



Health Check Report

7 February 2005

'Getting Better?'

Is the quality of treatment for eating disorders in the UK getting better?

Headline statistics

- 42% of GPs did not make an early diagnosis.
- 55% of people are not being treated by a specialist.
- Only 17% of young people are treated in an appropriate setting.
- Only 14% of people were treated close to home

Report on the survey initiated by Eating Disorders Association (EDA) in Feb.2004

Published 7-1-05 by
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GETTING BETTER ?

The Government confirmed its commitment to providing better treatment services for eating disorders sufferers when it commissioned the National Institute for Clinical Excellence (NICE) to produce guidelines for the treatment of eating disorders and set the standard for NHS treatment in England and Wales, based on the best available researched evidence and expert opinion. The Guideline was published in January 2004.

EDA welcomed these guidelines as a major move forward in the delivery of effective treatment for eating disorders. We also value the emphasis given to involving families and carers, the need for good information to be readily available, and the important part played by self help.

However we were concerned that it would prove difficult to implement a number of key recommendations contained in the Guideline and that the situation for sufferers and their carers would not get better until these were addressed.

Testing our concerns about getting understood, getting help, getting treatment

In order to test our concerns we drew up a 'health check card' which we asked 1700 of our members and other people affected by eating disorders including sufferers, carers and professionals to complete. We asked them to rate each of the key issues below based on their personal experience over the previous 3 months.

The ratings were as follows...

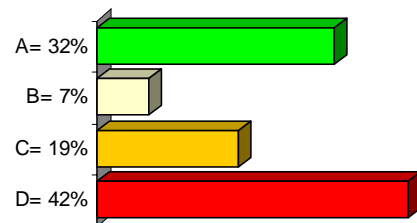
- A ■ - Excellent, met all expectations and needs
- B ■ - Most needs met
- C ■ - Room for improvement
- D ■ - Unsatisfactory, needs and expectations not met

Our concerns about getting understood, getting help, getting treatment.

The key recommendations which we asked people to evaluate include...

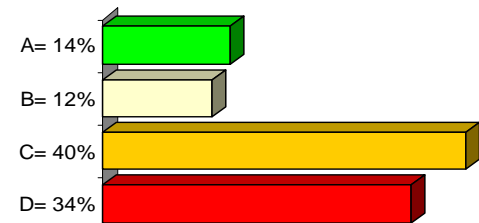
GP's making early diagnosis.

We see this as perhaps the most important recommendation. The guideline says "People with eating disorders seeking help should be assessed and receive treatment at the earliest opportunity" Hardly a week goes by without EDA hearing from a family whose story includes the fact that their GP either didn't pick up on the problem, or else didn't act quickly enough.



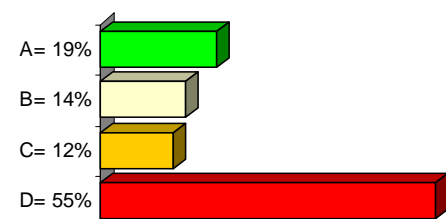
Being treated near to home.

This makes it easier for families to be involved, and for social ties to be maintained. For people in some parts of the UK, the nearest age appropriate specialist service can be 150 miles away.*



Receiving treatment from a specialist with experience of treating eating disorders.

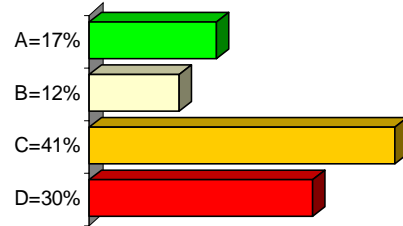
We know of many people who continue to be treated on general psychiatric wards, or for just their medical needs to be dealt with and little or no specialist psychiatric treatment.*



A ■ - Excellent B ■ -Most needs met C ■ -Room for improvement D ■ - Unsatisfactory

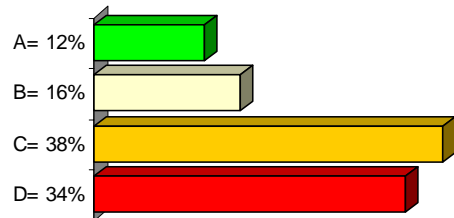
Young people treated in age appropriate settings.

Where this can be achieved, it is sometimes at the expense of receiving treatment from an appropriate eating disorder specialist, it shouldn't be a matter of 'either' 'or'.



Involvement of families.

