

NHS eating disorder chaos

# Waits of 16 months for anorexia care

Children and teenagers facing longer delays as charity warns growing crisis is putting lives at risk

By Laura Donnelly

THOUSANDS of children and teenagers with anorexia are being forced to wait months for help, amid growing pressure on services to treat eating disorders.

An investigation by *The Sunday Telegraph* reveals a dramatic fall in provision of hospital appointments for the condition, forcing patients to wait longer, with some in need of inpatient care travelling hundreds of miles. The NHS data shows that in just two years, there has been a 36 per cent re-

duction in the number of hospital appointments for people with eating disorders across the country.

Meanwhile, an audit of services for children and teenagers shows that only one in six areas is meeting standards intended to speed up treatment for the most vulnerable.

Charities said last night the disclosures were "alarming" - reflecting a "national scandal" in care of the most vulnerable. Some patients were effectively being told that they could not get help until they had starved themselves further, they warned.

NHS data obtained by this newspaper shows that in 2015-16, health services in England carried out 14,847 outpatient appointments for patients with eating disorders, a drop from 23,266 in 2013-14.

Experts said waiting lists were now

reaching 16 months in some parts of the country, with young patients in need of admission being sent from Leicester to Edinburgh in search of a bed.

Last night Jeremy Hunt, the Health Secretary, pledged sweeping improvements in access to services. "When children are in urgent need of support from the NHS it's vital that they get fast, high-quality care - and clearly in some of the cases highlighted this simply has not happened," he said.

"While mental health services have for too long been a poor relation to physical health, as the Prime Minister has said, we are determined to turn this round."

The Government has promised a "revolution" in mental health treatment, with specific targets to speed up access to help for children and teenagers with eating disorders. The stand-

ards include a four-week waiting time for most referrals, dropping to one week for cases that are identified as "urgent".

But an audit of NHS services, seen by *The Sunday Telegraph*, shows just 14 per cent of areas referring urgent cases

*'This is evidence of horrific rationing of care, whether it means longer waiting times or fewer appointments'*

within a week, while only 18 per cent managed to ensure remaining cases started treatment within a month.

In total, one in six areas was compliant with both standards, the report from August shows.

The NHS does not publish official

figures on waiting times for treatment for eating disorders, although it has promised to start publishing those for children and young people from May.

The Royal College of Psychiatrists warned last night that some patients were waiting as long as 16 months for help, amid a growing NHS financial crisis.

Dr Agnes Aytton, vice-chairman of its faculty of eating disorders, said: "We are seeing waits of up to 16 months for non-urgent referrals. It is really worrying, because we know the more quickly people start receiving treatment the quicker they are to respond to it."

The consultant psychiatrist from Oxford Health NHS Foundation Trust said strain on NHS finances was forcing patients to wait. "A lot of trusts are trying to make savings at a time when we have seen a huge increase in demand,"

she said. Andrew Radford, the chief executive of Beat, the UK's charity for eating disorders, said the situation had become "a national scandal".

"These figures are evidence of fairly horrific rationing of care - whether it means longer waiting times or fewer appointments once you are in the system," he said. "This is threatening lives."

Mr Hunt said by 2020, 95 per cent of children with suspected eating disorders would be seen within the four and one-week target times, thanks to a £150 million investment in services.

Consultant psychiatrist Dr Navjot Bedi, who runs an inpatient unit for adults at the Glenfield Hospital in Leicester - the regional unit for the East Midlands - said its waiting times had doubled over the past decade, from four to eight weeks.

## 'Sometimes it is harder to see your child live than die'

Interview



By Laura Donnelly  
HEALTH EDITOR

It begins as an everyday story: a teenage girl who feels out of place among the catty sixth-form girls who make cruel remarks about her weight.

Where, then, does it end? For Charlotte Green, the anorexia that dominated every day of her adult life ended quite predictably - at the age of just 39.

She died, alone in her flat, on a summer's day, when her emaciated body finally gave up on her.

It was four years since an interview with *The Sunday Telegraph*, in which she had outlined her determination to ensure that no court directive or medical panel could force her to live.

After two decades spent in and out of hospital, with 14 psychiatric admissions, several against her will, and force-feeding by tube, it was an achievement she fulfilled.

