

I CARE FOR MY DAD WHO'S GOT SCOLIOSIS OF THE SPINE WHICH MEANS THAT HE FINDS IT REALLY HARD TO MOVE ABOUT. ONE OF MY CARING ROLES IS TO HELP HIM MOVE AROUND THE HOUSE LIKE UP AND DOWN THE STAIRS. I KNOW ITS NOT HIS FAULT BUT I WISH WE COULD DO MORE TOGETHER LIKE FOOTBALL BUT WE CAN'T WHICH MAKES ME FEEL sad

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My mum is an alcoholic and suffers from depression. I used to look after her, then I moved out to look after my dad, who had kidney failure.” Jade Zerk, now 16, recounts her life looking after both parents and her little brothers as if it was completely normal. But her eyes give her away. As she talks, she constantly looks to her brother Ethan, 14, for reassurance.

She remembers being conscious that as a small child she smelt. “My mum didn’t look after us. My school uniform was dirty, the house was always filthy and I hated that. I became a hygiene freak, but however hard I tried to keep it tidy, I couldn’t keep up with it.” She was so busy looking after the boys that she never had friends of her own. “I’d have a sleepover or a birthday party and no-one would turn up.”

When she was 12, Jade started to break down at school. She says suicide was constantly on her mind. A referral was made to Pembrokeshire social services, but nothing happened because her case wasn’t seen as “serious enough”. You can see how the unfairness of that judgment hurts her even now. At 13, in an act of both self-preservation and compassion, she moved out with Ethan and her youngest brother, Tyree, 11, to live with their father, Andrew, who was by then desperately ill.

Earlier this year she nursed him through a kidney transplant, and she still does all the shopping, cooking and cleaning for the four of them. She makes the meals, she washes up. Before and after school, she washes, sorts and irons clothes, and makes sure the boys have everything they need, and she’s done all this on some level since she was five years old. Then it was a case of standing on a chair to find Ethan crisps or cereal for his tea, because there was barely any food in the house. Now, at 16, she’s still a fully fledged “mum” to everyone. The house is always spotless. It’s her way of staying in control, but it’s not really the doing of it that gets her down; it’s always carrying the responsibility in her head. She’s never been free to be a child.

A few miles away, high above Pembroke Castle, is the estate where Lee Herring, 14, >>>



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Angry, annoyed, worried, sad: children at Sandwell Young Carers project in West Bromwich, one of just a handful in the country, are in no doubt about how their home life makes them feel



# CRYING OUT TO BE HEARD

These children — and 200,000 more in Britain — nurse sick or disabled parents with little support or respite. Why have they been abandoned to a childhood of despair? Report by Caroline Scott. Photographs: Richard Davies



and his mum and dad live. We are parked outside Lee's house, but he doesn't want me to go in. "It looks normal," he says, "but it's not. It's a mess." Lee's mum suffers from mental health problems, including paranoia. "She thinks everyone is out to get her, especially me." So we drive down the hill to McDonalds, Lee chatting merrily all the way. He points out the freshwater stream where his sister, who lived at home until he was seven, would take him for picnics. "She got away – and I can't blame her," he says.

"When Mum's bad, I need to be there to give her the confidence to do things," he explains, oblivious to the role reversal. "I take her out of the house step by step, telling her all the time, 'It's okay, you're with me.'" But when things go wrong, and they often do, Lee's mum calls the police on him. He shrugs. "She does it all the time."

His dad, who lives round the corner, suffers from diabetes and chronic arthritis, so Lee is effectively sole carer for both, staying with his dad when things get unbearable at his mum's. "In the morning I lay out my dad's medication because he's not a very good reader, then I get mum up and dress her, make sure she's nice and tidy and tell her everything will be all right while I'm at school. I have had problems," he admits. Those problems include disruptive behaviour



## In areas like Sandwell, hundreds of children care for sick parents. Hopelessness seeps across the generations and sets like concrete

and attendance that at one point was down to 50%. But the thing that really rankles is that as punishment for lateness the school would give him detentions. "That was so unfair," says Lee. "I was late because I was looking after my parents. If they kept me behind, it meant I couldn't get home to give my dad his insulin."

