

# Scottish Infected Blood Support Scheme

## 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 expected to be 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](#).

Any SIBSS beneficiaries can apply for support from the Support and Assistance Grants. However, in recognition of the fact that the regular payments for beneficiaries with HIV and/or advanced Hepatitis C are higher than for those with chronic Hepatitis C, the Support and Assistance Grants are mainly targeted at supporting those with chronic Hepatitis C (previously referred to as 'Stage 1') and widows, widowers, civil partners or other long-term partners of deceased beneficiaries who had chronic HCV (see the separate guidance on support for widows, widowers, civil partners and long-term partners). Dependent children 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. In addition, to ensure that Support and Assistance is targeted at those who most need it, it will particularly provide support to people on lower incomes.

### Categories of grants which are available

The following types of grants are available:

#### **Living Costs Supplement** – not means tested

For everyone who receives a regular annual payment, the living costs supplement is included in your annual payment. This payment is for those with chronic Hepatitis C who have either never applied for an annual payment or who have confirmed that hepatitis c has 'no noticeable impact on their day to day life' and is also available to widows, widowers, civil partners or other long-term partners who were living with a beneficiary who had chronic HCV when they died if they are not receiving a regular annual widow's payment. You can receive the living costs supplement each autumn. Once you have applied for this once, you will automatically receive it once each year.

This supplement is to help provide support for additional costs associated with Hepatitis C – such as winter fuel costs, insurance costs, travel costs for hospital visits, to help support healthy eating and other costs linked to the infection. This list is not

definitive – SIBSS recognises that the associated costs and impacts of infection and bereavement are varied so beneficiaries are free to spend the supplement in line with their own specific needs. You will be able to receive **£1000 per year** if you are the only person in your household claiming it. This payment is not means tested so anyone can apply for it if they are not eligible for an annual payment.

You can still apply for one-off grants in relation to additional costs associated with your Hepatitis C if you receive the living costs supplement.

If you are not the only person in your house with chronic Hepatitis C who is a SIBSS beneficiary, given this is in part support for household winter fuel costs, each infected household member will be able to receive £750 (so £1,500 for the household).

## Income top-up support

Income top-up support is also available to help people with chronic Hepatitis C or widows, widowers, civil partners or other long-term partners who lived with a beneficiary who has died who are on a low income. It will also be available to support people with chronic Hepatitis C if they need to take time off work while they are undergoing Hepatitis C treatment and will lose earnings as a result of this. Anyone who is receiving either a chronic HCV regular payment – see link below - due to being either severely or moderately affected by their HCV can apply for income top-up support. In addition any widows, widowers or partners of deceased beneficiaries who had chronic HCV and are receiving chronic HCV widows' regular payments – see link below - can also apply for income top-up support. If you are not eligible for either of these payments because HCV does not have a noticeable day to day impact on your life or that of your spouse or partner then you cannot now apply for income top-up support, but if you are already receiving income top-up support at the moment you can continue to get this.

Link for full details:-

<https://nhsnss.org/services/practitioner/medical/scottish-infected-blood-support-scheme/existing-members-of-the-scheme/>

SIBSS will provide support to top a beneficiary's household income up to the threshold levels below, which are based on 70% of net median UK household income (rounded up). The baseline amount for a household with two adults has been adjusted based on Organisation for Economic Cooperation and Development (OECD) equivalence scales to adjust the threshold levels based on the size of the household.

- £17,500 for a couple with no children under 21 years old
- £11,500 for a single person
- £22,500 for a couple with one child under 21 years old
- £28,000 for a couple with two or more children under 21 years old
- £17,000 for a single parent with one child under 21 years old
- £22,000 for a single parent with two or more children under 21 years old
- £23,000 for a three adult household
- £29,000 for a four adult household

This means that, for example, if there are two adults and one child in your household, you would be entitled to have your income topped up to £22,500. So if you and your partner between you receive an income (including benefits) of £15,000 per year, then you would be eligible to receive an income top-up of £7,500. In addition, if you have a child/children under 21 who either does not live with you the majority of the time or who is not in full-time education then they would not normally be included in calculating the threshold level you are eligible for, although they may be included in certain limited circumstances.

SIBSS will be able to give you advice on completing an application. 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).

If you live with someone, such as a flatmate, where you are not financially supporting one another then you do not need to include their income, but they would not be included as an extra adult in the household when working out which of the threshold levels applies to you. If someone is completely financially interdependent with you (e.g. you support them or they support you; resources are pooled or household income shared and used jointly) then their income should normally be taken into account and they should be included as an extra adult in the household for the purposes of the threshold levels. If income is only pooled partially for a specific, limited purpose (e.g. shopping, bills or rent contribution) then this would not usually be considered financial interdependence.

