



# Life after hepatitis C treatment:

## Health, wellbeing and the future

**Life after hepatitis C treatment: Health, wellbeing and the future**  
(Broadsheet No. 4)

This broadsheet is the fourth in a series of four that summarise key project findings.

Copies of this broadsheet or of any other publications from this project may be obtained by contacting:

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## Broadsheet No. 4

Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals

# Life after hepatitis C treatment: Health, wellbeing and the future

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For more information about the research on which this broadsheet is based, or to read more about experiences of hepatitis C treatment, please visit [Vital voices: Personal stories of treatment for hepatitis C](#).



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## Recommendations

This broadsheet is the fourth in a series of four that summarise key project findings. The recommendations from the four broadsheets are listed together below.

**Broadsheet No. 1: Experiences of hepatitis C diagnosis:** Testing, reflecting on diagnosis and seeking advice

- Health professionals conducting hepatitis C testing and diagnosis should provide patients with clear information about the tests being conducted, the disease itself, and the availability and effectiveness of DAA treatment.
- Hepatitis C diagnosis should be delivered with sensitivity to stigma and its potential impact on individual wellbeing, health and social relationships. Patients may benefit from being offered further support or counselling in the period following diagnosis and, depending on how they are diagnosed, may benefit from referral to a dedicated hepatitis C health or advocacy service.

**Broadsheet No. 2: Hepatitis C treatment uptake:** Understanding treatment incentives and obstacles

- Additional health education campaigning should be funded by governments and conducted by peer organisations and peak sector bodies to advertise DAA treatment availability and explain its features and processes, including its differences from the interferon-based treatment.
- More support should be provided to help people affected by hepatitis C to access appropriate models of care across different community sectors (e.g. housing and homelessness, mental health, and rural settings) and custodial settings, where hepatitis C is especially prevalent.
- Wide-ranging measures should be implemented to address the ongoing stigma, discrimination and criminalisation many people living with hepatitis C still face and which affect their access to, and decisions about, treatment.

**Broadsheet No. 3: Experiences of DAA treatment and hepatitis C cure:** Treatment knowledge, interactions with health professionals and questions after cure

- While DAA treatment is generally simple and effective, information provision during hepatitis C treatment should be improved. Health professionals should

provide patients with clear information about treatment procedures, the meaning and effects of cure, and any ongoing health issues that may occur following being cured.

- Health professionals should offer patients more information and support when hepatitis C cure is confirmed, including, where appropriate, follow-up appointments for liver health, and health education on issues such as alcohol consumption, cancer risk and harm reduction.

**Broadsheet No. 4: Life after hepatitis C treatment:** Health, wellbeing and the future

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.
- Peer-based education networks and peer support mechanisms should be embedded in the development and implementation of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake.

Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

## Background

Around 130,000 Australians live with the liver disease hepatitis C (MacLachlan et al., 2020). In 2016, the World Health Organization (WHO) announced a new goal of eliminating the virus as a health concern by 2030. Subsequently, the Australian Government adopted this goal (Australian Government Department of Health, 2018) and subsidised treatment, direct-acting antiviral (DAA) medications, through Australia's Pharmaceutical Benefits Scheme. This means treatment is generally affordable for people with hepatitis C. This is important as people who inject drugs are particularly over-represented among people with hepatitis C, with an estimated prevalence of 39% globally (Degenhardt et al., 2017). They experience significant financial disadvantage and have been a particular focus of treatment promotion efforts in Australia (Australian Government Department of Health, 2018).

When compared with the long, arduous and unreliable interferon-based hepatitis C treatment previously used, DAA therapy has been lauded as a treatment revolution (e.g. de Graaff et al., 2018; Martinello et al., 2018). DAA medication offers much shorter treatment durations (approximately eight to 12 weeks), far

fewer side effects and far superior cure rates (around 95%) and is delivered orally rather than through regular injections (Fierer & Wyles, 2020). Interferon-based therapy, by comparison, is associated with significant side effects and long treatment periods (between six and 12 months) and lower cure rates, depending on genotype and treatment type (Heathcote & Zeuzum, 2004).

While optimism surrounds the relative ease and simplicity of the new medications and the 'miracle' of cure (Rhodes & Lancaster, 2019), social research has complicated biomedical accounts of DAA success by drawing attention to the multiple meanings of hepatitis C cure and the complexities of post-cure life (Rhodes & Lancaster, 2019; Richmond et al., 2018). Madden et al. (2018), for example, contend that biomedical cure does not always meet the expectations or needs of people accessing treatment. As they argue, some of their participants felt let down by promises of a 'better life' following cure, and many desired further support for their liver health as well as information about liver health and ongoing risks after cure. Conversely, for other participants, experiences of cure extended beyond treatment and involved enhanced social connections and new perspectives on transmission risk (Madden et al., 2018). This broadsheet builds on and contributes to this growing literature by exploring experiences of life following treatment, including reflections on and concerns about life after cure.

## Method

This broadsheet is based on research conducted for a large qualitative research project on hepatitis C treatment uptake. Led by researchers at the Australian Research Centre in Sex, Health and Society, La Trobe University, the project was titled 'Lived experiences of treatment for hepatitis C in Australia: An online resource for people considering treatment, members of the public, healthcare workers and other professionals'. It gathered detailed perspectives on experiences of hepatitis C, the meanings given to diagnosis, decisions about and experiences of treatment, and life after cure for people affected by the virus.

