# Communication: the forgotten palliative care emergency

PERSONAL VIEW **Mark Pickering, Rob George**

A 67 year old man was transferred to our hospice from the local district general hospital. He had end stage cardiac failure, and an implantable cardioverter defibrillator was in place. The referral was clear: he was coming to die. Just as clear was the fact that he didn't know his prognosis but was apparently expecting rehabilitation.

By the time I (MP) had admitted him he had turned blue three times, and during one of these cyanotic attacks the defibrillator had discharged. It was clear he was near the end. As I began to explore his understanding of the illness and what the future held for him, I felt a subtle squeeze on my elbow from his wife, as much as to say, "Don't tell him he's dying." It was 4 30 on a Friday afternoon, and this had all the makings of a bad death.

This was obviously a communication emergency. Certain things had to be communicated clearly in a short period of time in order to prevent his death being a complete mess for him and his family. The first priority was to speak with his wife and daughter. Both were fully aware of the prognosis but adamant that he should not be told, as "he couldn't cope with it." He had always been the strong one who protected the rest of the family.

I explained that we had an opportunity that many people miss—to say the things that needed to be said, to "put the house in order" and say goodbyes. If this wasn't taken, they might regret for years that the parting was sudden and messy. They concurred, and we agreed that I should speak to him alone.

**A looming bad death had been transformed into a good one**

Another urgent priority was to deactivate the defibrillator. This had not been discussed, but the last thing I wanted was for a dying man to be repeatedly flogged back to life when his body was begging to be left alone, causing unnecessary distress to patient and relatives. I called the teaching hospital that had implanted his defibrillator and located the nurse consultant, who was known and trusted by the family. The patient's wife would not consider deactivation without speaking to her, but a brief conversation between the two assured her that this was the appropriate thing to do. It was too near the weekend to undertake the usual full deactivation, but a suitable magnet was sent by courier that evening for use by the nurses in an emergency.

This done, it was time to talk to the patient. As we discussed his prognosis, he turned his eyes up to mine and said, "I thought as much, doc." He had suspected for a while that he was near the end but needed it confirmed by someone in authority before he would discuss it openly. In a constructive conversation we discussed symptom control, explored some spiritual issues, and agreed on the need to speak openly with his wife and family. By now it was after 5 pm and I was booked on a train to get to a wedding at the other end of the country. I left hoping that the patient and his family would take the opportunity to talk.

On returning the following Tuesday I learnt that he had indeed required sedation with a syringe driver on the Saturday and had died peacefully on Sunday. That lunchtime the family was due to attend for a bereavement meeting and collect the death certificate. I wondered how they would look back on that last Friday evening they had spent with the man they all loved.

Although clearly sad at his death, they were deeply grateful for the frank discussions we had had. After I left on Friday they had spent the evening together saying goodbyes, agreeing funeral arrangements, even enjoying a laugh and a joke together as a family. What a difference from the cloak of secrecy that had prevailed on his arrival! I could not have imagined a better result—a looming bad death had been transformed into a good one by the diagnosis and treatment of a communication emergency. At the end of our meeting his wife presented us with the Christmas present she had bought for her husband before his death—an ornament that now stands in the hospice as a memorial to the short time he spent with us.

Many have written on the importance of recognising and treating emergencies in palliative care and oncology. Likewise, much has been published on the importance of communication in palliative care. But the two concepts have rarely been explicitly linked, with communication identified as a genuine palliative care emergency. Although in practice we often recognise what needs to be done in a particular situation, formally identifying communication emergencies as one of the main emergencies in palliative care would increase awareness and improve their management.

The consequences of misdiagnosing or failing to treat a communication emergency can be important. For patients themselves it could result in a difficult death, where existential distress may simply be labelled as terminal agitation, leading to greater levels of sedation. For relatives it could result in years of avoidable guilt, regret, and sadness. This will most certainly make the normal grieving process more difficult.

Palliative care professionals particularly (but also other healthcare professionals) should be as alert to communication emergencies as to any of the more physical ones. The consequences of missing them can be just as serious.

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**The "striped (and sometimes flashy)" sandwich of supinator containing the posterior interosseous nerve is "thin, so do not nick the nerve."**

**How not to make a mess during extensile exposure, p 1277**

REVIEW OF THE WEEK

# Fractured: picking up the pieces

An author's fractured arm led to a book on the intrusive surveillance of doctors, finds **Jessica Watson**

"Medicine can, and does, save lives and contribute to wellbeing, but much of it is a massive cultural deceit." This is the controversial conclusion Ann Oakley reaches after being treated for the fracture of her right arm. Increasingly the medical profession is becoming aware of the value of patients' narratives, yet Ann Oakley is no ordinary patient. As professor of sociology and social policy at the Institute of Education, University of London, she treats her experiences as a "field trip into the land of bodily damage, disability, and personal injury litigation." In an attempt to make sense of her experiences she launches a huge research project that touches on a myriad themes including limitations of Western medicine, medical litigation, the problem of ageing, disability, and the confusion between bodies and identity.

