

One & Other Project

My name is Verusca Calabria and today's the 26th July 2010 and I'm calling Gavin Cross using Skype on behalf of the Wellcome Trust for a follow up interview with regards to your time on the plinth, Gavin.

Good morning, very much looking forward to it actually. It's nice to that One & Other keeps popping back into my life. I really like it.

How come then, how has it been coming back?

I suppose in the big sense that it had quite an impact on me that was around for a long time. People still talk about it, people mention it still. Friends of mine mention it every now and again will say, "Oh, I never did tell you that I watched it." That happened very recently, that was really nice. People I only vaguely met a couple of times have watched it, they'd been steered towards it by other people, so that's been, it's been quite an event really.

So just to bring you back at the time. I listened to your pre-plinth interview only recently so I can remind you that some of the things you said and that you had plinth, 'plinth anxiety' you said].

Did I? I was trying to, I've been trying to ... obviously since being alerted that I was talking to you about this, I've been running over the whole experience and I ... because I think of the whole adrenaline of it even though it was very calm and they forget to talk about the process, that's what I reflected even though it was very calm and even though [?] I don't remember saying ... but it's a great line so I'll have it. I couldn't remember much of the interview, I could remember aspects. I can remember how it felt and I can remember that it had quite an impact on me but I couldn't remember anything I said and so I'm thinking, "Oh god, I hope I wasn't too..." because I've got a problem of just being ... just talking too much so you really will have to remind me.

That's absolutely fine, that's what I'm here for. Okay, so you went on the plinth to remember your son Tom who died when he was six from this illness from SMARD 1 and you were talking to us really about what you were planning to do on the plinth and then I watched almost all of the video yesterday evening and I just wonder what was it really like for you to be up there.

It was magical. It really was, both at the time ... and afterwards, it was ... but I have a background in performance and theatre but I didn't approach this at as that. It was a very public personal hour for me but when I applied I didn't intend to do that but yes, it went too quick. I did get to do everything that ... I wanted to do to a degree, I think. And I really very much enjoyed the spectacle of it from ... afterwards it was really exciting having friends there, friends who came and watched. It was very tense for a moment having people

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just calling up. Obviously I was the spectacle for them even though I was hoping it be quite a private thing as well but I came off on quite a high really ... that high you get when you're coming off the stage but I think it stayed with me for weeks honestly because it was just such a random and wonderful thing to do. It was so different, it was a real experience and when I tell people I've done it, you know, I don't tell people [?] all the time but if it does come up in conversation, and people have heard of it, they're really very interested and it brings it all back as well. Very strange thing to do I mean I [?] I'm a Londoner anyway and that was a special part of it but also the fact I so firmly wanted to put Tom on that plinth and then I did it ... that was what? Just I was flying ... my feet weren't touching the ground really when I came off.

And do you remember what happened once you came off the plinth, immediately after, whether you may have engaged in conversation with people in the square or with the staff?

Yes, I do because, as I say, we had friends there and we ... I assume we'll get to talk about the whole interaction with the One & Other team because I'd like to because it was really very, very positive but I immediately afterwards, after getting sorted with friends at, what was it? About a quarter past four in the morning in the square. We just opened a bottle of Champagne and sat watching the next plinther, chatting about it, drinking a glass of Champagne and saluting Tom because he, you know, obviously Kathy my wife, his mum, was there and his granddad was there and his uncle was there and friends were there and it was just ... it was just lovely and then picking up my phone and getting messages through from friends who'd watched it. So it felt ... it was really nice and there's something magical about being in a city like that at that odd time of the day, sober, just taking that it was because you can't help but be a part of the event when you're in the square and that was the reason why I came back down for the final twelve hours of it really because I really wanted to enjoy just taking in somebody else on the plinth. But because I had friends and family with me I needed to meet their needs as well so that was ... that was really pleasant and initially we sat there thinking, "Well let's stay here and watch the sun rise" but then we all got very tired and had our homes to go to which is what we did.

Okay, let's just unpack some of the things you mentioned to me this morning. You talked about not remembering what you said in the oral history interview before you went on the plinth but you said that you remember how it felt, so I'd like to know more about that.

Yes, it was [?] the whole event going into that Porta cabin which was ... it was very funny because when we arrived the chap who was on the plinth just before me was a guy who been picked up and sorted that evening, I think there'd been a cancellation so he was in there with a friend extraordinary

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height and very excited about what he was going to do and that was lovely. It was really lovely, he was ... because he didn't really have an idea of what he was doing, I'm sure and his friend ... and so the banter between them ... now the balance that was being struck in the Porta cabin staff was that they were very aware that I was there to do something specific and quite different and also very personal so they were concerned for me that the atmosphere in the Porta cabin was so light but I really liked that because, you know, my ... what I'd seen of the plinth it was it was such a personal thing that this young fellow's excitement was really positive so it was, as I say, I think that the One & Other staff were being extraordinarily empathetic about me but I was actually quite [?] reasonably calm about it and enjoying this energy that this fellow had so then when we went in and I'd never been involved in anything as formal as that before and also I suppose in the run up to going on the plinth I'd never really formally sat down and put into personal position, appreciated the magnitude of it so then to go in and have this really focusing conversation certainly it was like, "Okay, this is something very different."

I remember talking about why I signed up for it cause that I signed up for it out of interest in both Antony Gormley's work but also Artichoke and I didn't really know what I was going to be doing but I remember having a conversation about Tom but I don't remember what it was but I do remember that I got a bit emotional about it and I don't want to presume but I think the interviewer got a bit emotional about it in a positive way and it seemed to go on and then Kathy told me that the conversation had gone on quite a long time and they were outside waiting for me to get on a cherry-picker but it did centre me in a strange way because I had a rough plan about what I was going to do. I had this box with me and in it was a load of pictures and each picture was going to be a stimulus to what I was going to say but I didn't know really what I was going to say so that helped centre me because I suppose I had that practise really of pulling my thoughts together. It was positive but then you have that maybe it's just me that the ego side kicks in and I think, "Ah, did I just sound like an idiot? Was I performing?" which I didn't want to do and I wasn't there to perform was I? And the one thing I also didn't want to do was exploit any of the emotions of that for me. I wanted to keep it, you know, that that's the personal side, Tom lived a relatively public life but our emotions about it was always a personal part of it so, as I say, I think the adrenaline was kicking in and that's ... I had very little memory of what we actually talked about.

Well, you are welcome to your transcription of your pre-plinth interview which I can send you if you like?

I would be interested, yes; I'd be really interested in that. That would be really valuable.

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And of course you can have the transcript of this interview once it's done as well. Okay Tom, so just again to remind you, you told us quite a bit about your life but, of course, because like you mentioned you didn't have that much time for this interview so I'm here really to explore some of the things that emerged.

Sure.

So you mentioned, of course, that you're interested in Antony Gormley's work and you talked about the project as a snap-shot of life in Britain today.

Yes.

Do you think it really was and, if so, why and how?

Yes I think so. I think like anything it was such an unknown quantity, wasn't it? I was I think fortunate enough to watch it right from the start because I'd had this interest. I was able to follow it and I watched the first few hours and I enjoyed that and I enjoyed how homespun and simple the first few were but then suddenly people became aware of how visible it was and I hadn't appreciated the twenty-four hour feed and what that was going to achieve and so then of course we watched because we had this interest. We watched all of the Sky Arts programmes about it as well. It became you know became a big part of that of our summer I mean I work from home a lot, I've two screens running here and I've had my work screen here and then on the other screen I'd had the plinth running just to see what was going on. And I'd watch a bit. I loved everybody's, you know, I didn't watch everybody but I loved how personal some people made it, I loved how much effort some people put in, I loved how much non-effort people put in and made, I mean there was a really good few hours where people were very still and very much themselves and I really loved that as well. I thought that those were equally as powerful as those who'd invested in preparation and time. I found that it was really interesting comparing those who were very much about the performance as opposed to those who were very much about the personal event. I loved the fact that people used it as a platform, I thought it was very eccentric, I don't know, maybe I'm being naïve but it seemed a very British thing to stand up and overwhelmingly shout about causes ... I loved all of the fact that people were so passionate about things that they wanted/issues, they're like, "Yes, this is a an outlet, I'll go for that." Equally I found some of the hours so funny, even just the simplest ideas ... just there's such a huge amount of creativity involved ... yes, it was it ... I hope it did ... I think the snap-shot idea I'm assuming you probably ... from a historical ... you'd probably get more from the interviews. I think it's probably a snap-shot of Britain in the sense that we are quite media aware, we do have these perceived outlets where we can go

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up and be recognised for being talented, for whatever reason, and that's not a criticism but it's very much at the moment, you know.

