

Firstly, thank you Professor Keighley for inviting me to speak today. It's very humbling to see so many people here.

So, just how did I get to be standing up here? My name is Jenny and this is my story.

My daughter – my first child - was born just over 7 and a half years ago.

Almost straight away after her birth I realised things weren't quite right. I'd had a very traumatic experience in hospital and my daughter was roughly delivered by forceps (those damn things) after an exceptionally long second stage –it was later found to have been around 9 hours. An episiotomy and few superficial tears was all that I was told.

After a few days at home, I'd had occasions when I hadn't been able to get to the toilet in time, and I was in constant discomfort. Things did not improve and my stitches hadn't healed so a month later I went to see my GP. My GP told me what I was experiencing was normal, and to be expected after having a baby. She was reluctant to refer me to see a specialist (as I had come at 4 weeks, rather than at the usual 6 weeks post-birth check), but I insisted. I felt that my birth story was not believed and that I was not being taken seriously.

Two months later, I met with the consultant obstetrician and gynaecologist who confirmed my growing fears. The stitches were infected and I had a very bad internal tear affecting both sphincters (the tear was later identified as a 3c tear). I'd also sustained what appeared to be a significant neuropathy, likely from the long second stage and forceps, so I was suffering from bladder incontinence as well as bowel. The third degree tear had been completely missed at birth. Again, when I recounted my birth story the consultant didn't believe my birth story. The consultant told me that it was best to repair large tears immediately after delivery, and that belated repair of missed tears did not usually fare so well. With the addition of a nerve injury, surgical repair would not be beneficial to me anyway. I was shown how to do targeted pelvic floor exercises with a neurotrac device to improve the remaining muscle control. I diligently did my exercises every day for weeks, but hated every second (it's not very comfortable). When I returned for assessment six weeks later, the device had not made any difference at all.

Shortly after my appointment with the consultant I began to have frightening flashbacks to the day my daughter was born, to the moments when it all started going wrong. I had difficulty sleeping, and got into an exhausting pattern of insomnia which would go on to bother me for years.

I spoke to the hospitals PALS, and set up a meeting with the head of midwifery to complain about how I had been treated. The woman on the phone said to me "we've been expecting this call". So somebody involved in my daughter's birth knew there had been a near miss. I had to find out what happened. I was very angry and bitter about my birth experience. How could they not notice such a big tear? Why didn't they tell me anything after she was born? I was angry I did not have a choice as to how my daughter should be born (I had wanted an elective section but was coerced into a natural birth.) I got hold of my notes and saw for myself that my experience in hospital was shocking. My injuries should have been prevented.

Six months on from the birth physically, I was not in great shape. I had hardly any control of my bowel or bladder and had frequent accidents. I had completely altered sensation so couldn't always tell if I needed the toilet – or not. I was anxious about leaving the house because if I needed the toilet, I could not hold it in – I just had to go there and then. My new mum friends were back to normal – going to yoga, swimming, returning to work - meanwhile I was uncomfortable, leaky, and feeling very left behind. Activity, even brisk walking made my problem worse, there were days when the incontinence was so bad I couldn't leave the house. I felt unclean, degraded, unhappy and isolated - I even wished I had died in childbirth. My

relationship with my husband was suffering, our sex life was non-existent. At one clinic appointment I asked if I could contact other patients that might be going through the same as me – but no, patient confidentiality meant they could not give out names or numbers. I was desperate to speak to someone, someone that would understand, someone that could give me advice, someone that knew exactly what it was like. Add to this a baby to look after – inside I was breaking.

My maternity leave over, I had to return to work. I had been a Rights Manager for a well known UK publisher, a job I was good at, a job I loved. I had to tell my employers that I was not well enough to return to my job – without going into too much detail I gave them some indication of my health problems, and so my contract was renegotiated to a junior position, along with a pay cut. I found the commute to North London too hard, I was scared about having an accident on public transport, and during a working day I would eat little and drink even less. I felt awful. After 3 months I quit, my self esteem in tatters.

