

## Richard's story

I'm here to share Richard's story - I want to enthuse you so that you leave here ready to turn learning into action. Improving care and reducing health inequalities will improve both quality of life and life expectancy for people with a learning disability.

I want to bring Richard into this room so you see him as a real person, not just another name on a page, another death by indifference. So, here is Richard...

That was Richard, enjoying the normal stuff of family life. Aged 33, he died a premature, preventable death- from constipation. You heard the song... "Are we gonna wake the world?" Do you have the motivation for change?

Downs syndrome was quickly confirmed after his birth. We spent 10 days in hospital because Richard had a problem with his bowels. He didn't poo for days...concern grew. Doctors were on the point of operating...his bowels cleared. After several days of monitoring, they concluded that Richard probably had Hirschsprungs Disease – meaning that a small section of bowel wall doesn't have a nerve supply so faeces doesn't move along it properly. They said surgery might eventually be needed.

At the time there was no talk of confirmatory tests, no early operation to rectify things. **Was this an early example of health inequality?**

Richard started on solid food and the constipation began. He needed daily laxatives and a high fibre diet. Growing older, his bedtime routine included a lengthy spell on the toilet. I played silly games to make him laugh and threw toys in the air so he stretched to catch them. This encouraged him to poo - his muscles relaxed and his bowels would empty. I devised an effective way of managing his constipation, making the reasonable adjustments needed to keep him safe.

We raised concerns and he was twice referred to a gastroenterologist, the outcome? – we were managing it pretty well, so surgery wasn't advised even though x-rays showed that Hirschsprungs was still suspected.

**Was it the best decision? Was it a sign of health inequality in learning disability care? Did they assume he wouldn't cope with the surgery? Could surgery have prevented Richard's lifelong suffering from constipation?**

Aged 18, Richard changed. Mental health problems began. He lost interest in many things, became withdrawn... his sunny disposition faded. He'd suddenly look up into the corner of the room as if seeing something scary. He started to believe that characters in his favourite films were real... and was frightened by them. His GP prescribed antidepressants but there was little change.

At Christmas he became very agitated. He suddenly flipped. My gentle boy thumped me in the face and, though I was bleeding, he continued to hit me. My Dad was knocked over. I shouted to his sister: "Call the police". Richard paced the room, yelling obscenities I'd never heard him use before. The ambulance and police arrived, he calmed completely. At the hospital, my face was stitched, Richard was given medication to calm him.

Anti-psychotics were prescribed to go with the anti-depressants, a referral was made to the mental health team and psychiatrist. We stumbled on for 6 months. Richard's behaviours became harder to manage and, to my distress, he was suffering. I described it to the professionals... they never saw it for themselves.

They said "if things become extreme, call the team, someone will come." One evening Richard ran through the house, shrieking as if being chased. He eventually cowered in a corner, arms round his head whimpering. It was very distressing. **Now** was the time to make that call. Did anyone come? NO. I was told "give him an extra tablet, see if that calms him and call back in a couple of hours if necessary." I called back, did they come? NO. Just, give him another tablet. None of the professionals witnessed Richard's extremely agitated state. Nothing was done to check for a possible physical cause of the changed behaviour.

In June '98, it became too much. Emergency respite care was arranged. Within weeks, the manager gave the go-ahead for a camping trip with his Dad and sisters because "under her care he was fine". **I knew** he was still very unwell.

The Richard I knew had gone. I tried to explain the changes in him – they seemed to think I was exaggerating. Nothing could have been further from the truth, I just wanted him to get better. My 18 year history of caring for Richard, always fighting to get the best for him, counted for nothing.

In the next couple of weeks Richard attacked his dad twice. Camping was cancelled. Maybe things were not so fine after all. **Why didn't carers listen to me?**

During the first 4 months of respite care Richard needed manual evacuations twice because of faecal impaction. A barium enema suggested Hirschsprungs

- a biopsy was planned. His diet had deteriorated, the evening games had ceased. Family advice about care was ignored...so Richard suffered.

He moved to a hospital for observation and assessment. The psychiatrist cancelled the biopsy... saying - "it might be detrimental to his mental health". Psychiatry made a major decision about Richard's physical health. **Would this happen today? Or would a multi-disciplinary best interests decision be taken?**

A report detailed all Richard's care needs. It included everything to manage his constipation and keep him safe. **It made the link between constipation and his mental health.**

A residential care place, close to home was commissioned. I was delighted.

Richard received excellent support in the time before the move. Manager and key-worker were both fantastic, working with us and the hospital to ensure they gleaned every detail about how best to support Richard. We had meetings, visits, they listened to us. **It was a great example of nhs and care provider working in partnership with a family to ensure the best outcome.**

For years things were fine. Richard received excellent care. Changes in medication kept him on a fairly even keel. The weekly diet sheet was displayed, bowel charts were kept, manual evacuations were never needed. The care-plan was followed, it kept Richard safe. I never imagined that all this knowledge could be lost. BUT it was!