The guidelines state that the families of young people being treated for an eating disorder should be involved in their treatment and care. Not because they are part of the problem, but because they are vital to the solution. Yet we receive many calls from distressed parents who have been excluded from their child's care.



So are services getting better?

Whilst some areas of the UK, principally London and the Home counties are reasonably well served by specialist treatment centres and other support services, other areas are particularly poorly served. For instance there are currently no specialist * adult inpatient or outpatient services in the whole of Wales. Across the UK 33% of local health authorities have no specialist treatment services* which results in lower levels of expertise leading to poorer recovery outcomes, along with a great deal of travelling for sufferers and their carers and an absence of support generally.

More people are coming forward for treatment and help and the specialist services across the UK are becoming overwhelmed with referrals. The result is long waiting lists and often, reduced treatment plans to address the problem or worse emergency admissions into already stretched medical wards. This short term crisis management overlooks the real and growing future requirement for eating disorders services.

The political commitment to getting understood, getting help, getting treatment.

At a time when public attention is closely focussed on the services delivered by Government we asked Members of Parliament with an interest in health issues in each of the main parties to comment on the outcome of our survey...

"I welcome the initiative by Eating Disorders Association drawing attention to the plight of many thousands of people around the country affected by these devastating illnesses and urge the Government to commit itself to ensuring specialist treatment is more readily accessible."

David Amess MP Chair Conservative Party Backbench Committee for Health

"These results show the low priority which mental health care has been given by successive governments, particularly as it affects young people."

Patsy Calton MP Liberal Democrat Shadow Health Team

"I am extremely concerned that despite the implementation in January 2004 of national guidelines for the treatment of eating disorders, many individuals and their families are still not receiving the help and appropriate treatment which they so vitally need. Eating Disorders Awareness Week is the right moment for the Government to commit itself to working with specialist organisations such as the Eating Disorders Association to ensure the necessary guidelines are implemented as soon as possible to help all those across the UK affected by an eating disorder."

Brian Cotter MP Liberal Democrat with special interest in youth affairs.

* Specialist eating disorder services as defined by the Royal College of Psychiatrists Council Report CR87 London 10-00

"Food is now high on the political agenda and the work being done by the Eating Disorders Association monitoring the NICE guidelines across the country is most welcome. For too long many people, particularly young women, have had their lives ruined and their loved ones, families and carers have found it difficult to cope with this very serious health problem.

I congratulate EDA's continuing campaigning on this issue. At last it is beginning to pay off"

Dr Ian Gibson Labour. Vice-chair of the All Party Food and Health Forum Group

"I know from my constituency experience that access to services for those suffering from eating disorders is still a postcode lottery and requires substantial improvements if we are to achieve the standard of care patients need."

Andrew Lansley CBE MP Conservative Secretary of State for Health

"The Government must ensure that satisfactory services are in place to prevent these disorders blighting the lives of so many young people and their carers.

Dame Marion Roe, Conservative DBE MP Chair All-Party Breast Cancer and Hospice Groups

What is EDA doing to support the guidelines in order to make things better?

We are committed to supporting the NICE guidelines through our work. They inform our work on our helplines, in our publications, and the EDA website.

We offer training to GP's and primary health care workers, and have increased support to carers and families too.

We are evaluating our work against the guidelines recommendations, and welcome feedback from sufferers, carers and professionals working in the field.

We are gathering information about the current state of treatment, so that we can track the improvements the guidelines make. This report is a benchmark against which we hope to report improvements in every area in future years.

Our Health Check Report Card invites anyone who has experience of an eating disorder, as a patient, carer or service provider to send us their personal evaluation of the treatment they have given or received. We will use this information to continue campaigning for improved services and to highlight best practice.

Working with partners from the business world as well as professionals working in eating disorders and the voluntary sector we are planning a major campaign to reach young people who are at risk of developing an eating disorder

Further information about the NICE treatment guidelines

A leaflet for young people and another for adults about the NICE guidelines is available free from EDA. Just send a stamped, self addressed envelope to EDA, marked 'NICE adult/youth Leaflet' or visit the website at www.edauk.com/nice

Eating Disorders Association

Eating Disorders Association (EDA) is a UK wide charity providing information, help and support for people affected by eating disorders and, in particular, anorexia, bulimia nervosa and binge eating disorder. There is more information about eating disorders on our website at www.edauk.com and background briefing information for the media at www.edauk.com/media

Details of local services are freely available to callers ringing our helplines.

Telephone Helpline 0845 634 1414 Youthline 0845 634 7650 (Up to 18 years of age).

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