After leaving my job, emotionally, I was a mess. Little things would set me off – pregnant women, new babies, even an old lady cycling on her bike made me burst into tears one day. I felt like I had failed as a wife and mother. I must have cried every day for about two and a half years. Some days I would cry all day. I hated being me. I hated being doubly incontinent. I felt resentment towards the mums who I met at mother and baby groups who'd had easy births or sections. I wished misfortune would happen to someone else, just so that I would have somebody to share my misery. My personality changed. My husband said to me one day "you never laugh any more, you used to be such a fun person". He was right – all I could feel was loss and sadness.

I was frightened leaving the safety of home and often made excuses to avoid certain situations. When I did go out, it would be through gritted teeth and availability of toilets carefully researched! Apart from a couple of close friends and family, I hid my problems from everyone else. Their well-meaning but unintentionally hurtful questions depressed me further "so you'll be having number two soon, won't you? You don't want your daughter to be an only child"

My lowest point was around two and a half years from my daughter's birth. I had been told that nerves can take a long time to recover – typically around two years, and that any recovery would have been apparent by then. I was waiting for something magic to happen to me by then, but the two year anniversary went by, and no miraculous recovery had occurred, I was devastated to think that I would be incontinent forever. A teary conversation earlier in the year with my GP had led to me being referred for some counselling, as long as I was prepared to wait a few months as there was a long waiting list. The counsellor was nice but I felt she was too young and crucially had no experience of childbirth herself, and at every session she wanted me to just talk over the traumatic birth, which I did not want to do. After four sessions I decided not to continue –so in a way the counselling did help but not in the way that it was supposed to - if that was the best the psychological services had to offer then I would just have to bloody well sort myself out. It was the wake up call I needed.

I had two lots of surgery that Autumn - TVT to help the bladder incontinence and a trial of sacral nerve stimulation. The TVT ended any chance of having another baby, and it was a very difficult decision to make because once I'd had my daughter I did really want another baby. I knew my family wasn't complete but I couldn't live with bladder incontinence any longer. The TVT was disappointing at first, but in time the stress incontinence did improve, although it did not cure completely. A trial of sacral nerve stimulation followed the TVT but that was unsuccessful – the nerves that the electrical impulses needed to stimulate were completely gone. A course of biofeedback followed the SNS trial – the results of which proved that I

had practically no strength in the sphincter muscles, but I was shown how I could manage my condition by controlling diet (not quite so easy for a vegetarian), using more specific pelvic floor exercises and to add a rectal wash out to my daily routine. The delightful Qufora mini irrigation system– a rectal wash-out is as fun as it sounds – but once I'd got the hang of it made a huge difference. I found some other products that helped the bladder incontinence; and armed with my new routine, RADAR key, Just Can't Wait Card and 'Toilet Finder App' coping with incontinence and leaving the safety of home became easier. There was a tiny chink of light, shining at the end of the tunnel at last.

Last year we made some adaptations to our house, we now have a second toilet and shower where I can do my routine in privacy, and I always have right of way to the toilet. Having access to a toilet at all time when I am at home has had the unexpected but welcome benefit of significantly reducing my anxiety, which in turn has improved my anxiety levels when I leave the house. I understand my body so much better – planning my day around my bowel routine and access to toilets has become second nature. Perhaps it is because I have finally accepted my condition, and forgiven my body - and with acceptance comes the next stage of healing. I will probably find things deteriorate further as I age but until then I'll try to stay positive not let my problems hold me back. I'm ready to get my career back on track and recently retrained for a new life as a medical secretary. I'm excited about getting back to working again – but here's the thing, just how much do I tell my new employer?

For seven years I did very little activity, other than gentle walking. I used to be very fit and sporty 'before' and was devastated to find that exercising was just too uncomfortable but then... I discovered EVB shorts and last September I started running again – slowly and gently and with lots of preparation - the exercise has made me feel almost back to my old self again. I did a sponsored 10k run for MASIC recently (you may have seen me on the website). I'll admit I've got a bit addicted - I've just signed up to do another next week.

