

# Bliss Scotland position statement:

## Improvements to the Young Patients Family Fund

November 2023



### About Bliss Scotland

Bliss Scotland is the leading Scottish charity that champions the right of every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

### Background

Finances can be a considerable worry for parents when their baby is in neonatal care and financial pressure can mean that parents are not able to spend as much time with their baby as they would like.

Bliss' research across the UK shows that more than half of parents say that their finances have an impact on their ability to be by their baby's side in hospital, with around one in five saying that finances impacted their ability to be involved in their care "significantly". Travel is the biggest cost for most families, but when a family has an older child at home, the additional cost of childcare is their largest cost and can be prohibitive to being at the hospital.

The Neonatal Expenses Fund – now the Young Patients Family Fund (YPFF) – was first introduced in 2018 as part of the *Best Start* programme, and has since undergone [evaluation by the Scottish Government](#). The Scottish Government evaluation showed that the scheme relieved financial anxieties during a very stressful period, and helped parents spend more time with their babies in the neonatal unit as a result of being able to claim.

Through the current scheme parents can claim *some* expenses for subsistence and travel and can sometimes claim back the cost of accommodation. However, the scheme does not cover all expenses, the process for claiming is cumbersome and requires upfront payment, and parents do not always know about the scheme until it is too late.

The Young Patients Family Fund, and the availability and quality of family facilities on neonatal units, is of increasing importance as Scotland moves to a more centralised model of neonatal care. The [planned reconfiguration of neonatal services](#) in Scotland is in line with best practice in terms of clinical care for babies, both across the rest of the UK and internationally, but we know that babies do best when their parents are also able to be at their cotside and playing a hands-on role in their care. Bliss therefore believes that much more can and should be done to make this model of care work better for families, to improve the provision of Family Integrated Care and ensure that every baby born premature or sick in Scotland has the best chance of survival and quality of life.

## Bliss recommendations for supporting families in Scotland

### Young Patients Family Fund

Bliss recommends that the following improvements be made to the YPFF scheme:

➤ **Uprate the amounts that can be claimed**

Since the scheme's inception as the Neonatal Expenses Fund in 2018, the rates parents can claim for subsistence have not increased in line with inflation. We recommend that the Scottish Government conduct a rapid review looking at how much the additional cost of food and drink is to families in Scotland while their baby is in hospital, and move to uprate amounts in line with this assessment, as well as building in an annual uplift in line with inflation to future-proof the scheme. For comparison, Bliss' research ([conducted in 2022](#)) found that parents across the UK said they spend an **additional £96 per week** above their usual budget.

➤ **Expand the scheme to include other expenses**

While families can claim for some subsistence and travel under the scheme, there are other expenses that are a barrier to parents being involved in their baby's care, including childcare. In Bliss' UK-wide research, families with an older child at home said that paying for the additional childcare they needed to be able to be at the hospital was their biggest cost at **£122 per week**. We recommend that the scheme be expanded to help parents with the cost of additional childcare for older siblings.

While the scheme does cover most forms of travel to and from the hospital, we would also recommend expanding it to cover taxis. Particularly for families who do not have access to a car, and for women who are recovering from birth, the flexibility provided by being able to claim for taxi rides would support families to be together whenever they need to (without the worry of a bus timetable, or leaving the hospital to get the last train home).

➤ **Include accommodation costs routinely**

While the fund can be used to claim for accommodation, this is currently on a discretionary basis. The scheme should be expanded to enable parents to claim for accommodation costs automatically as part of the usual criteria. This is because there is often insufficient or inappropriate accommodation on offer for the families who need it on or close by to the neonatal unit. For example, there may simply be insufficient unit / hospital accommodation available, or both parents may be unable to stay together or other children may be unable to stay, or accommodation available might only be available ad-hoc or short term. Allowing the fund to be used to cover accommodation costs will support families to access accommodation which is suited to their needs.

➤ **Make it easier to claim**

Currently, to make a claim the process is a paper form and parents report to us that it is complicated to claim. We'd like to see funding identified to digitise the claims process to make it as easy, and standardised, as possible for parents to access the support that is available.

➤ **Review how upfront costs are paid for**

We would also recommend reviewing whether some parts of the scheme can be paid upfront. Particularly for parents on low incomes, the ongoing increase in expenses above their usual budget may continue to be a barrier to spending time with their baby, even if they would be able to claim this money back at a later date. Where there are high costs that need to be paid upfront – for example, paying for hotel accommodation or train tickets – the need to find this money before

claiming it back can be prohibitive to parents, and may impact their financial situation considerably.

➤ **Increase flexibility of the scheme**

Parents face differing barriers to being with their baby in neonatal care including availability of accommodation, caring responsibilities, work, the mother's own care needs, and travel distance (among others). For this reason, the YPFF must provide the support it promises in the most flexible way possible. This flexibility should be consistently applied regardless of Health Board.

For example, some families find that they can only access support with food and drink costs via unit-provided food or vouchers, but this requires them to be on the unit at certain times or to buy food exclusively in the hospital canteen. Providing cash to those parents who need it would increase the flexibility of the scheme. An inflexible approach means that some parents miss out. We would like to see the Scottish Government ensure that every parent can make the choices which are best for them and their family.

## Accommodation and facilities

The reconfiguration of services in Scotland does mean that a small number of babies will be cared for further from home than previously. Travelling a long distance to be with a baby in hospital can take a big toll on families. To ensure that an additional burden is not placed on these parents, we are calling on the Scottish Government to ensure that the necessary investment is available to provide appropriate accommodation for parents at each of the three Scottish NICUs. NICUs should be able to provide:

- Accommodation for both parents on-site or close to the unit
- Kitchen facilities so that families can make meals and hot drinks
- Areas on the unit where parents can relax and take time away, without leaving the hospital
- Facilities for older siblings to be present on the unit
- Shower and toilet facilities

## Funding to improve family support in Scotland

While the Young Patients Family Fund (and the Neonatal Expenses Fund before it) provides valuable support to families, it is underutilised. This suggests that the current set up does not work as well as it could for families who may benefit from support, and that additional benefits – along the lines of those we set out above - can be delivered within the existing budget. Previous underspend has been:

Year	Budget <sup>1</sup>	Spend <sup>2</sup>	% of budget spent
2018/19 (NEF)	£1,500,000	£235,321	16%
2019/20 (NEF)	£1,500,000	£269,454	18%
2020/21 (NEF)	£1,500,000	£652,819	44%
2021/22 (YPFF)	£5,000,000	£1,486,464	30%
2022/23 (YPFF)	£4,000,000	£2,692,814	67%

<sup>1</sup> Written parliamentary question: S6W-18481

<sup>2</sup> Written parliamentary question: S6W-20644

## Conclusion

As detailed planning starts to get under way to support implementation of the next phase of the Best Start programme for neonatal care, including the transition to the new neonatal model of care with 3 NICUs, there is an important opportunity for the Scottish Government to learn from and build on the success of the NEF, and subsequently the YPFF, in its first 5 years in operation.

As detailed above, the existing scheme is an excellent basis for supporting parents in Scotland when they have a baby born premature or sick. Going forward the scheme must now be updated and improved to offer the best support possible for parents with a baby admitted to neonatal care in Scotland in the future.