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veryone says the same thing. "It was just an ordinary day." Ollie's mum, Vicky, called it a "tea, bath, bed kind of day". Nothing anywhere to warn you that hours from now, the only thing of any consequence in your life is going to be the gut-wrenching battle to keep your child alive.

Ollie, now 2½, grabbed a grape from his sister's plate one balmy evening last summer and choked. It was obvious he was suffocating from the look of terror in his eyes. His mother tipped him over her knee, whacked him on the back, then, as he turned blue, she put her mouth over his, and desperately tried to force oxygen into his body, but it wasn't enough. In the minutes it took the ambulance to arrive, Ollie's heart stopped and he sustained a catastrophic brain injury.

Josh, 14, took his bike on his paper round for the first time ever one Saturday, was clipped by a lorry and hit the road so hard his brain rotated on its stem. His mum, Ginny, worried that he'd taken unusually long to cover the few houses on his round, had been putting on her coat to come and find him when a neighbour appeared at her door. She thought Josh might have broken a leg. In fact, the list of injuries, including a fracture to the bone the brain sits on, were so severe, no one thought he'd survive.

Every year, an estimated 20,000 children in the UK will acquire a brain injury – some minor, some life-threatening. Here, like in the US, where more than a million children sustain brain injuries every year, it is the most frequent cause of disability and death among children and young people. The Children's Trust in Tadworth, Surrey, which for over 20 years has provided care and therapy for children with multiple disabilities, is home to the only specialist rehabilitation unit of its kind in the country, its 12 beds accounting for three quarters of the UK's total provision. Every child here has suffered a loss of self so profound it is almost impossible to comprehend. The majority (45%) are referred after road traffic accidents, some



Choking on his food cost this little boy his sight, speech and movement. Now a dedicated team have enabled him to see again. But why do only a handful of British children ever receive such intensive treatment when 20,000 a year are brain-injured? And what happens to the rest?

**REPORT BY CAROLINE SCOTT.
PHOTOGRAPHS BY EMMA HARDY**

Investigation

Oliver Jack, whose brain was severely damaged after he choked on a grape, in the multi-sensory therapy room at the Children's Trust in Tadworth, Surrey





Above: Ryan Caton after a car accident last year. Right: Ryan, now 15, in his room at the Trust. Below: one of the 'miracle' cases, Alfie Russell, now 18, meets Cherie Blair

after falls, strokes and heart attacks and following complications during routine operations. Others are suffering the aftermath of infections like meningitis and encephalitis, which can wreak havoc on healthy brain tissue.

Many children are completely unresponsive when they arrive. Most can't walk or talk and have impaired hearing or vision or both. Some can't breathe independently and need artificial ventilation. Some can't swallow – when the brain is profoundly damaged, the swallow reflex is lost – and they're fed by tube either nasally or via a gastrostomy directly through the stomach wall. They are accompanied by shattered families who may have travelled across the country to be here and still cannot comprehend how this thing could have happened.

In the corridor leading to the therapy rooms and classrooms, all the paraphernalia of the newly disabled is lined up against a wall. Wheelchairs and standing boards are individually fitted to each child and have names on the back. Lewis, Cara, Daniel, Ethan. Every few minutes someone glides by, on their way to occupational therapy or physiotherapy, children who, up until recently were haring round a playground. In the hydrotherapy pool, a girl of about 10 with alabaster limbs lies motionless in her carer's arms. Her hands are drawn up in a spasm under her chin and her eyes flicker in an upturned face. Everything about the scene is wrong. The size and stillness of the child, the arms wrapped around her, the discomfiting quiet on this weekday afternoon.

Every member of the 226 staff here takes on a counselling role. This is because, as Helen Miles, head of physio, explains, the grieving process starts here. "Parents have spent weeks sitting by a child's bed in intensive care willing her to live. However realistic doctors try to be about long-term problems, they don't take it on board. Here, realisation sets in. They know their child is not going to die and they're starting to accept that that life is never going to be the same again."

The physios' first task is to get a child who has lain on her back for months on an acute ward

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'Ryan had carers for two hours a day at one point, but they weren't qualified and thought he was just badly behaved'

upright and in a wheelchair so that they can begin to regain the muscle tone they've lost. The occupational-therapy (OT) team then look for purposeful, rather than reflexive, movement. They test for vision, touch and taste and keep systematic records of the slightest response. Even at this early stage, each child's timetable is highly structured, periods of quiet time are followed by intense activity to help stimulate the brain's sleep-wake pattern. A multi-disciplinary team made up of physios, OTs and a play therapist discuss each case weekly and there is a family meeting every three weeks. Every parent wants to know: "Will my child get better?" It's a question staff dread, as no one has the answer. Yes, they'll be better than they are now, but they may never be "better" in the way parents mean. There isn't enough research to estimate how

