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Presented by Emma Tracey

What Happens To My Disabled Son When I Die?

EMMA

Hello, welcome to Inside Ouch. I'm Emma Tracey. This is a podcast from the BBC Ouch disability team. We do this three Fridays in every month. The other Friday we do a longer talk show with Simon and Kate. All four podcasts are packed full of disabled people talking about what's important to them. And sometimes we talk to people who aren't disabled too, as long as they're interesting enough and have a great story to tell.

When I die what will happen to my disabled son or daughter? That's a question that weighs heavily on the minds of parents who either care for their disabled offspring full time or who manage their care. It's something that we hear about a lot: will my child end up in an institution if there's nobody to look after them at home or if they can't be cared for properly at home? What will that new living situation be like? And who could possibly fight for their rights like I do every single day?

Mark Neary is one of those parents, and it's something he actually has nightmares about. Steven lives in his own home with a care package which Mark manages, he has also spent some time in residential care too. Mark Neary is with us. Hi Mark, how are you?

MARK

Hiya. I'm fine thank you.

EMMA Good. Mark blogged about that recently. The post is so powerful, your blog post; would you mind just reading the whole thing for us?

MARK Yes sure, okay. The post was called I Need a Whoopi:

I had my recurring dream again last night. I tend to have the dream, or a variation thereof, after I've had some great quality time with Steven. I guess the dream is inspired by the film, Ghost. Unfortunately, in the dream there is no Whoopi Goldberg to connect me to the person I love.

It is six months after my death. Needless to say, the council have moved Steven from his home to an assessment and treatment unit. He is heavily drugged and having difficulty walking but his spirit is hanging in there. My sister and partner Wayne visit and Steven rips Wayne's shirt as he pleads with him to stay.

Alan, the support worker, visits and as it's a Wednesday, Steven wants a Wednesday morning disco, like they have done every Wednesday for the past four years. Unfortunately music isn't allowed in the communal lounge.

Steven's collection of 24 photo albums are in a skip outside the back door. I walk past a charity shop and all Steven's DVDs are in the shop window.

That's the end of the dream. I have this dream at least once a fortnight

EMMA Mark, as a parent and a disabled person that actually breaks my heart. It's so sad and so powerful. I know a bit more about Steven because I've read a lot of your blog. Can you

put in context some of the things in the dream about the CDs and DVDs how important they are for Steven? Tell us a bit about him.

MARK

Oh god they're massively important. Steven's 27 now, he's got autism and learning disabilities. He moved into his own home last October and he's really thrived in there. He's very much king of his own castle in the flat. He has two support workers with him at all times, or one supporter, that's a support worker and me. And his day is very, very structured. Routine is crucial for Steven. Steven will have the same thing for breakfast every day: fruit salad of bananas, satsumas and grapes. Everything stops for Countdown at three o'clock every afternoon. And Steven goes out in the mornings, he either goes to water aerobics, there's an art centre where he does some music, two days a week he goes to our local Mencap pool for a swim.

EMMA

So, what happens if Steven doesn't get to do the things that he usually does?

MARK

I can give you a really good example from this week actually. My sister told me about an exhibition at our local motor museum, and Steven's a massive Mr Bean fan and they had Mr Bean's car as one of the exhibits in the museum. So, on Tuesday morning I said to Steven, "Do you fancy going to see Mr Bean's car?" "Yes, yeah, I want to see Mr Bean's car". So, I said to him, "Well, you can go with Alan and Michael on Thursday morning" and immediately he got agitated by that because normally on a Thursday morning he would be going swimming with Alan and Michael. So, even though it was something that he was really excited about and we knew he'd have a good time at, because it broke the routine that led to an increase in Steven's anxiety.

EMMA So, did he get to do it in the end?

