

# Care, compassion and charity: do they have a place in modern medicine?

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The Inaugural Ron Ball Memorial Lecture

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It's a pleasure and a privilege to be invited to deliver the inaugural Ron Ball Memorial Lecture here in Christchurch. I've set what I hope is a rhetorical question, as the topic for my lecture: do care, compassion and charity still have a place in modern medicine?

## Addis Ababa Fistula Hospital

Last month, I visited the Addis Ababa Fistula Hospital, which I learnt of some years ago, when I read Catherine Hamlin's *The Hospital by the River*.<sup>1</sup>

The book tells the story of how obstetricians and gynaecologists, Reg Hamlin (a New Zealander) and Catherine Hamlin (an Australian), arrived in Addis Ababa in 1959 to establish a midwifery school, and stayed for the rest of their lives. They founded a charitable fistula hospital that opened in 1975—a hospital dedicated to the surgical treatment and rehabilitation of Ethiopian women suffering from obstetric fistulas, caused by obstructed labour, often in very young women whose untreated condition causes them to become outcasts in their communities. At 91, Catherine Hamlin is still working at the hospital, which has become a major teaching institution for surgeons from all over Ethiopia, Africa and the developing world.

The story has a Christchurch connection. Reg Hamlin was a choral scholar in the Christchurch Cathedral choir, educated at the Cathedral Grammar School. He qualified as a teacher at Christchurch Teachers Training College and obtained a BA and MA from Canterbury University. He was a friend and fellow chorister of my school music master, Lin Saunders, whose wife Helen told me this story.

One day in their 20s, Lin and Reg, newly qualified teachers, played a round of golf here in Christchurch, and discussed how they were both thinking of studying medicine. They decided to ask their respective GPs for advice. Lin's GP told him to stick with music—which he did, becoming a music teacher at King's College, and reviewer for the *New Zealand Herald* for 53 years. Reg's GP thought he would make a good doctor, and so Reg headed off to Otago to study medicine and graduated in 1941.

The Addis Ababa Fistula Hospital also has another New Zealand connection. The initial funding for the hospital came from a £10,000 donation from the head of CORSO, the New Zealand Council of Organisations for Relief Service Overseas.<sup>2</sup>

Today, the fistula hospital relies on charitable donations from all over the world.

Care and compassion lay at the heart of the vision of Reg and Catherine Hamlin. Reg described their patients:<sup>3</sup>

*Mourning the stillbirth of their only child, incontinent of urine, ashamed of their offensiveness, often spurned by their husbands, homeless, unemployed, except in the fields, they endure, they exist, without friends and hope. They bear their sorrows in silent shame. Their miseries, untreated, are utter, lonely and lifelong.*

Catherine describes what the charity hospital can offer:<sup>4</sup>

*Somehow she hears about the hospital. Somehow she begs the fare or persuades a relative to take her on the long, frightening journey to the unimaginable confusion of*

*the capital. The hospital is quiet and clean, set amongst flowers. People treat her with kindness. She is bathed and experiences the strange luxury of a soft bed with clean sheets. And the miracle she has hardly dared to believe, happens. After a time she returns home, cured, to begin life anew.*

Visiting last month was a moving experience.

### Charity

The derivation of charity is from the Latin word *caritas*, sometimes described as altruistic love. Paul's 1<sup>st</sup> letter to the Corinthians, chapter 13, verse 13, in the King James version, reads: "And now abideth faith, hope, charity, these three: but the greatest of these is charity." Some of you will also be familiar with the well-known Latin text, often set to music: "*Ubi caritas et amor, Deus ibi est*"—where love and charity are, God is there.

The modern notion of charity is of the voluntary giving of help, often in the form of money or services, to those in need. The Canterbury Charity Hospital states in its 'Enduring Vision' that its single purpose is to "serve the unmet health care needs of the community", by providing "specialist health care services to as many people in Canterbury as possible";<sup>5</sup> people who have health care needs that cannot be met through the public health system and who cannot afford private health care. They are patients who otherwise 'fall through the cracks'.<sup>6</sup> Judging by the number of patients treated in the Canterbury Charity Hospital, it is clearly filling a need.

