

Parents unite for 'gutsy' kids

Helen O'Callaghan talks to a mum who is networking to support children with IBD



Reach out: Experienced parents offer support to families with children affected by inflammatory bowel disease.

PARENTS of children with Inflammatory Bowel Disease (IBD) have set up a group to advocate for better health services for the 450 kids nationwide with the condition.

Our Lady's Children's Hospital, Crumlin, is the centre of excellence for paediatric gastrointestinal (GI) care of IBD (long-term incurable disease, which includes Crohn's Disease and ulcerative colitis), but there are only two half-time GI clinical nurses catering for 450 young sufferers.

What this means hit mum-of-two Rachel Kane recently when her 12-year-old son, diagnosed with Crohn's Disease at age 10, had a bad flare-up in the middle of the night. With the GI nurse off duty, Rachel was instructed to either bring him to A&E or wait 'til morning and bring him to the GP.

"He's on immuno-suppressants so I wouldn't want to bring him to A&E, where he'd be exposed to infections, unless I really had to. The nurse, who has all the

child's case notes, provides a speedier route to the consultant rather than have the child sitting in A&E for hours."

The 11 parents have launched website www.gutsykids.ie to raise awareness about IBD. Many people confuse IBD with irritable bowel syndrome (IBS). But IBS does not cause inflammation, ulcers or damage the bowel, whereas IBD does.

The website aims to combat isolation felt by parents, especially those in rural areas, who don't know of any other children with the condition and who are in shock after hearing their child has a life-long illness. The parents also want to campaign for better facilities.

"There's no dedicated gastrointestinal ward in Crumlin. Teenagers are having commodes wheeled into wards.

"It's crazy having two toilets for eight children. A child with constipation could be in there for an hour — another could be knocking down the door."

It's difficult to verbalise the courage of the children, says Rachel.

"They just get on with it. Sometimes they have a really bad few days of chronic cramps, no appetite, no energy, diarrhoea or constipation and bounce back from it to play sports, dance and perform at school.

"They just want to be like everyone else. As parents, the best we can do is fight for their dignity and care in a health system that doesn't recognise their incurable disease." ■■

IBD SYMPTOMS

- Tummy pain – chronic, debilitating
- Diarrhoea – may contain blood or mucus
- Constipation – narrowing of intestinal wall
- Mouth ulcers
- Loss of appetite, weight loss and poor growth — affects body image, possibly leading to mental stress.
- Tiredness, lack of energy — can be mistaken for laziness

Distressing problem put to bed

MANY parents have a child who wets the bed. Research shows that bed-wetting occurs in more than half of Irish families, but children still feel distressed and humiliated when they do it. Also, parents worry the children miss out on many of the activities that are part and parcel of childhood.

According to a new study by the 'Search for a Dry Bed Campaign', 62% of participating parents say their child's bed-wetting prevents them from enjoying sleep-overs and summer camps.

Of those questioned, 14% say being away from home made the matter worse, yet only one in 10 parents seek medical advice.

Nine-year-old Emmet Doyle, from Waterford, has had problems with bed-wetting since he was a baby, and his parents, Alan and Cliona, tried every tactic to help him overcome the issue.

But it wasn't until six months ago that the issue was resolved. "We noticed the problem soon after we toilet-trained Emmet, as he just wasn't mastering the art of being dry through the night," says his mother, Cliona (who also has four other children, aged from one to 13).

"We had him in pull-ups at night, but he still seemed to be wet every single morning. It was very hard to deal with — there was a constant smell from the room and he was never able to have friends over.

"We cut out the late-night drinks,

Half of Irish families have children who wet themselves during sleep. Cliona Doyle was determined to find a cure her son, who is now happier and more confident, says **Arlene Harris**

