Chapter 14 Growth and development of the infant in neonatal care and the first year of life

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Supplementary information

Information and support for parents and carers of all preterm babies Adapted from <u>NICE (2017) on Developmental Follow-up</u>

The majority of children and young people born preterm have a good developmental outcome and good quality of life. However, we must be aware of the risk and prevalence of <u>developmental problems and disorders</u> in neonates born preterm and discuss this with parents, with accessible information tailored to their individual circumstances, taking into account:

- their child's potential developmental needs
- their level of education
- any social care needs they have.
- any cultural, spiritual or religious beliefs
- the need for consistency in information sharing among healthcare professionals.

For inclusivity, we must follow the principles in the <u>NICE guidelines on patient</u> <u>experience in NHS services</u> and <u>babies</u>, <u>children and young people's experience</u> <u>of healthcare</u> in relation to communication (including different formats and languages), information and continuity of care. Also see <u>NICE's guideline on</u> <u>shared decision making</u>.

Emotional and psychological support should be offered to parents or carers of preterm neonates, recognising the significant potential impact of having a preterm baby on all the family. Times when support may be particularly valuable include: when the baby is transferred between units or hospitals & leading up to and on discharge home. Provision of information to parents or carers of preterm neonates about opportunities for peer support is important.

Risk and prevalence of developmental problems and disorders

Be aware that children and young people born preterm are at increased risk of <u>developmental problems and disorders</u>.

Cerebral palsy

- the following are independent risk factors:
 - grade 3 or 4 intraventricular haemorrhage
 - o cystic periventricular leukomalacia
 - o <u>neonatal sepsis</u>
 - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age.
 - antenatal steroids not given.
 - postnatal steroids given to babies born before 32⁺⁰ weeks' gestation.
- prevalence increases with decreasing gestational age.

See also the <u>NICE guideline on cerebral palsy in under 25s: assessment and</u> <u>management</u>.

Motor function problems

- the following are independent risk factors:
 - brain lesions (for example, grade 3 or 4 intraventricular haemorrhage, periventricular leukomalacia, infarct)
 - necrotising enterocolitis that needed surgery
 - <u>neonatal sepsis</u>
 - severe retinopathy of prematurity.

There is an increased prevalence of developmental coordination disorder in children born preterm compared with the general population.

Learning disability (intellectual disability)

- the following are independent risk factors:
 - grade 3 or 4 intraventricular haemorrhage
 - o cystic periventricular leukomalacia
 - <u>neonatal sepsis</u> in babies born before 28⁺⁰ weeks' gestation.
 - necrotising enterocolitis that needed surgery in babies
 born before 33⁺⁰ weeks' gestation
 - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age in babies born before 28⁺⁰ weeks' gestation.
 - severe retinopathy of prematurity in babies born before
 28⁺⁰ weeks' gestation
 - small for gestational age
 - postnatal steroids given to babies born before 33⁺⁰ weeks' gestation.
 - mother from a low-income or disadvantaged background
- prevalence increases with decreasing gestational age.

Special educational needs and educational attainment and executive function problems

- the following are independent risk factors:
 - brain lesions detected by ultrasound & male sex.
- children born preterm are at increased risk of low educational attainment at the end of the Early Years Foundation stage and at key stage 1 (age up to 7 years), and that:
 - prevalence of low educational attainment increases with decreasing gestational age.

- children born preterm are at increased risk of low attainment for reading and maths, and this risk is greater in children born before 26⁺⁰ weeks' gestation.
- the following are independent risk factors for low attainment in maths in children born before 32⁺⁰ weeks' gestation:
 - o intraventricular haemorrhage
 - bronchopulmonary dysplasia for which mechanical ventilation was still needed at 36 weeks' postmenstrual age.

Speech, language and communication problems

- The following are independent risk factors for language disorder:
 - grade 3 or 4 intraventricular haemorrhage / cystic periventricular leukomalacia / male sex.

Attention problems, impulsivity and hyperactivity

- at preschool and school ages.
- children born before 28⁺⁰ weeks' gestation are at increased risk of attention deficit hyperactivity disorder (ADHD), and that male sex is an independent risk factor.

Autism spectrum disorder

children born before 28⁺⁰ weeks' gestation are at increased risk of symptoms of social communication impairment, which may suggest a problem in the autism spectrum. The following are independent risk factors:

> intraventricular haemorrhage in babies born before 34⁺⁰ weeks' gestation / male sex.

Emotional and behavioural problems

- particularly internalising behaviours and passivity, at preschool and school ages, and that the following are independent risk factors:
 - major brain lesions (for example, periventricular leukomalacia, parenchymal lesions) / mother with mental health problems /

mother younger than 25 years / mother from a low-income or disadvantaged background.

Feeding problems

 Oro-motor feeding problems (for example, problems with sucking and chewing), and that this increased risk persists until at least 6 years of age in children born before 26⁺⁰ weeks' gestation.

Sleep problems / sleep apnoea up to 6 years of age.

Visual impairment

- the following are independent risk factors:
 - grade 3 or 4 intraventricular haemorrhage with a shunt
 - <u>neonatal sepsis</u> in babies born before 33⁺⁰ weeks' gestation.
 - retinopathy of prematurity needing treatment.

Hearing impairment

<u>neonatal sepsis</u> is an independent risk factor in babies born before
 28⁺⁰ weeks' gestation.

Developmental delay

- The following are independent risk factors:
 - <u>small for gestational age</u> / male sex / mother from a low-income or disadvantaged background / black, Asian or other minority ethnic group / multiple pregnancy.

Glossary

Morbidity: The term used when someone is suffering from a disease/medical condition

Centile: A centile describes the percentage of infants/children who are expected to be below a certain line on a growth chart (please refer to Chapter 3).

Gestation/Gestational: The period of time between conception and birth.

Hypoglycaemia: Low blood sugar level, below 2.6mmol/litre in a neonate

Neonatal: The period of life up to 28 days post-term.

Premature/Preterm: Relates to babies who are born alive before 37 weeks gestation.

Surfactant: A substance that reduces the surface tension within the lung alveoli allowing them to expand in normal breathing.



EXTRA READING – Read more about growth and development as applicable to the neonate who has been unwell or born prematurely.

- Growth and Development after Prematurity (TOMMYs) corrected milestones. Download the 'My Prem Baby' App.
- NICE (2017) Faltering growth: recognition and management of faltering growth in children
- NICE (2017) <u>Developmental follow-up of children and young people</u> <u>born preterm</u>
- o BLISS Growing up
- Epicure <u>information for parents of very premature babies</u>
- PRISM <u>Resources on preterm birth for Education Professionals</u>
- Royal College of Paediatrics and Child Health (RCPCH) <u>Growth charts</u> <u>and plotting – Neonatal and Infant close monitoring</u> (for premature and low birthweight babies)
- o Tommys <u>My premature baby app</u>