

Scottish Infected Blood Support Scheme

Payments for People Infected With Hepatitis C or HIV or both from Infected Blood

Introduction

The Scottish Infected Blood Support Scheme (SIBSS) is managed by NHS National Services Scotland. This document sets out details of the policy on lump sums and payments for those who were infected via infected NHS blood, blood products or tissue. This document provides guidance on the policy, but the detail of the scheme is set out in the SIBSS Scheme Document, which is available on the [Scottish Government website](#). The Scottish Government has agreed that eligible beneficiaries should receive payments in accordance with the recommendations in the [Financial Review Group's report](#).

The payment amounts and assessment criteria will be subject to future review to ensure they remain responsive to the changing needs of beneficiaries and the latest scientific and clinical evidence.

SIBSS beneficiaries will be able to receive the following financial support to recognise the additional costs for individuals as a result of living with Hepatitis C (HCV) or HIV:

If you are a new applicant (who has never had support from the Skipton Fund, MFET or any other UK scheme)

- If you have **chronic Hepatitis C** (previously referred to as 'Stage 1') you will receive a one-off lump sum payment of £50,000 when you join SIBSS. You can also apply for a chronic Hepatitis C (HCV) regular payment if your HCV either severely or moderately affects your life – see separate guidance on these payments.

<https://nhsnss.org/media/3189/sibss-guidance-on-regular-payments-for-chronic-hcv-infected-widows-ers-or-partners-v1-2-final.pdf>

- If you have **advanced Hepatitis C** (previously referred to as 'Stage 2') you will receive a lump sum payment of £70,000. You will also receive regular payments which are currently £27,000 per year.

If you are already registered with SIBSS and previously received lump sum payments from the Skipton Fund, MFET or another UK scheme:

If you have **chronic Hepatitis C** (previously referred to as 'Stage 1'), you should already have received your £50,000 lump sum. You can also apply for chronic hepatitis c regular payments if your HCV either severely or moderately affects your life – see separate guidance on these payments.

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- If you have **advanced Hepatitis C** (previously referred to as 'Stage 2'), you should already have received your lump sum payment of £70,000. In addition, you will receive regular payments which are currently £27,000 per year.
- If you have **HIV**, you should already have received a lump sum payment from the Macfarlane Trust or the Eileen Trust. You will also receive regular payments which are currently £27,000 per year.
- If you have both **HIV and Hepatitis C** (often referred to as being coinfecting), then, in addition to the lump sum you will have received from the Macfarlane Trust or the Eileen Trust and from the Skipton Fund, you will also receive regular payments, which are currently £37,000 per year.

What happens if I was a beneficiary of the Skipton Fund or MFET, but am not registered with SIBSS?

If you were previously a 'Scottish' beneficiary of either the Skipton Fund or MFET prior to 1 April 2017, you should have received a letter from each of the schemes you were with to let you know about the change in the scheme and to ask for your consent to transfer your details to SIBSS.

If you did not receive a letter from the scheme or schemes you were with seeking your consent to transfer your details, please get in touch with SIBSS as soon as possible - most of the former schemes have now closed down, but it may still be possible to transfer your details over to SIBSS.

Once your details have been transferred to SIBSS, they will write to you to let you know about the scheme and how to apply for any extra support you might be eligible for. In particular, for those with chronic Hepatitis C, they will explain how to access financial and other support from the Support and Assistance grants part of the scheme (see section below on other support for more details).

What happens if I have never claimed from SIBSS or any other UK scheme?

If you have recently been diagnosed with **Hepatitis C** or have not applied earlier for other reasons, you can fill in an application form to make a claim from SIBSS if you think you were infected as a result of receiving infected NHS blood, tissue or blood products in the UK before September 1991 or if you were infected by someone who received infected blood. Application forms are available on the SIBSS website, but please contact SIBSS if you have any queries about this or if you are not sure which form to complete. When you have completed your form you should pass it to the doctor who is treating your Hepatitis C infection – this should normally be a Hepatitis C clinical specialist (either a hepatologist or an infectious diseases consultant), although it could be your GP if you have not seen a specialist. If you have any relevant medical records (for example that show you had a blood transfusion), please ensure your doctor has a copy of these.

They will be asked to complete information to confirm that you are infected with Hepatitis C and to provide relevant information on any records which would indicate you received a blood transfusion, blood products or a tissue transplant, as well as any

other relevant information available. If you have advanced Hepatitis C, then they will also need to provide some additional clinical information to confirm this (such as evidence that you have cirrhosis of the liver, liver cancer, B cell non-Hodgkin's lymphoma or that you are on the waiting list for or have had a liver transplant). They will then return the completed form to SIBSS.

