MOUNTING DREAD

Obsessive-compulsive disorder affects one child in 100. One family coping with the debilitating psychiatric condition talks to **Sally Williams** about how it took over their lives, and about the long, slow climb to recovery. Illustrations by **Darren Hopes**

Catherine can remember clearly the day her daughter started behaving strangely. It was three years ago, during the October half term, and the family – Catherine, her husband, Robert, and their two daughters, Lottie, 15, and Dulcie 12 – were in Venice. They were planning to visit one of Venice's most pictured landmarks, the church of Santa Maria della Salute, but Dulcie kept dawdling. She spent ages looking in the mirror, fiddling with her hair, but the odd thing was that each glance in the mirror was followed by a counter-glance behind her, her head turning back and forth, as if checking the reflection against the reality. This was not typical behaviour as Dulcie usually never looked in the mirror. 'We all got very cross with her,' Catherine recalls. 'We were on holiday and we only had a few days, and it was Robert's birthday, and she was being so teenage and selfish – you know, all the horrible things you say before you realise.'

Dulcie's behaviour gradually became more extreme. Three months on, her obsessions had started to take over her life. She had elaborate rituals for crossing the thresholds of doors, and she had to count reflected lights in spoons before she could eat supper.

'I couldn't just look up and down three times,' Dulcie explains, 'I had to look up and down five times, but if I went on to six, I'd have to go to 10 or 20 times. Twenty times looking up and down.' She found it impossible to get up the stairs, and would stand at the bottom, as if repelled by some invisible force field. She gave her family extraordinarily detailed instructions for routine events such as watching television. 'Like a drill sergeant,' her mother recalls: 'Stand up. Sit down. Don't move over there.' It would take her five hours to get into bed at night.

Dulcie kept reassuring her parents that everything was fine, and she did not want to talk to anyone about her behaviour. In January 2008 Catherine succeeded in taking Dulcie to her GP under a pretext. 'But while we were there, I said, "Since we're here, shall we talk about the other things that are worrying you?" And Dulcie said, "All right."' The GP diagnosed obsessive-compulsive disorder almost immediately.

OCD is driven by extremes of anxiety. Its defining characteristic is unwanted thoughts or obsessions that pop into the mind and are difficult to stop. These thoughts are extraordinarily powerful, and sufferers believe that just thinking about bad things happening will make them happen unless they act to prevent this. So they are compelled to carry out a ritual to minimise or cancel out the perceived threat. To the average observer, OCD behaviour can appear odd – counting, repeating certain words or phrases, walking in and out of doors – but to the sufferer, it is a crucial way of averting doom.

Although powerful enough to make you do things you don't want to do, OCD thoughts are different from the psychological symptoms of such mental illnesses as schizophrenia. 'If you ask a child with OCD, "Do you really have to wash your hands when you get that thought, My hands are dirty?" they say, "No, of course not. I know I'm not really dirty,"' explains Dr Isobel Heyman, a consultant child psychiatrist in the Child and Adolescent Department of Maudsley Hospital, London, where she runs the national specialist service for young people with OCD, set up 13 years ago. 'Whereas the person with psychosis will say, "Yes, can't you see I'm filthy."'

Dr Heyman treats 60 to 70 new patients a year, typically the more extreme cases from across the country. Less severe cases tend to be treated at local Child and Adolescent Mental Health Services (CAMHS). Dr Heyman's patients range in age from six to late teens, with about half of her cases

starting before puberty. She says there is no gender divide (it affects boys as frequently as girls), and, while rates have remained steady – it affects about one in every 100 children under 18 – OCD is being detected and treated more.'

Causes of OCD are still unknown, although experts point to a 'significant genetic component' and 'stressors': bullying at school, a death in the family, for example. (Dulcie's grandfather died four years ago; her grandmother, to whom she was especially close, followed a year later; she was unhappy in her secondary school – a state comprehensive. 'I didn't have many friends and stuff,' she says.) But mostly Dr Heyman believes it's 'bad luck'. 'It's nobody's fault, just as it's nobody's fault if you have a child with asthma.'

