

Our hidden heartache

Gogglebox stars Steph and Dom Parker have a son with severe epilepsy – but now cannabis oil has given them hope

AS FANS OF *Gogglebox* know, Dom and Steph Parker are more than familiar with the premise of inviting television cameras into their home. Over the years, viewers have seen no shortage of intimate footage of the husband-and-wife duo, a charismatic pair whose larger-than-life personalities give the clear impression that, in Steph's words, they "live a very privileged life without a care in the world".

Their latest TV venture shows that assumption to be far from the truth: this time, the cameras reveal a different slice of family life.

The focus is on the couple's 18-year-old son, Max, who from infancy has had a severe form of epilepsy that can see him experiencing up to 130 seizures a day. The effect on his developing brain has left him with a mental age of five, and alongside the daily distress the couple endure in witnessing their son's regular fits, they must cope with the knowledge that these seizures bring with them a much higher risk of sudden death, particularly as he gets older.

To date, Max's condition is managed by a cocktail of powerful drugs – but those drugs come with equally powerful side effects. The couple's discomfort with what Dom calls these "mind-altering, powerful chemicals" has led them to contemplate giving their son cannabidiol (CBD) oil, a non-intoxicating marijuana extract credited with helping treat a host of medical problems from seizures to anxiety.

Last year, the Government announced that specialist doctors in the UK will legally be able to prescribe cannabis-derived medicinal products, and the documentary follows Steph and Dom as they explore whether medical marijuana will help alleviate their son's symptoms and give him a better quality of life.

The decision to open this journey to the documentary cameras wasn't easy, however. "It was a tough call," says Dom now. "We've spent

many years trying to keep our private lives private for our kids, but the timing felt right. We felt that, hopefully, we could move this whole debate a little further, and based on that it would probably be wrong not to do it. But in some ways scratching old wounds was really quite harsh – we were reliving all the horrid, nasty bits of the last 18 years."

It's clear that it's not easy for either of them, particularly Steph, whose emotions sit close to the surface and who is frequently close to tears as she talks of the couple's battle to give their son the best quality of life they can. "We've had great sadness for a very long time, and great pain, and we carry that pain daily," she says. "We just hide it very well and hide it through laughter." Yet both firmly believe that exposing that pain is worth it to show the reality of what it's like living with severe epilepsy.

Says Dom: "When it comes to Max's quality of life, on the one hand it's fabulous because he's very loved, but on the other hand it's s*** and we don't shy away from showing that."

THE LIFE CAPTURED by the documentary is indeed sobering: the electrical activity in Max's head is so ferocious that he gets only around six or seven minutes an hour of respite. "He's pretty much seizing nonstop," says Dom. "It doesn't get much worse than this."

Now married for 20 years, the couple were relative newlyweds when Max came along and until he was four months old they had little reason to suspect anything was amiss with their first-born child.

Then, one evening, Dom noticed a funny movement as he changed his four-month-old son's nappy. "I thought, 'That's a bit odd,' then I saw the same thing again as I was undressing him the following evening," he recalls.

Concerned, he and Steph took Max to the doctor, who, after a series of tests, confirmed >

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STEPH PARKER

THE PARKERS
Steph, Max
and Dom

◁ that he was suffering from infantile spasms. Over time, these progressed into frequent and violent seizures that had a catastrophic effect on Max's growing brain: as well as the distress of observing the fits, the couple also had to confront the reality that his development would be severely stunted.

"You go through a period of mourning," Dom reflects. "That was probably the hardest time - you know you've lost the child that all your hopes and dreams were invested in, the son you were going to play football with, have that first pint with. All that goes straight out of the window." His wife puts it more bluntly when she says, "It feels like the death of the future of your child."

OVER THE YEARS the couple and their 15-year-old daughter, Honor, have become accustomed to the vast emotional ups and downs that Max's condition brings with it.

"It can change plans, end plans, ruin plans. It can change everything in a heartbeat," says Dom. Running parallel to that, meanwhile, has been the frustrating, on-going quest to find the best drugs to manage their son's condition: at the moment Max, who attends a special boarding school in term time, takes four different drugs. Yet none has completely managed to control his violent seizures.