long a child's brain might take to respond and how long it will go on healing. Generally, recovery is slow and unpredictable. The brain acts as a control centre for movement, emotion and behaviour; following injury all these functions can be affected and unlike other cells, neurones do not regenerate or multiply. Instead, the brain reorganises its surviving connections to establish function in a different way. Initial treatment is aimed at protecting these surviving connections from further damage. No one talks much of miracles here, though all the staff remember Alfie Russell, whose parents were told he'd never recover and who is now studying sport at college. But for every Alfie, there is another child whose progress is to be measured not in terms of leaps in motor and language acquisition but in tiny flickers of purposeful movement. There is a mantra here: "No one comes through a head injury unscathed." In other words, a child who has a serious brain injury at 2 has a life-long condition and will need support for the rest of his life.

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Bob the Builder is Oliver Jack's favourite. He sits in his wheelchair, eyes fixed on the screen, displaying new-found powers of concentration. Next to him on a beanbag, a little boy with a nasogastric tube is lying under a fleecy blanket, gazing but not seeing. "Ollie never used to watch TV before his accident," says Vicky wryly. "He could never sit still long enough." Ollie's active, mischievous nature is very much working in his favour now. Children who were stropky and determined before their accidents tend to do better than those with more passive personalities.

Two weeks after his accident last August, Ollie was not only unresponsive but terribly distressed. Scans showed damage to the



Right: Justin, 4, who is permanently connected to a ventilator, with his nurse, Jane Foster. Below: his door at the Trust, which has notes of encouragement stuck to it

basal ganglia, an area of the brain responsible for co-ordinated movement, but there wasn't much more the hospital could do for him. When his parents took him home, he was still tube fed and couldn't walk, talk or see.

For the past six months, either Vicky or her husband, Ian, have stayed with Ollie in parents' flats at the Trust, swapping over mid-week. While one is here, attending intensive-therapy sessions with Ollie, the other stays at home with their two older children. After a couple of weeks, Ollie was swallowing again. By October, he could see. He can now roll, and can sit up on his own for a few seconds. Huge leaps for Ollie, but the pace is torturously, agonisingly slow. In the soft play area, the physio, Jacqui Borgia, pushes his knees up to encourage him to move his arms forward. His mum sings: "The children on the bus make TOO MUCH NOISE!" And he screeches with laughter. "Ollie, where are your hands?" He can't yet grasp, but he's alert and interested. Vicky looks exhausted. "You're so desperate to see improvements," she admits later. "Sometimes you imagine things. All they will say is that he has responded well for a child with this kind of injury, and he is continuing to respond. We don't allow ourselves to think further ahead. There are too many unknowns."

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Brain tissue consists of a soft, jelly-like substance containing billions of interconnecting nerve cells and nerve fibres (axons) supplied with oxygen by a vast network of blood vessels. But despite its ingenious protective layers – cerebrospinal fluid, three layers of membrane and the skull itself – the brain is still hopelessly vulnerable. When the human head is shaken or hits something at high speed, the brain rotates within the skull; it's called diffuse axonal injury and accounts for almost half of all cases of severe head trauma. As the different layers of the brain slide across each other, the axons which stretch across them are torn or broken, which means the nerve impulse can not be transmitted. And when the brain swells, as it often does in response to trauma, the bony ridges on the inside of the skull itself cause yet more damage.

If you have a focal injury, like a stroke, where only a part of the brain is damaged, the problems are likely to be local. But a traumatic acquired injury is rarely that simple. When Josh Smith was hit by a lorry, the damage was utterly devastating.

On the Glasgow Coma Scale, which assesses response to stimuli, 3 to 8 indicates severe brain injury, 9 to 12, moderate, and 13 to 15, a mild injury. Josh scored 3. When he was still in hospital, Ginny remembers an OT saying: "Have you thought about moving? Otherwise the house will have to be adapted for his



wheelchair." I thought: "But I don't want the house messed around, we've finally got it how we want it and the garden's just been done... You sit in the meetings and you hear 'substantial brain damage' and you think, 'That's not my Josh.'"

When Josh arrived at the Trust in December 2005, he couldn't move, he was fed through a tube into his stomach and was doubly incontinent. Ginny describes it as like having "a 10¹/₂-stone baby". She stayed with him constantly while his father, Pete, made the four-hour journey from Stoke twice a week. "I've cried buckets," she says. Then corrects herself. "No, not buckets, rivers, over the past year."

Ginny recalls gruelling therapy sessions from 9.30am to 4pm every day. "He started to hold his head up, then a hand, then he could put his thumbs up. We pushed him and pushed him," she recalls. "By the time he left the Trust he knew how to make a cup of tea, but it would all be in the wrong order. Since then he's gone on

'You sit in the meetings and you hear "substantial brain damage", and you think, "That's not my Josh"'

and on improving. He's back at school, with support, and he can do most of the things he could do before. His wheelchair is in the garage now." Ginny is certain that without intensive therapy, Josh's outcome would have been bleak. "There's no speech and language therapy up here, and we haven't even seen an OT. Without the Trust, Josh would never have got out of a wheelchair."

