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PRESENTER: JOHN WAITE AND WINIFRED ROBINSON

WAITE

Hello and welcome to the programme.

ROBINSON

Today we devote the whole of You and Yours to the eating disorder anorexia. No mental illness has a higher death rate, none has a higher suicide rate. More than a million people suffer from eating disorders, they often begin in adolescence and affect, in the main, bright young girls who are high achievers. One in five with anorexia will die as a result - a higher mortality rate than leukaemia. Yet specialist services are patchy and piecemeal.

Exactly one year ago Roz Dunham, who was 23, hanged herself in a cupboard off a psychiatric ward in the West Suffolk Hospital in Bury St Edmunds. She'd spent 10 years fighting anorexia and bulimia. Like many patients her case was complex and difficult, yet until she was 18 she'd had textbook treatment. Once she became an adult though she was thrown into the general mental health service where there is little specialist knowledge or treatment for people with eating disorders. Later I'll be discussing the lessons that can be learned from the death of Roz Dunham with a panel including the health minister Jacqui Smith. But first John Waite reports on a life and death - some parts of this story are very disturbing.

ACTUALITY - SCHOOL TOP OF THE POPS

WAITE

Children at County Upper School in Bury St Edmunds perform their own version of Top of the Pops as part of their charity fortnight. Today they're raising money for the Roz Dunham Trust, a charity set up in memory of a much loved former pupil.

VOX POPS

She was a party girl, she really was and I just think of her dancing like a mad woman, like really just like going for it on the dance floor.

I think she was a very courageous girl. I used to say to Roz I thought she was one of the toughest people I knew.

She was just so intelligent and incredibly sharp, very bright but so clever that she never made a point of it at all and just very sort of charming.

When she laughed she laughed and she threw her head back and she was really, really alive when she laughed and that's how I'd like to remember her.

WAITE

The Dunham family home is a beautiful deceptively large townhouse in the centre of Bury St Edmunds. Roz Dunham spent the last 17 years of her life there. Her father was an agronomist, who spent much of his time abroad, her mother, Gitti, a former nurse, is now a senior official with Amnesty International.

GITTI DUNHAM

Roz was a very happy child. She was born while we were living in Nigeria, her father was employed by the Nigerian government to do agricultural research and we lived there for eight years. But Roz lived in Nigeria for only the first four years of her life and we returned to England basically because we knew that they would have to be educated here. And very early on, I suppose from the age of three, it was quite evident that she was very bright, she was very academic, sensitive, creative, funny, extrovert.

WAITE

But that bright creative extrovert child turned into a deeply troubled teenager, gripped by a serious eating disorder which eventually led to her taking her own life.

GITTI DUNHAM

It was a sort of strange sense that you knew that everybody had given her up. And I have a feeling the reason why she actually committed suicide on the ward, because she could have gone outside, I think she did it on the ward because she wanted to show them that they didn't care.

WAITE

Roz Dunham's mental health problems first came to light at around the age of 12.

GITTI DUNHAM

We became aware that all wasn't well, when she was spending far too long on her homework, she was becoming obsessive with her homework and it was difficult to get her to bed at night because she was always doing her homework and it was when she had just started working on GCSEs that Genista, her sister, noticed that she was throwing away her lunches.

GENISTA DUNHAM

I suppose I did pick up on the first signs of her illness because I was with her more at school, I could see that she was becoming pretty fanatical about exercise, very funny about food, endless excuses, she seemed to pile a lot of food that she didn't want on to me which of course made me feel worse because I was going through that stage of I'm too big and I want to get thinner and things like that. I suppose it was those sort of ideas that she took on and took to an extreme.

GITTI DUNHAM

She was obviously losing weight, but it took hold really quite rapidly and quite perniciously, it was difficult really to get through to her after a while.

WAITE

Roz was first referred to her GP, then to adolescent psychiatrist and eating disorder specialist Dr Paul Laking.

