AIMS For a better birth...

Jean Robinson talks to Emma Ashworth about her time at AIMS

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Emma Ashworth (EA) interviews Jean Robinson (JR) about the years of support that she's given to AIMS, and to women and families. Jean retired as AIMS' Honorary President in 2018. We join the many thousands of families whose lives Jean has touched in thanking her for her work, her passion and her inspiration.

EA: When did you get involved in birth issues, and why?

JR: When I was Chair of the Patients Association in the early 1970s, I started getting horrifying letters and phone calls about induced labour. I decided that I needed to learn about normal labour! I found a local midwife, the great Chloe Fisher, who became my reference point, and for the first time I decided to read medical journals to find out about induction. At the time, the Patients Association was the only voice of patients in healthcare. I took over from Helen Hodgson, who had founded and run the Association with a tiny grant and a staff of one part- timer.

When I took over, it became a full time, unpaid job for the next three years! But I learnt so much from it – not least from the 100s of complaints that we received every week.

Letters about birth leapt off the page, with comparisons of induced labours against non-induced labours; this being at a time when maybe 60% of women were being induced! Gestational dates were less clear as there was no ultrasound at the time, and there was not a wide use of epidurals. Moreover, there were, as yet, no prostaglandins so women were struggling with oxytocin-induced labours and non-physiological contractions against an unripe cervix.

I was living in Oxford, and the local professor of OBS/GYN had done some early research on artificial oxytocin induction and he asked me to do a talk at the local maternity hospital about induction, and how women felt about induced labours. The room was filled with midwives and obstetricians! I talked about the hundreds of letters I had studied from women about their traumatic experience of induced labour, and mentioned a case study of a woman who had one straightforward, spontaneous birth and healthy baby and then her second baby was born following induction and an overdose of artificial oxytocin, following which the mother ended up suicidal. She spoke movingly about how she felt differently about her two girls. With her second daughter, her instincts were muffled and she had to consciously react to comfort the child if, for instance, she fell over, rather than it being a reflex action as it had been with her

first first.

I felt – listening to these women – that the hospitals were taking away something crucial. I couldn't define it; there were no papers on it. I just went back and forth between the helpline and the scientific papers such as they were, and they were worlds apart.

I was then asked by Woman's Hour on BBC Radio 4 to do a piece on women's health. This was just a general piece, not just on pregnancy and birth, but at that time many women's health problems were thought to be psychosomatic. I found that Women's Hour were getting letters on induction as well!

Following this, I contacted the agony aunt Claire Rayner. It turned out that she was anything but an ally. As a former nurse she strongly felt that "doctors must decide" and she berated me for suggesting that women should make up their own minds. However, she was also receiving hundreds of letters on induction which she passed to me. I read every one, and then I wrote to the Lancet, saying that the paper that they had published did not prove that induction reduced stillbirth, as they were claiming. An Obstetrician in the south of England replied.

"Who is this doctor hiding behind the skirts of the woman writing this letter, since no layperson would have known enough to write it?"

I started to read medical journals at the local library – medical dictionary in one hand, and medical journals in the other! I wrote back to the Lancet to say that no doctor had written it for me. All I needed was a Bodleian readers card and hundreds of letters from women who had been induced.

I think that this is a woman's way of working - listening to women and believing that what they said was true, was valid and it mattered. For their mental health, for their children and for their family.

I went on to speak to husbands who couldn't understand why their wives were in the state they were in – but I know now that they had Post Traumatic Stress Disorder (PTSD). There was nothing in the research at the time, but their letters reminded me of World War 1 Shell Shock. So, I went back to the library and found that work had been done on mental health in the military since then, following the Vietnam war. That was where the term PTSD came from. Then I read about similar conditions in police and ambulance crews, and I realised that all the research was being done on men! Women's descriptions of their feelings around their birth stories were closer to descriptions of rape - different to male PTSD.

I have since thought about it a lot. I feel that the birth letters were different to other forms of trauma, such as from surgery, misdiagnosis, mistreatment, and the difference was that women are particularly sensitive around the time of birth and shortly afterwards due to their raised oxytocin levels. This makes them intuitive – they sense whether the midwives and doctors around them are being kind and helpful and mean well, or are antagonistic. Research shows that memories of birth, both good and bad, are very long lasting, detailed and exceptionally durable. What happens in birth is so important. We need to drill into every student that increased hormonal levels can increase psychiatric damage.