Lauren Malin's *Life in the Day* in this magazine back in April caused a storm of protest and a wave of stories in the media about the lives of young carers. Lauren, who looks after her disabled mum, Nikki, felt she didn't have a voice. She believed nobody on the outside really knew what her life was like. She raged and sometimes she cried herself to sleep, but nobody heard. It was Sunday Times readers who began to put things to rights. You sent money and kind words and wonderful letters of support, and with the charity Miracles we are well on our way to making her life a whole lot better. But what of the others?

Over the past few months, I've met dozens of children like Lauren and Jade and Lee whose lives are diminished, not just by caring, but by poverty and low expectation and lack of proper adult support. The last census, in 2001, estimated that there were around 175,000 children in Britain caring for another member of the family, but most of those working in the field believe the figure to be far higher. Several independent studies put the figure at nearer a million.

Added to these is the huge number of "hidden carers" of all ages. Thousands of children cope alone with their parents' addictions and substance



abuse: according to Home Office figures, 1.3m children live with parents who are alcoholic and a further 250,000 have parents who misuse drugs – and few of these are likely to be known to outside agencies.

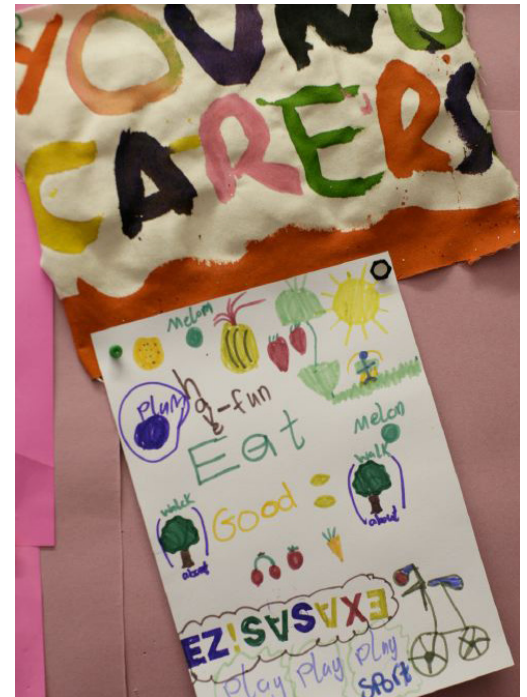
The Barnardo's study *Hidden Lives* suggests that, on average, young carers – most are aged between 12 and 15 – spend four years looking after a parent or relative before they receive any support. Four years. Imagine it. We know that 18% of those are getting a parent on and off the loo in the night, washing and dressing them. And, most disturbingly, that 82% provide emotional support. They're too exhausted and worried to concentrate at school or socialise afterwards, especially if a parent may self-harm. It's a terrible burden for any child to carry and it effectively obliterates their childhood. As I listened to these children's stories, in almost every case I thought: "You are coping with a situation most adults



would find intolerable." And yet it continues. I set out to find out why the millions we pour into social care every year can't prevent children from having to care for their parents.

Every other Saturday morning, a minibus snakes around the streets of West Bromwich picking up half a dozen small children and dropping them at Sandwell Young Carers' project in the town centre. In the activities room, a little boy of six chews at his sleeve furiously and a girl wearing a filthy jumper sits colouring as if her life depended on it. Children are very good at accepting what they cannot change and adults, endlessly preoccupied with other matters, are very dim when it comes to picking up the telltale signs. Liam, a fragile boy of nine, looked after his mum, who has MS, for four years before a school nurse realised that his poor attendance, exhaustion and disruptive behaviour didn't mean he was a naughty boy. It meant he spends his





**Jade, 16, keeps the home spotless, cares for her father (left), does the washing (far left) and helps Tyree, 11, with homework (bottom left). Above: a Sandwell drawing**

nights half-awake listening out for his mum and his days worrying in case something happens while he's at school.

