Guidance on Support and Assistance Grants

# Introduction

The Scottish Infected Blood Support Scheme (SIBSS) is managed by NHS National Services Scotland. This document sets out details of the Support and Assistance Grants part of SIBSS to provide guidance on what support you may be able to apply for. Support and Assistance Grants are the one-off and regular grants, which are broadly similar to the support previously provided by the Caxton Foundation, the Macfarlane Trust and the Eileen Trust. However, a number of improvements have been made to these grants to take on board key recommendations of the independent [Financial Review Group](https://haemophiliascotland.files.wordpress.com/2015/11/contaminated-blood-financial-support-conclusions-and-recommendations.pdf).

Any SIBSS beneficiaries can apply for support from the Support and Assistance Grants. Dependent children (either under 18 years old or under 21 years old if they are in full-time education) who have a parent who was a beneficiary and has died can also apply for one-off grants to help with education or training courses.

# Categories of grants which are available

Please note that for everyone who receives a regular annual payment, the living costs supplement of £1,000 per year is now included in your annual payment to help cover smaller costs such as for travel to hospital appointments or insurance costs. You don’t need to apply for this separately anymore.

The following types of grants are available:

# Lower value one-off grants – up to £1,000

The increased regular annual payments should reduce the need for scheme beneficiaries to seek small one-off grants. However, there will still be cases where additional support is needed. Therefore, this element of SIBSS will provide grants **of up to £1,000**.

The grants will normally only be available to cover costs of items or services which are needed – at least indirectly – as a result of the impacts of a beneficiary’s Hepatitis C or HIV infection. This could include health-related support and also support, such as training, to help with the transition back into work following a period off work linked to the infection(s). In the case of widows, widowers, civil partners, long-term partners or children under 21 years old who are in full-time education where their spouse, partner or parent has died, the grants will also be available to support costs primarily to help with the transition following the infected beneficiary’s death, such as support for courses to help develop particular skills to allow them to move into/back into work.

The following are examples of the types of item/support that can be applied for as a lower value grant:

* mobility aids,
* lower value health-related adaptations to the home,
* vehicle repairs or adaptations if a car is essential, for example to get to hospital,
* advance payments for the Motability scheme,
* education or training courses,
* private counselling or psychological support (see separate section on this below)
* respite breaks and/or respite care due to treatment complications,
* support with removal and packing costs where a person needs to move to a more suitable home due to their infection, for example a more accessible property,
* for people living outside Scotland, prescription prepayment certificates,
* costs of medical treatment or tests related to Hepatitis C or HIV or their impacts (where you cannot access this on the NHS where you live or would have to wait a long time for health service treatment/tests).

While these are the main forms of support available, there is flexibility to cover other items where appropriate if the applicant can demonstrate the need for it and how it links to their illness or will help them move on to become financially independent, particularly following the death of their loved one. Therefore if what you need isn’t included in the list above, please contact SIBSS staff to discuss it with them.

Respite breaks are restricted to the UK and are intended to give carers a short break from their caring responsibilities, or allow a short period of recuperation following or during a particular decline in health and wellbeing. There are a number of UK agencies that support respite breaks; please contact SIBSS if you would like information on such agencies.

There are no longer any income thresholds or means testing so anyone can access grants up to £1,000 regardless of your income. You will not normally be able to receive a grant for an item or service if you could receive it or funds for it from another public body (such as the NHS, your local Council, the Student Awards Agency or the Motability scheme) so you should check first if you can get it from another body – however, in some cases this requirement may be waived, particularly if you would have to wait a long time for another public body to provide the support.

If you need a grant to fund medical treatment or tests relating to either Hepatitis C (HCV) or HIV then this would normally only apply to people living outside the UK as UK residents should be able to access treatment free of charge on the NHS. However, if you live in the UK, but either need specialist treatment linked to the effects of HCV or HIV which is not available on the NHS or if you would need to wait a significant amount of time for NHS treatment, you can apply for a grant to access private treatment.

For people living in England or outside the UK, you can receive a grant to fund an annual prescription prepayment certificate to cover the cost of your prescriptions. You can apply for this as long as you can confirm that at least some of your prescriptions are for medications related to your HCV or HIV.

Applicants will normally receive a cash transfer to allow them to pay for the item/service. If you receive such a grant you will be required to keep copies of receipts or invoices and submit them to SIBSS for the scheme’s records.