The Trust's main house, a Grade 1-listed building, was once the country home of Great Ormond Street Hospital. Children with TB and chronic lung conditions were sent here to convalesce. After the war, vegetables were grown in its vast gardens and sent up to London. Now a rat run of wheelchair-friendly covered walkways dissect the grounds, leading to clusters of residential houses.

Justin, a perky 4-year-old, came here from Great Ormond Street in August having been in and out of hospital throughout his short life. He suffered damage to the nerves in his diaphragm during a tracheostomy operation and is now permanently connected to a ventilator. A sign on his door reads: "Well done Justin for always working hard and for enjoying all the new experiences you've had and remembering them later." Despite all he's been through, he a sweet child. His parents, Christa and Tim Tuohy, who moved house to be near him, are now taking their tentative first steps towards managing his complex health problems at home.

Right: the play-therapy room at the Trust, which is kept tidy to create a sense of order for the children

Children with acquired brain injury live at the Trust for anything from six months to a year, depending on whether further improvement is possible and for how long funding is available. Five members of staff are permanently locked in negotiations with primary care trusts (PCTs), some of whom are reluctant to stump up the £697 to £1,230 a night it takes to keep a child here. One in 10 applications for places are unsuccessful, which means a child who would have received two sessions of physio and OT a day at the Trust instead might have one session every other week at home. Conversely, some children stay longer than they should because problems with planning applications mean that homes are not ready to receive the newly disabled child who can no longer skip through doorways. For people who are already traumatised, it must feel as if at every turn a fog of bureaucracy enfolds.

The Trust needs to raise over £7m to re-build the rehabilitation centre. The new, state-of-the-art centre would have 10 beds downstairs for technology-dependent children and a further 10 upstairs. Currently, the bedrooms on the residential unit are small and most are shared. Each door bears several names in wooden painted letters or on hand-written signs. The normal clutter of childhood sits side by side with hoists and feeding pumps. A little body forms a hump in one bed, wires from the monitor tracing oxygen levels in his blood snaking across the Thomas the Tank Engine duvet cover.

In the sitting room, a mother sits, clutching a mobile phone in one hand while her child sleeps, daytime TV flickering silently in front of her. There is no private space here at all, which is a problem, since there is less socialising between parents than you might imagine. People can't bring themselves to say: "What happened?" The answer is too awful. The stages of grief unpredictable. One child's progress can cause unimaginable distress to the parent of another whose recovery is less dramatic. Ginny Smith recalls one father having to leave the room when Josh finally stood unaided.

"Parents don't want to be seen to be not coping," says a senior social worker, Anne Caldwell. "But the grieving process may have only just begun. You get denial first. As if accepting what has happened somehow makes it permanent. What parents find most difficult is that there are many definitions of getting better. To them, 'getting better' means getting back to where their child was before the accident. Getting on a bike again, going to school. For many, that just isn't going to happen. We're trying to help them accept that their child may not get better in the way they imagine, but that where they are now is good."

In a large hall, visiting musicians strum their harps while all around, tracheostomies are



In the play-therapy room, the children often choose a toy that is quite close to the thing they're frightened of

cleared and children with darting eyes are soothed and suctioned and tube-fed. One little boy with an acquired injury sits in a wheelchair so new it still has the instruction manual hanging off the back. His mother wears an expression of quiet desperation.

A team of play specialists led by a play therapist, Jan Vance, work on each of the Trust's houses. They greet children and their families and practise intensive interaction skills with those who are devastatingly injured. "You watch and you listen and you wait for the child's responses," says Vance. "Sometimes these are very minimal things. The flicker of an eye, or a groan. Then you mirror that and amplify it. You don't know at what level the child is comprehending but you're saying: 'I'm here for you and the pace is yours.' It's almost as if the child is a house with all the doors and windows shut. There'll be a tiny chink somewhere and it's my responsibility to find a way in."

The play-therapy room is eerily, disturbingly tidy. There's an ambulance and lots of cars set out on a table. Stiff limbed and officious, the Playmobil people seem to be looking at something. There's a sense in here of extraordinary control. And of something explosive waiting to happen. Sometimes a child will come in, flip the Do Not Disturb sign on the door and talk about what has happened to him and how he's feeling. Other days, he'll just line all

the figures up and crash the ambulance.

"There's often a theme of brokenness," says Vance. "Or children will use the characters to explore sadness and fear. Until now, everything has been about keeping them alive and managing the loss. Now they're worried about how they'll cope in the world from a wheelchair."