Oakley portrays doctors as self serving and insular. One recurring theme is a lack of communication and in particular an inability or unwillingness to listen: "It quickly becomes clear that what worries me is not what worries the doctors," she writes. The doctors in her case were interested in the problems they saw—the state of the scar, the movement of the arm, and the degree of pain. No one took the time to find out what Ann Oakley's concerns were, largely that her hand felt like "an alien object": "I don't feel I have a right hand. It just hangs there at the end of my arm. I hate it." She is not only right handed but a writer of sociology books and novels, and devotes a whole chapter to exploring the personal, cultural, and psychological significance of the right hand.

The medical model of Western medicine, or "body as machine" approach, "distorts the human experience of living in a body," Oakley argues. In this model "objective," quantitative tests are seen as providing the answers, and in the process the patient's subjective experience is ignored and delegitimised. Nerve conduction studies are an example of "the mechanical model of the body par excellence; the patient doesn't have to speak, or even, really, be conscious at all." On the basis of these "objective" tests, doctors discharged Oakley as "cured"— even though "these tests said nothing about sensibility—about what I felt."

Oakley portrays her physiotherapist in a much better light than the doctors: "the difference is that Theresa listens when I tell her; she isn't a machine." Disappointed by mainstream medicine, Oakley also turns to acupuncture, and its more holistic approach makes her hand "feel a little bit more like part of me again." A fundamental difference between Western medicine and acupuncture, she argues, is the inseparability of mind and body, and this theme of embodiment is central in the book.

Within this theme Oakley explores several other areas, with some controversial conclusions. Screening "isn't to prevent disease, but to change identities—to produce patients." To back this up she says that evidence to support the benefits of screening is minimal, yet screening subjects large numbers of women to unnecessary investigations and anxiety.

She feels that ageing women are excessively medicalised and medicated, with hormone replacement therapy being "the ultimate case study in pharmaceutical marketing, in how to make millions by inventing new conditions that need treatment, playing on people's susceptibilities, and ignoring the bad news about what drugs do to the body." Also, one chapter is devoted to a damning criticism of the American system of litigation, blame culture, and lawyers as "ambulance chasers."

This is a surprisingly readable book, given the complexity of some of the issues discussed. It interweaves the author's own experiences with other patients' stories and evidence from research. Some of Ann Oakley's statements seem to overdramatise the facts to court controversy, but the book has some interesting lessons for doctors.

Although patient centredness, communication skills, and the holistic approach are increasingly being incorporated into medical teaching, this book finds a gap between the theory and practice of these skills. It would be easy to dismiss the concerns raised as the anecdotal experiences of one patient, but many doctors will recognise an uncomfortable reflection of some aspects of medical practice. Whether the doctors did a technically good job in the medical task of fixing broken bones was, to this patient, secondary. Her book reminds us all of the importance of listening to and learning from our patients and encourages reflection on the universal experience of living in a body.

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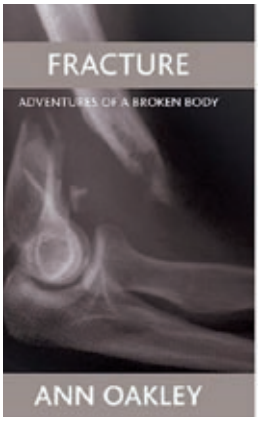


**Fracture: Adventures of a Broken Body**
Ann Oakley
Policy Press, £12.99, pp 186
ISBN 978 1 86134 937 8
Rating: ★★★☆

**The doctors in Oakley's case were interested in the problems they saw—the state of the scar, the movement of the arm, and the degree of pain. No one took the time to find out what her concerns were**

# 110%

FROM THE FRONTLINE
**Des Spence**

I am going to give this 110%. Sporting analogies are everywhere, for sport is a microcosm of life itself. Sport incorporates important themes like the team over the individual, obeying rules, the threat of sanctions, persistence, endurance, pride, effort, structure, hierarchy, and—all important—the need to meet defeat and victory with equal measure. Perhaps these crude analogies are legitimate and we should view the NHS as just another big team game.

