



BANNFU

British Association for Neonatal
Neurodevelopmental Follow-Up

Neonatal Follow-Up (NNFU) and your baby





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What is Neonatal Follow-Up (NNFU)?

Your baby is a patient on a Neonatal Unit (NNU), so they must have been unwell. We understand this will have been a very difficult time for you and your family.

The most common reason for a baby to be admitted is prematurity (birth before 37 weeks of pregnancy); other babies may have had a difficult birth, or had infections, feeding difficulties or jaundice; or been born with concerns about their internal organs such as the heart or gut, or had another medical concern that needed intensive care.

Your baby's conditions, or treatment for these conditions, may affect their ongoing health or development. So we would like to offer them follow-up after discharge.

The Neonatal Follow-Up (NNFU) programme consists of experienced health care professionals seeing your child at intervals after discharge. They can give information and advice about treatment that is tailored to each baby's needs.

Why do we need NNFU?

The NNFU programme monitors your child's progress and gives expert medical and/or developmental advice according to each child's needs. The professionals you see can make sure other experts are involved if and when necessary. We know it is important to intervene early when problems arise – this gives the best results.

Beyond this, the professionals can provide helpful advice on everyday matters which require special solutions because your baby was unwell. Families find this very reassuring and supportive.

There is variation in the way the follow up is provided. Some services offer clinics where several families are seen together, other hospitals prefer a one-to-one approach. At your appointment you may see several different members of the multidisciplinary team where several professionals with different specialisms will meet with your family at the same appointment.

There are usually several families attending clinic in the same session, so you have the opportunity to meet old friends from the NNU, or to discuss shared concerns about your children, or just to establish new friendships.



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What happens in the NNFU clinic?

Somebody will chat with you about your child's abilities and problems, going over the whole range of daily living, including sleeping, eating, toileting, medical needs, mobility, speech, and so on. You may be asked to complete a questionnaire about this before coming to the clinic.

The child will be examined, including measurements of their growth; and especially looking at their movements and developmental achievements.

Sometimes, with your permission, the infant's spontaneous movements are video-recorded so that we can look back at them after the clinic, with our colleagues if needed.

At various age points there will be assessments of the infant's development, using a play-based assessment. Usually both you and your child will enjoy these sessions as they are fun for the child and interesting for parents.

If there are specific concerns there may be tests of hearing, social interaction, and vision.

For older children, there may be a more detailed test of thinking skills.

Who are the staff in the clinic?

This will vary from clinic to clinic, but generally there will be several types of professionals. There may be nurses, who might be based in the Neonatal Unit or NNU discharge support team.

There will be paediatricians, who might be based in the NNU or specialising in Community Paediatrics.

There may be occupational therapists, physiotherapists or speech and language therapists. Some clinics may also have a psychologist.

Receptionists and administrators will ensure the smooth running of the clinic.

Several professionals may be responsible for the co-ordination of the NNFU programme, including the paediatricians.



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When will my child be seen?

It is likely that this will be at set ages and intervals, often around 3 months, 6 months, 1 year and 2 years (all adjusted for prematurity if relevant). Some clinics have extra visits or different timings and may see your child whenever you are concerned. In some cases there may be a further visit around 4 years.

Where will the clinic be?

Many of the NNFU clinics are in the hospital your baby was discharged home from, or occasionally the hospital where the baby was looked after when most unwell. Some take place in community clinics serving your local area.

What about the paperwork?

Before your child is first discharged home, you should be told where and on what date and time your child's follow-up appointment will be.

At each appointment, the team should make a plan of when the next appointment should be. If they can't tell you the exact date/time there and then, they should send this on. If you haven't heard by about a month before the next appointment is due, contact them to find out.

If your child needs a referral for a medical opinion or to start therapy, the team should tell you how soon you should hear about it and how to contact the department if you do not.

You should receive a written report about your child's assessment after each visit. If you do not, contact the clinic to tell them. If there is something in the letter that you are unclear about or disagree with, contact whoever prepared the letter through the details given in the letter.



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Do I have to take my child to NNFU appointments?

We know that it can be difficult to fit additional appointments into a busy family schedule but we still recommend attending even if it seems like your child is completely fine. Subtle signs that the professionals can spot may lead them to make early referrals to achieve the best outcome for your child. On the other hand, if your child already has many different appointments to deal with a variety of problems, speak to the clinic to see if the NNFU appointments can be combined with another visit.

If you miss an appointment, inform the clinic as soon as possible or let us know in advance if you can't attend and we will do our best to give you a new appointment. Our priority is for you and your child's health and wellbeing to give them the best start in life.

About BANNFU

The British Association for Neonatal Neurodevelopmental Follow-up (BANNFU) is a Special Interest Group of The British Association of Perinatal Medicine (BAPM). BANNFU is a multidisciplinary group which exists to improve the long term outcomes of all babies that have had neonatal care by disseminating best practice and improving care.

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