"Every time you try a new drug, there's always a bit of hope that comes with it," says Dom. "We've been going through trying new drugs,

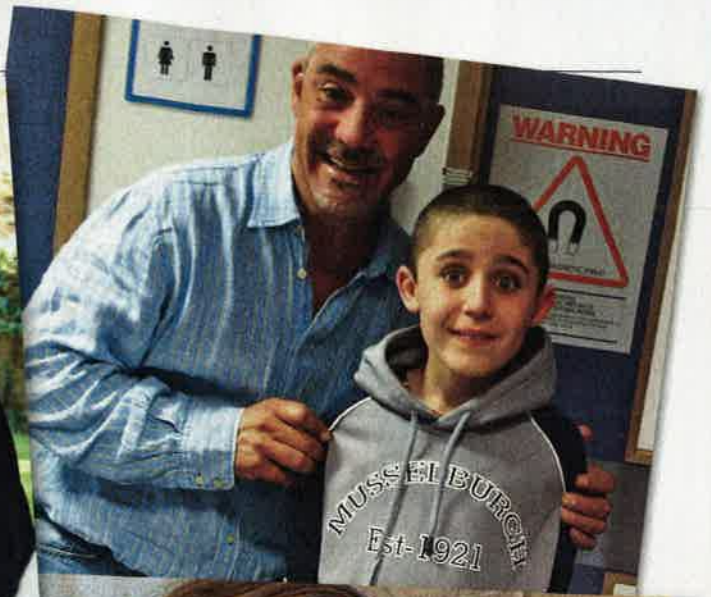
'You've lost the child that all your dreams were invested in'

DOM PARKER

dumping them, trying them again. Each time you hope that this is the one that will make a real difference."

It's a quest that has taken on heightened urgency, for the risk of sudden death from epilepsy increases as Max approaches adulthood. "It means they have a big seizure and they never wake up," Dom explains. "We don't dwell on it, otherwise I'd end up blowing my head off or crying my eyes out. We've had to sort of mentally box it off. Our focus is on improving his quality of life."

And, after speaking to others in their position, they've encountered plenty of evidence that this is possible. One of the most moving parts of the documentary comes when the couple talk via Skype to Charlotte Caldwell, mother of 12-year-old Billy Caldwell, who was given the first ever NHS prescription for medical marijuana to help control his epilepsy. She tells the Parkers that while it's far from a cure, it helps to manage his



OUR LAD
Max as a boy, with dad Dom (above right) and with sister Honor (right)

condition. But it's not just her message but her interaction with Billy, who comes to hug his mother while she's chatting, that moves Steph to tears. "We've never had that from Max," she says.

Their meetings with other parents in their position and with medical specialists left them convinced that pharmaceutical-grade cannabis oil could help manage Max's condition. Yet despite new legislation allowing specialists to prescribe to suitable candidates, actually obtaining properly licensed CBD oil has proved impossible so far.

"Along with everyone else we assumed we could run along to the GP, say, 'Can we please have medical cannabis for our son?' and it would be a case of 'Here's your prescription. Nip along to the chemist and there you go,'" says Dom.

"But of course there have to be protocols - who can prescribe it and supply it, who is going to monitor it, who's going to pay for it - and setting up those protocols could take months, possibly years. It has to be done properly. It has to be prescribed with the supervision of a specialist in epilepsy and it has to be a proper, regulated pharmaceutical-grade product. So it's going to take time."

NONETHELESS, HE ADMITS the delay is frustrating. "Max has just gone back to school and we know we could get a call any day to say he died in the night," says Dom. "So knowing there is something out there that could improve his chances... it's hard. You have four pretty grim chemical drugs and you think a little pot of herb can't be worse than that horror show. So if one or two drops of oil could take these things out of his body - well then, that would make me the happiest man alive."

ISOBEL JAMES

MEDICAL CANNABIS

In November, the Home Office changed the rules on cannabis-based medicines, allowing their use to treat some medical conditions.

- The exemptions include the treatment of children and adults like Max with severe forms of epilepsy, and adults with vomiting and nausea caused by chemotherapy.

- It was stressed that the prescriptions will only be issued by specialist hospital doctors (ie not GPs) and only when all other treatment options have failed. The NHS went on to say the changes would benefit only a "very small number of patients".

- In terms of epilepsy, one of the drugs available is Epidiolex. It has passed drug trials, and is in use, in America and is expected to be licensed in the UK very soon. However, hospital doctors have been told it can be prescribed while that official clearance is pending.

- Epidiolex, which has been developed by the British company GW Pharmaceuticals, uses a chemical substance known as CBD (cannabidiol) that is found in cannabis.

- The NHS says that online products professing to contain CBD oil risk being unsafe to use and would also be illegal to possess or supply.

