



Welcome to issue 8 of the Scottish Infected Blood Support Scheme (SIBSS)

Scottish Infected Blood Psychology Service Survey 2021

Thank you to those who took part in the Psychology Service Survey. A separate communication has gone out with details of the service and how to access it.

Changes to Make One-off Grants Easier to Access

One-off grants are still available for beneficiaries who need support relating to their hepatitis c or HIV infection or for widows, widowers, partners and children following the death of their infected partner or parent.

Following feedback from beneficiaries and the recent increases in regular payments, we have been reviewing the one-off grants processes. We are making changes to remove means testing in the great majority of cases and reduce the amount of information you need to provide in the application form – this will hopefully make it easier for people to apply. From now on, anyone can apply for a grant up to £5,000 without any means testing.

Please see the updated grants guidance for more information on how to access a grant. While this lists the types of grants you might apply for, if there is something else you need that is related to your infection please contact us for advice as SIBSS can consider other types of grants as well.





Your Advisory Group Needs You!

If you are a beneficiary in receipt of regular payments, do you have what it takes to represent Scheme members by joining the Advisory Group?

A strong advisory group will ensure that the Scottish scheme takes account of beneficiaries' concerns and views on areas for operational scheme improvement, in light of the budget available. It will provide advice on positive action to ensure that lessons are learned, that trust in the scheme is maintained as far as possible and that the available budget is targeted effectively.

The Group should ensure respect and courtesy between beneficiaries and scheme administrators and others involved in contributing to the scheme, such as medical professionals. The Group will need to sustain the confidence of the public, beneficiaries and the NHS through demonstrable impartiality.

Contact the SIBSS team if you are interested in joining.

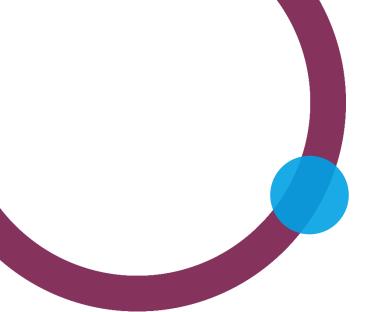
Learn about the advisory group

Treatments for Hepatitis C

Many of you have hopefully already been treated for hepatitis C (HCV) and achieved a 'sustained viral response' (SVR). However, in the survey of members last year two people asked for information on treatments or follow-up checks so this article provides information for those of you who have not yet been treated or may have had treatment in the past, but that was unsuccessful.

All patients have access to treatment with direct acting antiviral treatments; these are available to you regardless of the stage of your disease. These treatments have much fewer side effects, are safer and much more effective than previous treatments, such as interferon. The medicines are tablets which you normally need to take for 8 or 12 weeks. All licensed HCV treatments are available in the UK your doctor will discuss with you which treatment medication is likely to be best for you based on your own circumstances. These medicines cure at least 95% of those treated, first time. For the small number failing treatment, they are eligible for further alternative treatments that cure most patients. It is therefore extremely rare for someone's hepatitis C not to be cured after these antiviral treatments.

You will be given regular blood tests during and after your treatment to check if the medication is working. Doctors are now confident from the evidence that if you achieve a sustained viral response after your treatment this means your HCV has been cured and won't come back (unless you were re-infected





with HCV from another source in future). Therefore, if you don't have any evidence of cirrhosis damage to your liver you won't need any follow up treatment for your HCV if your doctor or nurse confirms after treatment that you have achieved SVR. However, if tests show you do have cirrhosis, you will still be asked to attend regular follow-up appointments – while HCV treatment will stop your cirrhosis from getting worse it won't unfortunately reverse all the damage to your liver which occurred before your treatment so you will still need your liver to be monitored.

While coronavirus has impacted somewhat on HCV treatment, treatment is still available and we would still encourage you to seek treatment as soon as you can as the sooner you are treated the better to reduce the risks of long-term liver damage. Therefore, please speak to your specialist doctor (hepatologist or other specialist in your local NHS Board); if you have never (or not recently) seen a specialist, contact your GP and they will be able to refer you to a specialist. If you don't live in the UK and don't have access to treatment free of charge via your country's health service, please speak to SIBSS about help with paying for your treatment if you have not yet been treated.

You can find more information on hepatitis C treatments and living with hepatitis C on the NHS Inform website at https://www.nhsinform.scot/illnesses-and-conditions/stomach-liver-and-gastrointestinal-tract/hepatitis-c.

Website Improvements

The website has been updated to meet accessibility standards – see link to new, improved website.

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We have also added video guidance to assist members with the self-assessment application process – see link to video - https://youtu.be/HAz4a2INCxg





Did you know?

- If you do not have access to the internet, or prefer to talk directly, the SIBSS team are happy to give advice and assistance over the phone.
- If you receive a regular payment; you can request a monthly remittance advice to be sent to you.
- You need to inform us if you move address or your circumstances change. See link to change of detail form. SIBSS Change of Details Form

Links Section

Scottish Infected Blood Support Scheme (SIBSS) **Grant Information** Support Groups Scottish Government Website Written statements - Written questions, answers and statements - UK Parliament

Contact Us

Scottish Infected Blood Support Scheme

Practitioner Services Gyle Square 1 South Gyle Crescent EdinburghEH12 9EB Phone: 0131 275 6754

Email: NSS.SIBSS@nhs.scot

