

Spoons Charity - Written evidence (PRT0021)

Spoons background

1. Spoons is a Greater Manchester based charity founded in 2015 by Kirsten Mitchell. Kirsten's little boy Tom was born at 24 weeks gestation and spent 127 in neonatal intensive care. Tom was discharged from neonatal care on home oxygen therapy and spent the first year of his life in and out of hospital. Kirsten, a mum to two other children found it hard to adjust to life beyond neonatal care and became isolated, which had a huge impact on her mental health. She struggled to find support locally for parents who had experienced neonatal care and decided to set up a support group linked to the neonatal unit where Tom had spent the majority of his time. She sought support from other parents she had met on the neonatal unit and Spoons was founded – Spoons was an acronym for Supporting Families of Oldham Neonates. The sole aim of Spoons was to facilitate a community where families who had experienced neonatal care could come together and feel safe in sharing their experiences and supporting one another. Parents often feel universal baby groups don't meet their needs and they can struggle to relate to parents who haven't had a neonatal experiences.
- 1.1. Spoons identified a gap in support for families who had experienced neonatal care across Greater Manchester. In 2016 Spoons became a registered charity and developed a range of services to support families on the neonatal unit and in their local community.
- 1.2. Services include:
 - Peer to peer support delivered by lived experience
 - Community based play sessions and support groups exclusively aimed at families who have experienced neonatal care
 - Trauma therapy and counselling

- Family support to enable the family to better navigate their neonatal journey from admission to the neonatal unit and beyond
- Support for families from diverse communities
- Working with the North West Neonatal Operational Delivery network and Greater Manchester neonatal services to understand parent experiences and support collaborative working with families to improve neonatal services and family experiences

2. Variation in care and health inequalities

- 2.1. Spoons is based in Greater Manchester which is one of the most culturally diverse areas in the UK. Our staff and volunteers meet many parents on the neonatal unit for who English isn't their first language or who do not speak any English at all.
- 2.2. Having a premature or sick baby on the neonatal unit is incredibly stressful for parents. This is hugely intensified for parents who are unable to communicate with the NHS staff providing clinical care for their baby due to a language barrier. Spoons employs a family support coordinator whose role it is to support families from diverse communities, she speaks Urdu and is able to communicate with other families who speak Urdu. She has met many families who have had a premature baby and have not understood anything about the care their baby is receiving, as staff have been unable to communicate with them, particularly when the baby has been discharged and is under community services.
- 2.3. Health care professionals can make assumptions on parents ability or desire to care for their baby when in actual fact some of the issues are that parents do not understand what their baby's needs are and how to address them, simply because there is a language barrier.
- 2.4. Whilst many neonatal units across the UK have a culture of Family Integrated Care, which is a great step in the right direction for

empowering parents to be parents. There are many language, cultural and socioeconomic barriers to families engaging in Family Integrated Care and more needs to be done to breakdown these barrier and enable families from marginalised groups to have their voices heard.

2.5. Neonatal Networks do have Parent Advisory Groups but our experience in the North West is that the majority of the parents who join these group are from white middleclass backgrounds and not representative of the whole neonatal community.

2.6. Since Spoons was established we have worked with the North West Neonatal Network and Greater Manchester neonatal services to amplify parent voices. This work has historically been carried out by Spoons out of goodwill. We would like to see more investment into neonatal units and networks working with local VCSE groups who can work with services to understand the barriers that parents encounter and work collaboratively to reduce them, and appropriate funding in place for this to work.

3. Prevention

3.1 Very few women expect to experience premature labour and birth and we don't feel there is enough education and information shared with women antenatally to recognise the signs and symptoms. Whilst we are not suggesting that we scare women antenatally, most of the families that we have spoken to would have welcomed more information antenatally to enable them to act quicker and also empower them to speak out to maternity professionals who often dismiss women who think they may have signs of premature labour. Sadly this is something we hear a lot. It is important that we hear the voices of women who have experienced premature birth and parents who have had a premature baby. These lived experience voices should be part of work in the prevention of premature birth. A potential

premature birth is very stressful for parents and this can be intensified when parents do not realise that they may not be able to stay at the hospital they have chosen for the birth of their baby. Very premature babies will need to be born in a level three intensive care unit and their chosen hospital may be a level 1 or 2 local neonatal unit or special care baby unit. This means either the women will be transferred in utero or the baby will be transferred as soon as possible after birth. Often this is to a hospital in another trust which will not have full access to the mother's or baby's electronic patient records.