LAKING

I first saw Roz in 1993 when she was about 14 - so 10 years ago virtually to the day. She'd had a problem for a number of months of losing weight and becoming obsessed with it and when I first saw Roz she was very withdrawn, head down, hair across her face and that was the sort of picture one saw of Roz when she was ill and that really contrasted with her rather bouncy, sharp, young person that one saw when she was better. Although she wasn't incredibly low in weight at that time, she actually was very low in mood and that was related to the starvation and so on.

WAITE

Roz was showing the classic signs of anorexia nervosa, a serious, potentially fatal, eating disorder. The condition's been around for centuries but wasn't formally described until 1873, in a paper by Charles Lasegue - L'anoxeie hysterique. Anorexics effectively starve themselves, often reducing their food intake to an absolute minimum. Dr Peter Webster is a consultant psychiatrist with the eating disorders unit at the Maudsley Hospital in South London.

WEBSTER

Anorexia nervosa has the highest mortality rate of any mental illness and is up to 20 per cent of sufferers over 20 years. In fact if an anorexic patient needs to be sectioned, they're that unwell, and treated under the Mental Health Act, one study suggests that 40 per cent of those patients will die over 20 years. About half of the deaths are due to medical complications and the other half due to suicide and the suicide rate is 200 times that of the populous.

LAKING

The first time she went to Douglas House she was so ill and so determined, at that time, that I was genuinely compiling in my own mind what I was going to say to the coroner. I was genuinely fearful that she was going to die as a result of her very low weight. And at that time one obviously thinks well have I done absolutely everything I can possibly think of to enable Roz to get better and I couldn't think of anything else we could do and thankfully she stayed there and did gradually get better, gain weight and came out of herself more.

WAITE

One of her fellow patients was then 14-year-old Antony Pascal, himself severely anorexic.

PASCAL

Douglas House was unlike any other hospital ward I've been in before. It was run like a family really rather than a ward. People would have to take regular turns in cooking the meals, which is not done in normal psychiatric hospitals, keeping the place tidy and the nurses were very unlike any other ward I've been in before as well.

WAITE

Why is that?

PASCAL

They actually did take a notice in what you were doing, they would actually care if you were upset, which doesn't happen in psychiatric wards. If they applied that system to all hospitals then I think people would be a lot happier and would get better a lot quicker.

ACTUALITY - IDA DARWIN HOSPITAL

WAITE

Ida Darwin Hospital now has its own specialist eating disorders unit - the Phoenix Centre. It has 10 beds for adolescents with severe eating disorders and it's run by consultant psychiatrist Tony Jaffa, who also treated Roz. The ethos here is similar to that of Douglas House.

JAFFA

All the young people have education everyday, not as much as at school but not far off. There are a number of community meetings where problems in the day's routines are discussed. Of course mealtimes are a major focus because the young people here find it very hard to eat, so mealtimes can be quite stressful and there are a lot of staff around to provide support. Then for different patients there might be a range of individual or family therapies happening. Some of the patients require a lot of supervision to support them in not exercising or not nipping off to the loo to vomit after meals. But I think we try and create a pleasant atmosphere that is at least most of the time comfortable, occasionally it can get very tense.

ACTUALITY - IDA DARWIN HOSPITAL - CHILDREN SINGING

Having patients with different illnesses together does have some advantages but it has a lot of problems. If we're trying to treat patients with depression in the same unit as patients with psychosis, eating disorders, it's very hard to meet the individual treatment needs of the particular patients. Of course there are problems in having patients altogether too, that I have up to 10 patients staying at any one time on the Phoenix Centre, sometimes they all support each other to move forward and recover and they can be the most positive aspect of treatment experience for all of them, other times it's hell and they make each other worse and they compete to be the one who hides food most or eats most slowly and then it's rather negative.

The fact that Roz got such good psychiatric care as an adolescent was an accident of geography. A survey by Community Care magazine last year found that 80 per cent of social care professionals thought child and adolescent mental health services in this country were in crisis. There are only 900 beds in the whole of the UK, offering specialist care for adolescents with serious mental health problems. Peter Wilson, the director of the charity Young Minds, says many more are needed.

