INFORMATION GUIDE FOR HEALTH CARE PROFESSIONALS

London Neonatal Network NHS

Parent Support Groups

Implementing & facilitating parent support groups in neonatal units

Information leaflet produced by the London Neonatal Network

This leaflet has been designed to support healthcare professionals around the topic of parental support groups.

This guidance has been designed to provide supportive information to neonatal units on the different types of parent support groups that can be made available to families, and other service user groups you may have contact with.

This guide also includes advice to assist healthcare professionals in implementing, restarting, and facilitating these groups.

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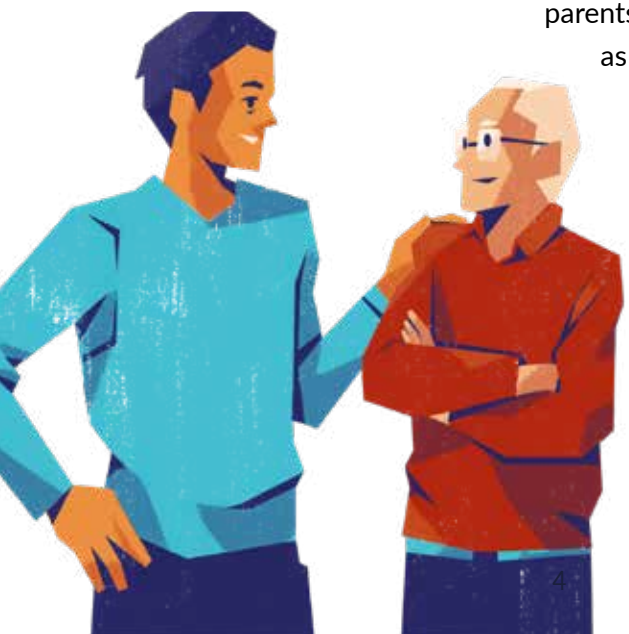
Background

Various national reports published in recent years advocate for improving the family experience in the neonatal unit, and implementing Family Integrated Care (FICare) is a vehicle to achieve this. Under the Wellbeing principle of the British Association of Perinatal Medicine (BAPM) FICare framework (2021), neonatal units are encouraged to create opportunities for peer-to-peer support and family group activities, among other examples, to embed this part of the principle.

Equality, Diversity and Inclusion

While planning, developing and delivering support groups, it is important to ensure they are welcoming and inclusive for all families. This will require careful consideration to ensure, for example, that families from different cultural backgrounds, ethnic minority groups, parents/carers who speak English as an additional language, and parents/carers with disabilities (e.g. deaf, mobility difficulties) can participate equitably.



It is recommended that any information targeted at families is translated into commonly spoken

languages for your area and that interpreting services are available to ensure accessibility.

Additionally, it is advisable to engage with relevant Trust departments, such as Equality Diversity and Inclusion (EDI) and patient engagement teams, along with third-party organisations like local neonatal and hospital charities.

This collaboration can help promote the inclusion of other minorities in these forums and ensure they receive the necessary support during their neonatal stay .

Environment and other barriers to attendance

Creating a welcoming and comfortable environment that respects privacy and encourages sharing experiences is vital to engagement, attendance, and satisfaction. Remember, not all families will be able to attend parent groups even if they would choose to; this may be due to barriers, such as financial burdens, other caring responsibilities or work commitments.

Healthcare professionals will need to think of novel ways to reduce or mitigate these barriers as much as possible within the resources available to them.

Parent support group Recommendations

This is a forum for parents/carers with a baby in the neonatal unit. The purpose of this group is to provide a safe space for parents/carers to share their experiences, express their feelings and receive emotional support. Targeted forums for specific groups, such as siblings, LGBT+ community, and fathers, could be made available based on the needs of local service users.

A psychological professional should plan and facilitate this group alongside other healthcare professionals if they have the capacity. If a psychological professional is not available, it can be conducted by a healthcare professional trained to provide psychologically safe support and trauma-informed care. In cases like this, where units do not have a psychological professional or where there is no capacity within the current psychological provision, a business case is recommended to develop more provisions to support families.

The group facilitators should be able to identify and act upon any signs that parents/carers are finding it challenging to cope with the neonatal journey. There should be agreed pathways in place to support both the parent/carer and staff member, such as a discussion with the parent/carer if they would like a more private, individualised conversation or a consideration of a referral to psychology support.

The frequency of the group meetings will depend on the unit's capacity but offering it once a week is recommended.

It is also recommended that all healthcare professionals facilitating parent support groups have regular 1:1 or debriefing sessions with an identified, appropriately trained support person such as a Professional Nurse Advocate (PNA) or senior staff member; this is to support their well-being and ongoing ability to facilitate.

