

## Scottish Infected Blood Support Scheme

### Regular Payments for people infected with Chronic Hepatitis C and their widows, widowers or partners

#### Introduction

Following the [clinical review of the impacts of chronic hepatitis c](#) (HCV), led by Professor David Goldberg of Health Protection Scotland, if you are registered with SIBSS, you can now apply for regular monthly payments if you either have chronic HCV (formerly known as Stage 1) or if you are the widow, widower, civil partner or other long-term partner who was living with someone with chronic HCV who has died.

This guidance sets out the eligibility criteria for these payments and the categories of payments.

#### Who can apply

You can apply for this payment if you are registered with SIBSS. If you are not already registered with SIBSS, please contact the SIBSS team on **0131 275 6754** and they can advise you which form you need to complete. In order to apply to SIBSS you must not be receiving any financial support from any other UK scheme for people with infected blood (such as the English Infected Blood Support Scheme, the Welsh Infected Blood Support Scheme or the Northern Irish Infected Blood Support Scheme).

In addition, to apply one of the following must apply to you:

- You are a chronic HCV beneficiary who was either infected by NHS blood or blood products or is a secondary infectee (someone infected by someone who was infected by NHS blood).
- You are a widow, widower, civil partner or long-term partner of someone who has died who was a chronic HCV beneficiary registered with SIBSS or was registered as a Stage 1 beneficiary with the Skipton Fund. To qualify for this payment, you must have been in a relationship with the beneficiary when they died and not since have got married to or entered a civil partnership with someone else or be in a long-term cohabiting relationship with someone else.

#### What support is available

For regular payments you will receive monthly payments equivalent to:

##### **For someone infected with HCV**

- The new payments are at the following levels for people who are infected with HCV: Those in the severely affected category - £18,900 per year
- Those in the moderately affected category - £6,300 per year

Please note that these new annual payments include the £1,000 living costs supplement so you will not be able to receive the living costs supplement any more if you receive one of these new annual payments. If you have already claimed the living costs supplement since April 2018 your new annual payment for this year will be reduced to take account of this.

You would not receive a regular payment if you say that your day to day life is not noticeably affected by your HCV or if you do not submit an application, but you can still claim the £1,000 per year living costs supplement.

### **For a widow, widower or partner of someone infected with HCV who has died**

You will be able to receive 75% of the amount your spouse or partner would have received if they were alive. Where your spouse or partner has already died, this will be based on your assessment of how their life was impacted by their HCV over the two years before they died. If your spouse or partner has only died recently or dies in future, you will receive 100% of the payments they would have received for the first year after they died and then 75% after twelve months.

This means if your spouse or partner died over twelve months ago, you will receive:

- £14,175 per year for those whose spouse or partner was severely affected by HCV;
- £4,725 per year for those whose spouse or partner was moderately affected by HCV.

Please note that, as for those infected with HCV, these new annual payments include the £1,000 living costs supplement so you will not be able to receive the living costs supplement any more if you receive one of these new annual payments. If you have already claimed the living costs supplement since April 2018 your new annual payment for this year will be reduced to take account of this.

### **For someone who is receiving income top-up support**

If you are receiving income top-up you can still apply for chronic HCV regular payments or widows, widowers or partners chronic HCV annual payments. Your new annual payment will be taken into account in calculating how much income top-up you receive. This means that if your new regular payment is higher than the income top-up you currently receive you will only receive your new regular payment. This will make it easier in the future as you won't need to provide updated income details each year; however, if your other income falls in future, meaning you would be entitled to more income top-up, you can always reapply for income top-up at that point.

If your income top-up is already higher than the new regular payment your income top-up payments will be protected so you will still receive the same amount of money as long as your circumstances (either your other income or the number of people living in your household) do not change.

## Beneficiaries with chronic HCV

If you wish to apply for an annual payment, please fill in an application form and state whether your life now is **severely** or **moderately affected** by your hepatitis c infection, or alternatively whether your hepatitis c infection **does not have a noticeable day to day impact** on your life. You should receive an application form from SIBSS, but if not, you can download a form on the website or call the SIBSS team and they will send you a copy. The SIBSS website can be found at [www.nhsnss.org/sibss](http://www.nhsnss.org/sibss).

We have provided guidance below to indicate what should count within each category, although everyone's circumstances will vary. If you are unsure which category you should include yourself in or need assistance with completing your form, please contact Scottish Infected Blood Support Scheme staff on **0131 275 6754**.

