

THE HOPEWELL CENTRE

A Community of Hope and Wellbeing

11 Dunkirk Close, Arundel



Hopewell offers a haven, and other practical and spiritual support, to people facing the prospect of death. All involved with Hopewell are encouraged to explore issues of life and death, and to provide a service based on compassion, unconditional love and hope.

Established 1994

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Hopewell Hospice Services Inc
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As a Registered Charitable Organisation, donations of \$2.00 and over to Hopewell Hospice Services Inc. are Tax Deductible

1 March 2008

National Patient Charter of Rights

GPO Box 5480

SYDNEY

NSW 2001

To Whom It May Concern:

Re: Draft National Patient Charter of Rights

Having been involved in Hospice and Palliative Care as a minister, educator and counsellor for the past 14 years, I am keen to make some suggestions for the Draft National Charter of Rights.

In our work at Hopewell Hospice, we are committed to caring for the wellbeing of our residents and also of our staff and volunteers. Statements such as the proposed National Patient Charter of Rights can be a useful resource in this process.

Having struggled to maintain our services since we opened the Hospice in 1994, and aware of the limitations on funding available for palliative care, I am concerned that the Draft Charter may be making claims about rights that are beyond the health system to provide.

How meaningful is a statement of "rights" if the funding is not available to deliver the service? Are these statements of actual service possibilities or wishes based on an ideal that cannot be realised at present?

For example, how meaningful is it to say in **Item 1 Access** that "*patients are entitled to: equitable access to public health services regardless of place of residence.*" At this time, that is just not the reality for people in rural and remote areas. It may be an ideal but to what extent can it be called a right?

In **Item 2 Respect**, the health system can take steps to ensure that care is provided in a manner that is "*respectful of a person's culture, beliefs, values and other personal characteristics such as age and gender.*"

On the other hand, the ability to provide "*relief from suffering, including palliative care, that is dignified, comforting and supportive*", while strongly commended, will depend on funding decisions of Treasury, and this does not provide adequate resources at present.

While I commend the statement of rights, if it is to be meaningful it will require a commitment from State and Federal Governments to provide the funds that will make these ideals a reality.

The attached Statement provides further points of discussion.

Yours sincerely

Rev. Dr Ian Mavor, OAM, FACE
Executive Director
Hopewell Hospice Services

Statement by Rev. Dr Ian Mavor, OAM, Executive Director, Hopewell Hospice Services

1. With the mobility of the Australian population, it makes good sense to have a Charter that applies across all States and that intention is to be commended. The document is long and wordy, which is probably necessary at this stage. The final version needs to be more easily accessible.

2. As palliative care emphasises the family unit as the focus of care, I commend the affirmation that the Charter specifically applies more broadly than to specific patients or specific locations:

“The principles included here apply wherever and whenever care is provided. The Principles recognise the important role that families and communities play in receiving and delivering care, and these rights, entitlements and expectations also apply to families, carers and other nominated support people where appropriate.”

3. While reference to “the patient” is strongly entrenched in the health system, it would be helpful to use the plural “patients” throughout the charter.

Although it is pointed out that “the word ‘patient’ includes, as appropriate, families, carers and other nominated support people” the use of the plural form, as in “Patients are entitled to:” would make this point easier to recognise. Similarly reference would be made to “health care providers”.

This change actually happens when the discussion identifies the responsibility of patients to provide information to the care providers in

Item 5 Information:

“Patients (who are able) are expected to provide information about their history, current treatment, medication and alternative therapies directly or through their family, carer or other nominated support person”

4. Even better, the term “clients” could provide a more positive image of equality between the givers and receivers of health care, as well as making more apparent the involvement of families and carers that might be less likely to be included when referring to “the patient” (singular).

5. As well as the descriptions of the **rights** of patients, more could be made of the issue of **responsibilities**. Although there is some recognition given to this, it is only discussed in any detail in regard to one of the eight explanations

of the Principles.

“However they are based on the understanding that any interaction with the health system involves expectations of patients, as well as expectations of health care providers and the system itself. In some cases expectations of patients have been described in the Principles.”

Reference could be made to the **responsibility** of patients to provide feedback on the nature of the care provided. This goes beyond the right to make critical comments. Patients can also contribute to the culture or climate of a health care context and the reference to “respect, dignity and consideration” in **Item 2** could be given greater emphasis by being framed as a responsibility of both patients and care providers.