Sandwell was the first centre in the country to provide play facilities, respite and one-to-one support for young carers, and there is still only a handful like it across the country. In the 12 years since it opened, it has supported over 500 young carers, both at the centre and at home. But despite its crucial pre-emptive work, it faces a continual battle for funding and starts every year with a huge deficit. "Please let it be known," begs the director, Tracey Smith. "We're only scratching the surface here in Sandwell, and it's the same across the country. We rely heavily on fundraising and local sponsorship which may or may not be there next year. If we had sustainable funding from government, we could focus on reaching out to more children and developing our service rather than worrying how to pay the bills."

Of 150 boroughs in the country, Sandwell is ranked 16th most deprived. In areas like this, where there is rampant unemployment, and illness and disability are almost endemic, hundreds of children care for sick parents and hopelessness seeps across the generations and sets like concrete. Despite the best efforts of the centre's staff, dropout rates are high even when a car is sent to the child's doorstep. If you think about it, the reasons are blindingly obvious. They're little – this group are all under 10 – and they can't get themselves ready in time. And anyway they're needed at home. These children are socially disengaged. All the excitement the project offers means nothing to an eight-year-old who has never had a chance to play.

Behind the centre, the high street is awash with pound shops, and in the distance, The Public – an arts centre that has had £52m pumped into it and which has now gone into

administration – sits like a purple bruise amid the net curtains and rubbish-strewn gardens. Children's services here are so overstretched that they frequently operate on a child protection basis only, which means that unless a child's life is in danger, social services are unlikely to step in. In 2005, the Commission for Social Care Inspection reported that Sandwell Borough Council was considered to be "serving no children effectively, with uncertain prospects for improvement". And it was not alone: 21 councils have been rated zero or 1\* since 2002. A maximum 5\* rating means very good; 1\* means investigate urgently.

When the project discovers, as it did recently, a family of four children under 12 looking after a single mother in a wheelchair, it has to follow a head-bangingly frustrating procedure which goes like this. Contact social services. Direct all enquiries to the assessment and referral unit, even though no young carer assessments have been done in Sandwell since the first Carers' Act was passed 12 years ago. After that, it's pretty predictable. Children's services can't get involved because the children are technically not "at risk", and adult services maintain it is not within their remit to provide a service to a mother to enable her to look after her children. Result: the children stop coming to the project. They're exhausted, overburdened – and now increasingly isolated.

"Older children regularly come back to thank us for giving them a childhood," says Smith, aware that, as they can only give each child on average two hours per week, this is a fairly bleak indictment. But the children here will tell you it's not just the time. It's knowing that in the ➤➤➤ 37



unspeakable chaos of an upside-down world where children look after adults, someone is there for you. To them, that bond is both a lifeline and a means of survival.

Some 300 independent projects around the country – mostly tiny and dependent on local sponsorship – organise outings for children who otherwise wouldn't get out of the house. Lee has never been known to miss a trip, but the Pembrokeshire Young Carers Outreach is so short of cash this summer, having lost its BBC Children in Need funding, that its two part-time workers, Mandy Fynney and Alison Silk, are left to try to think up outings that are free.

Mandy describes the first time she met Lee. "He was all hunched into himself. His shoes were two

Beverley Hughes, minister of state for children at the time, announced, a tad simplistically given the monstrous complexities of health and social services: "The five outcomes give all agencies a simple and coherent view of what it is they are supposed to be doing and give responsibility to everyone for a child's wellbeing."

Crucially for young carers, Every Child Matters offered responsibility to everyone but gave it to nobody. A peripheral group, not really on anyone's radar, child carers rarely get help from school or adult or children's services until problems reach crisis point – and maybe not even then. Difficulties cluster round hard-to-reach families with multiple problems. Families who are struggling to cope quickly become

## Bizarrely, supporting adults to be parents is seen as the job of children's services, yet they have neither the time nor the funds

sizes too small and he smelt. He didn't take his coat off because he was so conscious of his dirty clothes." But the hardest thing for this very bright boy – he taught himself to play the piano "because it calms me down" – is that he has nobody to talk to. "I get back from school and my mum is slumped in a chair, staring at the floor. I try to tell her how I got on, but I get one-word answers."