Let's work this sporting analogy further. The NHS is at risk of becoming American football: teams within teams, producing reams of meaningless statistics; constantly changing shifts of players; superspecialised players performing one single task; start-stop, clock watching, pointlessly technological; glitzy, covered in layers of padding, pumped up on growth enhancers with unknown long term consequences—even the gleam of the pitch is utterly synthetic. Just expensive and complicated, but worse still: interminable and dull. Our population of health spectators, now obese, gazes on, chomping on foot-long hotdogs as they guzzle down their gallons of fizzy drinks. The announcement system blasts out a deafening and distorted version of "We are the Champions," drowning out any dissent. All attempts to export this sport, perhaps not unsurprisingly, have failed.

But the traditional model of the NHS is one of a soccer match in a dog fouled city park. The nurses are the defence: solid, dependable, organised, and quietly getting on. The GPs are the midfield: holding the ball, playing it around and holding the possession, helping in defence but sometimes going forward. The consultants are the two fiery glory hunters up front, aggressively seeking to score that all important diagnosis.

So you can stuff staying up half the night for the medical superbowl party. Give me my NHS football world cup, a truly global event with poverty no barrier to success—an event where a truly gifted individual can make a big difference and raise the morale of a whole nation. There is the odd shouting match, but these get "sorted" in the pub afterwards. It is the NHS's complete simplicity that makes it so beautiful and highly regarded. Had enough? I've done my best and you can't ask more than that.

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# Jobs for the boys

PAST CARING
**Wendy Moore**

Climbing the medical career ladder used to be so much simpler. Before the advent of tedious form-filling, maddening technical hitches, and the rush for too few posts, obtaining a plum job for life was governed by an application system everyone could understand: nepotism.

For centuries, all that was needed for an aspiring trainee physician or surgeon to secure a lucrative countryside practice or a top post at an eminent teaching hospital was the right family connections. In a spirit of continuity only equalled by *The Forsyte Saga*, medical dynasties ruled supreme. While the Chamberlens kept their midwifery practice in the family for five generations, so the Monros—the unimaginatively named Alexanders I, II, and III—maintained a steely grip on Edinburgh University's chair of anatomy for 126 years.

Admittedly there were disadvantages. Impatient sons and nephews had to bide their time until dad or uncle retired through ill health or died—although given prevailing medical ignorance this need not be overly long.

And naturally the system proved unpopular with anyone lacking appropriate blood ties. Devoid of illustrious ancestors, surgical apprentice John Flint South gamely accepted the appointments procedure at St Thomas' when the death of his tutor Henry Cline created a vacancy in 1820. "Several of the other hospital apprentices sent in their humble petitions to the Governors to be chosen their surgeon, I among the number," he wrote, "but it was a mere matter of form." Cline's cousin, Joseph Henry Green, was duly elected to the job.

With no recognition of merit, experience, or competence, the system was similarly unpopular with patients—should they live to voice a complaint. When William Lucas succeeded his father at Guy's in 1799, his butchery became so notorious that one trainee was put off surgery for good: the young John Keats sought employment elsewhere. After witnessing Lucas amputate a leg from the wrong direction, leaving a generous flap of skin on the discarded limb and a protruding bone on the stump, even the amiable South conceded that his operations were "generally very badly performed, and accompanied with much bungling."

Ultimately the system became discredited under intense media scrutiny. *Lancet* editor Thomas Wakley crowned a sustained campaign against nepotism with a dazzling exposé in 1828 of a fatal operation to remove a bladder stone by Bransby Cooper, inept nephew of the esteemed Astley Cooper, at Guy's. Despite Bransby's victorious libel suit, the jury's derisory award of £100 damages made plain that relative values were no longer sufficient recommendation for a medical job. Uncle Astley's pleading that young Bransby would make a "brilliant operator"—given time—would probably cut little ice even today.

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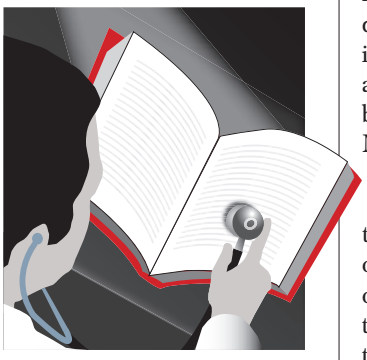
# The casualties of Waugh

BETWEEN THE LINES
**Theodore Dalrymple**



**What exactly is Waugh satirising in his story? Not least, surely, the do-gooding propensities of the well-placed**

My father was not very good at telling jokes. If something was a fact he couldn't leave it out, and over-inclusiveness is not an aid to mirth. Still, he had a repertoire of old favourites, and one of them, which he told many times, concerned what in those days was still popularly known as the loony bin.