Parent Peer support group

This group is similar to a parent support group but is supported or facilitated by parents who have previously experienced neonatal care as service users and would like to share their lived experiences to benefit other parents going through a similar journey. Peer supporters (also known as veteran parents or parent volunteers; see section 8 for more recommendations for peer supporters) must have access to local psychological support, as revisiting the neonatal journey may trigger difficult memories. Peer supporters may benefit from co-facilitating alongside a healthcare professional until they are confident.

London Neonatal Network Parent Advisory Group

This group consists of parents who have experienced neonatal care as service users. PAG members work voluntarily alongside the PAG Chair and collaborate directly with the wider ODN (Operational Delivery Network) team. The primary aim of this group is to enable co-production within the ODN workstreams and ensure that the parent voice is included in all strategic work. The PAG's role is also to provide a listening platform for parents' voices to be heard on a wider scale and for any themes to be fed into the ODN and wider structures.

Maternity and Neonatal Voices Partnership (MNVP)

MNVPs listen and reflect the views of families from local communities. They have a strategic influence and bring together service users, staff, and other stakeholders to plan, review, and improve maternity and neonatal services.

MNVP Chairs are commissioned and funded through either the LMNS (Local Maternity and Neonatal System) or Trusts providers.

Peer Supporters - Veteran Parents & Parent Volunteers

These service users, who have lived experience of having a baby in neonatal care, volunteer their time to support neonatal services and families at a unit level.

Veteran parents can volunteer their time to co-produce resources, participate in staff training by sharing their personal experiences, and identify and get involved in local-level service improvement. Parent volunteers can have a more substantial presence in the unit and more direct interaction with families, providing peer support, offering unit orientation and preparing packs for families.

It is recommended that a minimum of 12 months have passed from a family being discharged from neonatal care before volunteering. This is because the neonatal admission can have a significant impact on parents, babies and their families, and they need time to recover and process their experience first. Healthcare teams should engage in open conversations with parents and families who wish to volunteer to understand their expectations regarding the roles.

Considerations when working collaboratively with peer supporters

Recruitment

- The recruitment process varies depending on the Trust's local policies. It can be organised by the Trust and advertised on their website via the neonatal/hospital charity and/or directly through adverts on the neonatal unit. It is advisable for units to look for support from their local patient experience team as they have significant experience in working with service users.
- Some Trusts require all volunteers to go through specific Trust checks and training. It is essential to adhere to local Trust policies and procedures. Understanding these processes is recommended so you can support parents with knowledge and signposting. These processes can be lengthy and time-consuming.
- Parent volunteers must reflect the service user's demographics of the neonatal unit they support. If recruiting people from ethnic minority groups or less heard groups proves difficult, consider discussing with the Trust patient experience teams.
- Veteran parents who apply to volunteer to support inpatient parent groups understand that this experience is not intended directly for their healing, even though they can find it helpful for this purpose. The Trust/neonatal unit should provide supportive supervision including access to a trained psychological professional.
- Though predominantly a voluntary role, consideration for remuneration of travel expenses, etc, (i.e. vouchers) could support recruitment uptake.

Induction

- A structured induction to the unit needs to be provided, as well as an ID badge and Trust induction, depending on the Trust's requirements for volunteers. Volunteers should have a named person on the unit to support them with any queries and a staff member they can directly report to.

Access to support

- Considering the potential emotional impact ofreturning to the neonatal environment, peer supporters should have access to regular psychological support,and an initial conversation with a psychologicalprofessional is recommended to ensure theirpsychological safety.
- When parents volunteer, they may also prefer toparticipate in sessions for their own psychologicalsupport rather than taking on a facilitator role. It isadvisable to clarify this before each group session.

Time commitment:

- Time commitment should be agreed upon with local units and it must be in line with work plans. Contingency plans should be devised, if a peer supporter becomes unavailable to facilitate a group.

Additional resources

Psychology Staffing on the Neonatal Unit

Recommendations for Psychological Provision
www.acpuk.org.uk/Psychology-Staffing-on-the-Neonatal-Unit.pdf

Intensive Care Society Video

Three helpful Ps What are psychologists, PNAs and peer supporters and how can they work together for ICU staff wellbeing.
www.youtube.com/watch

Reference list

Family Integrated Care

This BAPM framework describes a model of FICare and provides a structure for implementation in UK neonatal units and networks.
www.bapm.org/resources/ficare-framework-for-practice

Supported self-management: peer support guide

NHS England, September 2023.
www.england.nhs.uk/long -read/peer-support

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For further information you can visit the organisations via the links below

London Neonatal Network NHS

Bliss for babies born premature or sick

NHS

London Neonatal Network NHS

For more information please visit

www.londonneonatalnetwork.org.uk

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