

Care Alliance Ireland



SUBMISSION

Department of Health and Children and HSE

Proposed National Charter/Guide

MAY 2010

INTRODUCTION

- Care Alliance Ireland is the National Network of Voluntary Organisations supporting Family Carers. We currently have over 70 member organisations and a representative board of directors. See www.carealliance.ie
- The vision of Care Alliance Ireland is that the role of Family Carers is fully recognised and valued by society in Ireland.
- Care Alliance Ireland exists to enhance the quality of life for Family Carers. We will achieve this by supporting organisations in their direct work with Family Carers through the provision of information, research, the sharing of resources and opportunities for collaboration.

SPECIFIC FEEDBACK ON THE PROPOSED NATIONAL CHARTER/GUIDE

- The term ‘health care’ is limiting and exclusive. This document emanates from the HSE/DOHAC, which together fund a wide range of social care services, as distinct from purely health care services. A more appropriate term to use would be health and social care which would reflect the reality of where much of the resources go.
- Whilst family members are stakeholders in any health and social care partnership, if they have an active caring role (i.e. are family carers), then their legitimacy in being considered named stakeholders is even greater. Family Carers are estimated to provide over 80% of care in our community and as such need to be specifically acknowledged.
- The use of the term carer is not used entirely consistently throughout the document. Family carers need to be identified as separate from paid care workers/health care professionals.
- The terms *carers*, *patients representative*, *nominate support people* and *family* are used throughout the document, but it appears that they are sometimes referring to the same person.

Our specific suggestions are the following:

P 3 – Glossary – Service User.

‘Sets out supporting arrangements for a partnership of care between everyone involved in healthcare – patients, families, *family carers* and healthcare providers.

Also (p3)

‘Contemporary health and social care is a partnership between patients, families, *family carers*, and providers.’

‘Is intended to guide the relationship between patients, families, *family carers* and providers of healthcare a relationship which is based on partnership–“people caring for people”.

P 10 Discharge Plan

Add:

‘You can expect to have role of your family in supporting you be considered in all discharge planning’

P 11 – Participation;

Add

You can expect to;

‘have your family carer actively involved in your care. This may involve health care professionals actively facilitating family carers to continue in their caring role even if you are no longer living in your own home.’

Responses to specific questions posed on Pages 20/21

- **Should this document be referred to as a Guide or a Charter?**

The first section should be a charter with a summary of values whilst the Implementation of values could be referred to as a guide.

- **To what extent does this Guide/Charter represent the concerns of service users when receiving healthcare and/or accessing healthcare services**

This document does not adequately acknowledge the health and information needs of Family Carers who are likely to be providing ongoing care at home. It would also help to acknowledge the health and support needs of Family Carers.

- **What additional points, if any, should be included to adequately explain the meaning and application of the values?**

Health care professionals need to be more proactive in recognising the role played by the 161,000 Family Carers in Ireland. As we move away from hospital based services to more community based services the role of family carers will be even more central in the delivery of health and social care.

- **How do we ensure that this Document is implemented in practice and thus improve the quality of how services are delivered?**

Regular monitoring with results made publically available.

- **Is there an appropriate balance between the roles and responsibilities of service users and healthcare providers?**

Family Carers are by and large willing and able to provide quality ongoing care to a loved one. However, they need support to continue in their caring role. Health care professionals can be supportive by respecting the knowledge and expertise that family carers bring to the partnership, and by sharing their own knowledge appropriately to enable the family carer to continue to provide safe and effective care.

- **Any other key issues or comments?**

- ❖ The definition of a Family Carer needs to be included in the glossary. We suggest the following;

‘Family Carers are usually immediate relatives, who provide very high levels of care, generally but not exclusively at home for children and adults with severe disabilities, frail older people and people who are terminally ill.’

- ❖ It should be circulated to all homes
- ❖ It should be plain English