I salute Phil Bagshaw and fellow trustees of the charity hospital for their vision, and all the volunteers who give their time and services at the hospital, as well as the many donors who support its work. I commend the health practitioners involved in this venture, for recognising that "there is a moral imperative and a professional responsibility to address the unmet health care needs in the community".<sup>7</sup> This is consistent with the statement in the New Zealand Medical Association Code of Ethics, in the section entitled 'Doctors in a just and caring society', that "[w]hile doctors have a primary responsibility to indi-

vidual patients, they have a concurrent responsibility to all other patients and the community".<sup>8</sup> Meeting that responsibility entails more than simply following the latest Ministry guidelines on prioritisation.

Interestingly, in the US, which has a market health care system *par excellence*, the American Medical Association Code of Medical Ethics spells out a professional obligation for individual physicians to care for those with medical needs, but limited financial means. The oft-cited 1847 Code stated:<sup>9</sup> "But to individuals in indigent circumstances, ... professional services should always be cheerfully and *freely* given."

The wording of duty in the latest version of the AMA Code (dating from 1994) is less clear-cut, but it still specifies an obligation on physicians to care for the poor:<sup>10</sup>

*Each physician has an obligation to share in providing care to the indigent. ... All physicians should work to ensure that the needs of the poor in their communities are met. Caring for the poor should be a regular part of the physician's practice schedule.*

I have no doubt that many individual doctors quietly and routinely provide free care to patients who cannot afford to pay. That is certainly true in New Zealand.

A few come to public notice. One whom I know personally, is Dr Sharad Paul, a GP specialising in skin cancer surgery from a clinic in Blockhouse Bay in Auckland. Dr Paul provides around 7,000 free skin check consultations each year, and has provided this service since 1996.<sup>11</sup> He has been honoured with several public awards, including last week from APAC (the Asian Pacific Healthcare Forum), for 'Leading Health Improvement on a Global Scale', for his role in improving skin care management, education and patient-centred care internationally. But Dr Paul has also faced fierce resistance from some surgeons and dermatologists. Doctors who provide high quality, charitable services may be ostracised by colleagues who have different motivations in the practice of medicine.

Critics say that the charity care provision of the AMA Code is an empty platitude, and argue that instead of reliance on the altruism of some individual doctors, a community

obligation would make more sense.<sup>12</sup> That is precisely the direction of Obamacare, or the Affordable Care Act in the US.

In New Zealand, of course, we have our own form of socialised medicine. Arnold Nordmeyer was the architect of the Social Security Act 1938, passed under the first Labour Government, headed by Prime Minister Michael Joseph Savage. The so-called ‘cradle-to-grave’ welfare system made comprehensive provision for health, for security of income, and for the general welfare. It paved the way for free hospital care and access to a wide range of health benefits, many of which were rolled out while Nordmeyer was Minister of Health from 1941 to 1947, and which endure today.<sup>13</sup>

Interestingly, one of the concerns expressed in Parliament in 1938 was that social security could embarrass the professional commitment of doctors. There was certainly professional resistance. The attempt to introduce free primary medical care was fiercely resisted by the New Zealand branch of the British Medical Association. A contemporary cartoon shows a jar with the tag “General Practitioner Service” with the BMA inside it, and the text has Minister of Health Walter Nash, saying “Snappy work Nordmeyer, Are you sure he can’t bite?” The BMA could bite, and it did. It ran a very effective public relations campaign, and demonised Nordmeyer and his reforms. Debate about free primary medical care and fees surcharges continues to this day.

In the decades since, the publicly funded health system has struggled to meet patients’ needs in both primary and secondary care. Last year, Robin Gauld and colleagues published an article in the *New Zealand Medical Journal*, entitled “The importance of measuring unmet healthcare needs”.<sup>14</sup> They propose regular, objective and comprehensive measurement of unmet health care needs, by formal interviews of representative samples of the community. A pilot survey is planned for later this year.

In the meantime, health officials, policymakers, politicians, funders and health practitioners grapple with growing demands for health care, in the face of the inability of the system to cope, even at a government spend of 6% of GDP on

health care and a total spend of 10% of GDP on health care, slightly above the OECD average.<sup>15</sup> One finds little discussion of the role of charitable funding and provision in official documents.