So maybe actually a lot of the hours were more of the cultural zeitgeist than any form of, "This is 2009 Britain as a representation." Because you have to be a particular type of person anyway just to choose to be part of it, it wasn't a 'dick' test was it? You didn't know they weren't taking random [?] people you had to choose, I was really disappointed when the third round was published and I didn't get in which tells you that I had invested and was looking forward to it. I got in because obviously somebody had said I'm not going up at three in the morning and I said, "Yes" to it. So it's a snap-shot of a particular type of person isn't it? I like to think it was very, I like to think that the eccentric side of it all ... because it was very eccentric and the idea was very eccentric let alone the people ... very much represents, you know, the type of people we are because people are very funny and people are very warm, and people are very passionate and we very rarely see those outlets in people. We only see them interact with each other in very facile ways at work even with our friends sometimes and so that's what I thought was lovely about it.

You mentioned the importance of interactivity and going back to the profile of the One & Other website project, you also said to people that were following you ... invited them to interact with you either via the Facebook group or on MSN or on your Hotmail account and Twitter.

Yes.

Now it became quite apparent after a bit at the beginning of the project that people were using their own self set-up groups on Twitter and Facebook to follow the project and communicate and interact with the plinthers and I noticed that here because one of the people that says that he's a self-professed Tweckerler he was following the One & Other project and apparently he said that he wanted to influence people or at least tell them what he thought about their performances he made two comments on your profile it's called 'BrainCoffee.'

Yes, yes ... I know, I know, that was a really interesting aspect of it. I found that I did find that interesting and again it appealed because you want to have a feedback don't you? You know, if you're [?]. I think that I'm not an artist I'm a performer and as a performer I like people to tell me what they think. One of the things also is even ... though I suppose I had an issue. I wasn't there to have an issue based ... but I know that because I talk about Tom in my professional life as well now and again. Not so often, I know that people want to interact I know that people want to ask questions, but also because I was casting the net out, you know, I thought, "I would be interested in what people have got to say." So I suppose I grasped the mettle on that a little bit. I found

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that ... I mean I'm not a big Twitter user. I do use it; I like the aspect of Twitter that is having it running as a running commentary to things that are happening that's what I really like about Twitter. I like having ... if I'm part of an event, if I'm part of a festival or if I'm part of something I like to see what other people think about it. I really enjoyed ... I mean I thought Twitter was a fantastic way to follow the election and it was a fantastic way to follow One & Other and I found the ... I don't feel I was part of that community so much and because I didn't really have the time to be honest as well and I found it really interesting that people, there were this strata of people involved, there were those who were just watching the telly, there were those who would watch it on online now and again, there was those really involved via the Twitter route and it was quite a small group of people who were constantly involved and then you could see other plinthers coming in just wanting that feedback, "What do you think?" "How did it go?" It was really a layer to it all and a really interesting capture, I'm sure, and if you've captured the Twitter feed around One & Other I think it that that would be as much part of it as anything else.

I enjoyed the people, you know, I want to talk about Tom and I'm really pleased that people responded because I want Tom to be talked about or thought about. I suppose. So when people come back and say, "You know that was ..." I had some very extraordinarily positive contacts from people. I also, out of interest, did go back and look at the Twitter feed for the hour that I was on and I found that really interesting as well because there was certain, there's an aspect and I ... but I believe that this is the right, absolutely ... but it was certain aspects sometimes of the Twitter community became a bit of a chattering classes sitting knitting, watching sometimes, that guillotine come down and or, you know, it very much ... I know a number of the Twitterers also took part as well but sometimes there's that "Oh, come on a minute don't say that about that person out there because what they're doing is theirs it's not yours." So there was, you would often if I had the Twitter feed running as well as the video, you know, people would be waiting for something to happen. Well it was the plinthers right to do nothing as well, absolutely equal right to ... I thought sometimes it's like "Oh, that was all right." Thankfully only a small amount of people are reading this and I hope the plinther doesn't read it so I was following my feed afterwards and I thought, "Oh no, and the people were very positive and part of me was relieved." Because and then obviously that's silly because I didn't do it for them, but they were this small vocal community, but people were very, very pleasant. I really liked how passionate people got about One & Other and even if that was quite a small amount I really liked how the ... so if you [?] I'm assuming you watched the Sky Arts programmes, yes?

Yes I have.

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And that created quite a bit of a furore, you know, because it was a ... really it was a critical position about it all which I think was really interesting as well. It took a very media savvy slant to it so it picked a lot of the very, you know, this obsession with showing images, "Oh isn't it cheeky when people take their clothes off and let's show that again and again and again." And that was very much the media angle that was taken which I thought was interesting as well and again that's as much a snap-shot of British culture as anything else, that for a lot of people One & Other was the art piece where people took their clothes off, which it wasn't, it was such a small part of it. So all of those layers were very interesting, with Twitter and television and what the papers were saying and the ... being so involved with it. We read every article we found, it was a big part of our summer here, as I said I really ... I'm glad people enjoyed it because, as I say, I'm a fan of Gormley, big fan of Gormley. I very rarely go up to the northeast but when last week I was there and this week I'm there but when you go past the Angel of the North it's something really special we've got his Another Place statues on the beach and that's always a place we take people, that's where I went for my birthday recently, you know. There were thirty of us, twelve children and eighteen adults on the beach next to Gormley's statues, making sandcastles and having a picnic on a grey day you know, it's a, you know, and so I'm glad that One & Other was also another art piece that Gormley created that people just interacted with.

Thank you for that Gavin, just to bring you back to the interactivity element, when you were up there for your hour were you also doing Twittering during the time?

No, I had an idea that I would have a look but I didn't at the time. I think I got lost in the most ... the hour went very quickly and I suppose ... I think it's my teaching background because I went up there ... planned, I had three hours worth of thought vaguely thought through material. But, you know, roots and that included me talking, that included music, I had the ability to play music which I didn't get round to, that included aspects of interactivity which I didn't get round to, that included dozens of stories that I didn't include, I didn't get time to. So it was an option and I suppose it was an option if I was going to become ... because I think one of the things the Twitter feed and the online feed made me aware of is that there were two, at least two, different, two very different audiences. That some plinthers you could watch were very much about the interaction with the online community and some that were very much about the interaction with the community around the actual plinth and some who were very much about themselves as well. The only person they needed to interact with was themselves and I really like those, I like all three aspects really and I didn't know what I was going to do and also when I got up there I didn't watch my hour. For a good few weeks my wife made me watch it ... I'd forgotten it as well, again the adrenaline of it meant that I was just such an improvised thing that I was surprised and the people around were saying

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that I hadn't remembered it. I think I shifted from ... and I'm very comfortable with interacting with people anyway so I tried to address everybody who tried to speak to me from beneath the plinth. I tried to make sure that they were as included as they wanted to be, what I [?] I also ... I don't think I looked for the cameras at all but I knew that it ... I was aware that it was there but that third aspect which I really wanted to put in which was that take some time for myself which I tried to do at the end. I spent the last about eight minutes just sitting there and it was lovely and I don't remember doing it but I noticed that when I watched it that I was actually talking to Tom which I don't do very often. I'm really glad that I did that. What I would want to put on record is what Cathy my wife told me was that one of the things that made my hour work I think ... because like you know I'm very aware that that I'm you know I when you're up there you can draw ... I mean we've talked about what the community call themselves 'Tweckerlers' but real hecklers people who ... and I had some but the One & Other staff apparently, I didn't know this, Kathy was my wife was saying if they would go [?] they were going round quietly telling people what I was doing and then they would move on or they would stay and listen. I found that afterwards such a humbling thing for me that, so aware and supportive were that team that they protected me and it happened, again, on reflection, there was one guy who was giving me 'what for' from off cam, off the actual square and out of the corner of my eye I did see one of the One & Other staff just go up quietly and then he stopped and I didn't put that together in my head and that made me feel really very valued that my hour and Tom's hour was protected that way because I didn't get a rough ride at all and three o'clock in the morning, Saturday morning in London, central London, the potential for it was really high.

