



# Growing up after premature birth A lived experience

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# My early start

Gestation: 26 weeks

Birth Weight: 430g (15.1 Oz)

Cause: Pre-eclampsia

< 15 - 20% chance of survival



Ventilated for 11 weeks  
Oxygen until discharge

No surgical intervention

5 months in hospital

Noticeable outcome  
= vocal cord paralysis





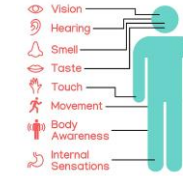
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# Early years – We just catch up...right?

- Neurodevelopment assessment 
- Health assessment (not holistic!) 
- Developmental delays – slow > catch up?
- Rickets – noted by osteopath as an adult
- Nursery - Feeling different – interaction with peers and adults.
- Change in behaviour and emotional state – “like a different child”
- Mum’s concerns dismissed – ‘over anxious’ parent
- Nursery – raising concerns > not ‘severe’ enough for additional assessments



# Education & Work

- Processing speed / information recall – coursework vs exams
- GCSE's – 10 inc: English, Maths + Science at C
- Burnout ?
- 3 years to complete 1 A-level > Higher National Diploma
- BSc (Hons) – First Class – small group, felt safe & supported, given encouragement and direction.

## Work (Learning Support / Canine Hydrotherapist)

Customer facing, multi-tasking, noisy & busy environment & fine motor skills.

- Insomnia & energy levels.

## Assumptions

- Behaviour / Attitude?
  - Deliberate?
  - Lazy?
- Selfish – doesn't like being interrupted?
- Poor social + communication skills?

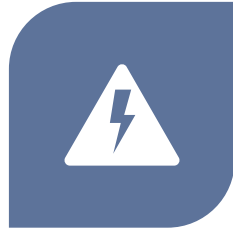
## Real world outcomes

- Self esteem, relationships, career progression & salary
- Implications for mental & physical health = stress

# Health: Childhood & Adolescence



TONSILITIS &  
CHEST  
INFECTIONS



ENERGY  
LEVELS



EXERCISE  
CAPACITY –  
SPORTY BUT NO  
ENDURANCE



SLEEP



SUGGESTION  
OF ASTHMA AS  
A TEENAGER

# What does this look like in adulthood?

Exercise capacity

Self regulate

Energy

Self employed -

Throat & Chest infections

Air pollution

Limit exposure

\*Vaccines

\*Only available once diagnosed with chronic conditions



# Out of the blue... At 26 years old

Fatigue + rapid skeletal muscle loss (6kgs) Joint pain

Blood Tests = Diabetes and Chronic Kidney Disease

No Family History – Early on-set chronic diseases

3 rheumatoid factors > gone on follow up blood tests.

Symptoms extreme compared to blood results.

Diabetes - Not meeting diagnostic criteria to see consultants.

GP prescribed inappropriate medication (kidney function)

Discharged back to Primary Care



## Contributing Factors

- ✓ Trigger - Virus ?
- ✓ Preterm Birth
- ✓ Pre-eclampsia
- ✓ Ext low birth weight
- ✓ Chronic Insomnia
- ✓ Chronic Stress

# What did I learn?



- Lack of awareness and understanding of preterm birth & impacts
- Evidence not translating to professionals in our day to day lives

- Personal impact & Family impact

**Mum – “I just didn’t know, no-one told me”**

- Kidney nephron numbers – gestational age
- Prescribed medication
- Assumptions - Diabetic foot checks

Reduced sensation > **NICU** Heel sticks?



- **Treated in a conventional way**
- **Preterm birth not considered chronic / lifelong condition**
- **Observable earlier with routine monitoring?**
- **Prematurity – valid explanation?**

# Adult Premie Advocacy Network CIC

## Lived Experience > Advocacy

**2020** Adult Premie Network

**2021** Adult Premie Advocacy Network

**2023** APAN > Community Interest Company



350 + Adults born preterm

## What do we do?

- Peer support
- Raise awareness
- Share resources
- Research Involvement

## Who Contacts Us?

- Adults born preterm
- Parents
- Research – Co-production

# Reaching out - Do **you** believe me?



Can you signpost me to professionals that understands prematurity?

“You made it out of NICU – you’re fine now.”

“Prematurity is irrelevant”

- ☐ Impact across multiple areas of life
- ☐ Personal finances – including private assessments & ‘tools’ to help with fine motor skills
- ☐ A sense of being ‘let down’ – palpable sense of frustration > distress



Prematurity has a legacy & is a relevant risk factor across the life course

**Positive change** – neuroprotection, family integrated care & awareness in education

Translating knowledge to practice > communicate risk > empowers us all

**Please do not let us fly under the radar!**

# Thank you!

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