

## **Anonymous - Written evidence (PRT0014)**

I am 52 year old male preemie who was born by c-section in the early 70s. I was estimated to have been born 4-5 weeks premature and I was very poorly and not expected to survive because my lungs were so underdeveloped. In those days, ultrasounds were a new phenomenon on maternity wards and it was thought that I was further along than I actually was. My planned c-section birth was needed because my mother required an emergency c-section with my older brother.

In the 70s, all c-sections were done under general anaesthetic so when I was born (5lbs 4oz), my mother was unconscious. Because I was in immediate respiratory distress, I was rushed to the NICU, where I was intubated and placed in an incubator. I remained there for > 1 month as I was critically ill and not expected to survive due to respiratory ill-health. After a month in my incubator, I was stepped down but remained in the children's hospital for a further few weeks.

Of course, maternity care was very different back in 1971 and much has been learned over the last few decades. I survived but missed out on breast-feeding, kangaroo-care and post c-section swab because these concepts (or importance of these concepts) were yet to be established through evidence-based research. Without emergency care I would have died, so I'm grateful for the interventions I received and believe that what was done for me was done with the best of what was known at that time.

My rocky start continued with childhood illness and I experienced multiple physical health problems and hospital admissions due to respiratory infections. Aged 5, I was admitted to hospital and diagnosed with meningitis. At 16, I developed shingles for the 1<sup>st</sup> time (the first of four episodes to date) and at 17 I was incapacitated for months with glandular fever. Arguably, these conditions evolved from me having a compromised immune system.

While managing my adult life and relationships relatively well, I've had issues with anxiety/depression by being neurodivergent and experiencing trauma. I was diagnosed with ME/CFS 5 years ago (though it's legacy dates back much further). Having ME/CFS has had a major impact on my physical, cognitive and mental health. I am now no longer able to work and I retired early because of my ill health. I have diagnoses of ADHD (combined type) and autism (both of which are more prevalent in ex pre-termers), as well as asthma, hypercholesterolaemia and hypertension. However, it is the extreme fatigue and joint pain associated of ME/CFS (and probable Fibromyalgia) that debilitates me the most.

While much has changed in paediatric care since the 70s, awareness re the long term implications of premature birth remains in its infancy (slight pun intended!). This is also the case regarding the long term implications of being c-section, being in an incubator, the absence of colostrum via breast-milk, history of meningitis, glandular fever, shingles etc. However, what *is* known through current evidence-based research is that preemies are at increased risk of developing certain physical and mental health problems.

While more research is required, enough is already known to start the process of educating and training healthcare staff about the significance of pre-term birth history and associated risk factors.

Given the growing body of evidence, it is important that healthcare professionals learn about the health challenges encountered by those born pre-term. This is an opportunity to improve health outcomes through sharing what has been learned from evidence based research.

It is well-documented that there is a higher incidence of neurodiversity in people born pre-term which is one of the reasons why birth history is explored by psychiatrists when assessing for ADHD and autism. So, it is puzzling as to why birth history is so rarely discussed in other areas of medicine (with the exception of maternity) given that a premature birth

history is a significant risk factor for so many other health-related conditions.

An obvious example is cardiovascular health and the fact that preemies experience a higher prevalence of hypertension. Yet birth history is an unlikely topic of discussion in cardiovascular healthcare settings because by the time the patient is under the care of a cardiovascular medical team, the opportunity to avert a cardiac event (eg. routine blood pressure monitoring) has passed.

The lack of adherence to existing guidelines (eg. health reviews of all preemie children aged 2-4 born <28 wks ) highlights a lack of training. Furthermore, policy and procedures (supported by NICE Guidelines) remain long overdue yet vital to provide a structured framework for healthcare staff to work from.

It is important that healthcare staff are given training so their preemie patients can learn and be guided appropriately. Without adequate training born from legislation and policy, risk factors will continue to go under the radar.

I am writing this because we know that preemie healthcare needs don't end on departing the NICU. They continue throughout the ex-pre term person's life, often only resurfacing in adulthood where the link to birth history is seldom raised or dismissed as being inconsequential.

Of course, it goes without saying that not every healthcare intervention relates to premature birth. It is the associated health conditions more commonly experienced by preemies that require consideration and early intervention.

The problems that evolve from premature birth affect >7.5% of the UK population who are born pre-term (58,000 new preemies every year according to BLISS, 2023) so the figures are far from insignificant.

Training healthcare staff about the long term implications of pre-term birth has the potential to help so many people while allowing >7.5% of

the UK population to make better and more informed decisions about their health and future healthcare needs. Through doing this, there is the potential to dramatically reduce future burdens on already over-stretched NHS services and resources.

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