MARK Yes, he did. I think he needs a lot of processing time. The support worker phoned me up at work on Wednesday afternoon, this is over 24 hours later, and the support worker was laughing and he said, "Steven's just done a complete U-turn" and he'd said to Alan, the support worker, "What are we doing tomorrow, Alan?" and Alan had said, "What do you want to do tomorrow, Steven?" and Steven said, "I want to go to see Mr Bean's car". So, as a general rule we kind of know that if there's going to be a change to the routine then it's good to give Steven not too much notice, but at least two or three days' notice that there's going to be a change.

When we're going on holiday for example if we tell Steven too much in advance of that then we know we're going to have weeks of kind of real high-level anxiety of, "Don't forget to pack the bags dad. Don't forget to put the Fawlty Towers DVD in the suitcase" and that's several times a day for days beforehand.

EMMA So, the Fawlty Towers DVD, the Mr Bean DVDs, going back to his house and his space, they're particularly important. What else is important? Does he keep everything exactly in the same place or is being in the same room very important to him? Tell me about Steven and his house.

MARK Yeah, if a stranger was to walk in the living room they wouldn't know that I live there; it's very much Steven's space. It's quite minimalist as well because I think Steven gets sensory overload really if there are a lot of things going on. He's got his sofa; we've got a giant Mr Bean cardboard cut-out that sort of stands over Steven while he's lying on the sofa; and then two or three units full of Steven's DVDs and his CDs, which are all in alphabetical order. Steven can't read or write but he kind of knows where things are. So, if he wants his, I don't know, Abba CD on he knows that's going

to be at the front of the CD cabinet.

EMMA His current situation is incredibly different to the situation that you mentioned in your dream that you have, in this recurring nightmare.

MARK Yes.

EMMA Is the dream, like a lot of nightmares, completely overblown and it couldn't really happen or are you actually genuinely worried that this or a version of this is what will happen to Steven?

MARK Of course like all dreams, anxiety dreams anyway, there's an element of paranoid in there; I'm quite prepared to accept that. But Steven has actually spent time in an assessment and treatment unit so I know the reality of what that's like.

EMMA It was well-documented at the time, back in 2010. Briefly can you remind us all what happened and what happened in the end?

MARK It was the day before New Year's Eve 2009 and I'd been struggling with the flu for a couple of days, and I did what Steven's social worker had always encouraged really, I phoned up the manager of the respite unit and said, "Do you have a bed for Steven for a couple of days?" which they did. It was a Wednesday, so when he left home on that Wednesday afternoon the plan was that I would pick him up on the Saturday morning. The day after he moved his social worker came to see me and said they'd reported they'd had a difficult night with Steven at the respite place, and they wanted to move him to an assessment and treatment unit, a local one. I can remember her words to this day, "Just for a couple of weeks, Mark, to give you a chance to get back on

your feet”.

EMMA How did you feel about that at the time?

MARK Well, at the time it sounded quite reasonable to me actually.

EMMA But you wouldn't have been surprised that he'd had a bad night, due to what we've just talked about?

MARK Exactly. One of the things I do regret was the suddenness of the move. It probably would have been better if I'd struggled on for a couple of days and then Steven would have gone.

EMMA What happened next?

MARK Well, it didn't occur to me at all that that two weeks was then going to extend into a month, six months and then a whole year. Immediately we kind of got locked into this position, from day one really, which lasted all the way through to the court case, which was that Steven reacted badly to the move. Because of the nature of the place Steven was in, it was an assessment and treatment unit, so they were logging every single thing that happened. And within the first week they recorded I think it was 29 incidents of Steven lashing out at staff and the other residents.

EMMA And is that something he'd done before at home? Is it something that you knew he was capable of doing before that, or was that something that specifically happened when he went into that setting?

MARK Well, nowhere near that level. We'd be hard pushed to get 29 incidents of Steven lashing out over the course of a year, not a week. So, for me it was so upsetting when they told me those figures because for me that was a sign of the real deep distress that Steven was in. But the local authority took the position – and this is what I mean about how their position started from day one and continued for the whole year – was that, 'well if Steven's behaviour is like this here then his behaviour must be like this everywhere, and therefore his behaviour is too challenging to be out in the community'.