You had people speaking to you as well in the square asking you what you were doing.

I did, and people again were very, very respectful and I also, I just spoke, I was [?] speak to them. I needed to respect the fact that where they were I mean it was very much ... I found it interesting that I was their property to begin with, they wanted to know who I was, what am I doing, they wanted, you know, I was very much in a cage for them. But then when I told them they were extraordinarily respectful and some people stayed and some people left, some people who were ... just sat down and yes, it was really, generally, it was very ... because one [?] in my head I was thinking, "Well, if I get a load of, you know, heckling, live heckling, I had that ability just to go into myself and just sit and do something very personal but I also didn't want to deny the fact that this was a, you know, a live event so to speak. I need to go back and watch it again, I'm sure I will at some point but yes, I remember people being interested and I mean people were obviously very oiled anyway but you know I could see people were emotionally engaged as well, I could see people having, getting an impact.

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Did you get to know anyone as a result of the project from the online community for example this chap 'BrainCoffee'?

Yes, well, I mean in so much as he sent me some very positive contact. Rita who was on the plinth after me, we had a very, that was very interesting having that connection meeting on the plinth and then we met up again on the last day. I mean I dipped my toe into the Twitter community a bit but I wasn't ... I don't know, I don't know, some people don't seem to sleep, didn't seem to sleep, they seemed to be up almost twenty-four hours a day so, yes, there were some connections I think. I mean if anybody comes and says my hour ... that Anthony he ... actually I would like to go for a coffee with him one day because I know you interviewed him, I heard that interview with you. He recommended my hour to students and things like that so that was really interesting, I met a good number of that community both plinthers and those who were involved in the Twitter aspect of it on that last night and it was really, really lovely meeting them. I'm not really ... I follow the feed and again it's one of my saved feeds and I see that people are very much linked by that and I see that the community ... I see that community has got that ... are holding onto that very much and that's what I think is very valuable for people. It hasn't helped me personally. I dip into it and I look into it, I look at it, but I'm not part of that really joined up community and I'm okay with that as well.

One & Other was a public personal event. I think I said, for me, so I don't really enjoy ... I'm enjoying this conversation about it but I don't need it all the time in a sense and so the connections that I made, and I think as a say it's really lovely being in contact with Rita who we ... so we met in the most random of places ... [?] in that there's a finite amount of people two thousand four hundred or whatever it is who met crossing the edge of a plinth so that that's a really, really lovely little contact there. I know that there's an online community of the 'Plinthians' who do meet up and things like that and I think at the time I was interested in that but I don't think so now because I have, you know, that was then, so I haven't been part of the kind of the reunion aspect of it. I got a real closure, I suppose, a very American term, going back down to the last twelve hours and because I hadn't seen any I wanted to watch. I wanted to close that, but I also got to have a very brief chat with Antony Gormley himself and that was really very ... that was [?] the circle complete for me. But yes, as I say, I'm a big fan, my allegiance bizarrely is very much, is more with Artichoke because I'm [?] ... as an arts organisation had an impact in Liverpool with their = La Machine event. So we are ... we follow that really and we were just talking about how to get down to Milton Keynes to their latest thing. So that's been one of the fallouts of that. I'm a big supporter of the work they do.

Okay, thanks for that. Just to unpack, you've just said, you said you heard the interview that I did with Antony.

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Say that again sorry.

Did you say you heard the interview that I did with 'BrainCoffee'?

I did.

Oh right, where, on his blog?

Yes, I did. I still have the hash tag on my Twitter and it was obviously you, you'd been down there and everyone was talking about it or the link was being thrown around and it was really [?]. I'd never seen, never heard Antony speak so it was really interesting getting that perspective of somebody who ... people who are hugely invested in that massive amount of time and people are still watching the hours or working their way through the hours aren't they? I find that really interesting that it's such a big focal point for people. I think that's really positive and you know I'm very much looking forward to the book, I've ordered the book, it keeps coming back into my life, that's great. I love going through the Square ... I'm in London for work and just family purposes three or four times a year and I, you know, I know that every time I'm going to go and look at that plinth and see what's on it and know that's going to be a little point for me, going up. That was mine and Tom's for a while, that's something that can't be taken away so it's all ... it's a positive, so much a positive and I really enjoy, you know, every now and again the Sky Arts channel will show the programme about One & Other and I'll, you know, I'll record it usually the same one but, you know, just in case there's anything there. So I think, you know, definitely there'll be a strong connection to it, well forever.

I want to ask you one or two questions more about the plinth and then we can move on to your personal like if that's okay?

Sure. Absolutely.

Did you get any media attention as a result of going on the plinth?

No, I didn't. One of the things that was in the guidelines was to promote yourself locally and I didn't choose to do that. One of the things that did happen was that a very short snippet of my hour was featured in the Sky Arts programme on a Friday and I was really pleased with that, you know. My wife was convinced they would and I said, "No, no there's ..." but I [?] ... no, not really. I didn't go looking for it either. I think I probably could have, you know, with respect I know that the power of the story and it's not a story to me but I know that I could package my story in a way that the media would be interested in it but I didn't want to do that either.

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Okay, thank you for that. So now just to go back on some of the things you told us in the pre-plinth interview about your life. You mentioned that you started going to youth theatre as a youngster.

Yes.

And then you started to do your degree in theatre up in Chester and then you moved up North ... I'm just obviously interested in finding out why you chose to live in the North since you were born in London and whether that's such a typical thing to do or not.

I don't know, for me it seemed the right choice because, on a couple of levels, what I was interested in was I always wanted to be a teacher, a drama teacher, and when I went to Chester it was a small college that had a focus on education and when I got there, where it was rooted was in such a strong tradition and network of theatre and education in applied drama, in that, in the northwest that from a professional perspective it's where I wanted to be. I wanted to be a part of that, you know, you get influenced by, you know, the people that influence you in your life. Well one of my drama lecturers was a great influence on me and the way they were working and I wanted to continue working with them so in a very simple sense I stayed to do my postgraduate teaching course but also practically there was a huge amount of work for drama teachers in the northwest. The other side of that was you know I was, at the time, do I go back and share a bunk bed in a box room with my brother at the age of twenty-one? And make a life for myself from that perspective? Well it seemed obvious to me that it was professionally better to stay where I was because the community was there and that's what happened. It wasn't ...there was no big plan I wasn't running away, my folks, my parents lived in London at the time so I still had the benefit of coming back to London and being part of that. They subsequently retired and left London ... still had friends in London but yes, I've not lived in the North. I talked about this weekend actually, I've lived in the north twenty-one years now. I lived in Liverpool for ten years and I love it, I absolutely love it. I was in a taxi with a guy from East London and we were talking, he'd been in Liverpool for thirty years and we were both saying that this is the place to live really; there are certainly truths in lives. I'm thirties, nearly forty with two kids at home, doesn't matter where we live, we don't get to go out anyway so living in Liverpool I've still got these opportunities to do these things, whereas in London our friends have more opportunity but seem to have less money so I love being a visitor to London and I have got to the point now when I meet people that they don't know I'm a Londoner and that's fine. That's interesting but my accent, there's certain words I know that are very much rooted in where I've lived for twenty-one years but I'm definitely not a Northerner up here, you know. I'll never be a Scouser, my kids are Scousers but I'll never be accepted as a Scouser here in Liverpool and that's fine as well.