Lee is usually stoic. The only time Alison heard him break down was one Sunday afternoon when he phoned in tears to say: "I'm locked out. Mum won't let me in and I'm stood in the garden in the pouring rain." Alison, at a loss to think what to do, suggested he go to a friend's house. "But I can't," he insisted, "I've got all the washing to do." So there was Lee, soaking wet under a gunmetal sky, worrying how he was going to get his school uniform washed and dried for the morning.

Alison is "a hardened crisis-intervention worker", in her own words. "I've worked with abused children, with the most serious young offenders." But nothing prepared her for this bitterly difficult role in which she can offer so little. "I come away from meetings in tears because I feel so helpless. When I worked with cared-for children, I had a budget, but there's nothing I can offer Lee. After he's put his mum to bed and tidied up the house, he'll text me: 'Good night, Al', because there's no-one else."

The Blair government understood early on that it is attention to the very young and the very old that puts the stamp of humanity on a party, and expediently put children at the top of its political agenda. The green paper Every Child Matters in 2003, followed by the Children's Act of 2004, were supposed to join up the dots in children's services, with the onus on education, health and social services working together. In a thoughtful piece of planning-cum-PR, it was children themselves – 2,500 polled across England and Wales – who identified the five desirable outcomes of Every Child Matters: being healthy, staying safe, enjoying and achieving, making a positive contribution to society, and achieving economic wellbeing.

isolated, and the more intractable their situation becomes, the more they tend to retreat, out of embarrassment and fear, from possible sources of help. I met a boy at a youth project who looked after both his disabled parents, neither of whom qualified for community care. He told me he'd dropped out of school for two years and nobody had even noticed.

This gap between what adult and children's services are briefed to provide is at the heart of the problem. The Princess Royal Trust has 81 projects across the country supporting 15,000 young carers. Its policy director, Alex Fox, says that health and social services routinely fail to ask adults in their care: "Are you a parent?" Bizarrely, supporting adults to be parents is seen as the job of children's services, yet children's services are so mired in child-protection issues that they have



neither the time nor the funds to step in. "Every local authority should have a protocol between children's and adult services," says Fox. "This isn't about money. They just need permission to talk to each other."

The Department for Education and Skills has given the Children's Society £600,000 over three years to circulate guidance to "front line service providers". Each local authority in England will receive a one-off training session empowering all its employees to ask the crucial questions: "Is there a child in the family who is helping to provide care?" and "What needs to be provided





**The Children's Society and YMCA's festival is a rare chance for young carers to get away from home and have fun. Below and inset: Lee, 14, cares for both his parents, who live apart. His father has diabetes and arthritis; his mother suffers from paranoia**

much in local authorities' performance indicators. "There's no point in making excuses here – young carers' issues sit around some of the very hard-pressed areas of children's services, and developing systems around them is not happening as quickly as we'd like."

The Children's Commissioner, Professor Sir Al Aynsley-Green, who has toured the country looking at children's provision, talks about finding "bunkers and silos" everywhere he goes: "Professional allegiances, territorial aspirations, the 'we've always done it this way' response – it stops people at local level really seeing and responding to the needs of the child."

A case worker from a voluntary organisation in Lancashire told me of a 10-year-old boy whose mother was suffering from cancer. When she went into hospital, he stayed at home alone. Far from all agencies working together, nobody involved in the care of this mother actually asked about her child. When she came home, he looked after her as best he could until her condition became terminal; then someone finally twigged and, instead of being offered support, he was taken into care, where he stayed, begging to be allowed home, until she died.