An inmate showed the chairman of the board of visitors around the establishment, and did so with such lucidity that the chairman asked him why he was an inmate at all. He replied that he didn't know, and asked the chairman to help him secure his release. The chairman promised to do so.

Just as he was leaving the asylum, the chairman felt a blow with a brick on the back of his head.

"Don't forget now," said the inmate, waving to him.

This joke is, in essence, identical to the plot of Evelyn Waugh's short story *Mr Loveday's Little Outing*.

Lord Moping is committed to the County Asylum for Mental Defectives (a term still widely in use during my childhood, although educationally subnormal was taking over) when he tries to hang himself during his wife's annual garden party.

Lady Moping refuses to countenance a more expensive establishment because she has been so humiliated by his social faux pas; but the richer lunatics have a wing of their own in the asylum, where they are allowed to dress as they please and to have a dinner party every year on the anniversary of their committal.

Mr Loveday, another long term inmate, acts as Lord Moping's amanuensis during his residence in the asylum. Lord Moping is forever dictating memoranda to the great ones of the earth on such subjects as the fate of major rivers, and his daughter, Angela, is so impressed on a visit to her father by the efficiency of Mr Loveday, who tells her that many years ago he made the slight mistake of knocking a girl off her bicycle and then strangling her, that she vows to secure his release. Mr Loveday tells her that he has only one small ambition, but does not want to say what it is.

This she does, and a meeting is held in the asylum to send Mr Loveday off to his freedom. The doctor assures him that he is so highly esteemed by both staff and patients that there will always be a place for him if he does not like life outside.

Mr Loveday is back within two hours; and all too predictably, he has knocked a young woman off her bicycle and strangled her. He announces with the greatest pleasure that now he will never be released from the asylum again. He had never really wanted to go in the first place.

What exactly is Waugh satirising in his story? Not least, surely, the do-gooding propensities of the well-placed, who are inclined to take up causes whimsically as a means to mere self gratification, without much thought for the possible consequences.

Of course, these days Mr Loveday wouldn't have been released without a proper risk assessment and follow up arrangements.

I'm not sure that would have preserved the young woman on the bicycle, however.

Theodore Dalrymple is a writer and retired doctor

# MEDICAL CLASSICS

**Extensile exposure** By Arnold K Henry

## First published as *Exposure of the Long Bones* in 1927

Arnold K Henry was a remarkable man. Born in 1886, he graduated from Trinity College Dublin in 1911 and became fellow of the Royal College of Surgeons of Ireland in 1914. In the first world war he served as a surgeon in both the Serbian and the French armies and was decorated by both. He was accompanied by his wife, Dr Dorothy Milne Henry, who was his close collaborator and assistant. He went on to work as a surgeon in Dublin, then as professor of surgery at the University of Cairo and at the Postgraduate Medical School at Hammersmith, and in 1947 returned to Dublin as professor of anatomy.

In 1927 Henry published a book entitled *Exposure of the Long Bones*, which was revised first in 1945 to *Extensile Exposure Applied to Limb Surgery* and then in 1957 as a second edition entitled simply *Extensile Exposure*. This volume remains an invaluable reference for surgeons of all persuasions, but particularly those who operate on the limbs.

The book covers a lot of ground; from exposures in the neck, the upper extremity, the thorax, the pelvis, and the lower extremity. As the title suggests, the approaches are extensile. For example, the nerves of the brachial plexus can be followed from the neck into the shoulder and the arm. Where other anatomical texts appear dry and uninteresting, Henry's descriptions of the practical aspects of surgical exposure are fascinating and are interspersed with anecdotes from his extensive surgical career. He suggests those not following his advice "will only make a mess." The "striped (and sometimes flashy)" sandwich of supinator containing the posterior interosseous nerve is "thin, so do not nick the nerve." The vessels on the deep surface of gluteus maximus sprawl like those of the placenta. Henry is refreshing in his honesty. His description of how his technique for pulmonary embolectomy evolved when operating on three patients is published despite the fact that none survived.

**Henry's description of how his technique for pulmonary embolectomy evolved when operating on three patients is published despite the fact that none survived**

Henry clearly has a sense of humour. He can't resist a dig at other texts, describing the "huge great sciatic nerve" as the one "oasis of description" Gogarty could find in Cunningham's anatomy. The whole is written in a style reflecting a classical education; in Henry's view the hamstring tendons and vastus lateralis are the "Scylla and Charybdis" between which the gluteus maximus may be palpated. His description of the function of gluteus maximus is a particular delight.

There is no doubt that Henry was a man of powerful intellect, with an enquiring and analytical mind. This book contains the distilled experience of many years of practice. It is an apt legacy. Fifty years have not diminished its relevance and usefulness.

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