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We're very lucky; we live in a lovely part of town. We've got very, very good friends and neighbours, old Liverpool families. Both our neighbours either side my kids [?] have got two extra sets of grandparents either side of us and I think because we arrived as a particular family with a particular set of needs, because we moved here with Tom, we were drawn into the community, the community drew us into them and they helped us massively and I think that's a big signifier. I don't remember living in London; I don't remember the aspects of community being so rich as they are here. There's a series of communities in London, a series of closed communities, perhaps, I don't know. Whereas here, you know, it feels much more open and that might be a cliché and it may be that I'm lucky but it definitely feels that way. I also think that's the signifier of the fact that I come from South East London and South East London is a series of closed communities that, you know, my friends who are ... we have friends who come from more multicultural parts of London and more linked parts of London whereas South East London was, at least, anyway, twenty-one years ago, you were very much ... you lived within the parameters of your estate which didn't appeal either. I don't miss London because we travel and visit there, we're very lucky, we've got plenty of places to stay and sometimes we come down as tourists as well, but I do love living in the North. I can never imagine myself living down there any more.

Okay, a few questions really come to mind. First of all, how did your parents end up in this particular estate in South East London?

It was a council estate built post-war to meet the needs of the those bombed out communities in Bermondsey and my gran, my nan, had the house from the time it was built in Kidbrooke in South East London and I love a bit of local history myself and so I've got a couple of really lovely books which show the real sort of rural agricultural nature of that part of [?] as it sprawls. I found it really fascinating. I did a project ... if I go too far off then draw me back in, but I did a ... I directed a play here in Liverpool last year which was made of the community in Kirby and Kirby was another one of those post-slum clearance council estates that was built in the fifties forties/fifties and sixties and even though they would never accept it because I was the, you know, I was the cockney, you know, it was extraordinarily similar as a community to the one that I was brought up in that it had the much older generation, fewer and fewer now, who remember why they moved there because they moved from the poverty but they also moved because of their the post-war nature of the damage that happened in both Liverpool, London, but my ... so like it was my gran's house from building and my mum had ... I believe my mum and dad moved out for a bit and then moved back in so very fortunate, I believe, to be raised with two generations in the house. But it was a small, three-bedroom semi on a very similar estate that you'd find anywhere really, of a particular time. I think South East London for me, as a young person, or maybe in

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reflection, it was such ... you were so separate from London, you know. If you were brought up in anywhere else you can jump on a tube whereas in South East London it was a couple ... you were isolated, it was a long way from London. I don't necessarily believe that ... I certainly didn't believe I was a real Londoner in that kind of archetypal media image of a Londoner. We were, you know, I suppose it was very much suburban. You were very much at a distance from everything.

Why did you decide to do theatre, do you remember back then?

Yes, I do. I think it's one of those things that I feel in teaching that's innate in you. I think some people are born to be more public and so, as a young person, I was always in the school play, with all the, you know, two or three others and my coffee's arrived, thank you. You know, right from infants, right through into primary school and then I remember my mum coming back, she'd been to see a play at the local amateur theatre and she said, "I've signed you up for the youth theatre." And I remember being really upset with her, really angry and just couldn't. I said, "And I'm not going. I'm not going to do it, I'm not ... I'm not going to be part of that, that's not for me." And then obviously you go once and you're hooked and you know I think it's such a ... we need so many different ... people are so different, but there's something about those [?] young people in particular who will good go at something a bit more public, something a bit bold. I think it's good, I really enjoyed the youth theatre life, I got a lot from it, it introduced me to a lot of different people. I came from one particular end of town and went to a particular school which served a couple of particular estates. Youth theatre was a huge amount of people, young people, you know; people my age from all over from all different backgrounds, from all different perspectives. I think it opened my eyes to different bents and again, at that young age, you're quite impressionable so here were people who were educated and who were, to me, inspirational. So I, you know, I picked the people that I wanted to be like and read the papers they read and went to see the plays that they talked about and, you know, and also it's a cliché but, you know, when you are a relatively ... at the time I think aspects of me, even though there was a real performance aspect to me ... anyway I was a relatively shy person outside of that. Suddenly if you had a little bit of confidence, that was my skill I think, I think my skill is a little bit of confidence, people are amazed by it, my next door neighbour, who's a wonderful carpenter can do things with his hands and wood that I can't imagine. He can't imagine ever going and standing up in front of a few thousand, hundred, dozen people and speaking, you know. To him that's alien, to me it's alien, we all have these skills and that was a skill that I had and found and so meeting different people, different perspectives, that was, I got a lot from it, I always encourage young people to have a go and being a drama teacher ... I mean I loved being a drama teacher and there were always kids who hated it and I appreciated that I'd try ... but always tried those who

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had a little bit of an interest in it. I always tried to push them because I think it, you know, having that confidence in yourself really pays dividends later on in life in so many ways. In the job that I ... and I think teaching helped me do that as well, it was always about ... I was influenced by a teacher, a drama teacher, I wanted that job and it was a great job to me and it was ... I had that job and I loved that job and so I suppose I was influenced by the people that impressed me and they were all performers.

So you became a drama teacher, you talked about that and, of course, to bring you back to the story of your son, your first son, that was a life changing experience of course when he became sick.

Yes.

Now we have a little problem with the camera, it just got stuck, but you can still hear me, can't you?

I can.

Okay, it's okay, it doesn't matter, maybe we can't see each other on the video but we can continue to speak anyway.

Well, shall I turn my video off and on again?

We could, yes.

All right then so it's still recording. Fine, so basically just to talk and try to unravel what happened to you when your son got diagnosed. You did tell us some of the event that occurred, you know, how it happened ... and I just wanted to try and ask you more about how his illness influenced your life, because you said it's a very huge impact, of course, on who you are today.

It's an absolute ... who I am today is very much influenced by what the experience of having Tom did for me I. You know my job mainly today is about helping to influence and develop services for disabled children and their families and that's a gift. I loved being a teacher but I couldn't be a teacher and be Tom's carer as well, that wasn't physically possible so we had to take ... and we had a few, like most parents of children with disabilities, we had a few ... a lot of negative impact on our life. I'm not talking about disability or having Tom but the, you know, having a disability, a child with a disability means that you will be more likely to be poor, more likely to have relationship challenges, all of these things. And that had a huge impact on us so I had to be much more hand to mouth and do a lot of supply teaching which was very challenging and then bits and pieces but then find myself again through work and also, you know, friends and family but through work. So I found myself

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moving from being, you know, a voluntary kind of advocacy role into paid roles so I'd end up working for a Primary Care Trust designing and delivering services myself in a different area to where I lived. And then, because of circumstances, Tom died. I'd just given up my job to be Tom's carer really and there are aspects of that that were going to pay some of the bills as well and then Tom died and so I was jobless. We had very good friends and family who supported us for a few weeks but I got straight back up, in fact the first paid job I did was about three weeks after Tom died and I had it booked in for months. It was to go and talk about our life with Tom and I went. I don't know why I thought, "Well I can't let them down" and I went and I talked about that and the fact that Tom had just died as well and I know it had quite an impact. But I pull back from that, I don't so much, I used to talk about our life with Tom a lot more before Tom died. I do it now and again and I make sure that it's for the right reasons but yes, I am definitely a different person in positive and negative ways I think. It's a huge challenge, it really is hard bloody work and I think, you know, I don't want to presume that you don't know that yourself, you know, in your own life and family but I think because I've been closeted from that I hadn't really had much experience of disability in my life before that and made some assumptions that actually, "No, we as a society ... we do make it easier for who are most vulnerable" and that's so naïve. It's really bloody hard, it's hard enough having a disabled child or loved one or family member or friend but it's even harder when you have to wade through the bureaucracy of it all.