Although the OCD mind can conjure any number of anxieties, the most common fall into categories: fear of dirt and germs; fear of harming others or coming to harm oneself; fear of death – both your own and of those close to you; fear that you will carry out some horrifying act of a violent or sexual nature.

The devastating aspect of OCD is that the ritual promises comfort but in fact delivers torment. 'The problem with OCD is that you get trapped in this vicious circle,' Dr Heyman says. 'The more you wash your hands in response to the unwanted thought, the more the thought comes back. I've seen teenagers spending maybe seven or eight hours a day in the shower, sometimes washing themselves in a particular order because they don't feel completely clean if they don't, sometimes using dangerously strong cleaning fluids, washing-up liquid, even bleach.' OCD can cause sufferers to shrink within themselves; it can make even the most apparently straightforward events fraught. At its most severe, people become housebound. 'It can be devastating, actually,' Dr Heyman says.

The World Health Organisation ranks OCD among the 10 worst illnesses in the developed world in terms of its impact on income and quality of life. And OCD is surprisingly common. Studies show that one in 50 people has full-blown OCD, while about one in 15 of us suffers at least some symptoms of OCD, according to a paper last year in the *American Journal of Psychiatry*. Yet there is a delay with diagnosis – up to 15 years for adults, according to studies, and an average of three and a half years for teenagers. But the problem is not so much diagnosing the illness as getting people to ask for help. Embarrassment is a factor. 'People are often very ashamed to have it because they know it doesn't make sense,' Dr Heyman says. The fears are so terrifying, sufferers do not like talking about them. 'In children,' she adds, 'it is particularly destructive because it stops a child going to school, stops them seeing their friends, stops them going out and exploring the world, doing all the things they should be doing.'

I meet Dulcie at her home in north London, where she lives with her mother, a home-based publishing consultant, her father, the head of strategy for a charity, and her sister, Lottie. Now 14, Dulcie says her OCD has improved. 'I still have some days when it seems really bad, but looking back at how far I've got, it's a lot better.'

Dulcie dates the start of her OCD to her grandmother's illness. 'There were lots of mirrors in the hospital she was staying in. Towards the end of her life, I'd start taking a lot longer to get out of the [hospital] room, because I had to check all the

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mirrors.' She remembers that mirrors have always fascinated her. 'If I saw a mirror, I'd always have to look back at the real thing being reflected, so I've always done it a bit.' But mirrors started to assume a symbolic significance. Checking and re-checking the reflection became her way to protect her grandmother. 'And [a way to protect] me.'

Dulcie's big anxiety is death. She became convinced something awful would happen, either to her or to her family. 'I was really worried someone would get killed or bad things would happen to me.'

Dulcie's grandmother died in May 2006 and the symptoms of Dulcie's OCD remained low-key until October 2007, when her behaviour became more extreme, exacerbated, her mother believes, by problems at school. 'Looking back I was quite unhappy at school,' Dulcie says. 'I didn't really have very many friends and people weren't very nice and quite rude. There was this really annoying boy who used to sit next to me, teasing me and stuff. He made me more agitated.'

It became increasingly difficult for Dulcie to stop herself carrying out her rituals at school. 'I'd have to put my pencil case in and out of my bag a couple of times and put it on the table and keep unzipping my bag, which was a bit embarrassing. I think people might have started to notice and think I was a bit strange.'

'Gradually she became more and more withdrawn,' her mother remembers. By January 2008 she looked thin and miserable. 'She hardly ever smiled, she had lost any pleasure in living, and really that was very distressing.'

Dulcie would try to hold it together at school, but 'it burst out at home', she says. So the family home became the focus of all the tension and drama. Her first challenge after school was getting through the front door. She would unlock the door, open it and walk in the house, but then walk out again and get 'stuck' on the step, as if some invisible barrier prevented her from entering. She would eventually take the step inside, but then walk out, to repeat the whole process again.