WILSON

By and large it's very much an under-sa m

overnight her eating disorder changed from straight anorexia to bulimic anorexia - periods of starvation interspersed with bouts of binge eating often accompanied by heavy drinking to give Roz the courage to eat.

GITTI DUNHAM

With an anorexic you're desperate to make them eat because it seems so unnatural for anyone to refuse food. But with a bulimic I just couldn't keep any food in the fridge - there was no way that I could possibly entertain people or plan ahead without actually buying food that day and making sure that they had it before she could have access to it. It was problematic from that way because the food would just disappear and there wouldn't be anything left for anybody else.

WAITE

She would eat literally everything?

GITTI DUNHAM

She would eat literally everything. At her very worst she sometimes could eat right round the clock for several days - eat right round the clock and vomit in between - that's EMC/P MCID 5 694.3404 Tm(6dEM4T

REPORT

The widespread and notorious lack of communication between adolescent and adult m

Time and again the staff on the medical ward were trying to get hold of the psychiatric team to do something about her. She was really, really very low and she attempted suicide by trying to hang herself from the shower curtain on the medical ward.

WAITE

Roz was eventually admitted to the psychiatric ward where she was rated a low suicide risk. She stayed on the ward for five days. During that time her mood fluctuated dramatically, at one point she told nurses that she'd scouted round the ward looking for somewhere to hang herself but hadn't found anywhere. Despite this she wasn't reassessed for suicide risk. Then on the night of February 13th last year Gitti got a call from the ward to say that Roz had gone missing.

GITTI DUNHAM

On the Friday, which was two days after she'd been missing, I received a telephone call from the charge nurse in the ward saying: "Can I speak to Roz please?" I said: "Why are you asking to speak to Roz, you know she's missing?" She said: "Well if she should turn up would you please tell her that we have discharged her in her absence because she's broken her contract?" So I said: "Well if she turns up I will tell her." And then on Saturday at about 6.30 a.m. the police came to the door to tell me they'd found her body hanging in a cupboard off one of the bathrooms on the ward. So she'303a12 451Bn

It did though recommend a number of changes to those procedures including better communication between medical and psychiatric sta

SMITH

Well firstly, of course, we need extra resources, that's why we've already devoted £105 million over the last three years. It's why in the next three years there is a clear target on local health services to use the additional money we're making available to grow those by 10 per cent each year. It's why we've also, in terms of the mental health national service framework for adults, made clear that there need to be these local arrangements for transition between younger people's mental health services and adults, it's why we've asked the National Institute for Clinical Excellence to undertake work, to produce a guideline on how we can ensure better trea

.. will go ...

SMITH

...children's national service framework, which will set standards for those services, we will set down what we think those services should look like and how they should be growing and improving.

ROBINSON

How much do you think ought to be spent, will be spent, on services for people with eating disorders and on services for young people who are mentally ill?

SMITH

Well what we've said in the planning and performance framework and what we will monitor local health bodies on is a 10 per cent increase year-on-year over the next three years, measured in terms of patients seen or in terms of staff increases. Now there will be a difference in different local areas about how they achieve that 10 per cent increase because we know, for example, with relation to eating disorders that there are some parts of the country that are better served than others. So it is important that there is - that local priorities can be taken into consideration. But we expect to see that growth and we're investing in that growth as well.

ROBINSON

So you're expecting to see a 10 per cent rise in the amount of money allocated by local health trusts to child and adolescent mental health services and to eating disorders?

SMITH

Well more importantly what we're expecting to see is a 10 per cent increase in the results and I think that that's what's important.

ROBINSON

How can you separate the two - you can't give people targets and then not fund them to meet them surely?