Absolutely. Just to say for the recording that you can't see me now, my camera isn't switching back on but we can continue the call anyway.

That's fine.

Since this will be just an audio recording anyway I'm just interested in really trying to see what your motivations were like, or were about at the time when you decided to go and work in the services that supported children with disabilities.

I don't know what my motivations were. I know my motivation when I got the first full time job was that we were having another child, we were having Libby, and one of us needed to be a carer and one of us needed work and as I say sounds disingenuous a bit. I'll have to unpick it, I couldn't go back to teaching because I loved it so much and I miss it and I miss working with young people. I still do that kind of work now and again it feeds my soul which sounds ... I know it does in the sense I needed a job which was important to me which would be strong enough to get me out of bed on the dark days, strong, you know, important enough to get to work when all I wanted to do was be at home with Tom. But not so important that if I couldn't do it I could walk away from it and that job was the job, you know, was being a project

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manager, was making things happen, not having to actually deliver those things, not be a service manager but make the service happen, not working with families but putting into place the people who will work with families, so it was a rational thing for me to do. It was a job that paid enough for us to, you know, exist on one wage, it was also a job that did get me passionate and I did think was important, there was a cathartic nature to it as well. I was helping to redesign services in one area and make it better for families hopefully, I hope it did, but as I said when it came to it, because of the role, because it wasn't integral that I did the work, I could walk away which I didn't have to, I chose to. It was a project, a project funded and they had invited me to stay but I chose to leave, to pursue an interest in developing services for us at home or to put in place for us at home. Some of the things I'd been helping in a different area but, you know, circumstance and it didn't happen which doesn't dismiss how important ... but I couldn't, I couldn't go back to teaching because I didn't want to take, you know, in my subject of drama you are ... you have such a relationship with the young people that it broke my heart a bit that I didn't get to finish the journey with some young people that were who I was teaching when I had to leave teaching in the first instance.

So to go into it with best intentions and then six months down the line I'd invested in relationships with young people and suddenly I had to pull those relationships and go home and stay at home and let those young people down, I couldn't really get back into it. I couldn't countenance that, you know, the drama teacher is the teacher that stays amongst latest ... there's the drama teacher and the PE teacher who stay and do the plays and come in at weekends and rehearse. I didn't have that capacity any more, that was heartbreaking but I had ... I didn't and I couldn't give that side of myself so I had to change careers and I'm glad I did. I think that I can always go back to it if I need to with teaching because I love it so much but I get that fix of working with young people with some of the actual, the other creative work that I do, as well.

Okay, thank you for that Gav. Just to go back now to life with Tom and watching your video performance. You talked about some of the issues you faced as parents and about the support, the ways in which you were portrayed or treated even and you mentioned particularly being reminded how much money it cost to support him. I just wanted to talk more about that for you, you know what it was like because, of course, as parents with disabilities you probably aren't in a position to be heard as much.

It's a strange thing because, you know, we live in a civil society where we're putting into the pot and we pay taxes and we're very much about, you know, the clichés we are, you know, you judge a society by how well it treats its weakest and such like but you know there are certain realities aren't there? You know the fact that like most other people I've probably got my head in the

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sand about old age and retirement and things like that and then because it doesn't impact on my life now and it was the same with that, we had fifteen months in the hospital where we were very cosseted and supported and empowered and it was all very close and tight and people were with us on the journey. But one of our aspirations was to go home, we needed to ... a new home but was to get home and one thing ... that what people kept saying it's much difficult, it's harder in the community ... and it really is because suddenly we went from a setup which was an acute hospital setting where everyone is there, focused on that job, that's what they go to work to, suddenly you're in and its you as a family, you fit that model, you live your life in that, meeting the needs of that hospital model and then you go home and you're in this arena where it's your home, it's your house, it's your lives. But it's not because you are that square peg and the round hole of ... services expects you to meet its needs and that's really hard because you all you want and ... the way we describe it was we always aspired to live an ordinary life.

Now actually I think you know whether it's about having a child with disabilities or not. I don't want to live an ordinary life. I'm not trying an extraordinary life, but want to live a life that's got some, you know, excitement to it and some edge to it now and again and then I also want to live a quiet life. I want to choose and it's that ability to make choices that is ordinary and some people choose to do crazy things and some people choose to do very sedate things, but the ability to choose when you have a dependency on services, that ability to choose goes and so it's really extraordinarily conflicting because you need the services to help you to live an ordinary life but the services seem to think they need you to meet their needs. We had adults, strangers in our house, for more than half a day, well it's strangers and we worked with them, but they were not friends, they were not family but our son needed an awake carer, Tom needed an awake carer, and that's really, really strange and I know that we were at the extreme end of needs; Tom's disabilities were very, very complicated but when I speak about this experience I never speak for other families but our experiences are very, very similar. When you have somebody telling you how you should live your life. I remember one story and I apologies if I've already shared this story in either the recording or the video where we hadn't been out as a couple for months and months and months and I was getting some support from family friends, families and friends and I remember a manager phoning me up and being really excited and saying to us, "I tell you what I've arranged for you, in three week's time on a Wednesday between half-six and half-nine, I can get you double cover so you can go out."

And it, of course, the first answer to that is well I think you're supposed to say thank you aren't you? But actually that's not really very exciting, you know, we've got a three hour window on a Wednesday, mid-week to go and be, you know to go out, and it's like, no, it must have come across as being really ungrateful, but we didn't want that because again the parameters were just

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set by somebody else. We did get to do things because we built our own support networks with families and friends where we can make those relatively random choices and get away but someone is saying and is saying to you, "And you must be back my half-nine, because that's as long as the person can do." Oh dear, that's no fun because you'd go out looking at your watch, spending money on a meal out and then you can't go to the cinema in that window and things like that so we created our own system around us and what was really hard as well is that you'd have people working with you and saying, "Brilliant keep doing that, what you're doing is helping other people and stand up for yourself and stand up against them because they are terrible." And you'll get professionals who also work with you, who just don't like you for it and that's really challenging because if ... sorry.

Yes, I know, I just remember you saying about your holiday with Tom in London that you couldn't get support from a charity that organises holidays for children with disabilities and you eventually managed to have a holiday yourselves.

That's right we ... again, I can't remember how much I said but the charity contacted us because somebody we knew who put them onto us ... and when we told them what we needed for instance you've got a very fragile item, whether it be this very fragile Roman glass vase made in the 5th Century, this beautiful thing, it's the most fragile thing ever. If you need that transferring there's a particular way of doing it, you've got to have this box to fit it, it's got to be transferred in a particular way, it's got to be carried by experts, that's the same with Tom. He had such particular needs; so when they said to us, "Tell us what his needs are." Those needs were so complicated and expensive ... now I don't know if I said this on the plinth at all but they rejected us, they rejected us because it was too complicated. They offered us something else, they said, "Why don't you take him for a weekend in Center Parcs?" Which to us was just painful because it would be, because we couldn't do anything there, you know, we'd be looking at other people doing things that Tom couldn't do so again must have come across ... but what I'm not conscious, if I said this on the plinth, the person that recommended us told us a few months later that also one of the reasons we were rejected was because the person personally against us, because they said I would never respond to a parent who'd sent me a business plan and that's what she saw our needs as, a business plan. So that person's need to give charity was just a fantastic thing to do, was challenged because we said, "Yes please that would be wonderful, here are our needs." And we, instead of saying thank you very much we'll take anything," we had to say, "No" to transfer this very precious thing, this needs to happen and she saw that as a vaguely aggressive act and that was really disappointing, heartbreaking almost, and as I said we did what we needed, we did what we did we ended up doing. We built, we saved, with family and friends who gave us money, we also used service money, instead

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of putting Tom for a week into a respite unit we took some of that money as cash instead and we got to London. We did those things, we were the tourists, we stayed in an interlocking room on the Jubilee line, which is accessible, the only accessible tube line. We went to museums, we did the things that I always ... you know, the clichéd things you want to do as a parent for a child, let's go to the Science Museum, let's go to National History ... it was part of a, there was a family wedding at the end of the week so it's been part of that as well and we did it and it was so heartbreaking. About three days after Tom died we got a letter from the same charity saying, "We see that Tom's still on our list and he hasn't had something from us, what would you like from us?" And I wanted write and tell them but you know you don't know because we don't live a life of bitterness but it was hard to get that level of rejection because we didn't fit, we were ... again we were the square and they were a triangular hole.