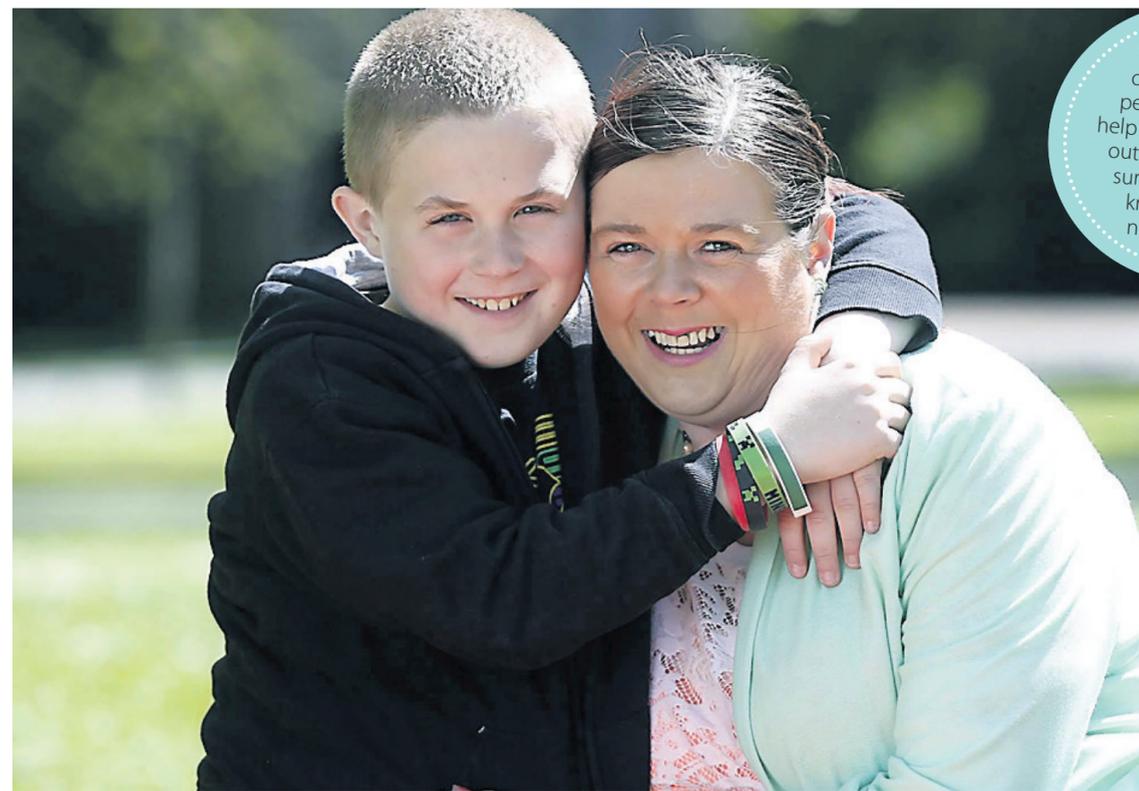
got him to go to the toilet before bed, put plastic coverings on his bed, lifted him onto the toilet during the night, and even took him to several healthcare professionals, including the public health nurse, a bed-wetting clinic and the GP, but nothing seemed to work."

Because Emmet had become used to wetting the bed, he began to view it as normal.

"He was very embarrassed about it when he was younger, but as he got older it seemed to have become a way of life for him," says Cliona.

"Last year, his local youth club was going away for the weekend and we assumed he wouldn't want to go, but he surprised us by saying he didn't want to miss out.

"So, we had a word with the



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Happy solution: Emmet Doyle with his mum, Cliona, took the medication route to deal with his bed-wetting.

group leaders and they said that there wouldn't be a problem — he would have all the privacy he needed to get ready for bed each night, and if he had any accidents they would gladly deal with it, as they had encountered the problem several times with other boys and girls."

But, at the end of last year, the Waterford boy finally had enough and asked his mother to help him to conquer the problem.

"On several occasions, we had taken him to the doctor, who had prescribed medicine, but Emmet refused to take it," says his mother.

"But, in December 2012, he asked me to take him back, as he said he had had enough and was ready to take whatever medicine the doctor

could give him to try and solve this problem. I think the real reason behind it was because he had asked for an X-Box for Christmas and he was terrified he would end up in his bedroom playing it alone and not be able to bring his friends in. So, we went to the doctor again and, within days of starting his medication, he was dry and still is.

"Today, he is a totally different child — confident, cheerful and happy — all the things he wasn't a year ago.

"I would advise other parents to persevere. Get the help and advice that is out there and make sure that the child knows that it is not their fault."