Looking back in time, I was intrigued by some of the references to charitable provision of health care in the 1975 White Paper, *A Health Service for New Zealand*,<sup>16</sup> presented during the term of the third Labour Government, by Minister of Health Tom McGuigan, MP for Lyttelton and a former Christchurch Hospital manager. It traces the history of public health provision in New Zealand. A key figure in the late 19<sup>th</sup> century was Dr D Macgregor, Inspector of Lunatic Asylums and Hospitals, who pressed for radical reorganisation in the number of hospital and charitable aid authorities, to “about twenty strong boards”.<sup>17</sup> *Plus ça change*. Macgregor played a key role in preparation of the Public Health Act 1900. He apparently tended to the view that “State sponsored charity should be given more in the spirit of Blake’s usurious hand than St Paul’s charity [that] suffereth long, and is kind”.<sup>18</sup>

In later years, the role of charitable funding of health care seems to have dropped off the political and legislative radar. In official documents, such as the report of the Royal Commission on Social Security in 1972,<sup>19</sup> the issue of concern was the growth of private health insurance and private provision of health care. Interestingly, the report of the National Health Insurance Investigation Committee of 1937 (at the end of the depression) had stated: “Self-respecting, freedom-loving New Zealanders will never ... tolerate ... one type of service to the poor and another type to the well-to-do.”

It seems that we have become a more tolerant society.

### Access

As an Ombudsman, an appointed, not an elected officer of Parliament, it is not my role to comment on the inability of the publicly funded health system to meet the needs of patients. But as a former Health and Disability Commissioner, and as author of a chapter on “access to health care” in the newly published *Health Law in New Zealand*,<sup>21</sup> I am well aware of the problems

of access to specialist assessment and treatment, and of the need for good information for patients left waiting while they seek to access care.

Many patients, in Canterbury and beyond, are unable to access charitably-funded health care, yet will not meet the threshold (so-called clinical priority access criteria) for specialist assessment and treatment in the public system. Many will lack the resources (including private health insurance) to access private care. Do they have any rights under the Code of Patients' Rights, which articulates rights when receiving health services, but not an actual right to access care in the first place?

I considered this situation in a decision issued on my final day as Health and Disability Commissioner, in March 2010. I stated:<sup>22</sup>

*It is well recognised that there is insufficient public funding to meet the immediate health needs of all New Zealanders, and that some patients who require elective services are unable to access them through the public system. Public hospitals are expected to treat those with the greatest need first. In this environment, it is essential that patients are treated fairly, consistently, and to an appropriate standard within the resources available.*

In that case, a young woman in her mid 20s, with hearing loss and worsening neurological symptoms, was referred three times over 30 months to the Nelson Marlborough District Health Board, before she finally had an MRI that revealed a tumour requiring urgent surgery. I found the DHB in breach of its duty of care to “appropriately assess and prioritise” the patient’s level of need for an MRI scan, and to operate a fair and consistent process for managing the care of referred patients; and of its duty to provide timely information about the outcome of the referral, whether the patient was likely receive an MRI, the option of a private scan, what the symptoms meant, and the risks of delay in being seen.

My Nelson Marlborough ruling built on my earlier decision in 2006 about a Southland freezing worker, Jim Logan. After a very high PSA test result and

urinary symptoms, he was referred by his GP to the Southern DHB, which classified him as ‘urgent’ on a waiting list for a first specialist assessment. Mr Logan waited 18 months without being seen and finally sought treatment from a private specialist, who diagnosed prostate cancer. In my opinion, he had the right to be told by his GP ‘what other options were available to him’, including the right to seek private assessment and treatment, if publicly funded services were not available ([www.hdc.org.nz](http://www.hdc.org.nz) Opinion 04HDC13909).<sup>23</sup> We need to be careful about assumptions about what means a patient can draw on to access necessary care.

## Care

Let me turn from problems of access, to questions of care. As patients, whether we access care in the public, private or charity system, we have the same legal right to receive services of an appropriate standard. I note that the Canterbury Charity Hospital states on its website that “the standard of health care will, in all instances, equal or exceed that expected of the public health system”.

Survey research by the Picker Institute in England in 2006 found that 78% members of the public rated whether the doctor makes the care of the patient his or her first concern as the most important duty of a doctor.<sup>24</sup> Patients want their interests to come first—and this is true both in relation to health practitioners and systems of care.

Luke Fildes’ iconic painting of *The Doctor*, commissioned by Henry Tate for an exhibition in 1891, is an evocative portrayal of the caring, attentive physician making a house call and watching over a sick child at night. It evokes a sense of care.