I see. Thank you for sharing that with me Gav. What happened when he died?

Did I talk about this about this on the plinth?

I don't think you did but feel free to talk about it anyway even if you think you did.

Yes I'd like to because I'm going to say something perhaps, so bear with me, Tom had a glorious death, a sad and heartbreaking but ... he died and we knew, we didn't know it was going to happen but we knew it was always going to happen and we were there and it was managed and what he, what needed to happen at that time, and it was a very heartbreaking and sad thing but we got to say our goodbye. I have a friend who's just lost her husband and she didn't get to say goodbye, friends whose children died through an accident. I don't understand that, it breaks my heart and I'm sure our story breaks peoples' hearts but we got to be part of his death as well as much of his life and we had ... we got to choose when Tom died the following day through contact with friends, because my wife like, you know, there's a lot of gender based dealing with disability. And women are ... there's some research to back this up, this is not just my top of my head basic sexism, women are pragmatic and practical and plan and men ... and lots of men with true disabilities live in the moment and they cope and so my wife had been practical and pragmatic and I didn't understand it at the time. But she had some ideas about what would happen at the point of Tom dying and they ... those things did happen, we had a, again bear with me this may sound strange, when I see Tom's funeral director, when I see the funeral director that handled Tom in death, I'm really pleased to see him because he became part of our life and Tom's life, well I see him on the high street and we know we had an impact on him because his staff told us that, it was, you know, a very much an undertaker, very serious, but they said it really [?] had an

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impact on him and because he also nominated us to talk about that for a corporate co-op video, through the Co-op Funeral. And we did and the reason we did is because we were so grateful. It was the first service let me put it this way that when we made a suggestion about how we want things they didn't say, "No" straight away. We can always handle a "No" but it was always the unqualified 'nos' with services, "No, you can't do that" "Why can't I do that?" "Well, you just can't."

With the Co-op when we made particular, we wanted a particular type of thing to happen, we wanted ... so for instance they said, "Part of the children's package for a funeral which is free from the Co-op, you get free cards." Well we didn't want funeral cards, but we did want the Mercedes Benz which came to pick up Tom's body and when they collected him, because that was what we were saving up for, and they just ... and then I saw the look on his face and he said, "Well, I don't know let's look into that" and apparently they went back and the guys who picked up Tom again and were quite effective apparently, said, "We'll do this, we'll polish it up, we'll clean it up, if that's what they want. I'll drive it." And we didn't want a coffin, but we couldn't find a child's coffin that was biodegradable, that or cardboard in the right size, so we made our own coffin, my next door neighbour the carpenter made it. We got to paint that, families and friends came and painted, we had a fantastic celebration for Tom, we had a very private ceremony, there were about fifteen people there. It was our friend who was a retired psychologist who'd worked with us for ... became our good friend, she conducted it and we just had a very, very small group of people in the actual crematorium. Then we came back to our house, ate, and laughed and cried, and then we went to a Victorian farmhouse here in Liverpool, we had 250 / 300 people come for a celebration where we talked about Tom and other people talked about Tom and we showed pictures and videos and we laughed and we cried. All of his school friends were there and they sang songs and it was lovely and as you saw on the plinth I let off some balloons, that's what we also did on the day and that's what we still do and it created the memories that sustain us, you know, because grief isn't always there, it's there underneath but when it comes back, it comes back wallop, but the fact that we were able to give Tom a glorious send-off has sustained us as well because you know we're never going to get over it and also I don't want to. It's that sore that you pick at, you want it to stay sore, you want it to stay raw because that's how you remember it, but as time goes on it's very natural to not be thinking of Tom every day, all day, it's very painful and very difficult as well, you know I'll go a few days and I haven't thought of Tom and wallop I feel the guilt of that but when we do think about it, we think about the life that we led and the short life that he led which we tried to make as good as it could be and as the death we experienced as a family because grief is about us isn't it? It's not about the person that died that sustains us hugely.

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Which sort of brings us back to you wanting to memorialise although you said you didn't like this word in your pre-plinth interview but as a way of remembering Tom using the plinth.

Yes, if I go back a bit as I said ... when I applied for the plinth I didn't know what I was going to do and I actually bought into the interactivity thing I started up a group with friends and I said, "Look, I'm on the plinth what should I do?"

I've just joined it.

Have you?

Yes.

There you go ... and you're [?] to that group for ages and in my heart ... the strongest idea for me was the Tom one, but I didn't want it to be just, you know, as simple as that. I wanted that interactivity and I wanted to see, I wanted to test the idea so I had some silly ideas, if you can see there in the discussions I threw up, but the idea about Tom came and I did get the most responses on there but I got people phoning me and saying, "That's the one you should do." I think there was a little bit of; I mean ... I suppose you have your category of 'mourner.' I wouldn't categorise myself as a 'mourner' when I did it, I wasn't there, it really was part, because as I say we had this celebration for Tom, it was about that celebration but also that right, and a little bit of class war perhaps, you know, to put Tom on the plinth for an hour. Now I had no understanding of how archived it would be, nor am I overegging how I'm the importance of it, you know, from my hour is a small corner of this whole experience but I knew that in the moment for an hour Tom would be on that plinth. Tom would be on that spot that is usually given to men of some dubious renown for dubious experience or war or whatever that he would have that right. I don't know if I mentioned this, we don't have a stone for Tom we don't, his ashes are ... we were actually yesterday in Hay-on-Wye where we put his ashes at this corner of the river bend, did you see my link? In my email to family of the old family website I sustain anymore?

I saw the video link of video footage and photographs of Tom, is that what you mean?

Well, what I've got the [?] that's a very old and rubbish work website but there's an old website that I just sent you a link for.

Okay.

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Which was a way of, you know, I mean it was pre-Facebook as well; it was a way of us putting photos and things on for family members, so I only had to do it once.

I'm looking at it right now.

Yes, and you'll see there's an image there of a field and it changes but that's where we put Tom's ashes and as it scrolls if you scroll down a bit. There's some very small pictures on the right of Tom in the river cause that's an a really important place for Tom's family and for us as a family and Tom was there so that's where we put his ashes and that's where we go all the time it's just literally a ten minute walk from Tom's granny's place where my kids are now and so that's where we go to think about Tom and we live quite close to a very big cemetery here in Liverpool and you know the grief of losing a child is just manifold isn't it? When you would drive past there are children's graves that have like lights and toys and things around it, but they get tired and they get and it looks it's not maintained it's just, it doesn't seem or feel right for us, as a couple, it's right for their families and not criticism so we didn't want to have also we didn't want to have ... we didn't know if we were going to stay in Liverpool as well. We knew that we would always want to go to Hay-on-Wye because it's beautiful and wonderful and that's where my wife's family is from and we can imagine ourselves there in the end, so why not have this spot that becomes you know a family spot for as it's important to us you know because you know we are all finite there's nothing, I worked in a building once which was built on top of an old graveyard and it nothing gravestones that were only 150 years old were broken flagstones you know and that's so death is a is a grief is a strange thing I know but this was this was what how where we get our sustainable experience, so putting Tom on the plinth was part of that ... that it was part of ... the whole putting giving Tom a moment in his short life.

