
The Centre for Compassion in Healthcare



26th February 2009.

Ron Paterson
Health and Disability Commissioner
PO Box 12 229
Wellington

Dear Ron

Review of HDC Act and Code – proposed amendment to the Code of Rights

This submission should be read in association with our letter of 17th September 2008, written in response to your invitation to make comments in preparation for a public consultation document for review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Consumers' Rights. The Trustees of the Centre for Compassion in Healthcare appreciate your inclusion in the Consultation Document of our proposed amendment to the Code of Rights.

In that letter we made our arguments for the Code of Rights to be strengthened by including "***The right to be treated with compassion***".

Since that time, we have led a public campaign to highlight the issue of compassion in healthcare and to encourage both the public and professional bodies to make submissions to HDC. The response to that campaign shows there is widespread support for the proposed amendment among healthcare leaders, professional bodies and the general public. In this letter we report on the submissions we have received and further thinking about how this amendment can be made to work in practice.

On-line public petition

An on-line petition was created at <http://www.petitiononline.com/compassn>. This is the text of the petition:

To: Health & Disability Commissioner and the Minister of Health

With respect to the **Review of the Health and Disability Commissioners Act 1994 and the Code of Health and Disability Services Consumers' Rights**;

And in accordance with the suggested change to the Code of Rights notified in the **HDC Consultation Document**, Appendix 2, Paragraph 2.3.1 on page 38;

We urge you to add to the Code of Rights, "***The right to be treated with compassion***".

We recommend that "Right 1: Right to be Treated with Respect" is amended to "***Right 1: Right to be treated with compassion and respect***".

We further recommend that an additional clause be added under Right 1, "***(4) Every consumer has the right to have services provided with compassion, including a prompt and humane response to distress, pain and suffering.***"

Why do we want to change the Code of Rights?



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Compassion is defined as “*the humane quality of understanding suffering in others and wanting to do something about it*”.

We believe that caring and compassion are core values that motivate health professionals but our institutions and professions have evolved in ways that limit the expression of compassion. While the majority of health consumers are satisfied with their care, the increasingly technical nature of healthcare means that some consumers have experiences of healthcare that can feel thoughtless or uncaring and that fail to recognise or attend to distress and suffering. We need to restore the balance between clinical treatment and compassionate caring.

While it may be hard to define a standard for compassionate caring, a lack of compassion is easily recognised when the basic human needs of health consumers are disregarded. This neglect is apparent when pain and suffering is ignored, when waiting is unexplained, when consumers are left cold or hungry or left to lie on soiled linen, when consumers are addressed with unfeeling detachment, when emotional needs are brushed aside, when apology or support is denied, and when hope is needlessly extinguished. The test of the Code of Rights is in the breach. The lack of compassion is usually obvious.

On the positive side, compassionate caring is defined less by the act than by the emotional response of the consumer and family – the experience of loving kindness and the relief of pain, fear and suffering.

Are the existing rights strong enough?

The Commissioner has stated his view in the Consultation Document that the existing right to be treated with Respect (Right 1) and with Dignity and Independence (Right 3) “*already encompass the elements of a right to compassion.*” We disagree.

The Encarta Dictionary defines “dignity” as *self-respect, seriousness in behaviour, worthiness, due respect, high office*; and “respect” as *esteem somebody or something, not go against or violate something, be considerate toward somebody or something*.

The same dictionary defines “compassion” as *sympathy, empathy, concern, kindness, consideration, care, warmth*.

We believe that these humane values at the heart of healthcare need to be more explicitly stated and that “respect” and “dignity and independence” do not adequately express our meaning and purpose.

We urge you to add the “Right to be treated with compassion”.

We draw your attention to our suggested wording of the proposed amendment to Right 1, including the addition of a new sub-clause.

To date, this petition has recorded 529 electronic signatures (all email addresses verified) in support of the amendment. Of greater significance, more than a hundred submitters have recorded comments in support of the amendment (and none against). These comments come from health professionals and the general public. Many speak strongly of the need to change the Code of Rights and to add “compassion”. The comments are tabulated in **Appendix 1** (Word Document). The full list of submitters is tabulated in **Appendix 2** (Excel spreadsheet).



