating and alive. It was indeed a miracle, and an unforgettable honour to witness..

Fred made a good recovery. He went initially to ICU where I was privileged to be able to be the first person to visit him after the surgery. I wanted to see how he was so I could prepare his family before I brought them in to spend some time with him. When Fred woke I was standing right beside him at the bedside. He reached for my hand and looked straight into my eyes. He asked me: ‘Is it all over, Mary?’ I remember saying to him, ‘Fred, you are in ICU – the surgery is over. Your family is waiting to see you.’ He squeezed my hand tightly. It was time for silence. After a few moments I said quietly, ‘Fred, you have a new liver. Cherish it with your own life.’ Fred nodded and said to me, ‘Mary, no-one has ever done anything like this for me – I didn’t think I was worth it.’ Fred began to weep. He wept on and off (more *on* than off!) for eleven days.

Fred’s family spent a lot of time with him during that period, each in their own way trying to come to terms with the enormity of the gift of new life. After the second day post surgery, the relieving psychiatrist declared to the team on the Unit that, in his professional opinion, Fred needed to be medicated with antidepressants: he was crying too much. I challenged this assumption and asked the psychiatrist how he thought he might respond if he had been offered a gift like this – a new liver, a second chance at life – if he had thought that he wasn’t worthy of such a gift. I suggested that Fred needed to make the (autonomous) choice about taking antidepressants for himself. Fred refused.

I was working on the day that Fred was discharged from hospital. He thanked each staff member who had helped him through the past four months. I was the last person he spoke to before stepping through the doors of the hospital into the family car. Before we said goodbye to each other, I asked Fred if he knew what day it was that he'd had his transplant. He looked at me wonderingly and responded, 'It was a Sunday, Mary. Why?' I replied, 'Your transplant, Fred, was on Mother's Day – you received your new liver on Mother's Day.' Fred smiled and nodded. He understood.

### **Reflecting within a theological framework**

Fred's story illustrates the essence of day-to-day pastoral care practice to uphold the sacred and can be reflected upon in light of an even greater and wondrous story – the Christian Easter story; a metaphor for Fred's journey from a terminal illness (liver disease) to a new life (a liver transplant).

#### ***Holy Thursday***

*Celebrating life, yearning in absence, and mourning loss (anticipated and experienced), discovered through the roles of counselling (vital listening, conversation /dialogue and education) and attending to thanatonic issues.*

Fred's journey begins with a referral to the LTU for an assessment for a liver transplant. At this point he is being invited to explore very difficult questions with the chaplain about what has been lost in his life so far, what is now left, and what is still possible (Schneider, 1994). For Fred, a pivotal moment emerges – in the 'pin' of life and death – where the essence of pastoral care practice is present. It is that moment between the stimulus (a question) and the response (Fred's) that calls for wisdom and discernment ... where the movement of the Holy Spirit can bring insight and understanding ... where choices are made.

#### ***Good Friday***

*Wrestling with the decision, embracing the choice; and the role of prayer as silence and presence.*

The decisions Fred was being invited to make required him to trust himself, and to back himself against the odds. The choices involved confronting his own mortality, his own sense of worth (or lack of), and whether he really *wanted* to live or not. A pastoral care practitioner, through spacious listening, holds up different options as questions are asked and responses made. The full weight, the full burden of his life was being remembered. As Fred tells his life story, the pastoral care practitioner attentively and prayerfully remains present to him, in silence, upholding the sacred – enabling Fred to make his choice, to choose life or death – and bear witness in his struggle to embrace that decision.

#### ***Holy Saturday***

*Bearing witness in theatre (the tomb) through silence as emptying/emptiness; and being a general team worker.*

Once the decision was made to go onto the liver transplant waiting list, Fred and his family experience the helplessness of waiting ... waiting on the transplant list ... waiting for new

life or death. The pastoral care practitioner remains available to Fred and his family and joins the wait with them, conversing with them on a regular basis. Fred and his family oscillate between hope and no hope as they wait and wait: one moment preparing for death, another moment anticipating new life ... and finally, the waiting through nine hours in surgery. The weight of waiting can be hard to bear; during this period the pastoral care practitioner offers compassionate service to Fred and his family, and endeavours to ensure there is a good flow of communication between the LTU staff and Fred and his wife and children.

The weight of sacrifice is palpable in theatre. In order for Fred to receive a liver transplant, another person has died. The surgeons and theatre staff skillfully and respectfully attend to Fred, having harvested a donor liver just a short time earlier. The emptying – the removal of Fred’s liver – is real. So is the silence.