SMITH

Well we are funding them and we're also being clear that it's not just about how much money goes in it's about what comes out at the end in terms of better services, more staff, more beds where those are necessary, more effective and joined up and coordinated services. And as I've already said, and as you in fact has already said, it isn't either just about money it's also about how we make sure that we commission effectively, how we deal those transition issues between young people's services and adult services, how we ensure, through the National Institute of Clinical Excellence, that we all understand what is good practice when we're treating people with eating disorders and we ensure that that is more widely spread across the country than it is at the moment.

ROBINSON

Some of the very basic injustices, the way, for example, services are rationed, in some areas, we heard in John's report, you're not referred to the adolescent psychiatric services 099 266.99 183B212 454.3501 2

child and adolescent mental health services and ensures that they are delivering services that make sense at a local level.

ROBINSON

Jacqui Smith thank you.

Dr Paul Robinson is here in the studio, he's a consultant psychiatrist and he chairs the eating disorders special interest group at the Royal College of Psychiatrists. That whe eating

ROBINSON

But what age do you do it - is there a cut off age?

PAUL ROBINSON

It is variable, we will accept patients in the adult service from the age of 16 if the child psychiatrists want us to do so. So in other words we don't have a sort of strict cut off point. We think - I think anyway 16 to 18 is not a good time to change, certainly 18 I don't think is a good time to change services from child to a

BAILEY

I think it's very easy to get hung up on treating the symptoms of this illness without actually looking

they're receiving and I think that's absolutely key as I'm sure others if they use services like that would absolutely say and testify to.

BAILEY

May I just say here that we take patients - we set up independently but most of our patients, 98 per cent, are NHS funded and they come from the South West, the North West, Scotland, Ireland - it's an absurd situation for these people and makes it much more difficult doing work with families when they have to make such huge journeys.

ROBINSON

It's a very difficult group of people isn't it? You heard Roz's mum saying that she spent three hours trying to feed her a carton of ice cream, when people are so hungry for attention, which was something else that came out in some of the professional judgements on Roz when she was in hospital, that she just wanted attention, how do you find people with enough to give that group of patients?

BAILEY

We have a staff of 65 people for looking after 16 beds. It is hugely labour intensive. Most of the people who joined us when we set up seven years ago are still with us. I mean are very, very dedicated, very committed - it's a very, very rewarding job. But they have to be trained specially in this particular field, it's a very specialist field.

ROBINSON

We're almost out of time now, I just want to end by asking you briefly if each of you, if you would, tell us what you think is the lesson from Roz's death, Paul Robinson?

PAUL ROBINSON

Well firstly how serious eating disorders can be, I think they're often trivialised. S312 0 0 1ph4 12 346.281 404.

ROBINSON

Richard Brook?

BROOK

I think for me it's recognising the reality of Roz's story and what we need to see is a change locally, so that services are there that prevent Roz's story being repeated, which it certainly is still very commonly in our country today.

ROBINSON

We have to bring our discussion to a close there. My thanks to Jacqui Smith, the health minister, Dr Paul Robinson from the Royal College of Psychiatrists, Richard Brook from MIND, Penny Bailey, founder of Newmarket House and Debbie, who has been treated there, many thanks to you all. If you want more information about eating disorders you can call our helpline: 0800 044 044. If you want to hear the programme again you can log on to our website:

www.bbc.co.uk/radio4/youandyours and you can e-mail us with your thoughts at the same address. John.

WAITE

That's it for today Winifred. Tomorrow the railways with passengers waiting longer for trains and overcrowding at its worse for many years, recent announcements have delivered yet more bad news with cuts to both services and improvement projects. Well tomorrow we'll be speaking the man whose job it is to shape the future of the network, he's Richard Bowker, chair of the Strategic Rail Authority. And we're very keen to hear your views on the state of our railways and any questions that you want answered. You can call us on 0800 044 044 or you can e-mail us through our website, as Winifred said, at bbc.co.uk/radio4/youandyours but remember if you do please to leave us your phone number so that we can call you back. See you tomorrow 4 minutes past 12.