As we know, patients do not always receive good quality care from attentive health practitioners and alert systems. Mistakes happen, sometimes from a lack of care. In my time as Health and Disability Commissioner, I spoke out about cases where patients had received poor care in private hospitals, an environment where members of the public sometimes assume that they will receive superior care. It is equally important that care in a charity hospital is of a high standard.

The duty of care owed by a surgeon, an anaesthetist, a nurse, a dentist or a counsellor,

or indeed by the hospital where they work, cannot be diluted based on the means of financing or the location of service provision. There can be no sliding scale of care. As a patient, I am entitled to expect that health services, wherever provided and however financed, will meet the legal test, affirmed in Right 4 of the Code of Patients' Rights, of being provided with reasonable care and skill, in accordance with professional standards, in a manner that minimises potential harm, and well coordinated.<sup>25</sup>

Quality assurance and improvement activities within a charity hospital should be as rigorous as we expect in the public system, with robust systems of incident reporting and peer review. Grateful patients who receive charitable services must feel no moral pressure not to ask questions, raise concerns or complain if they are unhappy about their care. They have the legal right to complain, and to receive a prompt, reasoned response. All service providers should welcome complaints as valuable feedback that can help improve the quality of care, and respond to the concerns of an unhappy patient.

In a national study of a decade of complaints about doctors to Australian healthcare complaint commissions, Bismark and colleagues found that 61% related to clinical care.<sup>26</sup> It is interesting to speculate how many complaints about care were precipitated by a failure in communication.

The verb, to care, has its roots in the Old English word *carian*, meaning to "be anxious, grieve; to feel concern or interest". This sense was captured by Boston physician, Francis Peabody, when he wrote (in JAMA in 1927) that "the secret of the care of the patient is in caring for the patient".<sup>27</sup> A patient who does not feel cared for, is more likely to complain when things go wrong.

This leads me naturally to compassion, and its role in health care.

### Compassion<sup>28</sup>

"Compassion" can be traced to its Latin roots: *cum* (with) and *patior* (to suffer); note that this is also the root of the word 'patient'. This meaning is well captured in the Oxford English Dictionary, which defines compassion as "suffering together with another" or "fellow-feeling".

The absence of compassion in health care is increasingly remarked upon. In 2009, there was a national campaign by some health practitioners to have 'the right to be treated with compassion' added to the Code of Patients' Rights. As Commissioner, I did not support the change.<sup>29</sup> I thought then (and still do) that compassion cannot be mandated by law, and needs to come from the heart of the healthcare provider.

That is not to say that compassion is unimportant. It should be at the heart of health care provision. But compassionate behaviour is a gift from the caring practitioner. Anatole Broyard, the American literary critic, wanted his doctor to "give me his whole mind just once".<sup>30</sup> As he faced metastatic prostate cancer, he wrote: "I'd like my doctor to scan me, to grope for my spirit as well as my prostate. Without some recognition, I am nothing but my illness."<sup>31</sup>

Palliative care physician, Harvey Chochinov, argues that compassion may be cultivated by exposure to the medical humanities and the arts. Martha Nussbaum believes that to develop compassion in public life, we must give the humanities and the arts a large place in education. She says that the imagination of poets is required, and cites Walt Whitman.

This brings to mind some Whitman lines from *Leaves of Grass*, which are inscribed above the entrance to the cavernous Dupont Circle underground Metro station in Washington DC. Whitman recalls his experience as a wound dresser, tending to Civil War soldiers in hospital. His words, carved in stone, are a subtle but eloquent reference to an epidemic that reminded us of the importance of care in the absence of cure:<sup>32</sup>

*Thus in silence in dreams'  
projections,*

*Returning, resuming, I thread my  
way through the hospitals, The hurt  
and wounded I pacify with soothing  
hand,*

*I sit by the restless all dark night,  
some are so young,*

*Some suffer so much, I recall the  
experience sweet and sad ...*

Sadly, many cases where compassion was notably absent crossed my desk as Health and Disability Commissioner. One that I remember well involved the neglectful

care of a 50-year-old man who struggled for breath as he lay dying at Wellington Hospital in 2004. In my decision, finding Capital and Coast DHB in breach of the Code, I stated:<sup>33</sup>

*Patients who have been admitted to hospital because they are acutely unwell are especially in need of care, comfort and compassion. As well as suffering from their present illness, they are likely to be frightened by the unfamiliar hospital environment and fearful for the future.*

In closing, let me tell you a personal story of the care for a patient, a former colleague and close friend. I do so to remind us all why care and compassion must still have central place in health care in New Zealand.