Thank you for that I have to tell you that the link you sent didn't work, it said that it's temporarily unavailable so I didn't see what you wanted to show me but I understood what you were telling me so I want you to know that.

That's strange I'm looking at it right now, but that's okay.

What happened in terms of his death if you don't mind me asking you? Was it natural or was it induced?

Tom's condition which was a neuromuscular condition we knew wouldn't kill him but the impact on that would ... so you know if you put it in context with other like muscular-dystrophy what's the condition?

Shall I say it for you?

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Yes, what's the what's the condition that Stephen Hawking has, sorry?

Oh, I'm sorry, I thought you meant ...

No, no, no, that's fine, that neuromuscular conditions don't necessarily kill you but the impact it has on the body ... so after six months of being ventilated Tom's body was very weak and each subsequent infection made it challenging for him to recover from, his recovery was slower and there's also the mechanical ventilator has a certain amount ... if you imagine a balloon yes, if you inflate a balloon, when you pick up a balloon and you haven't blown into it, it's very tight piece of rubber, you blow into it but then you when you let the air out, you know, it becomes loose, never goes back to that tightened shape. Well that's what's happening with the lungs when you ventilate it; a ventilator or life-support machine isn't designed to be permanent. So, you know, Tom ... so the machine always had to be turned up a little tiny bit each year to help cope, a little bit more pressure needed to go into the lungs so there you are having an impact on the mechanical ability to sustain life. So there became a point where one day he had an infection that was really hard to fight, he had an infection that we couldn't get him back on the ventilator for, that he was struggling [?], so we'd already had connections with the palliative team, we were already making plans for that time, plans came quicker so Tom hadn't ... had we managed Tom and we ... when Tom was six months old we had to make a choice, which was, "Do we permanently ventilate, or do we remove ventilation and give Tom his dignity then?" And we made that choice to permanently ventilate Tom ... really we knew that time would come around again and that time did come around again so it was a, you know, we had a very good conversation in the house with Tom's consultant who'd been there from day one in the hospital, you know, and Dr. Andrew Selby who I would walk across fire coals for, I have such respect for him and what he did for us as a family and what he did for Tom. We had a GP with this palliative care team and so Tom had reached the end of the his ability to cope with living an artificially maintained life, mechanically, not in terms of anything else.

Tom was very much, you know, his condition was physical, he was alive, he was very vibrant, very alert but his body had just failed him so we had to manage that and so that was by massive pain relief and then with the withdrawal of mechanical intervention Tom died very, very quickly and very gently and then [?] which gives you a hugely painful ... raw experience to share but also a huge ... it's hard to find words, it's a privilege to share somebody's death. I'm sure in those circumstances when it's managed and with dignity and when it is the right choice, it's really hard to see it in the papers when this debate comes up about having, you know, and making those choices and going away and going to Switzerland to Dignitas and suchlike when actually these choices are made in this country but they're

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made in under particular parameters. So we have been through that and then Tom stayed with us after he died, everything mechanical and health-based would be put into a big cupboard and out of the way and we opened the windows and we slept. Tom was put back in his bed and we stayed downstairs and slept with Tom overnight and family came and joined us and then Tom's body was taken away the following morning. So from, it was ... yes, I don't understand, personally, how people come back from losing someone suddenly because we didn't have that, we were there, part of it, we were able to start to process it because we were there as it was happening and it was in our house and it was in, you know, he was surrounded with love and we were able to, even though we didn't tell his grandparents, we were able to phone them and Skype them and video them and say, get him to wave and say ... and at that time Tom was on very high levels of sedation so he was, you know, away with the fairies. It was high levels of morphine but they were able to say goodbye, you know, we didn't want their goodbye to such a dramatic thing for them, we wanted them to remember that in a positive way but we knew even if it was unspoken.

I just feel now really that we haven't much talked about Tom, you know, his personality and his character and what he was like just before he got sick and you know the experience as it happened.

Tom was just, you know, fantastic. Before he was ventilated he was struggling really, he was a lovely good baby but, you know, his body wasn't able to breath properly for him, his body wasn't able to breath and eat so he wasn't thriving. Once he was ventilated he would ... you imagine if you've ever been into an intensive care unit of a hospital it's a strange place, the people in intensive care units are very poorly people, a children's intensive care unit in particular is a very specialist place, accident recovery, operation recovery, children at the end of their lives. Tom, once he was ventilated ... so he was getting the air he needed, the oxygen he needed and once he was being fed in a way that meant he was getting the nutrition, suddenly he came alive, he just grew and was wonderful and Tom was just such a character, such fun. My, I'm very lucky [?] in that all kids are lovely, I know, but my kids are double lovely, they're all ... but I've always found my children great company even though they're tiny and Tom was great company, Tom had so much, he brought so much just laughs, so many laughs into our lives let alone the complexity of what he had to manage. We laughed, loads, and he was fun, he had a ... really I mean he did struggle of course but he had such a vibrancy about him that when people met him they got him and he got them and he would, you know, he was non-verbal in his communication, he was so positive for people and if he let people know that he just wanted to know about them and come and be part of his life, we had so many positive experiences through Tom. But, you know, it's a lifetime of experience for us really, things that we draw on and so many pictures and so many videos that we have he,

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you know, he went to school, he went school, he went most days of the week, to be with his friends and be with him as much as we could, we were often limited by our ability to be awake because if we couldn't take a carer with us we had to stay awake twenty-four hours a day between us and that was quite challenging.

Did he manage to learn to speak okay because of his condition?

No, he didn't, he was non-verbal but he was very communicative. He communicated with his eyes, he communicated in very simple terms, with a series of raspberries and twitches and we that we know [?] so we did have big chats and conversations and we did laugh but it was entirely non-verbal. He did have some ability to say some words, lovely, simple, vocalisation but it was very challenging for him so that wasn't part of it for us. But he, if you were the person who was open to that, if you could cope with the fact that he was non-verbal you would be chatting with him within ten minutes, but there were some people who couldn't ... and one of his teachers hadn't cracked his communication style after a year but 90% of people after ten minutes with him were able to have a conversation with him, he was very charming.

What was it like when you were told about his condition?

Again, I mean that was a journey because Tom was born small [?] and suddenly so we were thrown into that world at his point of birth, six weeks in special care and sent home with a lot of scratching heads, people just didn't know what the reason was and then suddenly this summer in 2000 one Saturday he just was really not coping, struggling. We took him into the local hospital in the morning, he had a whiff of oxygen in the afternoon in a head box and by two in the morning he was ventilated and suddenly we were in a very different world and where everyone ... and he lost his physical abilities rapidly overnight, literally in a few days and that's when we started having these really challenging conversations. I remember this time when, you know, the conversation was, as I said, do we ventilate permanently or do we withdraw ventilation? And we chose, Tom chose to ventilate, but we knew it was that putting something off and that was challenging, it was challenging for us, it was challenging for our family. We tried to be ... I mean we were extraordinarily emotional and heartbreaking but we also tried to be pragmatic, you want to do your best by your kids don't you? So what was the best, we didn't know, it was out of our realm of experience. So we talked, the chap, the doctor I mentioned, Andrew Selby, I have a memory of sitting at three in the morning with him and Kathy my wife, just talking about the process of what would happen if we chose to withdraw ventilation then and also what would happen if we disagreed with the hospital and wanted to ventilate. But the hospital didn't, so it was a surreal, surreal experience and then for us it was a given then, that was our life, we had to adapt our life rapidly and we did, we

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moved house, we rebuilt our house, we stretched ourselves financially, stretched ourselves emotionally and physically and we changed. You do what you do, you do what you need to do for your kids, you become a different person, you become ... we met people with [?] in a very open way, but then after a while we experienced feeling let down by services and by individuals in the service so by then you would become more guarded, you'd meet people and you'd wait for them ... either be waiting for them to let you down or you wouldn't be so open with them and so that would have an impact on the working relationship with some people and you become hardened to it, which is a shame, but it's a survival instinct. There's another paradigm where parents of disabled children are described as gorilla warriors, you hide in the bush until the right person comes by with what you need and then you jump out and you give them what for until they give it to you and they run away and once you've got what you need that's fine, that's a learnt behaviour because you have to fight the system sometimes to get to that point of most parents which is ... well you do anything for your kids. And if your the kid is disabled you have to do anything and if that is annoying people to get what you think your child needs then that's annoying people.