SIBSS will provide a decision on all applications within 25 working days, although it may take longer if they need to ask you or your doctor for further information.

In applying to SIBSS:

For people who were directly infected by NHS blood, tissue or blood products you should be able to confirm that:

- you are infected with either chronic or advanced hepatitis C. You may still qualify for the scheme if your hepatitis C infection has been successfully treated.
- you are living in Scotland or, if you live outside the United Kingdom (UK), you lived in Scotland immediately before you moved out of the UK.
- you have not already received any payments from another UK scheme and are not currently eligible to receive funds from another scheme (either the Skipton Fund or any other scheme which replaces it which is approved by either the UK Department of Health (for England), the Welsh Government or the Department of Health in Northern Ireland).
- on the balance of probabilities, you were infected with hepatitis C as a result of receiving treatment in the UK before September 1991 from the NHS in the form of either a blood transfusion, a tissue transplant or blood products (see below for more details on what this covers).

In assessing your application, a balance of probabilities approach will be used to consider whether it is probable that you received your infection from infected blood, tissue or blood products rather than any other source. While it is much easier to determine this if you have medical records which show you received a blood transfusion before September 1991, your application may still be approved if you can provide other forms of evidence, such as witness statements or physical evidence that the medical procedure linked to transfusion has taken place.

SIBSS know that in many cases it will not be possible to trace the specific records related to the transfusion or medical procedure described, so the assessment will always be based on the strength of all the supporting evidence available. If you are unsure, please contact SIBSS to discuss the type of information you have and whether it is likely to be relevant to your case. They can also advise you on how to try to trace any old medical records.

SIBSS will also consider the available evidence regarding which products could have been infected with hepatitis C at the time you received any blood products or a blood transfusion(s) or tissue transplant. The following could have been infected, although some of these products were made completely safe (for example through heat treatment) before September 1991:

- If you suffer from haemophilia or another bleeding disorder, either Factor VIII or Factor IX blood clotting factor, cryoprecipitate or FEIBA, plasma or any whole blood transfusion.

- If you do not have a bleeding disorder, any blood you received through a blood transfusion, albumin, bone marrow, intravenous immunoglobulin (not including Anti-D), plasma or DEFIX.

For people who were infected by someone who had received NHS blood, tissue or blood products you will need to confirm that:

- on the balance of probabilities, you were infected with Hepatitis C and/or HIV by someone who was infected via NHS blood, tissue or blood products.
- that person has received payments from SIBSS or, alternatively, has received payments from the Skipton Fund as a Scottish beneficiary. If they have not yet made an application to receive a payment, they will need to apply and their application will need to be considered before SIBSS can consider your application.
- you were either married to, in a civil partnership with or living together in a long-term relationship with the person who infected you at the time you were infected or you were infected by your mother when you were a baby.
- you were infected due to either sexual transmission, transmission from mother to baby or an accidental needlestick injury, although you would not be eligible if you were an injecting drug user and were sharing needles. Other means of passing on the infection are also covered if the doctor filling in the form confirms that it is likely to have been how you were infected.
- at the time when you were infected, your spouse or partner either did not know they were infected or you both took reasonable precautions to prevent the infection being transmitted. This requirement does not apply if you were infected by your mother when you were a baby.
- you are living in Scotland or, if you live outside the United Kingdom (UK), you lived in Scotland immediately before you moved out of the UK.

While it is unlikely that someone who was infected with HIV has only just been diagnosed, if you have recently been diagnosed with HIV and have not yet made a claim to SIBSS, you can apply. Please contact SIBSS for further advice and an application form. Similar to applications for Hepatitis C support, you would need to show that:

- you are infected with HIV.
- you are living in Scotland or, if you live outside the United Kingdom (UK), you lived in Scotland immediately before you moved out of the UK.
- you have not already received any payments from another UK scheme and are not currently eligible to receive funds from another scheme (either MFET or any other scheme which replaces it which is approved by either the UK Department of Health (for England), the Welsh Government or the Department of Health in Northern Ireland).
- on the balance of probabilities, you were infected with HIV as a result of receiving treatment in the UK before February 1992 from the NHS in the form of either a blood transfusion, a tissue transplant or blood products. In fact, all NHS blood in Scotland was being tested for HIV from autumn 1985 onwards so it is very unlikely (although not impossible) that HIV was transmitted through infected blood after 1985.

How to apply for advanced Hepatitis C payments if I have already received payments from SIBSS or the Skipton Fund

If you are already a SIBSS claimant due to having chronic Hepatitis C (sometimes referred to as 'Stage 1'), but you have unfortunately progressed to advanced Hepatitis C infection, you can apply to receive:

- an additional lump sum of £20,000 (in addition to the £50,000 you should already have received), and
- regular payments which are currently £27,000 per year.