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.

If you are self employed you can use either of the following to determine your annual income:-

- If your annual income from self employment is fairly consistent then you can submit your tax return for the previous year and we will base your income top up payments on this figure.
- If your income from self employment fluctuates then you can send in an estimated total based on the previous 3 months income less business expenses and we will use this as the basis for your annual income.

Please note that we require a copy of your annual tax return to be submitted for audit purposes.

### **Timing of Payments**

Monthly payments will be made from the receipt of a successful application going forward; we do not back-date applications. Recipients must inform SIBSS of any change in their financial circumstances promptly to allow relevant adjustments in

payments. This is the responsibility of the grant recipient – SIBSS will not automatically adjust payment levels or make retrospective payments. Changes in financial circumstances must be stated explicitly by the recipient. Payments will be in your bank account on or around the 15<sup>th</sup> of the month.

### **How other support you have received from SIBSS will be taken into account**

For those with chronic Hepatitis C, you can still apply for income top-up support if you need it after you have received your one-off lump sum (either £50,000 for new applicants or the £30,000 top-up for existing beneficiaries). That payment will not be taken into account in calculating your income.

If you apply for income top-up support, your chronic HCV regular payments or widows' chronic HCV regular payments will be taken into account in calculating your income. If your regular payment is more than income top-up you are getting (or would get if it is a new application), you will in future only receive your chronic HCV regular payments. If you are eligible to get more income top-up than your chronic HCV regular payments then your regular payment will be 'topped-up' so that you receive the same amount as before of income top-up. If you were previously receiving the living costs supplement on top of this as well, you will also still get this so your existing payments will be protected (unless your income from other sources increases or the number of people in your household reduces).

If you have received one-off grants from SIBSS, these may be taken into account in calculating your income, although this would normally only happen where you had received a number of fairly recent grants or grants of significant value.

### **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.

## Lower value one-off grants

The increased regular annual payments, income top-up support and living costs supplements 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 **between £200 and £5,000**.

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, 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,
- other support or care to help a person to remain in their own home,
- vehicle repairs or adaptations if a car is essential, for example to get to hospital,
- funeral plans, or in some cases the cost of a funeral,
- education or training courses,
- respite breaks and 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.

While these are the main forms of support available, there will be 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.

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 - see link for further information -

<https://www.nhs.uk/conditions/social-care-and-support/breaks-for-carers-respite-care/>

Those primary beneficiaries and widows/widowers receiving regular annual payments over £20,000 per year would not normally be eligible for these lower value grants, but beneficiaries on higher annual payments can apply for support where they can show why they need this. In addition, 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) – however, in exceptional cases this requirement may be waived, particularly if you would have to wait a long time for another public body to provide the support. Applicants will normally receive a cash transfer to allow them to pay for the item/service, rather than vouchers. 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

Higher value grants would also be available to covers grants over £5,000 to support those infected by providing health-related support:

- higher value home repairs
- home adaptations
- costs for provision of care at home

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). If you wish to apply, you should explain why you need the repair, adaptation or care support and why you cannot fund it yourself or from any other source. While these grants would also be means-tested, the threshold level is higher - anyone with a net household income up to £37,000 per year can apply. If you are on a higher income though you may only receive a proportion of the cost of the item or service if it is judged that you able to make a contribution to the costs – this will be assessed on a case by case basis.

Applicants will normally receive a cash transfer to allow them to pay for the repair or adaptation 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.

## Exceptional payments

The Financial Review Group recommended that no one should lose out as a result of moving to SIBSS. We think that no one should be worse off and in fact most people should in fact be better off due to increased lump sum and regular payments, as well as more generous discretionary payments (such as income top-up support and the living costs supplement). However, if in fact you think your payments will or have reduced compared to regular payments you were previously receiving from one of the UK schemes, please discuss this with SIBSS so they can seek to ensure your payment levels can be maintained. As long as your household income has not increased and your family circumstances have not changed, then SIBSS will ensure you receive the same level of payments for at least the first two years. After that, your need for payments will be reviewed to check if you still require the same level of financial support.

## 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. If you feel you need counselling or psychological support, the scheme will be able help refer you to appropriate services if you are unable to get an appointment quickly through your GP/consultant. You do not need to provide your income details or go through any means testing to access counselling or other psychological support through SIBSS.

## 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.net](mailto:NSS.SIBSS@nhs.net). There is also further information about the scheme on the website at <https://nhsnss.org/SIBSS>.