6. In addition to my own academic and professional background as a minister, educator and counsellor, I have been greatly helped by reading the works of American philosopher Ken Wilber. In numerous books, he has developed an integral perspective that can be applied to healthcare as well as a wide range of other contexts.

Based on his extensive analysis of the different areas of human knowledge and inquiry, Wilber suggests that all phenomena can be organized into four general domains that are formed by interfacing the two dichotomies of **individual** versus **collective** and **interior** versus **exterior**.

The four quadrants that comprise his integral model are as follows:

Individual-Internal - I <i>Experiential, intentional, subjective:</i> Attitudes, feelings, thoughts, meanings, concepts	Individual-External - IT <i>Behavioural, empirical, objective:</i> Physical/ biological factors – cells, organs, tissues, behaviours
Collective-Internal – WE Cultural influences, beliefs, worldviews, values subcultures, intersubjective understanding	Collective-External – ITS Social structures and systems, families, tribes, nations, environmental factors, ecosystems

7. These four dimensions rely on different modes of inquiry and require different descriptive language. Applied to Integral Healthcare, it involves taking account of both the **individual** (singular) and the **communal** (plural) aspects and draws on data that reflects both **objective** and **subjective** perspectives.

8. From an “**It**” perspective, a person with an illness has an **objective** diagnosis that can be made through a range of techniques.

Here the **rights** include:

- a) availability of qualified and competent staff able to provide an accurate diagnosis; and
- b) appropriate care and treatment.

The **responsibility** of patients includes provision of information about personal health history that could impact on treatment decisions, such as the use being made of other treatments or remedies, and giving feedback on the services provided, whether as a complaint or a compliment. They also have a responsibility to co-operate with the care providers in the implementation of the agreed treatments.

9. From an “**I**” perspective, the individual **subjective** domain includes the humanity, attitudes and feelings of those giving and those receiving care; and the importance of mutual respect; as well as the role of open, effective and two-way communication.

The individual may have a significant **personal reaction** to the diagnosis, which can impact on the treatment process and how they are told about their diagnosis has important implications.

Patients have a **right** to:

- a) open and appropriate communication, that acknowledges their emotional state,
- b) is in an understandable language and provides adequate and meaningful information, and
- c) decision making that is transparent and accountable.

Patients also have some **responsibility** to seek information, to ask questions and to make known their lack of understanding.

10. From a “**We**” or **communal subjective perspective**, patients have a **right** to:

- a) an environment of care where they feel safe and respected;
- b) provision of care by staff with an appropriate professional and non-discriminatory attitude, even though the wider community will have varying attitudes towards particular illnesses, which will also have an impact on how patients view their diagnosis and its treatment, (as is well illustrated by the ways in which AIDS and mental illnesses have been regarded).

Patients also have a **responsibility** to contribute to the creation of relationships of mutual respect.

Patients have a **right** to be treated with cultural sensitivity, which includes:

- a) awareness of the prejudices that surround some forms of illness, and the impact these can have on both patients and caregivers,
- b) the recognition of the various cultures, beliefs and ethnic groupings represented in Australian society.

As some major illnesses can be linked to lifestyle choices, a **responsibility** rests on individuals and on the community generally to encourage healthy and hygienic lifestyles

11. From a **communal objective perspective**, the focus of patient **rights** is on the ability of the system to deliver services that are adequate, accessible, timely and effective.

Appropriate funding decisions will acknowledge the **right** of patients:

- a) to have decisions based on clinical diagnosis and need, rather than ability to pay;
- b) to receive continuity of care and appropriate referrals; to have access to services without undue delay or long waiting times and regardless of place of residence;
- c) to be confident in security of information; and
- d) to have systems that allow private and public clients in public facilities.

Because this depends on political decisions, the distribution of funds in areas such as research, provision of diagnostic facilities and treatment options will be influenced by community attitudes, as described above.

Thus, some of the “rights” in the Charter depend on decisions from beyond the health care system. This implies a **responsibility** on the community to ensure the availability of adequate and appropriately allocated funds, and efficient management of resources. There is also responsibility to develop health promoting legislation and implementation strategies, such as the restrictions that have been placed on tobacco sale and use.