EA: Did your personal experience of maternity care affect your involvement with AIMS?

JR: No. For many years I was sub-fertile, so we adopted a baby boy and four years later I had a daughter. I needed all the obstetric intervention available, but this did not prevent me from learning about the importance of normal birth from listening to AIMS helpline callers. I have always loved babies, but I was with AIMS for women's rights. I want people to start their family life on a good footing. Transitioning from being a couple to a family when you have your first child is such a challenge, and men and women should be given all the help they can. But not from officialdom! "Do not do unto others as you would be done by – their tastes may not be the same". G Bernard Shaw

EA: How did you get involved with AIMS?

JR: At the Patients' Association I used to suss out any special support groups which existed for people with problems. I explored AIMS and the NCT but I preferred AIMS! NCT is much more orthodox and I'm not orthodox! After I left the Patients' Association in 1973, I joined AIMS and I became the honorary research officer, monitoring the obstetric journals in the library and trying to explain things in more accessible language for AIMS readers. My husband subsidised my AIMS work and was wonderfully supportive. Later, he became unwell and needed more care and I had to give up the journal study, then later, when our founder, Sally Willington died, I became president. I'm not a title person, but it's been a tremendous honour and I liked writing official letters to tweak the minds of people at the Department of Health and similar! I consider myself to be politely irritating to officialdom! It takes me until the 3rd or 4th draft to get it polite enough, though…

EA: Can you tell me about some of AIMS' achievements whilst you were involved?

JR: The one thing I am personally pleased about was (after many years of trying) finally persuading the Department of Health to look at suicide as a cause of maternal death, since I spoke to so many suicidal women on the phone. Finally, we had a woman medical officer in charge of the Confidential Enquiries, Dr Gwyneth Lewis, and she listened. When the first study including psychiatric deaths was produced, suicide proved to be the largest cause of maternal death. Also, Beverley Beech and I wrote a letter to the British Journal of Psychiatry about nightmares after childbirth, and this is credited in the medical literature as being the first identification of post-natal PTSD. It was phone calls to the help line which taught us about this.

I was constantly asking "what is the evidence base for what you are doing" and often there wasn't one. I knew that no one would listen to a lay person without evidence so I went to Ann Cartwright, who was a well- known sociologist who worked on medical issues, and I persuaded her to do a study on how women felt about induction. Ann published a book which showed that women didn't like induction, but obstetricians did. So then we had got something published in the literature that we could quote.

Through helpline calls I suspected that women were concealing Post Natal Depression through fear of referrals to Social Services. I went to talk to my GP, who was a researcher, who then did some research

into this – found that it was true – and published it. This gave us some more research to work with!

We were constantly challenging things like routine episiotomies, and I wrote a column in the Birth Journal of Midwifery for 10 years where I talked about what women were complaining about, and what could be improved, in a way that midwives would read.

EA: What changes have you seen in maternity care - for the better or worse?

JR: The recognition – at last – of the importance of normal birth and the gradual erosion of standard practices in maternity hospitals which prevented it (e.g. routine episiotomies, denial of food and drink, the stranded beetle position for birth, etc.).

EA: How has AIMS evolved over your time?

JR: We have always depended on a surprisingly small number of hard-working volunteers. It is listening to women on our confidential helpline that has provided changes of direction, because they tell us about how things are changing on the ground in different areas. But, our greatest strength has always been the same – listening – and a willingness to be changed by what we hear.

EA: What is the biggest challenge for AIMS going forward?

JR: The shortage of money in the NHS which will prevent changes we would like going forward.

EA: What do you hope for the future of AIMS?

JR: That we shall go on listening to women and representing their different voices. We will continue to succeed by perpetually challenging obstetricians for their evidence.

EA: What has been your biggest frustration?

JR: The failure of the population to recognize the potential harm of ultrasound, and the dishonesty of obstetricians in claiming it was safe.I'll not be happy until we are routinely measuring mental health outcomes in wider research. We know that there is lots of evidence on how poor maternal mental health is bad for the baby, not just for the woman! If you look after the women properly, the mums and dads, you don't have to worry about the kids! How can you not do that? I get so upset and indignant and I should be past that but I shall die with my shillelagh in my hand!