Central to the relationship between play therapist and a child is the notion of symbolic distance. No child is ever questioned in here, but they often choose a toy that is quite close to the thing they are frightened of. It might be a car. Or a toy bus full of little figures might be used as a hospital stuffed with people. "They play with what best echoes their world of anxiety and loss and grief," says Vance. "Every child with an acquired brain injury, regardless of their cognitive function, has lived through a major loss and they are in turmoil, experiencing huge anxieties about the future and themselves."

After every session Vance restores everything in the room to its original position. "In a world filled with chaos and change, this room is always as it was, and that's a very powerful message."

Ryan Caton, 15, was hit and thrown in the air by a car, then dragged along by another after he ran across a road in Stevenage in January last year. He suffered broken shoulders and sternum, a punctured lung, fractured pelvis and needed extensive skin grafts. "But the worst thing," he says, tapping his head, "was this". When Ryan arrived at the trust six months ago, his body was hunched over, his speech was slurred and he was impulsive, agitated and restless, making it very difficult for his mum, Jen, to deal with him.

All he would say when he first came home from hospital was: "I want to go now. I want to go now," says Jen. "He didn't know where he wanted to be, he just had to be on the move.

Ryan had carers for two hours a day at one ➤➤➤ 59

BRAIN INJURY: continued

point, but because they weren't qualified they thought he was just badly behaved. I've got four children and I was trying to deal with him and pick up the rest of the family. In the end, I put up a white flag. I couldn't cope any more."

"Before I came here, I was walking and talking but I wasn't behaving normally," says Ryan. "If I thought something – and it wouldn't be nice – I couldn't stop myself saying it. My head still tells me to say horrible, sick things, but now I can stop them coming out of my mouth."

For the past couple of weeks an OT, Lorna Wales, has been preparing Ryan for a trip to a cafe later in the week. On Monday, she goes through a bus timetable with him then he uses his mobile phone to set various alarms, one to catch the bus, another to remind him when to leave the cafe. Later, Ryan attends lunch club with his friend Tom. Having said, "It's embarrassing and boring. I'm not doing it any more," he cheerfully cooks fish fingers in the mock-up kitchen, while Tom, 17, who is confined to a wheelchair, spreads Flora on two slices of bread with painstaking deliberation. Tom is dressed in Nike trainers and an Enjoi skateboard T-shirt. "How do you think you did, Tom?" asks another OT, Jo Lloyd. "Um, maybe a bit better than last time?" Tom looks up with Bambi eyes, unsure. "I think so, too," says Lloyd. "And you initiated questions. Well done."

Back in the permanent residential house, a little girl on shaky legs, dressed in a pumpkin outfit, is on her way to hydrotherapy. Daniel, 12, who can neither walk nor talk after a road accident but has a beatific smile, beams at everyone. "One girl I know thinks I should be a model," Ryan quips, showing me his aviator specs. Come Thursday, Ryan remembered he had to meet the OTs at the cafe, but missed the bus because he couldn't bring himself to cross the road. He'd forgotten he needed to walk to the traffic lights and wait for them to change.

Fiona Adcock, head of the Community Support Team, works in the community with children who look to the outside world as if they are back to normal but whose behaviour is completely changed. "Problems may only become really

apparent when they go to secondary school," she says. "They know they've got homework but they can't remember to do it. The timetable makes no sense to them, they can't follow instructions, and they can't self-motivate. Five or six years post brain injury, often no one is looking at their behaviour and putting those two things together."

"When a parent asks me will I ever get my child back? I have to say no," says Adcock. "There is child A and child B. The longer you hold on to child A, the harder it will be to accept that child B is the child you have brought home. In my experience, children never walk away without problems."

Around the walls of the school room, where all children follow the national curriculum, whether they're being taught science or to pick coloured letters from a sheet with their eyes, are written words chosen by themselves: Care, Courtesy, Courage, Celebration, Consideration. "Ryan has achieved so much here," says his mother. "And I feel very grateful. But you feel guilty, too, when you know that while he's had six months' funding, another child with serious problems might only have two months."

The question in my mind as I leave the trust for the last time is this: if thousands of children are brain injured each year and only a handful receive intensive rehab at the Trust, what happens to the others? The Department of Health gave us this statement: "Primary care trusts (PCTs) are responsible for commissioning healthcare and receive funding relative to the health needs in their area." In other words, the department has passed on the responsibility, and each PCT is carefully minding its own budget.

Specialist rehabilitation is expensive. It's much cheaper in the short term to provide a care package at home – an hour of physio or OT once a week, speech therapy if you're lucky – but so much more expensive in the long term. The Children's Trust puts children who might otherwise end up in permanent residential care back with their families where they belong. If your child suffered a devastating head injury tomorrow, you'd feel he deserved this much ■

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