You can qualify to receive advanced Hepatitis C support if you have or have had any of the following which are likely to have been caused by your Hepatitis C:

- cirrhosis of the liver
- primary liver cancer
- B cell non-Hodgkin's Lymphoma
- if you have received or are on the waiting list for a liver transplant
- renal disease due to Membranoproliferative Glomerulonephritis (MPGN)

If you are currently in prison, you will not be eligible to receive these regular payments. However, you can apply to receive the payments as soon as you leave prison.

To claim this funding, you should complete the advanced Hepatitis C application form – copies are available on the SIBSS website or you can call or email SIBSS to request a copy. Once you have completed your sections of the form, you should pass this to a relevant doctor who will need to provide some clinical information to confirm you have one of the conditions specified above. This could be a Hepatitis C clinical specialist (either a hepatologist or an infectious diseases consultant) or it could be another consultant if they are involved in treating your illness.

Once your form has been considered by SIBSS, if it is confirmed you are eligible for advanced Hepatitis C support, you will receive your additional lump sum and your regular payment will start as soon as possible. Your regular payments will be backdated to the date you submitted your application.

Support available where the infected person has died before applying to join the scheme and has not previously been a member of any other UK Scheme

If the infected person has unfortunately died before applying to SIBSS, you can still apply to the scheme if you are the executor of the person's estate or are acting on behalf of or with the consent of the executor. You will need to provide the same information as specified above for new chronic or advanced Hepatitis C or HIV applications to show that the person would have qualified for support if they were still alive. You will also need to show that you are managing the person's estate or otherwise have the authority to make a claim on their behalf.

If your application is successful, the estate will receive £20,000 if the person had chronic Hepatitis C before they died or £70,000 if they had advanced Hepatitis C or HIV at the time they died. In addition, if you are the widow, widower, civil partner, or long-term partner or child under 21 years old (in full time education) of the deceased person, you will be able to apply for additional support. See the separate guidance information for widows, widowers and partners and on the Support and Assistance grants for additional information on what support you could be eligible for.

Support available where the infected person was previously a member of one of the UK Schemes or SIBSS, but has since died

In a small number of cases where a person did previously receive money from either SIBSS or one of the UK schemes, you can apply to the scheme if you are the executor of the person's estate or are acting on behalf of or with the consent of the executor. Apart from the support available to widows, widowers and partners of those who have died (see separate guidance on that support), the estate may be eligible for an additional lump sum payment in cases where the infected person received payments in relation to their chronic Hepatitis C, but had actually progressed to advanced Hepatitis C before they died.

If your application is successful, the estate will receive a lump sum of £20,000 if the person (or their estate) had already received both the initial £20,000 lump sum payment and the £30,000 additional lump sum in relation to their chronic Hepatitis C. If the person (or their estate) had not received the £30,000 additional lump sum then the estate will instead receive an additional £50,000. However, if the infected person or their estate had received £70,000 before then you would not be able to claim any additional lump sums. In addition, if the infected person or their estate previously received a lump sum in relation to their HIV infection (either from the then Scottish Office or from the Macfarlane or Eileen Trusts), then you are not eligible to receive any further lump sums from SIBSS in relation to HIV.

What other support is available for people who are infected?

In addition to the support set out above, you may also be eligible for support through the Support and Assistance grants element of SIBSS, particularly if you are infected with Hepatitis C through infected blood, but are not receiving regular payments.

Through the grants element, anyone with chronic Hepatitis C – along with widows, widowers and partners of the deceased who are not eligible for regular annual payments - will be able to apply for an increased living costs supplement of £1,000 per year to help fund the increased longer term costs associated with their illness. This payment is not means tested so anyone can apply, although you are encouraged only to apply if you feel you need extra financial support.

You can also apply for income top-up support if you are on a low income and are not eligible for chronic HCV regular payments or widows' chronic HCV regular payments. If your household income, including any benefits you receive, is below a certain threshold level, you will be able to receive payments to top-up your income to that threshold level. The threshold level varies depending on the size of your household – it is higher if you have a spouse or partner and children under 21 years old living with you. Contact SIBSS or look at their website for more details of the threshold level which applies to you and to get an application form.

Finally, if you have been receiving regular financial support from either the Caxton Foundation, the Macfarlane Trust or the Eileen Trust, but you think you will get less support from the Support and Assistance grants scheme than you did previously, please email or telephone SIBSS staff and they will be happy to look into this for you.

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. There is also further information about the scheme on the website at <https://nhsnss.org/SIBSS>.