SAMPLE CHAPTER FROM:

Eating Disorders

Core Interventions in the Treatment and Management of Anorexia Nervosa, Bulimia Nervosa and Related Eating Disorders

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1 Introduction

This guideline has been developed to advise on the identification, treatment and management of the eating disorders anorexia nervosa, bulimia nervosa and related conditions. The guideline recommendations have been developed by a multidisciplinary group of health care professionals, patients and their representatives, and guideline methodologists after careful consideration of the best available evidence. It is intended that the guideline will be useful to clinicians and service commissioners in providing and planning high quality care for those with eating disorders while also emphasising the importance of the experience of care for patients and carers.

Eating disorders comprise a range of syndromes encompassing physical, psychological and social features. Whilst the acute physical complications of these disorders may provoke great concern in family members and health service staff, anorexia nervosa and bulimia nervosa are frequently chronic conditions with substantial long-term physical and social sequelae, from which recovery is difficult. Long-term disabilities include negative effects on employment, fertility, relationships and parenting. The impact of a person's eating disorder on home and family life is often considerable and family members may carry a heavy burden over a long period of time. Family members are often at a loss to know how to help and offer support to an affected relative.

About 1 in 250 females and 1 in 2000 males will experience anorexia nervosa, generally in adolescence or young adulthood. About five times that number will suffer from bulimia nervosa. Other atypical eating disorders are more common still, though many will not receive treatment. As eating disorders commonly develop during adolescence, they can blight physical and social development and many sufferers fail to reach their academic potential. Depressed mood is a common feature, partly because of these adverse consequences and also because of the distressing nature of the central symptoms of these disorders. The adverse physical consequences of dieting, weight loss and purging behaviours are notable and sometimes prove fatal. Indeed, anorexia nervosa has the highest mortality rate of any psychiatric disorder of adolescence.

The treatment experience of those with eating disorders is extremely variable. In part, this relates to the inherent ambivalence to treatment commonly experienced by those with these conditions. It is also due to the uneven provision of effective psychiatric treatments that range from high quality age-appropriate specialist eating disorder services, to basic generic provision in areas of the country where skills and experience are scarce. Sadly, a number of those with eating disorders will receive negative attitudes from inexperienced clinical staff and they may on occasion fear being trapped in treatment rather than helped by it.

This guideline addresses aspects of service provision, physical management and therapeutic approaches for those with eating disorders from the age of 8 upwards. Although the evidence base is rapidly expanding, there are a number of major gaps and future revisions of this guideline will incorporate new scientific evidence as it develops. The guideline makes a number of research recommendations specifically to address these gaps in the evidence base. In the meantime, we hope that the guideline will assist

clinicians, patients and carers by identifying the merits of particular treatment approaches where the evidence from research and clinical experience exists.

1.1 National guidelines

1.1.1 What are clinical practice guidelines?

Clinical practice guidelines are 'systematically developed statements that assist clinicians and patients in making decisions about appropriate treatment for specific conditions' (NHS Executive, 1996). They are derived from the best available research evidence, using predetermined and systematic methods to identify and evaluate the evidence relating to the specific condition in question. Where evidence is lacking, the guidelines will incorporate statements and recommendations based upon the consensus statements developed by the guideline development group.

Clinical guidelines are intended to improve the process and outcomes of health care in a number of different ways. Clinical guidelines can:

- Provide up-to-date evidence-based recommendations for the management of conditions and disorders by health care professionals
- Be used as the basis to set standards to assess the practice of health care professionals
- Form the basis for education and training of health care professionals
- Assist patients and carers in making informed decisions about their treatment and care
- Improve communication between health care professionals, patients and carers
- Help identify priority areas for further research.

1.1.2 Uses and limitations of clinical guidelines

Guidelines are not a substitute for professional knowledge and clinical judgment. Guidelines can be limited in their usefulness and applicability by a number of different factors: the availability of high quality research evidence, the quality of the methodology used in the development of the guideline, the generalisability of research findings and the uniqueness of individual patients.