It is important to remember that annual payments are there to support you with living costs at the moment, for example if you struggle to work or to work full-time due to the health impacts of your hepatitis c (HCV). Therefore, when considering the impact on your life, this means your life as it is now, rather than in the past. However, we recognise that impacts in the past may in some cases have had a permanent impact on your life if they for example: impacted on your career, led to a relationship breakdown or impacted significantly on your family life. It is often not possible to know if your family life or career would definitely have been significantly different if you had not been infected with HCV. However, if you are sure that certain things would or would not have happened if you did not have HCV and that these have had a significant impact on your life, you can take account of these in this form.

If you confirm that your life is either severely or moderately affected by your HCV, you will be eligible for a new annual payment, which will include the living costs supplement. If you indicate that your life is not appreciably affected by your HCV (or if you don't return this form), you will not be eligible for an annual payment, but you can still claim the living costs supplement each year.

You do not need to provide evidence to back up the category you pick, but you must complete the additional information section giving examples of the affect of HCV on your life. While most applications won't be subject to further checks, SIBSS will seek further information in relation to a sample of applications to ensure that the guidance is being interpreted consistently by beneficiaries and funds are allocated fairly. You will be asked to reassess the impact of your HCV on your life every three years so that SIBSS can change your payments if you feel the impact on you has either reduced significantly or got significantly worse. This should not be a significant amount of work for you, but should make sure your payments are still right for your current circumstances. However, you can still apply for advanced hepatitis c annual payments at any point if you meet the criteria for this (for example if you develop liver cirrhosis or liver cancer).

Also, if at any point you think that the impact of hepatitis c on your life has got much worse for a particular reason, or alternatively has reduced, you can fill in a new application form at any time so you don't have to wait three years to do this. If you

want to do this, please get in touch with the SIBSS staff. The application form will be the same, but you will be asked to provide a medical report to support your move to a different category, for example if you feel you are now severely affected instead of moderately affected.

Please note that any beneficiary can apply for a regular payment, but if you are in prison, you cannot now receive these payments while you are in prison. You can however apply as soon as you leave prison. If you are receiving the payments and are later sent to prison, your payments will stop while you are in prison, but will restart as soon as you confirm to SIBSS that you have been released from prison.

### **Widows, widowers or partners of those who have died**

If you are the widow, widower, civil partner or long-term cohabiting partner of someone who has died, you may also be eligible for a regular payment if the following criteria apply:

- Your spouse or partner had chronic HCV and was registered with SIBSS - if they or their estate received a payment from the Skipton Fund, but were not registered with SIBSS, please contact the SIBSS team for advice on how to evidence this to allow you to be registered with SIBSS as widow, widower or partner.
- You were still living with this person when they died and were not divorced or separated. In some cases, you may still be able to qualify if you were not living together at the time when they died, but were still in a relationship together – for example, if your spouse or partner was living in a care home when they died as they needed full-time care or if you were living apart for a relatively short time because of the impact of hepatitis c on the relationship. Please contact the SIBSS team to discuss this if you were not living together.
- If you were not married or in a civil partnership with them, you were in a long-term relationship and living with them before they died – SIBSS would normally expect you to have been living with them for at least a year before they died, but please contact the SIBSS team if you want to discuss your particular circumstances.
- You have not got married to, entered into a civil partnership with or formed another long-term relationship living with someone else as a partner since this person died.
- You are not in prison.

If you meet these criteria, you can fill in an application form – this should be sent to you, but if you don't receive one, you can either download a copy of the form from the SIBSS website or call the SIBSS team and they can post you a form.

You will be asked to use the same form of guidance as is provided below for the beneficiaries who are alive, but in your case you will be asked to indicate **the impact of hepatitis c (HCV) on your spouse or partner over the two year period before they died.**

The focus is mainly on the impact on them, but you can also take account of wider, long-term impacts their HCV has had on you, for example, if you were their full-time carer and therefore unable to work for a significant time before they died. If you did not know him or her for a full two years, you can base it on a shorter period, but if you knew him or her for less than a year before their death please contact the SIBSS team to discuss as you may need to seek advice from others who knew him or her for longer. You will be asked to select from the following three categories:

- My spouse/partner's HCV had a severe impact on his/her later life
- My spouse/partner's HCV had a moderate impact on his/her later life
- My spouse/partner's HCV did not have a noticeable day to day impact on his/her later life.

If you indicate that the impact was severe or moderate, you will receive a regular payment of 75% of what you spouse or partner would have received if they were still alive. If you indicate that their HCV did not have an appreciable impact on his or her later life, you will not receive regular payments.

If your spouse or partner is still alive and receives a chronic HCV regular payment, but dies in future, if the criteria above apply to you, you will automatically be able to receive a payment based on how they had assessed themselves at the point when they died (either severely or moderately affected). For the first twelve months after their death you will receive the full amount your spouse or partner was receiving. After that, you will receive 75% of this.

