

Mrs Gillian Ingledow - Written evidence (PRT0012)

1 My daughter was born at 26 weeks gestation and extremely low birthweight (< 500g) and given a 20% chance of survival. She is now in her mid 30's. My submission is based on my lived experience and also from perspectives I have gained from having worked for the NHS as Registered General Nurse. I am now retired. I have no professional experience of working in Neonatology or Paediatrics. Within the context of extreme premature birth, I am, and will remain, mindful that with regards to outcomes we have been very fortunate. The focus of my submission regards access to informed advice and interventions. In my opinion this would be best provided by extended specialised follow up, by a multidisciplinary team, that includes those who are considered to be doing well in infancy.

2 The points I would like to make are a reflection of repeating patterns rather than single incidence. My emphasis on my concern that, outside of specialist areas, premature birth is rarely given the same amount of consideration routinely given to all the other factors that contribute to ill health or difficulty. From my observations, made over decades, my daughter is unable to precisely fit into conventional expectations, diagnostic and referral criteria or into conventional procedural formats, which were probably formulated without the needs of individuals born extremely prematurely in mind. This broadly applies not only to physical and mental health but socially, in education and in areas of employment. Without advice and guidance from informed support the impacts of this can be harsh and bewildering, affecting quality of life and obstructing good outcomes. Where informed or thoughtful support is given the results that I have observed are usually prompt and positive.

3 When my daughter was discharged from the paediatric clinic at the age of 3 none of us had the benefit of the commendable amount of information, much of it evidence based, that is available now. In my

experience, and that of my daughter's, informed support from primary care remains an expectation rather than a reality. I make the point with empathy. The impacts of premature birth on developing anatomy and physiology are complicated and contentious. Primary Care is overloaded and it is, in my view unreasonable to expect expert knowledge in every speciality.

4 Difficulties occur within the system when, as in my daughter's case, problems are subtle but multiple. Additionally, when presenting with one problem the signs and symptoms can appear to be routine. Routine intervention, however, has not always been appropriate for a premature individual. Although she was in her mid-twenties at the time, and well able to express her situation and concerns with clarity, my daughter required my support to get referral to consultant level. At consultant level the impacts of premature birth were recognised, and appropriate adjustments were made to advice and management.

Primary care practitioners could be facilitated by

- Birth history as mandatory inclusion on patient records.
- Routinely asking adults about birth history on initial assessments in all clinics
- A 'stand-alone' Premature Birth tick box for referral
- Access to a specialised advisory service
- A nurse specialist

5 The boundaries surrounding the specialities are strong and there appears to have been difficulty in sharing information which would assist healthcare practitioners, individuals born prematurely and their parents, in moderating impacts. Access to informed advice is likely to have a positive effect on statistical outcomes and, also, on quality of life for those born preterm. At the moment Primary Care is a key factor in achieving this due to the absence of extended specialised follow up.

6 The appearance of early on-set disease in adults might be reduced if premature individuals had the benefit of earlier intervention about lifestyle and diet, assistance with the management of stress and energy levels and sleep. The advice probably needs to come from those who have experience in Neonatology and / or lived experience. Advice and interventions that are known to be effective in those born full term may not be as effective or appropriate for those born preterm.

7 Greater recognition and acceptance that there are impacts to preterm birth might help improve outcomes in education and employment. Impacts vary in individuals. Impacts are a sensitive and contentious issue even now. I had the benefit of basic knowledge of anatomy and physiology and development when my daughter was born. To me it was common sense that a baby born in such unconventional circumstances may not enjoy entirely conventional anatomy and physiology. I was aware, however, that there would be the ability and potential to adapt and compensate. From my observations, the environment needs to be favourable to enable this to occur effectively. Socially there is room to manoeuvre, but in education and employment choice can be more restricted. The majority of people are born full term. Many do not have an understanding of anatomy and physiology. In this situation understanding that premature birth is not necessarily something that "is grown out of" can be difficult. I have observed my daughter, born prematurely and exposed to the unavoidable trauma of the Neonatal Intensive Care Unit, experience higher than average levels of stress and anxiety in noisy, busy environments where she finds it particularly difficult to execute executive skills, multi-tasking skills, fine motor skills.

8 Positive and informed interventions would moderate these difficulties but currently there are problems ascertaining their validity. Most do not appear to be obvious the general practice consulting room. Without official recognition, where appropriate, my daughter, and probably all those similarly affected, are exposed to unhelpful attitudes. Explanations

of her difficulties are often considered to be excuses and attributed to attitude and motivation. In situations of performance review this impacts on her potential for job satisfaction, promotion, her financial situation and her ability to maintain self esteem. From my observations my daughter appears to experience more difficulties than I observe in her full term peers. As a mother, my opinion can justifiably be viewed as somewhat subjective. However, the combination of difficulties I observe combine to form what is in effect a hidden disability, which if recognised would give some entitlement to a slightly adapted environment in which to work.

9 My daughter and myself attempt to be objective. Both of us are finding this exhausting due to the unusual, complicated, and sensitive context of our situation. Informed, objective and professional assistance would help to untangle the knots and enable her to effectively manage independently going forward. Currently adults born preterm but not in follow up are in an unenviable situation. Addressing the problem of their current lack of access to informed help would most likely lead to improved outcomes for her and all those who are following in her footsteps. It is reasonable to consider that this would be cost effective on the long term.

10 I am grateful for this opportunity to share my thoughts and experience. References to my daughter are made with her permission. I hope brevity has not interfered with clarity. My thanks go to all who are giving their time and attention to the complicated and sensitive issues surrounding premature birth.

11 Recommendations

- Extended follow up by a specialised multidisciplinary team that covers life course and includes those doing well in infancy.

Or

- Facilitating Primary Care to meet the needs of those born prematurely.

Education

Use of nurse specialists (possibly regional)

Adjustment of diagnostic and referral criteria and procedural formats.

- Specialised training for:

Speech Therapist / Voice coaching

Physiotherapists

Counsellors / Clinical Psychologists

Nurse led clinics. For example, respiratory and diabetic.

- Screening
- Holistic care
- Assessment for possible entitlement to an adjusted environment at school or in employment.
- Prem aware training for all teachers
- Tailored careers advice to include advice about self employment

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