### ***Easter Sunday***

*Experiencing fullness and arising into new life; the teaching of ethics to staff,  
and recognising, blessing, and strengthening the sacred  
(sacramental); identity, worth and belonging.*

And then comes the fullness ... Fred awakens to new life. This gift of new life is ‘new’ for Fred *and* his family. At this stage, the pastoral care practitioner spends time with Fred and his family helping them to recognise and embrace the responsibilities associated with caring for, and attending to, Fred’s ongoing health care needs. Other professional team members are challenged if necessary – Fred is empowered to make his own choices (for example, about taking the antidepressants). Recognising, blessing and strengthening the sacred comes to fruition when Fred understands he has received his new liver on Mother’s Day (it actually *was* Mother’s Day). The significance and fullness of this understanding for Fred grounds his sense of identity, worth and belonging.

### **Relevance to research**

Fred’s story demonstrates the integral role of the pastoral care practitioner as a member of the health care team in the LTU. The pastoral care position at this hospital is funded from within the hospital budget, and it is important to be able to justify this publicly funded position (and other similar ones), and to claim, identify and articulate best practice approaches to the pastoral care role as a basis for ongoing quality improvement. Research into pastoral care can help to address these requirements. Three research paradigms are offered here as possibilities to underpin future research in this area:

- research already undertaken by Carey et al. (1996, 1997) focusing on the role of chaplains;
- research undertaken by Tehan (2007), based on the Creative Ministries Network ‘faith’ construct in conjunction with Swann’s Compassionate Leadership in Schools Model, adapted to the workplace; and
- research proposed by Tehan, to be based on Rumbold’s public health framework for spiritual care (Kellehear, 2002); and Berry (1999) and Stanworth’s (2004) metaphors as domains of specific archetypal symbols.

## **The role of chaplains**

In this research paradigm, Carey et al. (1996, 1997) focus on the role of the chaplain in three liver transplant units across Australia. In particular, Carey, Aroni and Edwards (1997) reported that within specialist units, ‘the majority of clinical staff respondents and informants expected and greatly appreciated the contribution that chaplains made to the hospital environment, particularly in terms of their more traditional roles ...counselling, sacraments, thanatonic issues, the teaching of ethics to staff, prayer and general teamworker roles’ (pp. 190-210). Likewise, Elliot and Carey (1996) in their research, ‘The Hospital Chaplains’ Role in an Organ Transplant Unit’, demonstrated that the majority of specialist staff was appreciative of the chaplains’ input to the overall running of a transplant unit (pp. 71-2).

In this research, five questions were asked of clinical staff. The percentage of ‘Yes’ responses is shown in brackets:

- 1 Have you discussed this [traumatic experience] with the unit chaplain? (56%)
- 2 Is the chaplain involved in decision-making in the liver transplant unit? (89%)
- 3 Is the chaplain helpful in assessing a patient’s suitability for a transplant? (89%)
- 4 Is the chaplain’s input a help in the execution of your work personally? (67%)
- 5 Is the chaplain’s input a help to the overall running of the unit? (100%).

Fred’s story was encountered in the same LTU where Elliott and Carey’s (1996) research results demonstrated that the majority of clinical staff acknowledged the involvement of chaplains and felt that the chaplains’ contribution within the LTU was valuable (pp. 71-2).

Carey et al.’s (1996) research helps to articulate and unpack how a chaplain in an LTU can help, meaningfully and productively, with decision-making, assessing a patient’s suitability, and making a valuable contribution to the overall running of the unit, including in theatre. Elliott and Carey (1996) also identified the ‘unique comradeship’ which resulted in generating a ‘foundation of trust and friendship between the chaplain and the theatre staff’ (p. 68). Central to the pastoral care role is the ability to generate and maintain trusting and befriending relationships with staff, patients and their families. Tehan (2007) has developed an integrated approach to evaluation for grief support in the workplace that is, in part, underpinned by a befriending approach (adapted from the Kennedy et al. (2006) model). This befriending approach, in conjunction with Carey et al.’s findings, may be appropriate for use to monitor and/or evaluate patient/family/staff relationship status/outcomes.

## **Workplace support**

This research was undertaken at Creative Ministries Network as part of a Masters in Public Health Action Learning project in 2007. It focuses on a whole-of-workplace approach to workplace support in an integrated framework. A peer-reviewed paper for publication is near to completion (‘Leading the way – compassion in the workplace’ in Tehan, Robinson and Thompson, in progress, 2008). The project developed an integrated approach to evaluation for grief support in the workplace involving three domains: workplace ethos; compassionate leadership; and a befriending approach.

This research paradigm utilises both a faith-based and secular construct to identify workplace ethos, and integrates it with a befriending approach to monitor and/or evaluate a top-down *and* bottom-up approach to workplace support. This is then a whole-of-workplace approach to workplace support. The specific elements in each domain could possibly be used to define the different variables in future research on the recognition and/or effectiveness of workplace support that pastoral care practitioners offer in their day-to-day practice to prevent stigma and discrimination.

