

WORLDWIDE CHARTER FOR

ACTION

ON EATING DISORDERS



rights and expectations for people with eating disorders and their families

PREAMBLE

IN RECOGNITION that eating disorders – anorexia nervosa, bulimia nervosa, binge eating disorder and related disorders – are serious mental disorders that devastate the physical, psychological, and social well-being of millions of people of all ages and their families and loved ones; with one of the highest mortality rates (in the case of anorexia nervosa) of any psychiatric disorder

IN RECOGNITION that the highest quality of treatment involves a partnership among the treatment providers, the patient, and the patient's families or loved ones

IN RECOGNITION that patients with eating disorders and their families have a right to be involved in treatment decisions and to be involved in respectful ongoing communication with the treatment providers regarding important treatment-related information and developments

IN RECOGNITION that patients with eating disorders have a right to high quality evidence-based care delivered by competent practitioners at an appropriate intensity and duration

IN RECOGNITION that patients have the right to fully funded (by insurance or government) specialised eating disorder treatment provided at the earliest possible time

IN RECOGNITION that this Charter advocates universal ideals and standards of care which the government, the providers of healthcare and the public should strive to achieve

THE PARTIES HERETO ADOPT THIS CHARTER AND CALL UPON ITS OBSERVANCE BY ALL CONCERNED

CHARTER HISTORY

This Charter provides people with eating disorders, and their families and loved ones, with a list of their basic rights and reasonable expectations regarding eating disorder treatment and services. It was produced through collaboration between the Academy for Eating Disorders and other professional and patient/carer organizations around the world. The content is drawn from the results of a large web-based survey of key stakeholders (people with eating disorders, their families and other carers, and eating disorder health professionals) undertaken between February and May 2006.

This document was written in full knowledge that the quality and accessibility of eating disorder programs and services is not equal

around the world. This is therefore an aspirational rather than a contractual document. The Charter will serve as a tool to assist people with eating disorders and their loved ones in identifying high quality, appropriate services and practices, and to guide them in challenging unhelpful, outdated, and anti-therapeutic practices. This Charter will provide service planners and providers with the basic building blocks for quality program and service development.

The core value underlying this document is that a partnership among patients, their families, and the treating team, with rights and responsibilities for all sides, is imperative for any quality eating disorder service or individual healthcare encounter.

THE RIGHTS OF PEOPLE WITH EATING DISORDERS AND CARERS



RIGHT TO COMMUNICATION/PARTNERSHIP WITH HEALTH PROFESSIONALS



RIGHT TO COMPREHENSIVE ASSESSMENT AND TREATMENT PLANNING



RIGHT TO ACCESSIBLE, HIGH QUALITY, FULLY FUNDED, SPECIALISED CARE



RIGHT TO RESPECTFUL, FULLY-INFORMED, AGE-APPROPRIATE, SAFE LEVELS OF CARE



RIGHT OF CARERS TO BE TO BE INFORMED, VALUED AND RESPECTED AS A TREATMENT RESOURCE



RIGHT OF CARERS TO ACCESSIBLE, APPROPRIATE SUPPORT AND EDUCATION RESOURCES

I

RIGHT TO COMMUNICATION/PARTNERSHIP WITH HEALTH PROFESSIONALS

- As in all physical and mental disorders, eating disorder patients have a right to have their condition taken seriously.
 - Patients have a right to be treated with empathy and respect.
 - Patients have a right to have their illness, its antecedents, maintaining factors, health risks, prognosis and treatment options fully explained to them in user-friendly terms and to be given the opportunity to ask questions and discuss any concerns they have about their illness or its treatment.
 - Patients have a right to a full explanation and rationale for hospital/treatment program rules and regulations.
 - Patients have a right to being actively involved in decisions about their care.
- In regard to service evaluation and planning:*
- The input of patients and carers should be integrated in to the planning and setting up of new eating disorder services.
 - Patient and carer satisfaction should be routine outcomes included in the evaluation of services.

II

RIGHT TO COMPREHENSIVE ASSESSMENT AND TREATMENT PLANNING

- Patients have a right to a comprehensive assessment of their physical, emotional and social needs.
- Patients have the right to a Care Plan.

III

RIGHT TO ACCESSIBLE, HIGH QUALITY, FULLY FUNDED, SPECIALISED CARE

- Patients should expect to be treated by a health care practitioner who is competent in the assessment and treatment of physical and psychological aspects of their disorder.
- Patients have a right to the availability of accessible local specialized treatment services.
- Patients should have the right to equal access to fully funded specialised treatment and care.

IV

RIGHT TO RESPECTFUL, FULLY-INFORMED, AGE-APPROPRIATE, SAFE LEVELS OF CARE

- Patients have a right to be informed about the evidence-base for any treatments they are being offered including its harms and benefits and about alternative treatments.
 - Patients should expect that the duration of treatment matches the nature and severity of their illness.
 - Patients should expect that their individual's dignity and only after giving full consideration to all available alternatives.
- In Regard to In-Patient and Residential Treatment:*
- Where appropriate patients have a right to be informed about the treatment outcomes achieved in a particular treatment facility and how they compare to published outcome figures.
 - Patients should be treated in the least restrictive environment compatible with their physical risk.
 - Children and adolescents should be treated in age-appropriate treatment facilities.
 - Threats, coercion or punishments have no place in the treatment of eating disorders.
 - Patients have a right to be told how to access care in a crisis.
- In Regard to Transitions Between Services:*
- Patients should be alerted to any health risks as they arise and to have these monitored and taken into account in any treatment decisions.
 - In life-threatening situations, where detention and/or refeeding against the person's will are critical for their health and safety, treatment interventions should be provided in a specialist Unit. Moreover, any such procedures should be conducted with the utmost respect for the
 - Patients have a right to expect that health care practitioners will help them to plan for and manage the transition between hospital and the community.
 - Patients have a right to expect comprehensive, written handovers between services at the point of transition between one service and another.



RIGHT OF CARERS TO BE TO BE INFORMED, VALUED AND RESPECTED AS A TREATMENT RESOURCE

We use the term 'carer' here to denote any family member, partner or close other of a person with an eating disorder

- Carers have a right to be treated with empathy and respect.
- Carers have a right to be seen as a resource and a valued partner in the treatment of their loved one.
- Where appropriate, carers should be involved in the assessment and treatment of a person with an eating disorder. The precise nature and degree of carer involvement should be based on the wishes of the patient and their carers.
- Carers should be informed if the risks associated with the patient's eating disorder are high and where the patient is in the community be given clear instructions on how to act on these.



RIGHT OF CARERS TO ACCESSIBLE, APPROPRIATE SUPPORT AND EDUCATION RESOURCES

- Carers should be offered support to facilitate their care-giving role.
- Carers have a right to receive information and education about the illness of their close other.

THIS CHARTER CALLS UPON THOSE RESPONSIBLE FOR POLICY AND PRACTICE TO:

- Educate and inform the community with programs that:
 - De-stigmatize eating disorders by promoting the understanding that an eating disorder is not an illness of choice and by raising awareness of the causes of eating disorders
 - Increase public awareness of the signs and symptoms eating disorders
 - Make available comprehensive information about eating disorder services and resources
- Connect with the media to provide accurate information on eating disorders and to help shift the culture's perspective on body image issues and weight and food issues
- Develop and implement effective prevention programs targeting schools and universities
- Educate and train health care practitioners at all levels in the recognition and treatment of eating disorders to improve the quality of care
- Provide sufficient specialist services based on regional need
- Provide people with access to fully funded specialised treatment and care
- Fund research into eating disorders.