

## **Adult Premie Advocacy Network CIC – Written evidence (PRT0066)**

1 We are submitting evidence as co-founders and on behalf of the Adult Premie Advocacy Network CIC (APAN).

### Our Aims

- Provide a global network of peer support and advocacy through this website and our social media channels.
- Acknowledge that each individual's experiences are unique and valid.
- Combine scientific evidence with lived experiences to promote awareness and understanding of the life-long physical and psychological impact of premature birth.
- Provide resources to promote and share relevant information within the community.
- Create strong links between the community and researchers to facilitate and advance research into the impacts of prematurity.
- Promote opportunities for participation in research.
- Promote patient-centred care, including ongoing monitoring, assessments and healthy lifestyle promotion over the life course.

2 Our network has evolved from a group of individuals born preterm, seeking to connect and share their lived experiences. Our network welcomes all gestational ages, birthweight and causes of preterm birth.

3 The co-founding members are based in England, however, the group is engaging with adults born preterm across the world. Of those that responded to a survey on our social media, 16% of members are within England and Wales, 4% within the United Kingdom and 80% outside of this area.

4 Our adult preterm members span the decades and we acknowledge that there have been differences in our care as knowledge has progressed, therefore, it is likely there are differences in impacts and outcomes. However, from our observations there appear to be impacts across the gestational categories. Many of these issues may not be evident during the early years of life.

5 Whilst sharing our experiences there were commonly recurring themes and areas of challenge and difficulty. These include, but are not limited to: physical and mental health, neurodivergence, experiences within education; social interactions / romantic relationships and employment. These factors cannot be considered in isolation and must be viewed as working in combination to create a full picture of life following preterm birth.

6 Over time, our network has grown to include parents of children born preterm. These children span in age range, from parents of younger children seeking an insight into what the future may hold, to parents of adults born preterm who have on-going concerns, and are worried about what their future may hold when they are no longer able to assist with and advocate for them.

7 A prevalent inquiry we receive from adults born preterm and parents alike are seeking recommendations of professionals with "specialist" knowledge of prematurity across the life course. We must highlight that the sense of frustration and distress is often palpable. Many have been seeking support, assistance and validation for a growing number of years where prematurity is an important piece of the puzzle in understanding the issues they are experiencing.

8 Peer support can play a vital role in sharing information and providing support to reduce the isolation often felt, but it is not a substitute for well-informed professional guidance.

9 We appreciate that in many ways, care has progressed and changed since our time spent in NICU. For example, that family integrated care has become a priority and that there have been adaptations made to the NICU environment, such as lighting and noise reduction, to reduce excessive stimuli.

10 We would suggest that there are many issues that need to be acknowledged and addressed in a retrospective way, to improve the experiences and outcomes of current and future generations of the preterm population.

11 A key point often raised within the network is that lack of awareness of these often complex interplaying issues is far reaching, and that this is having negative impacts upon mental health, and confidence and trust in the professionals we engage with in day to day life.

12 It is important to recognise that each individual born preterm may be impacted in differing ways, support and interventions need to be tailored to accommodate their specific challenges and strengths. In daily life we are interacting with people, the majority of whom were born full term. Our issues can appear to be similar but the impact of prematurity is not sufficiently considered.

13 We would suggest that prematurity in itself should be considered a category of disability due to the increased risk and incidences of widespread impacts across multiple areas of life for many individuals born prematurely.

14 There have been conversations regarding prematurity as a disability within the group. We would propose that those who wish to can identify as disabled, where their levels of impairment or health challenges impact their daily life and where they feel this would enable them to access the support they need. We recognise that is a complicated and sensitive issue. Also, we would appreciate the consideration of prematurity as an Adverse Childhood Experience.

15 The growing body of research into long-term outcomes after prematurity points clearly towards prematurity itself being a risk factor for developmental and chronic health conditions manifesting at varying ages beyond infancy.

16 From our experiences, it is evident that primary health care providers often do not have the underpinning knowledge around the longer-term outcomes, particularly issues that present after the neonatal period.