### Future research

A third research paradigm, proposed by Tehan, will be based on Kellehear's (2002) public health framework for spiritual care (see Table 1); and Berry (1999) and Stanworth's (2004) metaphors as domains of specific archetypal symbols.

**Table 1** Strands of spiritual care

Strand	Spiritual Need
Identity	Supportive relationship until security is restored [existential insecurity]
Meaning	Skilled listening and support as people review their lives and fashion new meaning [loss of meaning and purpose in life; loss of vocation]
Destiny and purpose	Maintaining, reviving or initiating connections with an appropriate religious community [loss of community; loss of hope]
	Encouraging affiliation with alternative spiritual belief systems and practices as source of hope [loss of community; loss of hope]

*Source:* Kellehear, in Rumbold, B. (2002), pp. 221-2

This research would focus specifically on the patient in an LTU, as a pathway to identifying the spiritual needs of the patient, and the types of archetypal spiritual meanings that underpin their journey. O'Murchu (2000) describes spirituality as 'the will-to-survive ... itself driven by a will-to-grow (become) which in turn is fuelled with a will-to-meaning ... and this is the kernel of [that] spiritual energy' (p. 227). In addition, O'Murchu suggests that the theologian of the future needs to offer 'wisdom and discernment to befriend the strangeness, so that we discover its paradoxical will-to-life rather than be overwhelmed by the shadow of its debilitating alienation' (p. 221). In this context, this research may also be helpful in establishing whether a patient has the will-to-survive or not; a constant uncertainty for the medical/allied health LTU team, patients and families in the lead-up to, during, and after liver transplant surgery. The evidence for the intuitive belief that those who actively want to live do better than those who just don't want to die may possibly be addressed through this research paradigm.

### Conclusion

Fred's story, the reflection in a theological framework, and the three research paradigms have been offered to further the discussion on how to articulate and demonstrate that the pastoral care practitioner is an integral member of the health care team in the liver transplant unit. In addition, where ever the pastoral care position is funded from within the hospital budget, it is important to also be able to justify this publicly funded position to management and health care funding authorities. Finally, it is necessary to ensure accountability to the public for pastoral care services; and to identify, claim and

demonstrate best practice approaches to pastoral care as a basis for ongoing quality improvement, in the interests of the patients and families we serve.

## References

- Berry, T. (1999) *The Great Work: Our Way into the Future*. New York: Bell Tower.
- Carey, L.B., Aroni, R., Edwards, A. (1997) Health and Well-being: Hospital Chaplaincy, In: Gardner, H. (1997) *Health Policy in Australia*, Oxford University Press, Melbourne, 190–210.
- Creative Ministries Network (2004–2006) Creative Ministries Network Board of Governance, Minutes of Board meetings held 11 February 2004 – 13 December 2006.
- Creative Ministries Network (2005–2006) Creative Ministries Network Board of Governance Annual Report. Melbourne.
- Elliot, H. & Carey, L.B. (1996) The hospital chaplain's role in an organ transplant unit, *Ministry, Society & Theology*, July, 10, 1, 66-77.
- Kellehear, A. in Rumbold, B. (2002) *Spirituality and Palliative Care: Social and Pastoral Perspectives*, Oxford University Press, South Melbourne.
- Kennedy, J., McKenzie, I., & Wilson, H., (2006) *The Evaluation Toolkit*. Prepared for Befriending Network Scotland, the Scottish Mentoring Network and Evaluation Support Scotland. <http://www.befriending.co.uk/publications.uk>.
- O'Murchu, D. (2000) *Religion in Exile: A Spiritual Vision for the Homeward Bound*. Gateway, Dublin.
- Rumbold, B. (2002) *Spirituality and Palliative Care: Social and Pastoral Perspectives*. Oxford University Press, South Melbourne.
- Schneider, J. (1994) *Finding my way – Healing and Transformation through Loss and Grief*. Seasons Press, Colfax.
- Stanworth, R. (2004) *Recognising spiritual needs in people who are dying*. Oxford University Press, Oxford.
- Swann, R. (2001) Ecocentrism, Leader Compassion and Community. *Leading & Managing*, 7, 2, 163-80.
- Swann, R. (2002) *Compassion in School Leadership*. Australian Council for Educational Leaders, Monograph 31, October.
- Tehan, M. (2007) An Approach to Evaluation for Grief Support in the Workplace. Masters in Public Health Action Learning Project, School of Public Health, La Trobe University, Melbourne.

Tehan, M., Robinson, P. and Thompson, N. (2008) *Leading the way – compassion in the workplace* (in progress).

**Acknowledgements** The contribution of Dr Priscilla Robinson (School of Public Health, La Trobe University) and Dr Lindsay Carey (Palliative Care Unit, La Trobe University) to this paper is gratefully acknowledged.

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