



Supporting people
affected by
acquired brain injury



Headway East London

at ABIL

20.03.2018

Richard Symes and
Amanda D'Souza

MISSION:

Supporting people
affected by brain injury



VISION:

A society where people with brain injury are valued, respected & able to fulfil their potential to lead full, active lives.

VALUES:

- **Respect** the distinctive worth of every person
- **Co-Production**; all people have something to contribute to Headway East London & the community
- **Empowerment**: Support & challenge people to take personal responsibility for themselves & lead fulfilling lives within the community

MISSION: Supporting people affected by brain injury



ACTION

- Help people with a brain injury regain quality of life through a wide range of services:
- Headway House / Carer & Family Support / Community Outreach / Young People's Network / Occupational & Volunteer Programmes / Respite Care / Therapies

Activism

- challenging preconceptions, pushing for policy change & asking difficult questions.

A separate Charity; affiliated to Headway UK



Headway East London



Day Service

Community centre

Occupational Projects

Young People's Group

Volunteering

Neurological
Therapies

Community
Support Work

Advice and
Advocacy

Family Support

Members with Epilepsy:

<http://whoareyounow.org/>



Who Are You Now?
Life stories of
brain injury survivors



Approx. 1/3 of Day Service Members have epilepsy (post ABI).

Brian: Who Are You Now

<http://whoareyounow.org/story/brian-searle>



Brian: Who Are You Now



7. Switch off and go

- I still suffer from headaches. The headaches are always here. I can't take painkillers for them. Painkillers don't work with the drugs I'm on for epilepsy. What the painkillers do is coat the brain, and that stops the epileptic drug reaching the brain. You just learn to cope with it. My memory's terrible too. I don't go to the GP on my own – if I have a conversation with my GP, by the time I get to the door, it's gone. It's like "What did he say? Oh my God, what did he say?"

Brian cont.

- I can't get on a bike at all now, because of my seizures. No more bikes! It's quite tough, having seizures. It's only in the past couple of years they've started. They get me down. Especially if I get long bouts of them. It drives you mad. Walking round London, I get strange looks sometimes – you get a strange look when you want a seat on the train. I have to plan my routes because of my seizures. When I go on the train I make sure it's a journey that finishes at the end of the line, so if I have a seizure I know that I'm not going to go any further than that.

Brian cont.

- When I work at home I do my paintings or drawings. I see my grandchildren. I have three of them, a girl and a boy from my daughter, and a boy from my son. My family look after me because of my seizures – if we're out, they know that in a split-second I could suddenly switch off and go on a walk-about. I've done that a few times. Switch off and wander. No memory. Switch off and go. Or I have a conversation, and it stops. Then between one and five minutes later the conversation starts off where I left it. And in that time, I just sit quietly. Eyes open, just stare. The doctor said it's quite surreal. I said, "It ain't surreal for me though is it?"

Daniel: Who Are You Now

<http://whoareyounow.org/story/daniel>



“After about ten years, I don't care now if I have a fit. Sometimes I know when it's going to happen. If I get to the mirror I can stop it a bit. Talk to myself, talk, talk. But some of them I go through the whole thing. It's like getting strangled. Thank God it's only a minute or two.”

Daniel: Who Are You Now

10 The episode with the cow



- I never drank heavy before the accident. I drank more, after. I think I was using the drink to feel I would be okay. I used to be terrified of having fits. If I thought I was going to have a fit, I'd drink, to put me to sleep.
- I haven't drank now for five or six years. I looked at myself and I thought, 'you've gone through all that and you're not going to die from drink'. I was taking tablets for epilepsy as well and the tablets weren't working, because of the drink.
- I stopped, then I started drinking again, but then I stopped it again. It was no big deal... well, no, it was a big deal. I didn't stop it just like that. The doctor told me to come down off it easy.

Daniel cont.

- I think it was partly the episode with the cow. See, what happened is, I woke up one morning and said "look, I'll take my tablets and then give it a while and I'll have a drink". I had a couple of beers and I went to sleep and I woke up and I thought it was the next day. And the next day, and the next day. So I took the tablets three times in one day by mistake.
- The fourth time I woke up and it was just wacky. There was a cow sitting in the middle of the room, talking to me. I was talking to the cow, then I was sitting on the sofa and the sofa started moving, and I see five people in the sofa, moving. And I said, "I have to get out of here". So I went outside and I felt truly weird.
- A friend of mine, Mary, she came around to see was I okay and as soon as she saw me she said "oh, you're still drinking." I told her what happened and she got the ambulance.