EMMA Sure.

MARK My position obviously was, 'well no, his behaviour is like this because he's here. Let him come home and it will completely change'.

EMMA Did you get to visit him when he was there?

MARK Yes, they had a policy that the person wasn't allowed any contact with their friends or family for the first two weeks, so that was really, really difficult. But then I was allowed to go and visit Steven once or twice a week, which was always really awkward to be in that communal space.

One thing Steven and I have always done at the weekends for years, it goes back to when he was about 11, is to do a compilation tape, an old C90 tape of favourite songs, so I would still religiously do this tape, take it along to him with his ghetto blaster, and we'd sit there in the communal dining room trying to listen to the tape. But there were staff coming in and out, other residents in the unit coming in and out, and it kind of played in to that agenda of Steven's behaviour being so challenging because invariably at some point during the course of the 90 minutes something would happen and Steven would kick off, and that was always logged as a

problem.

EMMA And then there was a human rights court case which is interesting that helped him to come home. Quickly give us the details of that.

MARK My sister encouraged me to set up the campaign group on Facebook, the Get Steven Home group, and through that group somebody contacted me who does a lot of work on the Mental Capacity Act and human rights. We found a solicitor and within three weeks we got a court date. So, the whole court case was based really on two things: one that Steven's human rights were being breached by A, being in the unit, and B, being kept away from his home. And secondly, the piece of legislation they were using to keep Steven there was the Deprivation of Liberty Safeguards, and the lawyer's position was that these safeguards were also being used unlawfully. So, it was a double challenge really when we got to court.

EMMA And you won.

MARK And we won, yes.

EMMA And he got home.

MARK Yes.

EMMA So, do you think it could actually happen again?

MARK Yes I do because I think it's so difficult for someone with Steven's level of learning disability to be able to live in their own home without some person taking charge of the

incredible bureaucratic admin that goes hand in hand with having a home support package.

EMMA What's the best case scenario you could imagine for Steven if you weren't there?

MARK Well, actually over the last few months I've started to do – it sounds a bit morbid – but I have actually started to prepare my death plan. I've probably done too much actually because I've got this huge folder of things from how to do the support workers' wages to a list of the sorts of songs to go on Steven's compilation tape on a Saturday afternoon. I've sort of tried to cover all bases when really that's quite impossible.

EMMA So, it's something that is really on your mind clearly. What sparked you to do a death plan? Is it something that other parents do and you've spoken to about?

MARK Yeah, I've heard other people talk about it. I suppose the move last year...

EMMA When he moved into his own home.

MARK Yeah, because he took to it immediately. It's in a perfect location for Steven; it's just across the road from his uncle, who is Steven's favourite person in the whole world. There's a little parade of shops next to Wayne's House. So, the thought of Steven being moved from there is just so awful.

EMMA Who, Mark, will actually take that folder and carry out the death plan if, when you're gone?

MARK

One thing I've found really, really difficult is kind of actually asking people, because I know what a massive responsibility it will be. But basically in my head – this is the first time I've mentioned this publicly really – is I've kind of got in my mind's eye a team of three people: one person really to manage the day to day stuff like the online shop in Tesco's; somebody to manage the support team, which will include the payment of the wages and that sort of stuff; and then a third person to do the more doing the annual court reports, going to meetings when there need to be meetings.

I've spoken to my sister about it, in fact it was her who brought it up, so I expect she'll take one of the roles. But I find it really difficult actually to ask one person, "Will you take on the whole of this responsibility?" because I think it's too much to ask anybody really.

It's taken me a long time to do because it's such a depressing sad job to do really. I sit there in front of the computer screen for about an hour, and then I'm either in tears or my heart sinks with the nature of the task, so I then put it aside for a fortnight, then go back to it.