It has been a very long recovery for me, physically I'm not that much better from the day of the injury – my condition seems to have levelled out; crucially I haven't got any worse. What has changed in the past couple of years is my attitude towards my problems. Now, if I have an accident, I'm more likely to laugh it off and say "oh dear, I'm glad *that* doesn't happen every day", before I would crumble into a mess and hide myself at home. The support from my wonderful parents, my sister, my husband Rick - I'm so grateful to have the most patient and understanding people on my team cheering me on. I've recently confided in more of my friends and family, who have been really sympathetic and kind. And my beautiful daughter too – she survived the ordeal of her birth completely unharmed – she has been the most important reason to hold myself together.

Meeting Professor Keighley and getting involved with MASIC was another pivotal moment. Losing my career had been such a blow to my confidence, but now I had value as a person again. And of course, meeting the community of amazing mums was simply the best tonic and the very thing to get me motivated again. Being incontinent, is, to be honest, shit (excuse the pun) – but I've found what works for me and I haven't felt this good about myself in years. I know I'm one of the lucky ones.

From my point of view, this is why I think MASIC is desperately needed.

Broken is a word that many of us mums agree is how we feel about ourselves. Help needs to come from many directions in order to put us back together.

A problem like mine is expensive. I had to give up my job and my family lost an income. For a few years my husband worked overtime when he could to make sure we could manage financially. Not every woman is in that fortunate position. Equipment – like the Qufora - isn't cheap either. I get mine on prescription for now but if it is withdrawn from the prescription list as the NHS tightens its budgets I will be paying £60 per kit. And I use one kit per month. Pessaries, pads, wipes - the costs all add up.

A problem like mine affects the whole family. If you saw the Victoria Derbyshire feature on TV in the Autumn both the mums featured had relationships that broke down. It's easy to see why. There is little support for partners. Not everyone is strong enough to understand the frustration, the isolation and the anger that can come with an injury like this. We need to make sure that the families are not excluded. Losing a sexual relationship is a hard thing to come to terms with. I'm lucky I have the support and love from my family, but what if I was having to cope on my own?

A problem like mine is time consuming and tiring. I calculate that over the 5 years I spent getting treatment, I attended over 40 hospital appointments – for physiotherapy, for surgery, for follow-up appointments, for urodynamics, for counselling. Every appointment involved a journey to negotiate, a stranger to explain my situation to, a train fare to fork out for, all in all a mentally exhausting day. I'm lucky I live in the south east, where I have not had to travel for hours to get to appointments.

Because my experience in hospital was not "typical" I found I was not always believed by the medical profession. My GP told me my lack of control was normal after giving birth. The consultant obstetrician told me it wasn't possible to have a second stage labour of over 8 hours. Another had no sympathy when, fighting back my tears, snapped at me to stop crying as I wouldn't be able to understand anything she was telling me. The first person that truly believed my tale and took me seriously was Sally Nichols at Leigh Day. I took strength from her belief in me and started legal proceedings against the hospital trust, a process that took 6 years to resolve. I knew it was the right thing for me to do but I must stress that MASICs aims are not to encourage every injured woman to stampede towards the courts. When I received the hospital's letter of apology it didn't feel like a victory, instead like a release, like my life had been at a standstill for 6 years, and now I could finally move on. But I have learnt that sometimes it's worth throwing caution to the wind just to feel normal again.

None of the doctors, consultants and specialists have been able to predict how my condition will change as I age. I have the menopause just round the corner which may cause my current level of control to deteriorate. There may be more surgery ahead (I've got a couple of prolapses brewing). But I'm hoping that the advances in geriatric medicine and perhaps even stem cell research may provide new treatments in the future.

Not long after I had found out the full extent of my injury my mum said to me, "this has happened to you for a reason – you're going to do something about it". At the time I thought, what can I do? – but on my way to recovery I have met some dedicated people that can. That's you here today. I don't want any other woman to go through what I did. If only I'd had somewhere to turn to for advice about coping with incontinence, to find out treatments and products, to speak to someone that knew exactly how I was feeling, to support my family – well now, MASIC can do that.

Thank you.