In 2010 the care home changed to supported living. They said it would be beneficial... only affecting finances and admin. Residents would have more choice in their lives. It seemed positive, but I had reservations...perhaps Richard would be expected to make too many decisions. There was no liaison between care provider and GP... no consideration given to whether Richard's health care needs would still be met.

At the meeting to sign the tenancy agreement, I raised doubts about Richard's capacity to understand the contract. I was assured that he understood, because "they'd worked on it with him". I let him sign because it was required in order to stay. I knew it didn't commit him to anything because he'd no understanding of it. After he died, I discovered the logbook of the work done... it clearly showed he had no clue what it was about. **Is there a better understanding of the Mental Capacity Act now?**

I noticed that Richard was putting on weight. A carer told me he was being allowed to make bad decisions about food, his diet was poor. Senior staff said

“Richard had the right to make unwise choices just like everyone else.” Alarm bells rang... he didn’t have the capacity to understand the negative effects of unhealthy eating. I suggested he only be given healthy options and in order to maintain his health and his rights. It was agreed... I was reassured.

Richard was allowed to make many “unwise choices” because “under supported living he had the right to do so.” He quickly learned he could refuse - to get up in the morning, have a bath, clean his teeth, cut toenails, eat fruit and veg, be supervised when pooing. This new regime created health problems.

We only discovered this when we realised that carers had bought shoes which were far too big... to give room for nails which curled right under his toes. Although I saw staff every weekend, they didn’t tell me they were having difficulties giving good care. Things were allowed to escalate, becoming entrenched behaviours without family or GP being made aware. As soon as we encountered any problems, we had always devised a solution **This shows how improved communication between care provider, other agencies, and families is an essential part of improving the lives and the safety of vulnerable people like Richard.**

Previously staff had **expected** Richard to do things, helping him where necessary. Just like when he lived at home. Now **he** had control, it was unsafe. I believe this very poor application of the Act and the lack of best interest decision-making, coupled with the failure to involve the family ultimately led to Richard’s death. **Is the Act any better understood and applied now?**

After Richard’s death I discovered that when care changed to supported living, there was a mass clear-out of paperwork. Including details of so-called “non-negotiable” aspects of care, such as the need for a high fibre diet and the active monitoring and management of bowel functioning.

At the inquest a carer said that Richard was refusing meals, they were glad to get him to eat anything. How long had this been going on? Well, looking at his daily diary, the diet deteriorated long before meals were refused.

After Richard’s death in 2012, I learned that bowel charts had stopped in January 09, replaced by haphazard, not very informative comments in the diary. Despite the need for daily laxatives, carers didn’t think there was a big problem with constipation any more. Richard ordered staff out of the bathroom when he was pooing making monitoring difficult. They didn’t seek any help or guidance in dealing with this. No best interests decision was considered. Richard didn’t have the capacity to understand why monitoring

was necessary but he was allowed to refuse it on the grounds that he should be allowed privacy.

Major changes to care were made with no reference to family or health professionals - no new care plan, nothing documented. Raising the changes with me would have rung alarm bells... they'd removed the vital elements needed to keep Richard safe. **This shows the need for carers to work with families to avoid poor health outcomes. Care plans must not be changed in isolation.**

Social Services didn't carry out the required monitoring during the change to Supported Living, and didn't follow their timetable for reviewing. They didn't know whether or not the new regime was proving suitable. Neither GP nor psychiatrist attended reviews so there was no health input to decision-making. **If care providers and medics had worked together would things have ended differently?**

The GP and psychiatrist knew that Hirschsprungs was suspected. Both prescribed medications with constipation as a side effect, but gave carers no guidance on what to look out for. They both assumed that Richard's bowels were being managed effectively because carers didn't raise any concerns. So problems went undiscovered.

During 2012, the psychiatrist sent the GP 3 letters. They detailed changes in Richard's behaviour and asked the GP to continue with physical management. But there was no GP appointment between February 11 and October 2012. The system of annual health checks wasn't working, nobody was monitoring or coordinating Richard's care. **Should carers have been ensuring that health checks happened?**

From Easter 2012 Richard's mental health deteriorated. The Richard who'd been fairly ok for years, just disappeared. I didn't know the comprehensive care plan that had kept him safe had been downgraded. Despite the known link between mental health and constipation neither GP nor psychiatrist considered the possibility of a physical cause and didn't explore this with carers. It was all viewed through the lens of mental health. **Would closer collaboration have saved Richard's life?**

Monday 12<sup>th</sup> November – started an unforgettable, harrowing week. The psychiatrist advised a move to an ATU, to assess Richard's mental health.

He also expressed concern about the distension and hardness of Richard's abdomen. He advised an emergency GP appointment. He didn't contact the GP himself, but left it to the carers. Richard wasn't seen until the next day, Tuesday. Faecal impaction was diagnosed by a trainee GP. The normal

treatment of 8 sachets of movicol in 24 hours was prescribed. She didn't consider that he was in this state despite daily laxatives and didn't know Hirschsprungs was suspected, so she didn't escalate the treatment.