Charlotte died last June, after securing an "advance statement" affirming her intention to shun any enforced treatment - regardless of the consequences.

"People say that the worst thing is to have your child die before you," says her mother, Sharen. "But sometimes it's worse when your child is alive. To see them suffering, and to not be able to do anything about it. To have lost hope of any way out but death."

"I lost hope for Charlotte a long time before she died," she adds, quietly.

Mrs Green, 70, from Dorset, has agreed to share her family's experiences, in the hope that it could

prevent even a single case of anorexia taking its most deadly course.

Brought up in an army family, Charlotte had a peripatetic childhood, but a happy one, her mother says, with early years in Germany, Northern Ireland and Gibraltar before she was sent to boarding school in Somerset.

"She was a really happy little girl, very outgoing, very eager to please," Mrs Green says, from the family home in Wimborne. Things changed when the family moved back to Dorset, and Charlotte began studying for her A-levels at a grammar school.

"Suddenly Charlotte was at a school which was highly pressured. She had got 7 As and 3 Bs in her GCSEs, here the norm was 11 As. It was the sort of school where you were expected to apply for Oxbridge. She started getting really competitive."

Outwardly, academic performance was Charlotte's focus. But feeling isolated, she started comfort eating, only to become insecure about her appearance, in an atmosphere which she later described as "bitchy".

"There were a lot of girls criticising the way other girls looked at this school, which hadn't been the case at the co-ed," says Mrs Green.

At the age of 17 she told her mother she wanted to go on the Slimfast Diet. Mrs Green, who had struggled with her own weight, felt conflicted.

"I said 'no, no, that's not a great idea. But in the end, I thought, 'Well, she's got to make her own decisions, she is getting to that age'. But I really didn't want her to do it. I was saying why not do more exercise?"

The diet was successful. Too successful. Charlotte reached her target weight, but continued slimming. Just as her mother became fearful, it seemed that her teenage daughter saw sense. "One day she just stopped, and she started putting on



Sharen Green, holding a portrait of her daughter Charlotte, has shared her experiences of the effects of anorexia in the hope it can prevent other cases

weight again, and got back to a healthy weight," Mrs Green says. "I thought then phew, we've had a brush with anorexia. But I thought that was it."

After gaining three As in her A-levels, Charlotte went to St Andrew's University to read psychology. Although she made some good friends, she struggled to settle in, and became increasingly conscious of her weight, now hovering between 11 and 12 stone, with bursts of crash dieting.

In the second year of university she stopped eating solid food, subsisting only on soup and mugs of hot chocolate. As her weight plummeted, her flatmates became fearful for her; finally forcing her to phone her mother and tell her what was going on. She was referred to the local hospital, but it had a three-month waiting list, and no specialists in eating disorders.

Mrs Green took action. As a journalist on the *Bournemouth Echo*, she had interviewed the head of a new eating disorder unit in nearby Poole. She arranged for her daughter to be admitted. "I was optimistic. We had caught it early, we had an eating disorders unit, they took her quickly. I thought she will get better," she says.

In fact, it began 15 years in and out of psychiatric institutions - which Charlotte called "fat camps" - for up to six months at a time. Within two years, her weight was around half what it had been at university.

As the disease progressed, she was told that if she would not be admitted voluntarily, she would be sectioned. For short periods, she thought she was making progress, gaining weight and returning to university.

But the cycle kept repeating. In her final year, she was sectioned again for six months. She later told the *Telegraph* that by now she was only going through the motions - putting on as much weight as was required to get out of the institutions, and be able to start starving herself again.

At the age of 29, 10 years after starting university, she graduated with a first-class degree. But by then she was struggling to make herself eat more than 400 calories a day. After achieving academic success, the disorder began to overwhelm her. "She had osteoporosis, fractures, her health was shattered, her teeth were shot to pieces, her thick lovely hair had gone, her skin was terrible," Mrs Green says.

Nothing her parents said seemed to make any difference.