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Support from the health professions

The **College of Nurses, Aotearoa**, have strongly endorsed the need to add compassion to the Code of Rights. The following media statement was released by the College on the 19th February:

The College of Nurses, Aotearoa has lent its full support to the call to include “the right to be treated with compassion” to the Health and Disability Commissioner Code of Rights.

The **Centre for Compassion in Healthcare** is a new charitable trust, which aims to strengthen the heart of healthcare and to restore a better balance between clinical treatment and compassionate caring.

Professor Jenny Carryer, Executive Director of the College of Nurses believes that the current demands of working in health service settings allow the sheer pressure of work to overtake the critical aspects of care which are central to nursing practice and so important to patients.

We regret that such a move is necessary but fully support the Centre for Compassion in Health Care in all its endeavours towards raising awareness of the importance and value of compassion.

Dr Robin Youngson, an Auckland anaesthetic specialist and a trustee of the new Centre for Compassion in Health Care, says “Even though patients may receive technically correct treatment, the experience of care can be emotionally distressing. In our busy and stressed health services we sometimes focus so much on the disease and technology that we lose sight of the person.”

“Compassionate caring attends to all the human needs and helps people heal from their injury or illness. If we listen better to patients and families we become more effective in attending to unrecognised needs, relieving distress, and building the trust that is essential for good care.”

The College asserts that compassion is a core value that motivates health professionals but agrees with Dr Youngson that somehow we are losing empathy and compassion in our training and practice. We agree the time is right to highlight the role of compassion and kindness in clinical practice.

For further information see the website at www.compassioninhealthcare.org

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Senior medical leaders have also given public support to the proposed amendment.

Professor George Salmond, a renowned public health physician and former Director General of Health wrote:

Karen Armstrong, one of the world’s most influential scholars of religious thought, identifies ‘compassion’ as the common component in the world’s major religious traditions (1). At its best religion is less about belief and more about behaving differently, about reaching out to others, about human heartedness, about care and concern universally. It is not about ‘ego’ and always being authoritative and right. Put simply, it is about the age-old ‘golden rule’ – do to others what you would have them do to you (2).



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Inspired by this insight Armstrong now plays leading roles in the creation of an internationally generated and accepted Charter for Compassion (3) and in the Alliance of Civilizations initiated by the United Nations (4).

What do these major movements in global thinking about human behaviour have for us in the health system? Seismic shifts in global thinking along such compassionate lines will be needed if we are even to begin to grapple with the increasingly complex and inter-related challenges of a rapidly globalising world. But, where should we start?

Why not with compassionate health care? Most people entering the ranks of the health professions are motivated to serve, to make a positive difference. A commonly heard criticism of modern health care systems is that they are too mechanical, more about mechanisms and less about feelings. Of course, effective and efficient systems are important but so are feelings and emotions, even if they are less amenable to measurement.

Human heartedness and compassion have as much potential for care and cure as medication and other forms of medical intervention. Why should we not formally recognise and actively cultivate compassionate behaviour in our health system? At least this would be one significant step on the road to creating the more peaceful, healthy and sustainable world Armstrong and her fellow thinkers are talking and writing about.

Let's add 'compassion' to the Code of Health and Disability Consumer's Rights. By doing so we will at least be formally recognising the 'golden rule' and its application to the promotion of health and wellbeing as well as to the provision of care and cure.

Notes

1. The best quick introduction to Karen Armstrong's life and work can be obtained from her 2008 prize winning TED Talk, at <http://www.ted.org>
2. A more substantial account of Armstrong's relevant scholarship and thinking is contained in her book 'The Great Transformations: the beginnings of our religious traditions. Anchor Books, Random House Inc New York 2006
3. An introduction to the 'Charter for Compassion' is available at <http://charterforcompassion.com>
4. A similar introduction to the 'Alliance of Civilizations' is available at http://wikipedia.org/wiki/Alliance_of_Civilizations

Dr Johan Morreau, Paediatrician and Medical Director at Lakes DHB wrote:

It makes sense for "compassion" to be included in Code of Rights. It is a core value that needs to be reflected in the way that we plan and deliver our services as well as assisting us to "put ourselves in the patient's shoes", when establishing what is best for them. This thought process is key to the practice of good medicine and assists "compassion". Having "compassion" in the Code of Rights documentation will assist busy clinicians to incorporate this as an automatic response used by us all.

