

79%

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eating disorders
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Only
12%

get the
support
they need.

Failing Families?

February 2008

beatTM
beating eating disorders

“It has been awful, I have cried and cried, so much guilt, so much shame, just feeling so responsible all the time”

No one who loves and cares for someone with an eating disorder should feel ashamed; no one should feel so responsible and so alone. Yet time after time, families tell us that is exactly what they are feeling. Excluded by healthcare professionals, isolated from friends and other family members, without proper information, without adequate support, they cope on their own. No wonder they feel that they are failing.

Families aren't failing, they are being failed. They are failing to get support, while their loved ones fail to get treatment they so desperately need. And the cost of this failure? Families broken by the toll an eating disorder brings and promising lives at deadly risk. 1 in 5 people affected by an eating disorder will die too young, too soon.

Yet evidence shows that when families are supported and involved in helping their loved ones beat an eating disorder, the chances of recovery are greatly improved. The National Institute of Health and Clinical Excellence (NICE) guidelines on the treatment of eating disorders, published in January 2004, gave very clear and helpful recommendations about families. But four years later, these recommendations have yet to be turned into consistent and comprehensive practice.

We have surveyed more than 500 families across the UK: mothers, fathers, husbands, wives, partners, brothers, sisters. We are shocked at their responses and moved by the efforts they have to make to fight for the support that is theirs by right. Their responses highlight just how frequently they are being failed - by the services that should be helping them.

“I am confident that if my daughter had been referred correctly to someone who knew how to deal with eating disorders, she could have been saved.”

Information

NICE guidance says: “family and carers should be provided with education and information about the nature, course and treatment of eating disorders”

beat's survey found:

82% of families were not offered any information or literature by their GP.

54% said their GP was not well informed about eating disorders.

“I was told it was a teen phase and the more I made it an issue, the worse it would become”

Access to Support

NICE guidance says: “families and carers should be informed of self help and support groups and offered the opportunity to participate in such groups”

beat's survey found:

Only 12% of families felt they had access to the amount of support they needed and 23% had no support at all.

Only 8% of carers had been offered a Carer's Assessment - a statutory entitlement.

“This has put us under immense pressure. Financially I took unpaid leave. My husband had to take 6 weeks off to help me. He only received his basic pay during this time. Meal times are no longer a pleasure. Our son has also been affected too.”

Involvement in treatment

NICE guidance says: "the therapeutic involvement of siblings and other family members should be considered in all cases because of the effects of the eating disorder on other family members"

beat's survey found:

35% of families felt excluded by the hospital from the care and treatment of their loved one.
Only 45% of families were offered family therapy - the evidence-based treatment of choice.

"It's hard to get your head around things when you are watching your sister starve herself to death"

What does this failure add up to?

1.1 million people in the UK are affected by an eating disorder. Most are girls and young women aged 12-20, but it can strike anyone at anytime. It takes an average of six years to recover, six years when the whole family's life can be taken over in the fight to beat the eating disorder.

79% of families we surveyed said that the eating disorder had caused lasting damage to their lives. They talked about relationship breakdown and divorce; problems at work caused by the need to provide care for months at a time, or make regular long journeys for hospital visits and therapy; friendships and social life becoming non-existent; the burden that fell on other children in the family; and of lives that just got put on hold for years at a time.

Research by Prof Janet Treasure et al ¹ has shown that families caring for a loved one with an eating disorder demonstrated clinical levels of depression, but few were receiving any treatment themselves.

The cost of continuing to fail families is too high. Too many lives are damaged and destroyed by this most deadly of mental illnesses.

We know there are excellent, dedicated professionals working in the UK. The treatment they offer is world class.

But there simply aren't enough of them for every family to benefit from their expert care. This serious mental illness is still so often misunderstood, and some of the harmful myths that surround it are taken as truths by the very people who should be providing care – with life-threatening results.

"The doctor said he can't have an eating disorder - he's a boy"

Our call to action

Its simple- stop failing families.

- All GPs to provide basic information and improve their own knowledge where this is limited
- All carers to be offered the Carers Assessment to which they are entitled
- All families to know they can beat an eating disorder - with the right support and access to specialist treatment

"It has devastated us all. We have lost someone so precious because we were trying to do our best but did not have enough information or knowledge. It is difficult to bear the guilt and to carry on. My life is awful, the marriage is all but over, and my partner and I are unable to help each other through this."

¹ Treasure, J, Murphy, T, Szukler, G, Todd, G, Gavan, K and Joyce, J (2001) The experience of caregiving for severe mental illness: A comparison between anorexia nervosa and psychosis. *Social Psychiatry and Psychiatric Epidemiology*, 36, 343-347

The Response

“This report highlights how far we need to come to ensure the right information and support is available to the thousands of families around the UK caring for someone with an eating disorder. It is time more attention was paid to the needs of the whole family.”

Dr Ian Gibson, Labour MP

“I have had a number of constituents and their families facing these issues who clearly were not being provided with enough support. Being a parent of a young person who has an eating disorder is extremely frightening. It is vital that the level of support available to families affected by eating disorders is improved.”

Annette Brooke, Liberal Democrat MP

“Eating disorders affect an alarmingly high number of people with deep seated and long lasting consequences and deserve to be taken more seriously, more urgently. I hope this report contributes to recognition of that need.”

Tim Broughton, Conservative MP

“The research team at the Maudsley are developing educational interventions to give carers the information and skills they need. The website www.eatingresearch.com has information about this in a special section for carers”

Professor Janet Treasure, **beat** Chief Medical Advisor

beat

beat is the UK's only nationwide voluntary organisation of any scale working to make an impact on the issues of eating disorders. We are uniquely placed as an independent organisation respected by sufferers, families and professionals, and able to facilitate communication and contact between those groups.

beat's aims are:

- To change the way everyone thinks and talks about eating disorders
- To improve the way services and treatments are provided
- And to help anyone believe that their eating disorder can be beaten.

We do this by:

- Challenging the stereotypes and stigma that people with eating disorders face
- Campaigning for better services and treatment
- Providing information, support and encouragement to seek treatment and recovery

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Report published February 2008