Earlier this month, the former *ITV News at Ten* anchor Mark Austin told how he struggled to cope with his 18-year-old daughter's severe anorexia, telling her to "starve yourself to death, just get on with it". Looking back, Mrs Green says she and her husband Peter had no idea how to handle their



Charlotte Green in 2012, when she told the Telegraph she had no chance of recovery

daughter's illness. "We completely mismanaged it; we didn't know what the hell we were doing," she says.

At first, Mrs Green blamed herself. "I was dieting long before she was born. Growing up, she would hear me say things like 'I'm just so glad that Charlotte hasn't got my problem' - and I thought I was affirming her. But she didn't take it like that."

Now, Mrs Green says she has learnt to stop being driven by guilt. "Most women are dieting, at least at some point. They don't all end with daughters with anorexia," she says.

At the age of 32 in 2009, after a bout of food poisoning, Charlotte was admitted to Edinburgh Royal Infirmary, and fell into a coma. Her

*'I wanted her to die before the boys got there. I didn't want them to see her like that'*

parents raced to Scotland to be by her side, while her older brothers travelled back from Greece and Suffolk.

But by now her mother had lost hope she would recover. "I wanted her to die before the boys got there," she says, starkly. "I didn't want them to see her like that."

In fact, Charlotte regained consciousness. She was told she would be fed via a nasogastric tube. She refused, promising to eat, but was told she had no choice, and was held under a psychiatric section for six months.

The incident was among several that led Charlotte to a decision; that she would fight for the right to refuse treatment, even if the consequences were fatal. In June 2012, a High Court judge ruled that

Anorexia: the facts

◆ Almost half of those diagnosed never make a full recovery, and up to one in five will die prematurely.

◆ Bulimia is also associated with severe medical complications.

◆ Most eating disorders strike between the ages of 14 and 25. But in recent years rising numbers of children, even as young as five, have had to be treated for eating disorders.

◆ However, cases emerging later in life are also on the rise.

◆ More than a million people in the UK are estimated to be directly affected by eating disorders.

WHERE TO GET HELP

◆ Beat helpline (for those over 18) 0808 801 0677

Email: help@b-eat.co.uk

◆ The Beat youthline is available to those under 18. 0808 801 0711

Email: fyp@b-eat.co.uk

Sharen with Charlotte, aged 21



another sufferer of severe anorexia should be force-fed, because the 32-year-old woman's refusal to eat had brought her to the point of death.

Crucially, the judge ruled that while the patient might not see value in her life now, that could change if the disease lessened its grip.

Charlotte began battling for the right for her desire to reject treatment to be respected. In an interview with the *Telegraph* later that year, she said: "When you have been ill for a very long time, there is a chance of recovery, but just how small is that chance for me?"

"I have been ill for 15 years and it only gets harder. If it gets to that stage again, I want to be allowed the responsibility for what happens next."

By now, her appearance was skeletal. On a summer's day, thick woollen layers could not disguise her protruding bones, and shoulders sharp as wire coat-hangers. Her head was shaven, partly because her hair had become so thin.

"My parents are resigned to the fact I am going to die," she said. "Obviously they don't want me to die, but if I am never to recover, they agree that the whole process is torture for all the family, and it would be best to end it."

Mrs Green says: "She wanted to stay in control of her life. We went along with it. She had been ill for so long."

In October 2013, aged 36, Charlotte secured an "advanced statement" setting out her wish to have no enforced treatment, gaining agreement from psychiatrists that she had the mental capacity to take such a decision. She is believed to be the second such case to have agreed a statement under such circumstances.

Charlotte never entered a hospital again. She died last June, alone in her Edinburgh flat.

Mrs Green stresses that despite her daughter's troubled mind, there was happiness. "She was so fun to be with ... she could crack up a room. She loved swimming in the sea, she loved crosswords, she loved *The Archers*."

"And she was so empathetic. For her funeral, she had asked that everyone bring a tin for the foodbank, not flowers."

The couple's last memories of their daughter are among their most precious. "A couple of weeks before she died, we had a party here for my 70th birthday," Mrs Green says. "We had a marquee and the swimming pool was open and all the family was here, and friends she had known since she was a child. That was really special."

"And after we took her back to the station, I said to Peter, 'That could be the last time we see her alive'. And it was. But I was glad to keep that memory."

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