

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, and that eating disorders have 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 person with an eating disorder, and their family or loved ones

IN RECOGNITION that people 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 people 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 people with eating disorders 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 (AED) and other professional and patient/carer organisations 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. It is hoped that 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, out-dated, and anti-therapeutic practices. It is also our hope that 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 people with eating disorders, 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

I

RIGHT TO COMMUNICATION/PARTNERSHIP WITH HEALTH PROFESSIONALS

II

RIGHT TO COMPREHENSIVE ASSESSMENT AND TREATMENT PLANNING

III

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

IV

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

V

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

VI

RIGHT OF CARERS TO ACCESSIBLE, APPROPRIATE SUPPORT AND EDUCATION RESOURCES

I

RIGHT TO COMMUNICATION/PARTNERSHIP WITH HEALTH PROFESSIONALS

- People with eating disorders have a right to have their condition taken seriously, just like people with other physical or mental disorders.
 - People with eating disorders have a right to be treated with empathy and respect.
 - People with eating disorders 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.
 - People with eating disorders have a right to a full explanation and rationale for hospital/treatment program rules and regulations.
 - People with eating disorders have a right to be actively involved in decisions about their care.
- In regard to service evaluation and planning:*
- The input of people with eating disorders and carers should be integrated into the planning and setting up of new eating disorder services.
 - Satisfaction for people with eating disorders and carers should be routine outcomes included in the evaluation of services.

II

RIGHT TO COMPREHENSIVE ASSESSMENT AND TREATMENT PLANNING

- People with eating disorders have a right to a comprehensive assessment of their physical, emotional, and social needs.
- People with eating disorders have the right to a Care Plan.

III

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

- People with eating disorders should expect to be treated by a healthcare practitioner who is competent in the assessment and treatment of the physical and psychological aspects of their disorder.
- People with eating disorders have a right to the availability of accessible, specialised local treatment services.
- People with eating disorders 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

- People with eating disorders have a right to be informed about the evidence-base for any treatments they are being offered including its harms and benefits, and alternative treatments.
 - Where appropriate, people with eating disorders have a right to be informed about the treatment outcomes achieved in a particular treatment facility and how they compare to published outcome figures.
 - People with eating disorders should be alerted to any health risks as they arise and to have these monitored and taken into account in any treatment decisions.
 - People with eating disorders should expect that their treatment will address both their nutritional and physical health and safety, and their psychological health and quality of life.
 - People with eating disorders should expect that their treatment will include a focus on relapse prevention.
 - People with eating disorders should expect that the duration of treatment matches the nature and severity of their illness.
- In Regard to In-Patient and Residential Treatment:*
- People with eating disorders 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 (withdrawal of privileges) have no place in the treatment of eating disorders.
 - 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 individual's dignity and only after giving full consideration to all available alternatives.
- In Regard to Out-Patient Treatment:*
- People with eating disorders have a right to be told how to access care in a crisis.
- In Regard to Transitions Between Services:*
- People with eating disorders have a right to expect that healthcare practitioners will help them to plan for and manage the transition between hospital and the community.
 - People with eating disorders 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 person with the eating disorder and their carers.
- Carers should be informed if the risks associated with their loved one's eating disorder are high and where the person with the eating disorder is in the community, carers should be given clear instructions on how to act on these risks.



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-stigmatise 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 of 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 healthcare 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.