17 When individuals have received care and education from senior clinicians with a specialist interest in long-term outcomes they have felt heard and respected.

18 Education.

#### Recommendations

- Increased awareness across all education, extending the Prem Aware resources to cover pre-nursery through to further education and into the workplace to allow for reasonable adjustments and support.
- The topic of prematurity should be mandatory for all working in the education sector, given it is likely they are in contact with an individual born prematurely.

19 Awareness within Healthcare

We have often had issues and concerns dismissed where there is a lack of knowledge, or symptoms of physical deterioration. This has led to labelling as health anxiety or hypochondria.

#### Recommendations

- Increased awareness across all healthcare and allied professionals currently in practice and those in training (primary, secondary and tertiary healthcare, physical and mental health).
- Information for parents and families to support them in advocating for their preterm child's needs and to teach them about their birth history.
- Informing parents of potential long term outcomes, providing families with holistic health promotion and follow ups.

## 20 Long-term follow up

### Recommendations

- There are current structures to provide some children born preterm with follow ups into early childhood, but for children and adults born preterm who have not suffered significant disability or complex health within their NICU stay or early childhoods they will get lost in a system that isn't currently structured to provide long term physical, mental and neurological follow up.
- There is a need for long-term follow up which allows for monitoring and proactive / preventative interventions as required - this benefits the individual and has a wider benefit to economic activity / reduction in healthcare costs.
- Ask about birth history: gestational age, birth weight, cause of birth, neonatal journey, and understanding the significance of the answers.
- Prematurity should be utilised as a tick box for referrals to support primary healthcare providers in directing care in a timely manner.
- Prematurity should be recognised as a chronic condition. We would suggest this encompasses a Multi-Disciplinary Team and takes a holistic approach. These could be similar to previous "geriatric" clinics, encompassing all disciplines under the same roof.

- Creation of NICE and WHO guidelines to support the implementation of long-term care for individuals born preterm.

## 21 Health Advocacy

- Access to information for adults born preterm to enable safe and effective self advocacy.
- We acknowledge that there can be barriers for adults born preterm in engaging with professionals. This includes hesitancy to share, due to negative past experiences affecting motivation.

22 There must be an emphasis on utilising the body of research and lived experiences to educate healthcare workers, families, adults born preterm and the wider community about the impacts of premature birth and how to appropriately identify, monitor and intervene for emerging issues.

23 We would suggest that pro-activity surrounding the impacts of prematurity will be cost-effective in the long term, when compared with possible costs of no changes to the current situation.

## 24 Suggested reading

Bousquet A, Sanderson K, O'Shea TM, Fry RC. Accelerated Aging and the Life Course of Individuals Born Preterm. *Children*. 2023; 10(10):1683.

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Mood and anxiety spectrum disorders detected by neuropsychiatric interviews in young adults born preterm: A prospective cohort study, *European Journal of Paediatric Neurology*, Volume 45, 2023, Pages 57-60

Perez A, Thiede L, Lüdecke D, Ebenebe CU, von dem Knesebeck O, Singer D. Lost in Transition: Health Care Experiences of Adults Born Very Preterm-A Qualitative Approach. *Front Public Health*. 2020 Nov 30;8:605149.

Kelly, Michelle M. Griffith, Patricia B. The Influence of preterm birth beyond infancy: Umbrella review of outcomes of adolescents and adults born preterm. *Journal of the American Association of Nurse Practitioners* 32(8):p 555-562, August 2020.

Amy L. D'Agata, Michelle Kelly, Carol E. Green, Mary C. Sullivan, Molding influences of prematurity: Interviews with adults born preterm, *Early Human Development*, Volume 166, 2022, 105542,

Michelle M. Kelly, Jane Tobias, Patricia B. Griffith, Addressing Preterm Birth History With Clinical Practice Recommendations Across the Life Course, *Journal of Pediatric Health Care*, Volume 35, Issue 3, 2021, Pages e5-e20

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