Daniel cont.

- Mary has been there forever, you know. I met her in '91. We clicked it together but it didn't work because I started drinking. I didn't see her for years and then I seen her again.
- We used to be a thing but now there's just that we're friends and she comes to my place most of the time. She's staying with me since the bad fits I've been having lately. She's helped me out. Oh hell, I'd be dead only she found me a couple of times.

Daniel cont.

- I got rid of the drink but even now there hasn't gone a week that I haven't had a fit. I said "how long till I can come off the medication?" The doctor said "if you are two, three years clear of fits, I will take you off the tablets forever."
- Because I haven't been well for the last couple of months, Mary's been there more or less all the time. She don't get paid or anything like that, you know. I am terrible with leaving the oven on. I cook, but I have to be really careful. She put signs all around, you know like "don't forget...", "switch off...", "don't forget your keys". She's okay, you know.

Garry: Who Are You Now



<http://whoareyounow.org/story/garry-methven>



Garry: Audio recording



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Garry: Who Are You Now

3 I couldn't say the words



- Just as I was leaving rehab, one of the top doctors said to me, “You've got to try to do something. If you're just stuck indoors you'll spiral.” I thought, 'God, I can't just be sitting indoors, I'll become a cabbage. I don't want that.' I asked myself, 'What can I do?' I thought, 'I've got to do something. I can't be depressed and become one of those people who never goes out and is just scared and has to stay indoors.' I was trying to improve myself.
- That's probably why I went to my brother's fish shop. I don't see him that often but I'm quite close with him. He's my stepbrother but I call him my brother. I said to him, “I'm stuck indoors all the time. I need to try to do something work-wise.” I tried it for 3 weeks. In the beginning I was only supposed to go there for half a day, but that's fishmongers for you. If it's busy they'll be pushing you. He said, “You can stay the whole day, you can have a lunch break.” That was the trouble. He was thinking to himself that before I had the accident I was a good worker. He didn't realize that a brain injury is completely different to other injuries, like a back injury or leg injury. It makes you feel different. You think differently. It makes you behave differently. I was working all day and it was really, really exhausting. It was too much.

Garry cont.

- It was so annoying. I'd been a fishmonger for twenty-odd years, but when a customer came in and asked what something was, I wouldn't be able to say it. Whatever it was - a carp, a mackerel, this that or the other - the word wouldn't come out. If the customer asked me to weigh it, I couldn't say how much it weighed. If a customer would ask me how much he owed, even though it was showing on the till, I couldn't say how much it was. I knew how much it would be if I was taking money out of my pocket to pay somebody, but I couldn't say the words. Plus I was having fits day after day. I don't know why. Maybe it was stress. Maybe because I didn't sleep.
- Fits are terrible. The fits I have are violent. I'm on the floor. I can't move my body. I can't stand up. I can't talk. I can't do anything, but I can hear. It's horrible. Some people go on the floor and start shaking, then they get up. Or they'll be sitting on the chair. With me, I properly hit the ground. Maybe that's just me thinking that mine is worse than everyone else's. I've never had a fit when I'm out. God bless that I haven't. There's a lot of people who would laugh. That would really upset me.

Garry cont.

- I'm always trying to figure out what did I do to have those fits. Is there a reason? Have I done something wrong? I have tablets I have to take. They must be taken on the dot. When I have a fit, it'll make me hit the bottom for three or four weeks. I feel so, so low. Depressed. It isn't about me *feeling* depressed. It's about my mind. It feels terrible. I'm scared. Really, really frightened to talk to anybody. I couldn't be having this conversation. Also I have ... I can't remember what it's called. I'll just sit there. Somebody will talk to me and I won't understand what they're saying.