Homework, too, became the focus of compulsions. Dulcie had to write over the same word again and again, repeating each letter until the paper was gouged. 'She would be sobbing and saying she couldn't do it,' Catherine remembers. 'It was just a blur of everything taking ages and ages, her throwing things around her room and then about midnight she might be able to go to bed.'

The GP who first diagnosed Dulcie's condition referred her to her local Child and Adolescent Mental Health Service, warning them that it would 'take ages' to get an appointment. It was to take five months. In the meantime, her parents turned to the head of child psychology at a leading London hospital. 'She would say, "If you go to school with a smile on your face, people will smile at you," you know, wildly off the mark.' The sessions were also expensive: £175 plus VAT for an hour. From January to July, Dulcie's OCD accelerated. 'I think she just stopped resisting it so much,' Catherine says.

Dulcie could not climb the stairs, and if she got into the bathroom, she would not be able to cross the threshold to get out. Or she would perform an elaborate ritual of walking in and out of the bathroom for hours at a time without flagging. 'It took her a really long time to get in the shower, she had to tie her hair up, untie her hair, go to the loo, get off the loo, climb into the shower, turn it on, turn it off,' her mother recalls. Brushing her teeth took 50 minutes. 'I'd spend five hours in the bathroom just trying to have my shower and then giving up and crying on the bathroom floor,' Dulcie says.

'I thought OCD meant someone who was supertidy or a perfectionist,' Catherine admits. 'I didn't know it would make it difficult for you to wash, get dressed or leave the house. I didn't realise what a serious mental illness it was.' Her approach was to co-operate with her daughter's demands. She read aloud to Dulcie from Rumer Godden's *The Greengage Summer* until she was hoarse; she rushed around shutting doors, opening windows, getting a bucket when Dulcie could not use a loo; she would put up with abuse (the power of OCD to change personality is noted by specialists). 'Dulcie would be swearing and telling me to "f*** off you are such a bitch" – language I didn't even know she possessed.' Outbursts were followed by sobbing and apologies and 'I hate being like this'.

Robert took a harder line against Dulcie's OCD-driven commands. 'When Catherine gave in to the OCD I would steam. The problem with OCD is that if you give in to the rituals they only get worse and the fear intensifies,' he explains. But not giving in was fraught, too. 'It had the side effect of Dulcie

slamming doors, kicking in walls or something more destructive and would delay her getting into bed for an hour or more.'

Robert's role was practical. He would mend the spindles on the banisters broken during Dulcie's frequent violent rages or repair the loo blocked by her prodigious use of loo paper. 'Fixing the things Dulcie broke wasn't helpful for the OCD, but I had to put the house back in order just to keep my sanity,' he says.

Catherine says the impact on family life was devastating. 'Everything in the house revolved around Dulcie. We were eating meals very late and Lottie and Dulcie would have terrible rows because Lottie was trying to do her GCSEs and was being kept up very late.' The sisters share a room and Lottie had to sleep with her head under the pillow listening to her iPod. 'I would be going in and out of the [bedroom] door at midnight,' Dulcie remembers, 'and she would be really cross with me because I had to keep the light on.'

'It put a huge strain on my relationship with Robert,' Catherine says. 'We had the most dreadful rows and we were so exhausted we'd barely speak to each other apart from say something crossly as we crawled into bed.'

'At first my mum would cry a bit if I started doing my rituals,' Dulcie remembers, 'but I think after a while they got used to it and it just became really annoying. I think they thought it would go away quickly. None of us realised it's not going to.'

Finally, towards the end of June 2008, Dulcie had her first appointment with the CAMHS. 'The family were pretty much at the catastrophe level,' Sandra Barwell, a consultant systemic family psychotherapist, remembers. 'Dulcie's school life was totally disrupted, her family life was hugely distressed, and her social life – her capacity to lead the life of an adolescent – was hampered.'