- 3.2 We speak to a lot of parents who have been extremely stressed after being transferred to a different hospital and health professionals have been unable to quickly access all their medical records. We understand this is also frustrating for health professionals and we would like to see a system that allows all NHS trusts to share patient records. We believe this will minimise stress for families and improve patient care and outcomes.

4. Neonatal care and longer term care and support

- 4.1 The impact of neonatal care on mental health of both the parent and the baby cannot be underestimated. As discussed already the experience of premature birth neonatal care is an intensively stressful and traumatic event for parents, and parents are more likely to have experienced birth trauma. We would like to see all parents who have experienced neonatal care be offered a debrief with obstetricians . Parents often don't know that they are able to ask for a debrief, nor do they know how to arrange this.
- 4.2 Although introduction of psychologist on neonatal units will be extremely helpful for some families, it is worth pointing out that there are inequalities in psychological support in neonatal units, not all neonatal units have this in place. It should also be noted that not all parents will

be ready to accept support with their mental health when their baby is still in neonatal care and they may not actually realise that they need help until much later down the line. Therefore it is important to have investment in robust and accessible community mental health support for families who have experienced neonatal care, this should be delivered by professionals who understand neonatal care and the challenges that families experience. We also feel it is important to recognise the value of a local peer support offer which is delivered by those with neonatal lived experience both on the neonatal unit and in the community. We would welcome investment into local neonatal charities who are currently delivering these services, and a mechanism to ensure that support services for families are codesigned by those with neonatal lived experience.

4.3 The early experiences of babies who are born premature or sick and are very different to that of a baby who doesn't need neonatal care. Babies in neonatal care, particularly those born very premature or sick will have a lot of medical intervention and procedures which can be painful and cause psychological problems in later life. For example lots of babies who are ventilated at birth have gone on to have feeding aversions as they associate something solid in their mouth with pain. Very premature or sick babies will not have the usual bonding experiences with their parents as an incubator, medical equipment and being unstable can be a barrier to parents having cuddles. This can lead to problems for both parents and babies much later down the line. Parents often share with us that they struggle to feel like a parent whilst their baby was in neonatal care and they struggled to bond.

4.4 Parents often tell us that their health visitor does not always understand the neonatal experience and the impact that this has on their mental health, their babies development and milestones. A common frustration that families share is inconsistent information, they are told one thing by their baby's neonatal care team and

something completely different by their health visitor. This can be confusing for parents and can often cause parents to feel overwhelmed. Similarly parents report issues with their GP when it comes to medications that their baby has been prescribed on the neonatal unit. Parents can often struggle to obtain repeat prescriptions from GP's once their baby has been discharged. We should not underestimate the impact that some of these things will have on parents who are already exhausted, overwhelmed, stressed and traumatised by a neonatal care stay.

4.5 Babies who have been born prematurely are at increased risk of having long term health issues, disabilities or special educational needs. Many babies that are born very prematurely will have respiratory needs which will result in admissions to paediatric wards in the first one or more years of life. This is obviously stressful for the child, the parents, siblings and the wider family. We know that premature birth can result in permanent disabilities such as Cerebral Palsy which is lifechanging for families, and we support lots of families of premature babies to access other specialist services who can offer the long term help they may need.

4.6 We also support lots of families whose premature baby doesn't have a formal diagnosis of a disability or education need. We know from research that babies who are born prematurely are at an increased risk of having more subtle difficulties such as learning difficulties, attention deficit hyperactivity disorder, sensory processing disorder, coordination and processing difficulties such as dyspraxia, behavioural problems and social-emotional difficulties. These issues can often seem insignificant in the early days when parents are praying for survival of their premature baby. Health professionals don't always share with parents that their children are higher risk of these issues meaning parents do not always realise until the child is of school age, when it can be very difficult to access support in an educational setting. We

would like to see parents better informed about these types of learning and developmental issues and delays. And we believe that premature birth should be a red flag for school when identifying and supporting a child with difficulties, schools do need to be better educated on this, and services need to be easier for parents to navigate.

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