Dr Nick Van Der Spek, consultant paediatrician at Cavan General Hospital, says it's

BEDWETTING FACTS

- Under the age of five, bedwetting is considered normal.
- From the age of six and a half, it is considered a disorder or condition.
- 15% of five-year-olds and 10% of 10-year-olds wet the bed
- It affects boys and girls equally.
- Treatment depends on the cause or age — between the age of five and seven years, star charts can help, over-sevens are prescribed with alarms and both age groups can be supported with medication.

important to reassure children that they are not the only ones with this problem.

"Inform children that bed-

wetting is common and that there are probably other children in their class who wet the bed, but don't tell anyone," he says. "Ninety nine percent will become dry, but intervention from the GP or public health nurse will speed up the process."

Specialist help includes: alarms, medication and psychological assessments. Parents are advised to visit the GP for help, if the child is still bed-wetting after five, and after the age of seven.

"However, medical help should be sought at a younger age, if there are day-time problems, such as kidney infections, constipation and daytime urgency issues," Van Der Spek says. ■■

■ See: www.bedwetting.ie

Adrian Millar

DAD'S WORLD

WE go to Mass. Our communities are falling apart, the celebrant announces, and we need to do something about it, starting with gathering as a family around the kitchen table at meal-times and talking, like when he was young.

I return home full of good intentions. "Right! What are we going to talk about?" I announce as I put dinner on the table.

"Daddy, do you think the boy with the red hair who lives around the corner is nice?" my eight-year-old daughter says.

"Yes, he's a lovely boy," I say. "I know his mum."

"Well, he's not. Know what he



did? He shot poisoned berries at me with his sling."

"Okay, okay! No slagging other people off!"

"Does that include my sisters?" my 13-year-old daughter says with a wicked smile.

"Yes. You do enough of that the rest of the week." I say. "Anybody

“Great! Spell ‘knock’ for me. K.N.O.C.K. The ‘K’ is silent, daddy, unlike you”

got anything nice to say?"

Silence. Overwhelming silence, actually. There must be something to talk about, I think. My mind hastily peruses the week's events. The Dundrum Centre shopping trip? No, we can't mention that because my 13-year-old daughter will end up bawling again like she

Online and in the shops

■ **STEP ABED:** In response to customer demand for furniture that can adapt to the needs of a growing family, JellyBean in Douglas, Cork is now stocking the Flexa range. Made from Scandinavian pine, Flexa is designed so that you can convert a toddler's single bed into a mid sleeper with slide, high sleeper with storage/study desk underneath, or bunk beds. You can also add a pull-out bed for sleepovers. All beds and conversion kits come with a five-year guarantee and prices start from €264 for a basic bed. To reintroduce the brand to Cork, JellyBean is offering a 10% discount. Drop into their store at St Patrick's Mills, Douglas, or call 021 4898171; www.jellybeangroup.com.

■ **COMMON CENTS:** Ireland's national children's hospitals are asking you to do big things with your small change. Heaven Cent aims to raise €2m for Our Lady's Children's Hospital, Crumlin and Temple Street Children's Hospital, where more than 250,000 sick children are treated annually. The hospitals are asking people to shake out their bags, check their pockets and donate one, two, five and 10 cent coins at 1,000 drop-off points nationwide. See www.heavencent.ie.



■ **SENSITIVE SKIN:** Nappy rash is caused by a baby's delicate skin being in contact with irritating chemicals in urine and feces, aggravated by a nappy which rubs and stops air circulating. Bepanthen Nappy Care Ointment, €8.63, acts as a treatment for nappy rash and a preventative barrier for the protection of baby's skin. It contains no perfume, preservatives or antiseptic, so it can be used for the most sensitive skin, including premature babies. See www.bepanthen.ie.

■ **GREAT OUTDOORS:** With the holidays just around the corner, garden toys and games that can be used and reused for many occasions offer the quality and value for money that parents want. The budget-smart range at Mimitoys includes swings, sandpits, giant games and sports day sets. Some special offers this month are Junior Space Hoppers, €6.95; Tee Pee Play Tent, €19.95 and Jumbo Flying Disc, €7.75. Call 1890 520 025, or see www.mimitoys.ie.



Weekend tomorrow

Prince Charming: We interview Jon Bon Jovi as he gets ready to rock Slane Castle.