The national **Quality Improvement Committee (QIC)** debated the proposed amendment at the meeting on 20th February and we understand there was a consensus support on including "compassion" in the Code of Rights. We understand the Chair of the Committee, Pat Snedden, will make a submission on behalf of the committee.



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International support for this change

The work of the Centre for Compassion in Healthcare has attracted international interest and influenced a change in government health policy in the UK. The Policy Director of the NHS Confederation, Dr Nigel Edwards, made this statement:

The NHS Confederation is the representative body of all the organisations that make up the National Health Service

There is clearly a growing recognition that a focus on improving the technical quality of health care is vital but unless we also make the same effort to ensure that compassion is at the heart of our services we will have missed the whole point.

Inspired by the leading work of the New Zealand Centre for Compassion in Healthcare, the NHS Confederation commissioned a policy debate paper on the subject of compassion in healthcare, in preparation for our Annual Conference. The themes in this paper were highlighted by the Secretary of State for Health, Alan Johnson, in his speech to the conference and subsequently taken up by Lord Darzi in his review of the NHS. As a consequence, "compassion" is now established as a core value in the new NHS Constitution.

We watch with interest the campaign in New Zealand to add to the Code of Rights, "the right to be treated with compassion", which would set a new standard in the world for how we wish our patients and families to be treated.

The UK government had announced plans to measure the quality of compassionate caring of every nurse in the NHS, based on patient feedback, and to work in collaboration with the Royal College of Nurses to implement a measurement system.

The **Kings Fund** in London, a prestigious health research body, has launched a new programme called, "**The Point of Care: Seeing the person in the patient**". The Director of the Programme, Dr Jocelyn Cornwell, is seeking collaboration with the Centre for Compassion in Healthcare. The Kings Fund has also commissioned a comprehensive new report about the role of compassion in healthcare, to be published shortly.

In Australia, the NSW Department of Health sponsored a one-day workshop on "Improving the Experience of the Patient and Carer", in collaboration with the Centre for Compassion.

In the USA, the Colorado Coalition for Patient Safety invited a keynote address and workshop on compassion in healthcare at their annual conference, linking this strongly with patient safety.

Our correspondence shows that our call to strengthen the heart of healthcare is resonating around the globe and is attracting the interest of thoughtful media commentators. Daniel Goleman, the best-selling author and originator of the term "emotional intelligence" highlighted our campaign in his latest bestselling book, "**Social Intelligence**". **MindFood** magazine headlined our campaign on the health page of their website (www.mindfood.com). Cardinal Cormac Murphy-O'Connor, the leader of the Catholic Church in England, has discussed our campaign in conference presentations and on the BBC radio.

Two years ago, a Google search for the term "compassion in healthcare" yielded only a few 'hits'. Today, more than 1,500 links are found. This appears to be a global movement in line with shifting values in the wider geo-political scene. New Zealand can be proud of its pioneering role in this change.



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How can this change be supported in practice?

Of itself, amending the Code of Rights will not directly change the experience of health and disability consumers. However, it powerfully highlights a core value in healthcare and reminds the leaders of health and disability providers that they need to attend to more than clinical treatment, in their care of consumers. The Centre for Compassion in Healthcare is trialling a number of programmes that together will encourage positive change:

- A public programme of monthly lectures, the “Humanity in Healthcare” series
- Monthly “Compassion Rounds”
- Collaboration with Waitemata DHB Quality Improvement team in improving the care of patients with breast cancer. Using the principles of “experience based design” the emotional journey of patients has been documented and specific interventions designed to improve communication and relationship skills and the quality of attentive caring.
- Making resources available through a sophisticated website (www.compassioninhealthcare.org) and spreading the word through a ‘road show’ of visits to multiple DHB’s and through workshops and conference presentations.