It's such an appalling situation, and the solution so hopelessly wrong-footed, that I can hardly bear to write about it. But it's a situation



## Less than 17% of young carers have ever been formally assessed. Many don't dare tell their schools for fear of being bullied

to prevent the child's inappropriate caring role?"

The Children's Society's programme manager, Jenny Frank, wants to get across the message that social services must take a "whole-family" approach. "There needs to be multi-agency support and it should be delivered holistically." This might prevent, for instance, the hopeless inflexibility of a community care package which involves a carer coming to get a bed-bound mother up at 11am, after her children have got themselves up, made their own breakfast and hers and left for school. It's idiotic and it compromises her ability to be a parent, but it happens all the time. I heard another story about a community home help who would only do the disabled mother's washing, not her children's. Hobbled by targets and confused by endless legislation, none of the "service providers" dare step over the boundaries of their own job description. John Coughlan is president of the Association of Directors of Children's Services. He admits that, until now, young carers haven't featured

familiar to anyone working with young carers. "Children rarely complain about caring. They want to be with their parents and they want to help, however dire the situation," says Elaine McGonigle, director of the Princess Royal Trust. "What they need is recognition and reliable outside support to make their lives easier."

Under the Government's Fair Access to Care, when adults are assessed for community care, their parental and family responsibilities should be taken into account. But this rarely happens. Young carers can also be assessed under the Children's Act framework for Children in Need. In fact, a patchwork of reasons – partly to do with fear of being put into care – means that, to date, less than 17% of young carers have ever been formally assessed. Many don't dare tell their schools for fear of being singled out and bullied. And even if they are assessed, support is rarely forthcoming. To be eligible for help from local authorities, a child must be deemed "at risk" on one of the two highest levels. Their lives must be under threat, or a ➤ 39



substantial level of care must be needed – “substantial” here being open to interpretation. They struggle on, unsung and unsupported.

Elaine McGonigle describes current legislation as “a kind of endless rhetoric describing what we should be doing”. The Carers Acts state that all carers have a right to an assessment but, as McGonigle points out wearily, nowhere is it stated that services must be provided.

Does the future look brighter? Hardly. Young carers’ projects currently receive money – some 10% of their income – via two government funding streams, the Children’s Fund and the Carers’ Grant, both of which are due to end in March next year. The Department of Health is working on a new Carers’ Strategy, Scotland now has a Carers’ Manifesto, but neither means anything unless it is backed by financial commitment. Gordon Brown has hinted that the Carers’ Grant will continue but, crucially, this pot of money is not ring-fenced, which means it is routinely fed into the big black hole that is last year’s local authority budget deficit.

All local authorities already have statutory Children and Young People’s Plans, but when Sir Al Aynsley-Green reviewed these plans across England, he found that young carers barely appeared in them. He believes this reflects a cultural attitude that children are relatively unimportant. “We have to recognise that years of disinvestment and lack of focus on children’s issues can’t be solved overnight. I feel ashamed to have been a paediatrician for 30 years and failed to shout from the rooftops about the problems in children’s services.” He points out that we either demonise children or turn them into angels. Young carers come into the angel category, yet no young carer or their parents ever chose their circumstances, and they don’t want badges for bravery: they long, more than anything, just to be like everyone else.

Charities do what they can. But they can’t fill the gap left by underfunded, uncoordinated policy initiatives. The Princess Royal Trust runs a website, including a message board that reflects the myriad concerns of teenage young carers: bad skin, relationships, exams, Dad’s Parkinson’s disease, mum’s manic depression. The scale and complexity of their problems is heartbreaking. “Becky” writes: “me grandma is ill and me granda and me mum who is usually mentally ill but is now physically ill too. I’m so tired doing everything and looking after my little brother I don’t know what to do. I just want someone to look after me...” This is a 15-year-old who is taking GCSEs and says she “cries every night because I am so stressed and my best friend who I normally talk to won’t speak to me”.