EMMA

Is there support? Is there a kind of system like a Facebook group?

MARK

Oh yeah, and there's this huge online community that is just fantastic. I belong to a couple of carers' groups, I belong to a couple of campaign groups, to the kinds of themes that I talked about in that blog post they resonate a lot with other members of these groups.

EMMA

For someone who's listening how do people get that sort of support online, the unofficial support I guess?

MARK It's a tricky one, but I suppose the onus is on people to find that community rather than the community find them.

EMMA What search terms? What do they do?

MARK There are a number of Facebook groups. There's the Get Steven Home group that I started back in 2010, that's still going. There are a couple of great carer's groups, the Carers' Solidarity Forum, that's a brilliant one. And in the last year I've been involved in a campaign called The Seven Days of Action Campaign, and that's about getting people out of assessment and treatment units and stopping people going in in the first place. The actual aim of the campaign is about people in in-patient services, whether that's a hospital or an assessment and treatment unit or a forensic unit, that doesn't really matter; they're away from their normal home. But it's also for people who are in the situation that they're worried that their sons or daughters might end up in a place like that. Because sometimes family situations are so fragile, like my situation, going down with flu that resulted in Steven being away for a year.

I know another chap who's part of the campaign group whose son has been away now for nearly two and a half years, and he arranged respite because he wanted to redecorate the son's bedroom, so he arranged a weekend respite for that and two and a half years later his son's still away. People don't always end up in these units because of some major crisis, but a crisis quickly develops when they're there.

EMMA I don't think the general public realises that this is happening, that people are away in hospital for quite such a long time and that there are families who want them home and are really struggling to get them home.

MARK I don't think actually that families with a person with learning disabilities are aware of this as well until it actually happens to you. So many stories that we heard through the campaign it seems to happen a lot when people are in their mid to late-teens.

Just relating it to our situation: I can remember Steven's social worker changing one day and someone turned up and announced they were the transition manager – transition being from children's services to adult's services. And I think that's such a dodgy time during someone's life; everything is changing.

EMMA Everything is changing for them, everything is changing for the person involved.

MARK Yes.

EMMA But there's probably trouble joining stuff up as well, new services.

MARK Yes. And in our area for example as a child you come under paediatric services, well that stops at 16, but adult services don't kick in until 18, so there's a two-year gap when there's nobody involved really apart from this transition manager. So, I think for most families, certainly the case for me and certainly the case for lots of people I speak to, there you are, you're plodding along, the person's at school, you're going through children's services, that may be running smoothly, that may not be running smoothly, but then all of a sudden you kind of hit this transition time and a lot of people fall off the cliff.

EMMA Of course we don't have anyone from social services to talk about that side of things, but what they would say probably is that they are doing their very best to look after the needs of the individual and the needs of the community as well.

MARK Yes, I take your point that the local authority will say they're doing the best for the person, but there's a lot of evidence now that says that taking somebody away from their home is probably the worst thing you could do.

EMMA And Jane McGovern reported for BBC Breakfast about the Seven Days of Action Campaign, and actually I saw a piece today about a lady whose son was being assessed for a unit.

MARK Yes, that was brilliant, that was great.

EMMA And who actually, on seeing the reports, was able to turn that around.

MARK Yes.

EMMA The government told Jane, "NHS England says that hospitals should not be seen as homes. High quality community services are essential and being created. The Department for Health says that £25 million are being spent on this to improve outcomes". That's the statement the government has given, and they're not here to further talk about this so we'll have to leave that there.

Mark Neary thank you ever so much for joining us.

MARK My pleasure.

EMMA It's something that we find tricky to do without the disabled person, and I'm sure you find tricky to do without Steven as well.

MARK Sure.

EMMA You have been listening to Inside Ouch. I'm Emma Tracey. You can find more of our stuff at bbc.co.uk/disability, email us ouch@bbc.co.uk, you can tweet us @bbcouch or find us on Facebook. Goodbye.