You mentioned that this condition Tom had is a genetic one and of course I thought about two other children and wanted to ask you whether they were out of risk.

When Tom was three, I think it was, and I might be wrong there ... four, when Tom was four, in the run up to that, when he was three, there's a possibility of a diagnosis, and it was a possibility, because we had no idea, we had no diagnosis, then because one of Tom's doctors said, "Look, there's this conditional called SMARD 1 that's very, very rare and it's being looked at in Berlin, I think we should send some bloods off there and see if it is this." So we did, we had bloods sent off to Berlin, three of us, Tom, Kathy and I, and so in about January 2004 we were called into a complete ... we'd never met this guy, he was a neurologist, consultant neurologist, who was going to give us this diagnosis back from Berlin and so we took our psychologist with us who was still working with us at the time as support. He introduced himself and was ... and he had students with him and he said, "Would you mind if the students stay?" And we said, "Well, actually no, we'd rather not, if possible, we've been waiting four years for this, it's a very private thing." So I remember his facing going, "Oh, okay." And so they left, he said, "Okay, I've got this piece of paper here and it is a diagnosis of SMARD 1, S,M,A,R,D 1 spinal muscular atrophy with respiratory distress 1, Type 1" and he said what that means is that it will have a massive impact on respiratory ability. Well Tom had been ventilated for three and a half years so we knew that it would have ... it's a life limiting condition, we knew that. So these were all things we knew and then he said, "However, what that also means is that we have the ability to test for this now." And antenatally is it, before birth? Yes, so what that

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meant was because we knew that there was a one in four chance that this would happen again with any children that we had and one in four, I mean Russian Roulette is one and six isn't it? Now one in four is a huge, huge gamble, so we knew, we kind of ... it was challenging, particularly for my wife, to think that we'd never have more family because, you know, it was just an impossibility of stepping into this arena. But that what that meant was that at twelve weeks a pregnancy, a foetus, can be tested in the womb at twelve weeks, for whether the full SMARD 1 with both the gene, the broken gene for me and the broken gene from Kathy combined to make the broken gene SMARD 1 in the child, the one in four. So we got that diagnosis in January, by the end of February I think Kathy was pregnant, so less than a month and so we ... after about three months Kathy had this physically painful test where material was taken and we had the most agonising wait and we got the phone call, a very supportive phone call from the genetics department saying, "No, this pregnancy wouldn't have SMARD 1." And, you know, that was an amazing impact moment so that was Libby.

And Libby was born and then a few years later Kathy and we it was again, we went off was pregnant again and we were very fortunate again that the one in four chance went in our favour again and Ned was born. I say now twenty-two months so that that was very difficult but also very joyous in equal measures because we know that we wouldn't, we made a choice that we probably wouldn't ... well we wouldn't continue with the pregnancy at that point because we knew also the service wouldn't permanently ventilate because they didn't have a diagnosis so that's why they did choose to permanently ventilate. I don't think many children with a diagnosis of SMARD 1 would be ventilated like Tom, but that time has passed, because there is an understanding of how life limiting this condition is.

I just also wanted to ask you a question that about your work. You mentioned in the pre-plinth interview that, of course, you do help in the services of children with disability but cannot work with families, but you can work with the consultants or the people that offer the services.

Yes.

What is it that makes it difficult for you to work with families?

I think I'm reflective enough to understand my skill-set. I think I get emotionally involved so much with families but also my understanding of this very narrow band ... I understand what our family's experience was but I'm able to apply that learning to service development, I hope, reasonably well. I don't know for certain, but I keep getting asked back and also I'm more comfortable in that ability to challenge practitioners and challenge systems and services, but also nurture them into positive change whereas with family members, other family

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members, I just get so immediately emotionally involved. So I don't think that I can retain the critical distance that they need from someone who's there to help them, you know, it's really difficult ... positive when people have an empathy for you but you need someone to be practical with you as well and I find that really hard. I get upset with the injustice of systems and a lot of really good people who offer support with families and the skill-set is about working with services and practitioners, I think, and that's what I focus on. I couldn't ... that's what I think I bring to this better, it's just a choice really because you know we want to do ... I'm assuming most of us, in our work, if we're lucky enough to choose something ... we want to have a positive impact and that's where I think I can have the most positive impact. I can, you know, we delivered some training recently, well, last week. And the outcomes of that we hope are going to be really positive and really exciting for families ... that we skilled them up to work with families better but we don't ... that they have other people who have skills working, making connections between them and families and also because I'm, my experience, I'm quite open about them. I can offer them to people and say look, "This is my experience, you can ask me anything, you know I'm not going to be offended." I've also been a service manager I know what it's like a bit. I was challenged as well, but I'm safe, I'll challenge you back but you're allowed to ask me those questions you don't want to ask families who you're working with because of the impact that question might have on the relationship. And so again that's what I offer. I think there's a lot of people who do work with families directly and I don't think I'm missed.

Thank you very much Gav. I wanted to ask you now, as a closing question, well, obviously if there's anything else you want to add and also what has it been like being interviewed today? I want to know.

I've really enjoyed it, being interviewed again. I think if we talked about Antony 'Risser' the BrainCoffee his title and I think to him I described the plinth as the ultimate cathartic opportunity, you know. Tom has gone but Tom is such a part of my life. I've got the opportunity to talk about Tom ... I pay an emotional price. I spoke about Tom last week at work and it had an impact on me, I know that when we close this conversation it will have an emotional impact on me, you know, but that's okay, I'm glad it does. If it didn't I wouldn't do it, if it became just a good story, well told, if it is or not that's not my presumption but then I'd stop doing it. But having a conversation about Tom is a good thing for me, it's interesting being part of something else, you know, and the performance that the egotist ... someone, whether it's your job or not, if someone is showing an interest in me so I get to talk about me, so that's interesting. You don't get that opportunity very often. It was the chance just to speak and formulate thoughts, you know. It's a learning thing, isn't it? When you just get the chance to verbalise some thing and it helps me with my understanding about things and some of my reflections and memories and it's

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really positive. But the whole One & Other thing was really an experience. I think it had an impact on me for months genuinely. I couldn't, you know, it felt like I was on the plinth because it was a good place to be because, as I say, I was so immersed in that moment with Tom and that was such a positive thing, the one thing we didn't get to talk about, as I say, or I didn't I feel I didn't get to say was that for the record the people who worked on that project were so amazing, such an amazing experience. Positive, nurtured, supportive, I got to meet that team on the last day as well and it was really positive, you know. My contact with them was so limited, I got to read, because it was released on the net for a short while, I snatched it off and then it was taken off, I got to read the notes from the production team for my hour and that was lovely to see that, you know, something [?] for them to watch hour after hour after hour and they ... I could see from their notes that they were interested in what I was doing and that was really positive as well. It's been ... all round, I'm really pleased that I did it in the end.

Thank you so much. It's great to meet you and I really enjoyed listening to your story as well, thank you.

Thank you, you're a very good listener, of course it's your job.

I'll just stop recording now and then we can still talk for a little bit if you like. Thank you.

That's fine.