On Wednesday, Richard moved to the ATU. A psychiatric nurse was so dismayed by Richard's abdomen that he immediately took him to A & E. Richard was admitted to hospital.

His Hospital Passport, written solely by carers, said "he is a mostly independent man..." What a misleading picture – he was assessed as needing 24/7 care. It made no mention of constipation; a vital element of his care needs ... omitted. It did describe his fear of needles, BUT on Thursday, he was held down screaming while anaesthetic was administered ready for a manual evacuation. No reasonable adjustment, such as the use of a pre-med, was considered. **Could carers liaise with GPs, producing a more useful document? One that included all health conditions and suggested reasonable adjustments to avoid such trauma.**

The procedure involved the removal of 10kg of faeces but Richard's abdomen remained huge. Projectile vomiting of dark brown liquid didn't trigger further investigations. It was just assumed that the normal pathway of fluids and laxatives would clear things and he'd soon be discharged.

During Friday he had breathing difficulties and was put on oxygen. I learned from records that despite his early warning score going up several times, senior staff weren't called, so Richard didn't benefit from their greater experience. No action was taken until 10pm when the score hit 8. This is disaster level. **Was this another example of health inequality?**

We weren't told that Richard's condition was deteriorating during Friday evening, so he was alone. I was called to the ward in the early hours, on Saturday, I've never been so shocked by anything in all my life – Richard was dead. I wailed like a wounded animal, I couldn't take it in. To make matters worse, a nurse told me several times that "I just had to accept that his time had come." At 33, from constipation – he'd died. At the inquest an experienced colorectal surgeon said: patients don't die from faecal impaction. Well Richard did.

This happened before the LeDeR Project, so no automatic review. The Coroner called for an inquest and we submitted our questions. It was to take over 5 years.

The hospital investigation had no family involvement. The report contained weaknesses, inaccuracies, and omissions; weak actions were recommended based upon it. Our meeting to discuss it with them was a travesty. We raised concerns - at every turn they were defensive and tried to fob us off with unsatisfactory explanations.

An inquest, based on this, wasn't going to fully explore the failings and wouldn't prevent further deaths. So, in October 2013 we sent comprehensive complaints to the 5 agencies involved. This triggered a Serious Case Review, almost 12 months after Richard's death. Yet, in May, a lady with a learning disability had died in very similar circumstances to Richard. 2 deaths but no SCR until our complaint was received.

The inquest and complaints were put on hold. The SCR dragged on... the report finally published nearly 2 years later. The process was horrendous... with no meaningful family involvement. When we questioned, they became defensive and unpleasant.

It was a one way process, entirely dependent on the candour of the agencies. They could omit what they liked. For example, the hospital didn't include the early warning scores, arguably the clearest evidence of their failings.

**Are LeDeR reviewers more likely to receive a full and correct disclosure of information? Can agencies still cherry pick to protect their reputations? Meaningful involvement of bereaved families is vital.**

The 2 most publicised recommendations from the SCR, were that adults with learning disabilities and complex support needs should have a named care coordinator, and, their needs be **jointly** reviewed **at least** annually.

**Would a care coordinator have created better communication between agencies?**

Well, it might have ensured that Richard's needs were being met. If carers hadn't made decisions in isolation, with no regard for the consequences, Richard wouldn't have developed the severe faecal impaction which put him in hospital in the first place. It would have prevented a lot of Richard's suffering.

I sat through a lengthy inquest and received responses to complaints. The main aim seemed to be to minimise, justify and defend anything that could have been a contributory factor to Richard's death. This just won't reduce the number of premature, preventable deaths.

The agencies involved in the care leading to Richard's death all engaged barristers whose sole purpose seemed to be to ensure that no blame was attached to their agency. Shortcomings in care were brushed aside in the quest to avoid blame. For bereaved families this is appalling. Care providers especially have been closely involved with families; the pain inflicted when they argue that they did no wrong, is immeasurable.

I so often hear that “lessons have been learned” from investigations. I detest this phrase. The deaths continue... so lessons have clearly **not** yet been learned.

Care is complex and there will always be mistakes. There will be near misses and even deaths; I can accept that. What **is so** hard for me, is the culture in which there is so little transparency and a lack of candour. So much can be learned if there is a willingness to recognise and acknowledge the things that went wrong or could have been done better.

I believe that if care providers engage fully and honestly with LeDeR reviewers and with families, then progress can be made.

This is a vital aspect of LeDeR: no matter how many reviews are done, no matter how many recommendations are made, deaths will only be prevented if the people providing care engage and do things **differently**.

Today’s event gives me **hope, hope** that things can change.

I want Richard’s Story to inspire you to work **together** and **with families**...so that premature, preventable deaths become a thing of the past.

**Nobody should die from constipation in 21<sup>st</sup> century Britain.**

**Are you GONNA wake the world? Will YOU make a difference?**