### Guidance on the three categories

The following guidance gives some illustrative examples to guide you on what may be expected, although it cannot consider every possible impact or circumstance. If you are a widow, widower or partner of someone who has died you can use this guidance to consider how HCV impacted on them over the last two years of their life, but if you are unsure or have any queries, please contact the SIBSS team for advice.

#### **'My life is severely affected by hepatitis c'**

This category is for those who are very seriously affected by their HCV. You should select this option if your hepatitis c still has a **significant impact on your ability to carry out routine daily activities**, such as for example at least one of these statements applies to you:

- You are unable to work due to the impact on mental health problems.
- You are only able to work part-time due to mental health problems.
- You had to leave a previous better job, job role or career due to mental health problems and this has had a permanent impact on your career. This could also include cases where your previous earnings have reduced as a result of your mental health problems.

- Your mental health problems have directly resulted in the breakdown of your marriage or other serious relationship and this is still having significant effect on your life. This is likely to apply to you if it wasn't your choice to end the relationship, but your partner ended the relationship because of the impact hepatitis c had on you and them.
- Your mental health problems make it very difficult for you to leave your home or socialise with others – this could be all the time or it may be that this happens to you quite often (at least a number of times in the past couple of years).
- You are unable to work full-time or carry out day to day activities due to physical health impacts caused by hepatitis c – see examples below of some conditions that may be caused by hepatitis c or interferon treatment.

Where we refer to mental health problems, this means problems such as depression, anxiety or low self-worth, which are caused by your hepatitis c. While the clinical review did not find strong evidence that physical fatigue is caused by hepatitis c, mental health problems could also include mental fatigue where this is linked to conditions like anxiety or depression.

Please note, the clinical review showed that there is limited evidence that chronic HCV leads to significant physical health impacts other than liver conditions, but it is recognised that in some cases there could be other ongoing physical health impacts. In order to tick this box, you need to be confident that there is a significant impact on your daily life, caused by your hepatitis c.

Some examples of physical conditions which may be caused by HCV include:

- type 2 or 3 mixed cryoglobulinaemia,
- sporadic porphyria cutanea tarda causing photo-sensitivity and blistering, or immune thrombocytopenic purpura with anti-platelet antibodies.
- in addition, autoimmune diseases, such as coombes positive haemolytic anaemia, idiopathic fibrosing alveolitis of the lung or rheumatoid arthritis, may sometimes be caused or worsened by interferon treatment.

If you think you may be affected by one of the physical conditions above, but are not sure, please consult your doctor or nurse about this.

### **'My life is moderately affected by hepatitis c'**

You should tick this box if you have some mental health problems due to your HCV or stigma caused by having HCV, but this does not now significantly affect your ability to work, leave your home or manage day to day activities, such as shopping. You can also take account here of ongoing mental health problems caused by HCV treatment (such as interferon). You might also tick this box if you took decisions because of having HCV that have affected your relationships and family life or your work – this could include cases where:

- you do not have a relationship or children because, for example, you chose to end a serious relationship because of your infection or decided not to have any children because you had HCV, or
- you felt unable to apply for a promotion at work as a result of your HCV, where there was a good chance that you would have secured the promotion.

In these examples, where you chose for example to end a relationship, this is more likely to fall into the moderately affected category, but if the relationship ended against your wishes because of the impacts of hepatitis c then that is more likely to come under the 'severely affected' category (see description above).

You can also take account of ongoing physical health impacts of your HCV - such as any of the conditions listed included under the 'severely affected' section above or other physical symptoms where your doctor or nurse has advised you that there is a strong chance these have been caused by your HCV. These would apply as moderately affected where your physical condition does impact on your life to some extent, but does not prevent you from carrying out day to day activities.

#### **'My life is not noticeably affected on a day to day basis by hepatitis c'**

You should tick this box if you do not have significant ongoing mental or physical health impacts caused by your HCV. This may include a situation where you have suffered significant impacts in the past, but where these are no longer affecting your day to day life. It might also include a situation where you still have some ongoing impacts, for example, due to stigma or in accessing insurance products, but where these issues only occur occasionally and don't have a constant impact on your life.

#### **Where to go for further information**

If you have any questions about anything in this guidance, please contact the SIBSS team on 0131 275 6754 or email [NSS.SIBSS@nhs.net](mailto:NSS.SIBSS@nhs.net) for more information. You may also wish to speak to one of your doctors or nurses for advice or contact one of the organisations which provides support to beneficiaries and their families – their details are available on the [Further Support Available](#) page on the SIBSS website.