Garry cont. 4 Aphasia

- When I got home from hospital I could speak, but not the way I can speak now. Where I used to work, they rung my house. They didn't know how serious the accident was and they were asking whether I could go back to work. I said "I – I – I..." I said "a week! A week!" I couldn't say what the problem was. I think with aphasia, when you're nervous and especially when you're on the phone, it really doesn't come out. When I've had a fit I can't speak properly for a week or a week and a half. And just before I'm going to have a fit – it really starts to get mixed up. *Euston!*

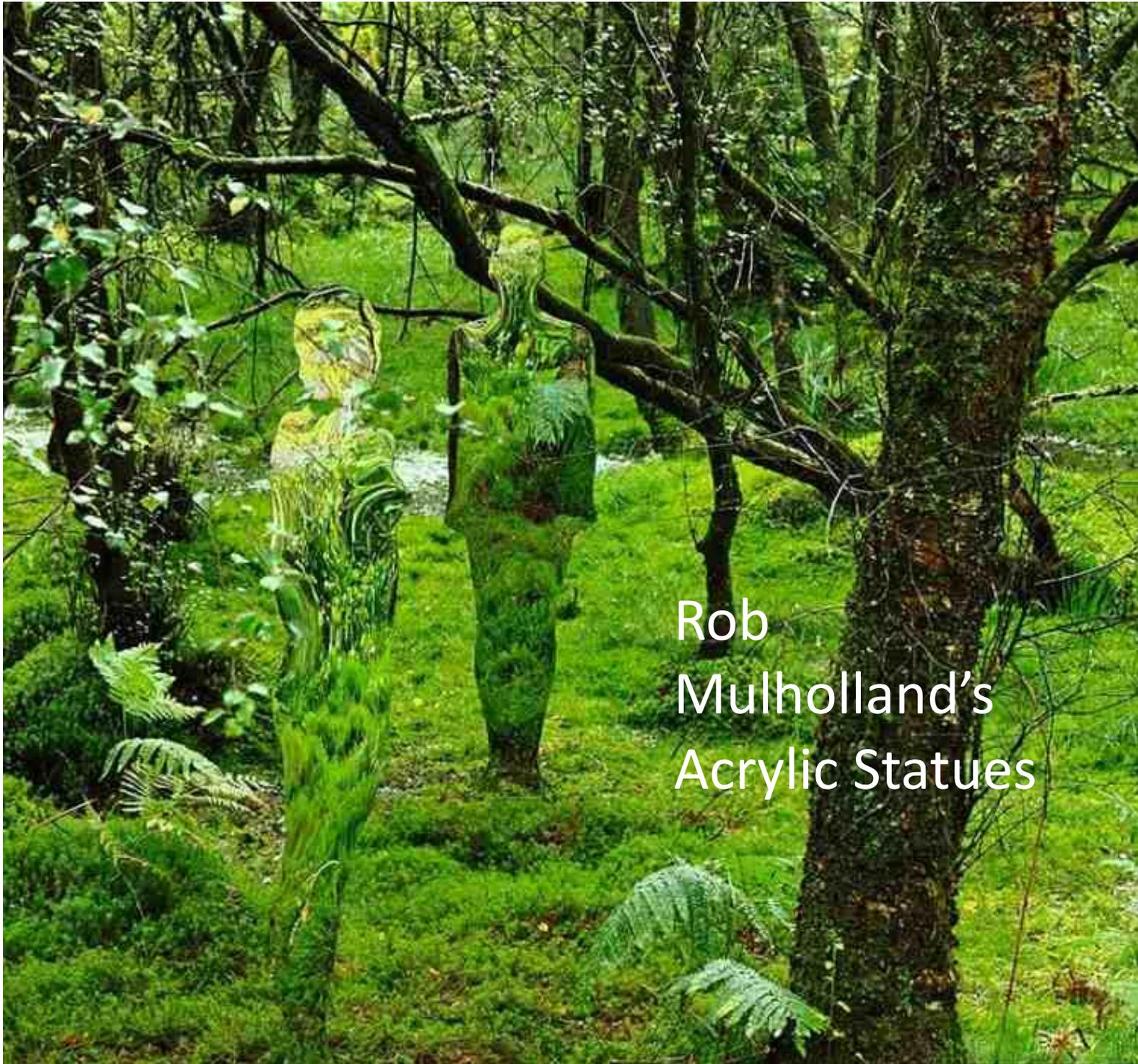
Richard – Brain Injury Survivor



Experiences of Epilepsy:

A 'Predator' – like sensation:

<https://www.youtube.com/watch?v=4OYpQq0tfuw>



Rob
Mulholland's
Acrylic Statues

Thank You for Listening!



www.headwayeastlondon.org