Every year, the Children’s Society, together with the YMCA, takes 1,200 young carers aged 10 to 18 on a Festival Weekend. Projects fundraise over the year to raise the cost of £55 per child, but many can’t afford it because they are dependent on bits of funding that may or may not be there the next year. Nobody came from Pembrokeshire this year because the money was



SOMETIMES I DON'T WANT TO GO TO SCHOOL. I'M NERVOUS THAT MUM'S GOING TO FALL OUT OF HER WHEELCHAIR

**The story in this magazine that brought the issue of child carers to public attention**

expect all local authorities to fulfil their obligations to children in need. But the solution is not primarily about either law or money. Children’s and adults’ services must work more closely together to provide better, more integrated support. We expect young carers to be given the same consideration as their adult counterparts.”

A group of MPs and peers last year tried to amend the Education Inspections Bill so that school governors would be required to designate a person in each school to support young carers, but the government rejected the move. It is not surprising, then, that 91% of teachers polled for the Barnardo’s Hidden Lives survey believe most young carers remain unidentified. At the festival I met a head teacher

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needed to buy a computer for a girl taking her AS-levels. Emily, 13, whose mum suffers from agoraphobia, has come looking for “fit boys and fun”, and the torrential rain is no barrier. Hordes of teenagers are having their faces or nails painted or they are bungee-jumping or gleefully diving into a tank of freezing water. In the voice zone a market research company hired by the Department of Health has posted the question: What would help change young carers’ lives? The answers, scrawled on green Post-It notes, will be fed into the government’s new Carers’ Strategy to be announced next year: “a carer once a week for my disabled mum”, “more restbite [sic]”, “more people 2 understand”, “some 1 2 talk 2”.

It’s a start, and it means, as Jenny Frank of the Children’s Society points out, that someone is finally listening, but it does not address the deep flaws in the system. Carers UK maintains that the single greatest threat to young carers is the persistent underfunding of social care. And Dame Denise Platt, author of the Green Paper Every Child Matters, reported last year that there is still “insufficient co-ordination between adult and children’s services”.

In April, responsibility for children’s services was removed from the Department of Health and given to the new Ofsted, which talks of “ambitious standards” and “better life chances for service users”. But it’s difficult to see how this will facilitate a more connected service. Kevin Brennan, the new minister for children, was keen to point out that the quality of social care continues to improve. “In 2005-06 the number of households receiving intensive home care [defined as more than 10 hours and six visits a week] rose by 62%. There is no reason why young carers should miss out on their childhood. It is disappointing when levels of support in some areas fall short of what they should be, and we

who has begun to “look at data differently” and now has a staff team who are fully aware of young carers in her school. “You have to forget baseline assessments for a moment,” she said, “and remember you’re dealing with human beings.”

Alex Fox says he’s never met a young carer who hasn’t been bullied. He’d like the government to establish how many of what it calls “serial truants” are actually children caring for sick parents and siblings. Not only do these children tend to do less well at GCSE, but it’s clear from a poignant Children’s Society report, *On Small Shoulders*, which talked to former young carers, that they’re more likely to suffer from mental health issues in the future.

Lee, under unbearable pressure, has moved out of his mum’s and is living with his dad. “I’m better,” he says. “But mum’s much worse, and I feel bad because I know she needs me.”

I worry most about Jade Zerk, who has spent the whole of her short life caring and now can’t stop. She’s a lovely, gentle girl trying to find control in a life which has been utterly chaotic. “Last term I became so depressed, I went to the doctor and cried and cried and said: ‘I give up. I can’t cope any more.’” The family don’t qualify for practical help but they now finally have a social worker and things have improved. Jade’s had a week’s respite, surfing in Cornwall, and she’s having counselling “to help me be a sister and a daughter, because I don’t know how”. Does it help? Her eyes dart around the immaculate sitting room tidied and vacuumed for my benefit and she seems to shrink into herself. “I do want a normal teenage life. I long for it sometimes. But caring is all I’ve ever done and I’m struggling to let go. I can’t stop worrying what the boys are going to wear to school tomorrow.”

*Consent was obtained from parents for children’s interviews and pictures in this article*