### Judi Strid

The patient was my friend, Judi Strid, who died in February. Judi will be known to some in this room through her health advocacy work.

For 10 years, until a few months before her death, Judi was Director of Advocacy for the Health and Disability Commissioner. She was a leader in the home birth and midwifery movements in the 1980s, and in the 1990s worked in women's health to implement the recommendations of the Cartwright Report. Judi was a tireless champion of health and disability consumer advocacy and of consumers' rights—especially for vulnerable consumers, including mental health consumers, deaf consumers, and residents of aged care facilities. She also cared deeply about informed choice, independent ethics committees, consumer engagement and evidence-based health care.

Judi was diagnosed with a brain tumour, a glioblastoma of the left frontal lobe, in November 2010. And with lymphoma, causing tumours in her face and bladder. That month, Judi appointed me her enduring power of attorney and made me promise to tell her story of care publicly.

Judi kept a 60,000 word health diary for four years, until the final months of her life. The family gave it to me shortly after her death, to use in telling her story. Judi never told the people treating her that she worked at HDC. She wanted to be a mystery shopper in the health system.

What Judi experienced wasn't pretty. It certainly wasn't patient-centred care. I will give you two examples, from her diary.

Time after time, Judi didn't get the information she wanted and needed. Her brain tumour was diagnosed on November 7 2010, after an ED admission. Unsurprisingly, Judi wanted information about her tumour and prognosis. Yet, despite calls by her and her GP, Judi waited over 6 weeks for the first contact from neurosurgery, a phone call from the booking clerk on December 23, to tell her she was booked for surgery on December 29. During this time, Judi had several appointments with haematology. She writes in mid-December:

*Once again at the Haematology appointment I explain that the most important matter I wish to deal with relates to the brain tumour and the rest is just background. ... All my questions relate to the brain tumour yet I have not had an opportunity to ask them and get the answers I need.*

Judi never got told about her tumour before surgery. She saw the anaesthetist the morning of surgery, and learnt for the first time that she was to have a craniotomy with resection of the left frontal tumour.

The coordination of Judi's care was also woeful. It's hard to imagine having a brain tumour and lymphoma and going through months and months of debilitating treatment. To be sent from pillar to post every time you're referred for a CT scan or an MRI or more radiation, and to wait for hours to be seen by consultants, is a cruel waste of the patient's time and energy.

I am following up these concerns with Auckland DHB, and am heartened by their willingness to learn from Judi's experience and to improve care and coordination for future cancer patients.

The second example from Judi's diary highlights a lack of care and compassion. In 2011, Judi was admitted to her local hospital with pneumonia and very low haemoglobin, and received blood transfusions and intravenous antibiotics. Judi woke in the middle of the night to hear another patient being put in the other bed in her room and helped to use the bathroom. She overheard the woman tell the nurse she had ESBL, a readily transmissible infection, whereupon

the woman was moved to another room. Judi asked the nurse if the bathroom could be cleaned, given her own compromised immune system. The nurse told Judi off for listening to a personal conversation in breach of privacy! Soon after, the nurse arrived back with a rectal swab, “to check my infection status”. Judi recorded that it felt “humiliating and like a punishment.”

This happened at the same public hospital where a national Centre for Compassion in Healthcare had been launched in 2007. Again, I have followed up these issues, with Waitemata DHB. They wrote to the family, through me, in August, saying:

*Judi's case reminds us that every encounter matters and can have a significant impact on a patient. It also remind us of the need to demonstrate respect, kindness and compassion as essential elements of our care.*

Judi's experience is sad and painful to relate—but I am confident it will lead to change.

### Joy

Let me express again my admiration for the vision that underpins the Canterbury Charity Hospital, and for everyone whose charitable efforts support the endeavor. Having visited the hospital on Harewood Road, I have a sense of the joy and fulfillment that you find in your work.

I leave you with a blessing from the Irish philosopher and priest, John O'Donohue:<sup>34</sup>

*May the sacredness of your work bring healing, light and renewal to those who work with you and to those who see and receive your work.*

*May your work never weary you.*

*May it release within you wellsprings of refreshment, inspiration and excitement.*

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#### Competing interests: Nil

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