Although the quality of research in eating disorders is variable, the methodology used here reflects current international understanding on the appropriate practice for guideline development (AGREE: Appraisal of Guidelines for Research and Evaluation Instrument; www.agreecollaboration.org), ensuring the collection and selection of the best research evidence available, and the systematic generation of treatment recommendations applicable to the majority of patients and situations. However, there

will always be some people and situations for which clinical guideline recommendations are not readily applicable. This guideline does not, therefore, override the individual responsibility of health care professionals to make appropriate decisions in the circumstances of the individual patient, in consultation with the patient and/or carer.

In addition to the clinical evidence, cost-effectiveness information, where available, is taken into account in the generation of statements and recommendations of the clinical guidelines. While national guidelines are concerned with clinical and cost-effectiveness, issues of affordability and implementation costs are to be determined by the NHS.

In using guidelines, it is important to remember that the absence of empirical evidence for the effectiveness of a particular intervention is not the same as evidence for ineffectiveness. In addition, of particular relevance in mental health, evidence-based treatments are often delivered within the context of an overall treatment programme including a range of activities, the purpose of which may be to help engage the patient, and provide an appropriate context for the delivery of specific interventions. It is important to maintain and enhance the service context in which these interventions are delivered; otherwise the specific benefits of effective interventions will be lost. Indeed, the importance of organising care, so as to support and encourage a good therapeutic relationship, is at times as important as the specific treatments offered.

1.1.3 Why develop national guidelines?

The National Institute for Clinical Excellence (NICE) was established as a Special Health Authority for England and Wales in 1999, with a remit to provide a single source of authoritative and reliable guidance for patients, professionals and the public. NICE guidance aims to improve standards of care, to diminish unacceptable variations in the provision and quality of care across the NHS and to ensure that the health service is patient centred. All guidance is developed in a transparent and collaborative manner using the best available evidence and involving all relevant stakeholders.

NICE generates guidance in a number of different ways, two of which are relevant here. First, national guidance is produced by the Technology Appraisal Committee to give robust advice about a particular treatment, intervention, procedure or other health technology. Second, NICE commissions the production of national clinical practice guidelines focused upon the overall treatment and management of a specific condition. To enable this latter development, NICE has established seven National Collaborating Centres in conjunction with a range of professional organisations involved in health care.

1.1.4 The National Collaborating Centre for Mental Health

This guideline has been commissioned by NICE and developed within the National Collaborating Centre for Mental Health (NCCMH). The NCCMH is a collaboration of the professional organisations involved in the field of mental health, national patient and carer organisations, a number of academic institutions and NICE. The NCCMH is funded by NICE and is led by a partnership between the Royal College of Psychiatrists' research unit (College Research Unit – CRU) and the British Psychological Society's equivalent unit (Centre for Outcomes Research and Effectiveness – CORE). Members of the NCCMH reference group come from the following organisations:

- Royal College of Psychiatrists (RCPsych)
- British Psychological Society (BPS)
- Royal College of Nursing (RCN)
- Social Care Institute of Excellence (SCIE)
- College of Occupational Therapists (COT), now replaced by the Clinical Effectiveness Forum for the Allied Health Professions (CEFAHP)
- Royal College of General Practitioners (RCGP)
- Royal Pharmaceutical Society (RPS)
- Rethink Severe Mental Illness
- Manic Depression Fellowship (MDF)
- MIND
- Centre for Evidence Based Mental Health (CEBMH)
- Centre for the Economics of Mental Health (CEMH)
- Institute of Psychiatry (IoP).

The NCCMH reference group provide advice on a full range of issues relating to the development of guidelines, including the membership of experts, professionals, patients and carers within guideline development groups.

1.1.5 From national guidelines to local protocols

Once a national guideline has been published and disseminated, local health care groups will be expected to produce a plan and identify resources for implementation, along with appropriate timetables. Subsequently, a multidisciplinary group involving commissioners of health care, primary care and specialist mental health care professionals, patients and carers should undertake the translation of the implementation plan into local protocols taking into account both the recommendations set out in this guideline and the priorities set in the National Service Framework for Mental Health and related documentation. The nature and pace of the local plan will reflect local health care needs and the nature of existing services; full implementation may take a considerable time, especially where substantial training needs are identified.

