

Anonymous - Written evidence (PRT0002)

Thank you for running this investigation into the care of pre-term born babies, children, and adults. I was born in the extremely pre-term range of 28 weeks gestation or less, over forty years ago. I think I still benefit daily from my birth at a specialist hospital with advanced skills and not all pre-term born people were so lucky. However, having spoken to other pre-term born adults, to build on the excellent neonatal care available, I would like to make the following points.

It is known many preterm born people have hidden disabilities.

From speaking to pre-term adults, and reading research, my understanding is that many experience neuro developmental conditions, pain, and severe fatigue. Some are diagnosed with postural orthostatic tachycardia syndrome or chronic fatigue. I think it is vital more research is done in this area to support the ever-increasing number of preterm born people.

High quality life-saving neonatal intensive care is in sharp contrast to the lack of GP- based follow-up care.

Most people I have spoken to have referred to their difficulties not being connected to their preterm birth. Crucially, some people have said this has had a worse impact on their well-being than being pre-term itself. Comments along the lines of 'the doctor thought I was just making a fuss, that I wasn't really in pain.' In fact, much is now known at research and specialist level, but it has not disseminated down to GP level.

The emotional impact of hidden disability

Many people commented on:

The emotional impact of growing up with learning difficulties such as dyscalculia.

Many have said that because prematurity has mostly a hidden impact, they feel friends, family, teachers, employers, and doctors do not recognise that it is genuine.

Other people have commented on anger and sadness about what they see as a lack of life achievements due to long-term health issues related to prematurity.

Many have commented on severe fatigue and lifelong lack of stamina, and some have said this means they cannot undertake enough paid work to support themselves financially. This naturally has caused frustration, sadness, and anxiety.

Suggestions:

Ensure GPs are trained in the chronic nature of prematurity, and the emotional impact of unrecognised hidden disabilities.

1. When the treating doctor is unaware that they are seeing a pre-term birth impact, it is unlikely to be taken seriously. This often conveys to the patient that their physical pain can be dismissed as unimportant. Several patients have simply been told 'I'm sure it feels real to you' and sent on their way! This is damaging to a child's self-worth. It conveys that the child is neither valuable enough to be believed nor to have their pain treated.
2. Neuro developmental symptoms include difficulties with reading, writing, and working memory. They may not lead to significant illness. However, a child's 'working day' requires achieving these skills and so the child needs to be heard and supported.
3. Clear NICE guidelines would make a significant difference as would setting targets for the long-term care of pre-term born people.

4. Training for GPs and therapists and teachers on the emotional well-being aspects of prematurity for the pre-term born child and adult. Ideally, this would lead to specialised mental health care. At present, some symptoms are seen as psychosomatic in pre-term born people. However, I think they are often the result of prematurity, for example, eye tracking difficulties, fine motor coordination difficulties, and exhaustion. For pre-term adults now approaching middle-age, many were put in the wrong school year if they had a summer birthday. Premature children have a raised risk of learning difficulties, and this combined with being young in the year is likely to have led to constant, daily struggle. It is not surprising this would have led to unhappiness. It does not mean that unhappiness was causing the pre-term symptoms!
5. Ideally, specialist clinics would be created where pre-term born children and adults could receive support for the above-described difficulties. This would also be helpful because many pre-term people report more health issues as they age.

Medical resistance to new knowledge

My belief is that significant numbers of pre-term born people have hidden disabilities which are neither recognised, diagnosed nor treated. When they begin to question if their pre-term birth has impacted their health, most go straight to the GP. Most GPs will acknowledge that they are not familiar with the long-term impact of prematurity across the lifespan. Unfortunately, at present many are unwilling to read information on the topic, even if it is very short. The patient is left without knowledgeable care. It would be helpful if this could be conveyed to GPs so that optimum care could be provided. As busy professionals, doctors are unlikely to have learning difficulties and chronic health problems. Therefore, many may be unaware of the unrelenting daily hidden struggle many pre-term born people face. They unwittingly

compound it by conveying that the child is not sufficiently valuable for it to be worth gaining the knowledge to help them. Many people have said this is like being kicked while they are down.

The good news

Survival rates of pre-term babies are increasing, and rates of severe disability are falling. This is well worth celebrating and I am sure that after-care can be made equally excellent. I do not think disseminating findings and providing GP training would be excessively expensive and it would be straightforward to achieve. Then we would not only have excellent care in the neonatal unit, but for the lifespan as well.

The positive impact of accurate diagnosis

On occasions when a doctor has recognised the prematurity impact, I have heard people using words like 'I no longer felt invisible' and 'it was life changing.' One person described how, now her chronic health issues have been diagnosed, she feels able to participate in disability sports. She is gaining all the benefits of physical exercise as well as making new friends. Now she knows her health issues are due to prematurity, she no longer needs to visit the GP on a regular basis seeking diagnosis. This saves public money. I am sure all GPs want to provide excellent care. Working with patients who have been at the cutting edge of advanced neonatal medicine and who have survived at the earliest gestation dates possible could be very exciting. I think GPs just need additional training to give them the tools they need.

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