Experts agree that OCD is very treatable; sufferers generally respond well to cognitive behavioural therapy (CBT), and some people also benefit from anti-depressants, which act on the brain chemical serotonin and are thought to have an 'anti-obsessional' effect. 'We deliver 14 sessions of CBT over 17 weeks, and even in very severe cases we get most people better within that time,' Dr Heyman says, although she admits symptoms 'can creep back'.

Dulcie started off with weekly sessions with Betty Hancock, another clinical psychologist at the local CAMHS, but after a few months these became fortnightly. 'We worked on one very small thing, like the way I had to go over my writing, repeating each letter,' Dulcie remembers. 'So instead of going over the whole word, I'd just go over the first and last letter.' She was also prescribed anti-depressants: 75mg a day (the maximum for someone Dulcie's age and size is 100mg).

The family, too, went for monthly sessions. The strategy of OCD treatment is to separate the condition from the sufferer and treat it like an obnoxious gate-crasher: something to stand up to, rather than indulge.

'Enough already' is the response Sandra Barwell encouraged in Catherine. 'We said to Dulcie, "Your mother is on duty until 10pm, after that, your mother isn't going to come and get you."' Catherine was worried that this would mean Dulcie being stuck in the bathroom all night. 'Why not?' Barwell replied. 'We don't think she'll die.' Barwell and Hancock see their role as re-introducing boundaries for families who have lost touch with what is normal.

'The turning point was realising the longest anyone can be hysterical for is 35 minutes,' says Catherine, who was told this by the CAMHS team. 'Once we realised that, we just kept our heads down and let Dulcie scream and shout and throw things around, and gradually the time she spent screaming and shouting did shrink.' The team also advised a healthy diet and exercise, so Catherine would take Dulcie swimming.

Eighteen months on, Dulcie is still taking anti-depressants, but her treatment at the CAMHS is now monthly with a view to stopping soon. In January 2009 she started at a new school (a girls' comprehensive), where she is doing well, and is visibly brighter. 'They're much more sympathetic [than her previous school],' Dulcie explains. 'All my teachers know and I've got a mentor and she's given me this card which says DULCIE HAS PERMISSION TO LEAVE THE CLASSROOM, so if I get agitated I can just put up my hand and leave. It's very discreet.' She pauses. 'I haven't used it yet because I haven't been worried at all.'

'She's become good at shortening her rituals,'

Hancock says. ‘She does things quicker, she’s not late for school any more, and bedtimes are easier. But the rituals are still there.’ On a scale of one to 10 with 10 being severe, she now puts Dulcie at five. (She was on eight when she started treatment.)

Dulcie talks me through her morning rituals: ‘When I wake up, I probably sit up in bed and maybe lie back down and sit up, but I don’t always do that, then I go into the bathroom and get out of the bathroom and go into the bathroom again, and then I probably do that a couple of times, but not that much, then I go to the toilet and wash my hands, and turn on the tap a couple of times, or just tap the tap – that’s another thing, I used to have to wash my hands loads of times, now I just tap the tap instead.’

‘I’ve realised it’s not going to go away,’ she says. ‘I had hoped that if there was a fire I would be able to get out of the house without doing any rituals, but I probably wouldn’t. That’s how bad it is.’

Do you ever feel at peace? I ask. ‘When I’m with my friends and out doing stuff and I’m really distracted, just shopping or something, but even then little bits of OCD creep in. Even reading a book, I had to re-read pages, so I just gave up on reading because it took so long to get to the next chapter.’ But life is definitely improving. She no longer has to do rituals in her dreams – and says she used to feel ‘guilty’ and ‘wimpish’ for having OCD. But now she just thinks it ‘annoying’. There is another positive development. ‘Looking back,’ she says, ‘it’s made me a much stronger person and now I’ve got some really great friends.’

Some names have been changed. The Maudsley clinic is running a telephone treatment trial for young people with OCD. If you are aged 11-18 with OCD and want to find out more, ask your doctor to contact the clinic on 020-3228 5222

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