1.1.6 Auditing the implementation of guidelines

This guideline identifies key areas of clinical practice and service delivery for local and national audit. Although the generation of audit standards is an important and necessary step in the implementation of this guidance, a more broadly-based

implementation strategy will be developed. Nevertheless, it should be noted that the Commission for Healthcare Audit and Inspection (CHAI) will monitor the extent to which these guidelines have been implemented by NHS Trusts and Local Health Boards and specialist secondary care trusts responsible for mental health and social care.

1.2 The national eating disorders guideline

1.2.1 Who has developed this guideline?

The Guideline Development Group (GDG) was convened by the NCCMH based upon advice from the Centre's reference group representatives, and supported by funding from NICE. The GDG included members from the following professional groups: psychiatry, clinical psychology, nursing, family therapy, social work and general practice. In addition, the GDG included a patient[1] and a representative of the Eating Disorders Association.

Staff from the NCCMH provided leadership and support throughout the process of guideline development, undertaking systematic searches, information retrieval, appraisal and systematic review of the evidence. Members of the GDG received training in the process of guideline development from the Centre for Evidence-Based Mental Health (CEBMH), and support from the NICE Patient Involvement Unit. The NICE Guidelines Technical Advisor provided advice and assistance regarding aspects of the guideline development process.

All GDG members made formal declarations of interest at the outset, which were updated at every GDG meeting. The GDG met a total of 23 times throughout the process of guideline development. The GDG formed sub-groups, or 'Topic Groups' for ease of evidence identification and analysis and to address identifiable treatment approaches. Each Topic Group was led by a national expert in the relevant topic and the groups supported by the NCCMH technical team, with additional expert advice from special advisors where necessary. Topic Groups oversaw the production and synthesis of research evidence before presentation to the wider GDG. All statements and recommendations in this guideline have been generated and agreed by the whole GDG.

1.2.2 For whom is this guideline intended?

This guideline will be of relevance to all people with a diagnosis of anorexia nervosa, bulimia nervosa or related eating disorders aged eight years of age and over. The guideline will not explicitly provide guidance on the diagnosis or treatment of people with eating disorders if there is a separate physical or other primary mental disorder of which a disorder of eating is a symptom. This may be dealt with in a future guideline.

1 The term 'patient' was the preferred term for use in the guideline based on a survey of Eating Disorders Association members.

The guideline will review the issue of diagnosis and assessment, as many people suffer with eating disorders that fall outside established diagnostic criteria.

In sum, this guideline is intended for use by:

- Individuals with a diagnosis of anorexia nervosa, bulimia nervosa or related conditions aged eight years and over and their families/carers.
- Professional groups who share in the treatment and care for people with a diagnosis of an eating disorder, including psychiatrists, clinical psychologists, mental health nurses, community psychiatric nurses, social workers, practice nurses, dietitians, secondary care medical, dental, nursing and paramedical staff, occupational therapists, pharmacists, paediatricians, other physicians, general medical and dental practitioners, physiotherapists and family/other therapists.
- Professionals in other health and non-health sectors who may have direct contact with or are involved in the provision of health and other public services for those diagnosed with eating disorders. These may prison doctors, the police and professionals who work in the criminal justice and education sectors.
- Those with responsibility for planning services for people with a diagnosis of an eating disorder and their carers, including directors of public health, NHS trust managers and managers in PCTs.

The 'Information for the Public' version of this guideline, published by NICE, is a good starting point in providing patients with written information about the sort of care they can expect.

1.2.3 Specific aims of this guideline

The guideline makes recommendations for the identification, treatment and management of eating disorders. Specifically, it aims to:

- Evaluate the role of specific psychological interventions in the treatment and management of eating disorders.
- Evaluate the physical management and role of specific pharmacological agents in the treatment of eating disorders.
- Evaluate the role of specific service delivery systems and service-level interventions in the management of eating disorders.
- Integrate the above to provide best practice advice on the care of individuals with a diagnosis of an eating disorder throughout the course of the disorder.
- Promote the implementation of best clinical practice through the development of recommendations tailored to the requirements of the NHS in England and Wales.