How can we measure compassion?

A practical consideration in amending the Code of Rights is how compassion might be measured?

This question may be asked in two different contexts:

1. Considering the Code of Rights, how would we know if there is a breach of rights?
2. If we are wishing to lead improvements in services, how could we measure the quality of compassionate caring?

1. Code of Rights

The test of the Code of Rights is in the *breach*. The lack of compassion is usually obvious because any ordinary person would judge that a health consumer was allowed to *suffer unnecessarily* (no independent expert is necessary here).

In our view, these are the kinds of circumstances where a breach of a right to be treated with compassion might be found on the basis of available evidence:

- Severe pain, unrelieved for many hours, in a setting where immediate pain relief is easily available
- Suffering, such as prolonged hunger or starvation, owing to system failings such as staffing shortage, repeated cancellation of scheduled surgery (Nil by Mouth), inability of patients to feed themselves, etc
- Gross neglect of physical, mental and emotional comfort such as lying many hours in wet or soiled linen, extremes of social or mental isolation, denial of access to family at times of distress, etc
- Denial of apology, open disclosure, explanation and support after healthcare error and patient injury

All of these examples cause great distress and suffering yet none of them are likely to trigger a breach of patient rights on clinical grounds, which is why the Code of Rights needs to be strengthened. These practices are indefensible and are largely the consequence of system failures for which institutional leaders must be accountable.



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2. Improving the quality of compassionate caring

On the positive side, compassionate caring is defined less by the action of providers than by the emotional response of the consumer and family – the experience of loving kindness and the relief of pain, anxiety, fear and suffering.

Patient satisfaction questionnaires generally do not ask specific enough questions about behaviour of practitioners to judge the quality of caring. However, Press Ganey (<http://www.pressganey.com>), among other leading companies engaged in measurement of patient experience, has developed well-validated instruments that can be used to give specific feedback and coaching to individual health practitioners. Typical questions include rating on:

- Friendliness/courtesy of the nurses
- Promptness in responding to the call button
- Nurses' attitude toward your requests
- Amount of attention paid to your special or personal needs
- How well the nurses kept you informed
- Extent to which nurses placed things within your reach
- How well your pain was controlled
- Degree to which hospital staff addressed your emotional/spiritual needs
- How well staff worked together to care for you
- How well staff listened to you
- Extent to which staff were around when you needed
- How well staff organised your care with other departments in the hospital

The responses to these rating scales tells us a lot about the quality of personal attention and caring, which is strongly linked with compassion and loving kindness.

These questions are among the ones used by Hutt Valley DHB in their Press Ganey survey of inpatients.

Studer Group (<http://www.studergroup.com>) in the USA and Australia have implemented very specific programmes of coaching and training clinicians in interpersonal skills and in proactive, attentive patient care (such as hourly rounds by nurses). Using the Press Ganey feedback tools they coach teams and individual clinicians to achieve dramatic improvements in their patient scoring, which is associated with improved patient satisfaction, improved clinical outcomes, reduction in complaints, reduction in complications (such as patient falls) and reduced costs.

Thus we can measure the quality of compassionate caring of both individuals and institutions and can, with confidence, recommend proven interventions to address identified deficits.



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Conclusion

We are hopeful that the Health and Disability Commissioner has received many other submissions in support of our proposed amendment of the Code of Rights. The evidence we have gathered suggests there is widespread interest and support for this change and that including “compassion” in the Code of Rights would be a practicable step in improving the quality of health and disability services, in improving the experience of consumers, in reducing complaints, and in improving the work satisfaction of health and disability professionals. We look forward to the Code of Rights being amended accordingly.

On behalf of the Trustees

Yours sincerely

Robin Youngson, Founder and Trustee

**Isabelle Sherrard, Trustee
Pat Armitstead, Trustee
Sharad Paul, Trustee
Joan Campbell, Trustee
Barbara Wickenden, Trustee**