# Higher value one-off grants – over £1,000

Higher value grants would also be available to covers grants over £1,000 to support those infected by providing health-related support:

* higher value home repairs
* home adaptations
* costs for provision of care at home
* costs of medical treatment for hepatitis c or HIV

The grants will normally only be available to cover costs of items or services which are needed – at least indirectly – as a result of the impacts of a beneficiary’s Hepatitis C or HIV infection.  In order to apply, you will need to first check if local authority, NHS or other public body support is available to support what you need; in some cases, they may only provide a contribution or some of the support you need – in that case, SIBSS may be able to supplement that support or can provide interim support (for example while you are waiting for an appropriate care package to be put in place).

Even if they cannot provide funding, they may be able to give advice to help confirm what you need – for example if you feel you need adaptations to your home your Council’s social work department can give you an assessment by an Occupational Therapist and provide advice on changes to make to your home. If you wish to apply, you should explain why you need the repair, adaptation, care support or treatment and why you cannot access funds from any other public body.

Any SIBSS beneficiary can apply for these higher value grants, but if your total annual household income is over £40,000 you would normally only be eligible for a **grant of up to £5,000** (for ongoing costs such as care at home this would be £5,000 per year). If you are seeking a grant of less than £5,000 you do not need to provide your income details on the application form.

Where you are seeking a grant to pay for treatment for HCV or HIV because you live outside the UK and cannot access it free of charge, the maximum funding contribution will normally be £20,000. However, this can be considered on a case by case basis if your treatment costs would be higher than this.

SIBSS will be able to give you advice on completing an application. If you are seeking a grant of more than £5,000, you would need to provide details of your income and any benefits or tax credits you receive, along with (if applicable) the income or benefits your partner or any other adults living with you receive (that only applies to adults who are 21 years old or over). Please note that if you receive payments from the Independent Living Fund Scotland, Personal Independence Payments (PIP) or the Attendance Allowance then these payments will not be taken into account in calculating your income, although you should still mention the payments when you complete your application form.

Applicants will normally receive a cash transfer to allow them to pay for the repair or adaptation, treatment or care support, although for large-scale adaptations this may be paid in phases. In some cases, the scheme may pay invoices directly to the supplier.

# Referrals for counselling or advice

In addition to grants, the scheme will be able to signpost or refer beneficiaries to advice providers who can provide debt and money management advice and support by phone, online or face to face advice, such as the National Debtline and Citizens Advice Bureaux. The scheme also has a benefits adviser who they can refer you to if you feel you need advice or help in relation to a benefits query.

If you feel you need counselling or psychological support, the scheme will be able help refer you to appropriate services, such as the Scottish Infected Blood Psychology Service. If you prefer to have private counselling, SIBSS can pay for this for you; do not need to provide your income details or go through any means testing to access private counselling or other psychological support through SIBSS.

**Needing time off work for Hepatitis C treatment**

If you need to take time off work while you undergo Hepatitis C treatment and your employer will not continue to pay you in full while you are not working or if you are self-employed, you can apply for support to cover lost income that cannot be covered by benefits. Any grant will be available for up to a year, depending on the type of treatment you are having (although this may be extended if necessary). If you are on a higher income, the support may not cover your salary in full, although your total income will normally be topped up to a level of up to around £37,000 per year. Please get in touch with SIBSS if you have any queries about this support.

# Support for children whose infected parent has died

In circumstances where you are looking after a child or children under 18 years old, or under 21 if they are in full time education, if their infected parent has died and you are not entitled to your own annual payment (either because you are not their parent, but a guardian or because you were divorced or separated from their infected parent) please contact SIBSS as they can make special arrangements for payments to help with your childcare costs.

**Funeral Costs**

A non-means tested grant of up to £4,500 is now available for the person arranging the funeral, when an infected beneficiary has passed away if they died on or after 1 April 2025 – this support replaces the bereavement lump sum, which was previously available. To apply for this grant, the relative arranging the funeral should fill in the application for a support & assistance grant – in these cases you can use the one-off grants up to £1,000 form, even though your claim may be higher.

If you are an infected beneficiary and have unfortunately been told by doctors you are nearing the end of your life, then SIBSS may also as an alternative be able to help with paying for a funeral plan if you would like to make your funeral arrangements in advance. If this applies to you, please speak to SIBSS staff for advice.

# Contact details

If you have any queries about this or would like to be sent an application form, you can call SIBSS on 0131 275 6754 or email NSS.SIBSS@nhs.scot. There is also further information about the scheme on the website at <https://www.nss.nhs.scot/browse/patient-support-schemes/scottish-infected-blood-support-scheme-sibss>.