The project used a purposive data

collection strategy to recruit and interview 50 people who had either been diagnosed with hepatitis C or were at risk of acquiring hepatitis C (e.g. people who inject drugs) but whose status was unknown. Participants were recruited across Australia's two most populous states: New South Wales and Victoria. Prospective participants were screened to ensure variation in the types of treatment experienced (participants who had not accessed treatment were also included); hepatitis C acquisition routes, reinfection and treatment outcomes; and gender, sexuality, age, ethnicity, geographical location and socio-economic background. All participants provided audio-recorded informed consent. In-depth, semi-structured interviews were conducted to explore participant experiences of hepatitis C diagnosis, treatment, cure and life following treatment.

Interviews were conducted via audio/videoconferencing and phone calls, and in person. These collection methods were adopted because the project was conducted during the outbreak of COVID-19 in Australia, meaning in-person contact was highly restricted for much of the data collection period. Interviews ranged between 30 and 90 minutes in length and were digitally recorded. All participants were compensated with A\$50 cash or an A\$50 gift voucher for a major retail chain in recognition of their time and contribution to the research. The study was approved by La Trobe University's Human Research Ethics Committee (HEC20078).

Interviews were transcribed verbatim by a professional transcriber. All transcripts were imported into QSR NVivo 12 for management and coding. A coding framework was generated using a combination of methods: codes were identified in response to the project's aims and previous research on hepatitis C treatment, based on themes emerging in the data and in consultation with the project's advisory board. The interview transcripts were coded by the first and third author using an iterative process, in collaboration with the lead investigator to maximise coding consistency and comprehensiveness.

The interviews conducted for this project were used to produce a public website on personal experiences of DAA treatment, issues to consider in decision-making about treatment, and advice on looking after health during and after treatment.

# Summary of findings

Interview material from selected codes was carefully analysed by members of the research team to develop website content for this online resource. Topic sections for the website were developed in response to the research aims and main themes arising from the interviews. On the basis of these topics, members of the research team have developed four broadsheets to provide accessible information about experiences of DAA treatment to health professionals, policymakers and service providers. This broadsheet is the fourth of a series of four that explores issues related to hepatitis C diagnosis, treatment decision-making, experiences of treatment and health and life after treatment.

In these broadsheets, key demographic information about each person interviewed is presented in brackets after their pseudonym. For all participants this information includes their gender, age and treatment experience, for example, 'Dave (male, 65, experience with both DAA and interferon-based treatment) said that the DAA treatment was "quite easy" to incorporate into everyday life.' For more details about participants, see the demographics table in Appendix 1.

The people interviewed for this project expressed a range of views about their health, wellbeing and vitality after hepatitis C treatment (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*). For some, treatment was a positive experience that led to feelings of optimism about the future and ongoing changes in how they managed their health and wellbeing. For others, treatment experiences did not have long-term significance, and hepatitis C was simply something they no longer considered relevant.

While treatment had cured them of hepatitis C, many participants in our project said that they had ongoing concerns about the impact of the virus on their health, and explained that they engaged in routine hepatitis C-related testing and monitoring. Some participants who inject drugs expressed concern about reinfection, and reported adapting their injecting practices to reduce this risk. Some discussed hepatitis C as one of several health issues they have continued to manage since treatment. Related to this, some said that post-treatment life could be improved by access to more support. A few people had such positive experiences of treatment that they engaged in informal and formal advocacy and peer work to improve treatment access and wellbeing for others (see Broadsheet No. 3, *Experiences of DAA treatment and hepatitis C cure: Treatment knowledge, interactions with health professionals and questions after cure*).

In the following sections, this broadsheet covers experiences of health and life in general after treatment, including how cure shapes perspectives on health and wellbeing. It also covers testing and support needs after treatment, and concerns about, and hopes and plans for, the future. It concludes with recommendations to improve support and care following hepatitis C treatment and cure.



## Reflections on life after hepatitis C

# Looking after health and wellbeing

The people we interviewed for the project on which this broadsheet is based offered a range of different perspectives on what being cured of hepatitis C meant for their everyday lives. For some, their cure led to them having a greater focus on their health, often adopting practical strategies to look after it. For many, while welcome news, a hepatitis C cure addressed only one of a range of health issues that needed their attention. Several people said that following their cure, they started paying greater attention to their health and wellbeing. For many, this involved eating regularly and having a balanced diet, drinking less alcohol, exercising and seeing family and friends.

Following treatment, Sana (female, 71, experience with DAA treatment) described 'maintaining her diet' and avoiding 'salty, sugary and oily stuff'. Colin (male, 44, experience with both DAA and interferon-based treatment) said after being cured he had 'more energy [...] and colour' and was 'heavily involved

in yoga and exercise and [watching his] diet'. Rohan (non-binary, 38, experience with both DAA and interferon-based treatment) said that the break they took from drinking while living with hepatitis C helped them realise that it contributed to their anxiety. After their treatment, Rohan considered returning to drinking, but they decided to stop altogether.

*Yeah. I mean, I didn't drink alcohol when I was living with hep C, just because like... mostly because I didn't have a high tolerance. It was also, like, making my liver, that was already under pressure, having to work, and, like, I got a really bad taste and kind of a bit of a reflux when I was drinking alcohol. So, when I [was cured of] it, I was like, 'Oh, cool. I can drink again now.' [...] What I realised is that actually, like, alcohol causes me anxiety, yeah, and I always thought, like, when I was younger, I was, like, smoking cannabis and drinking and I was just, like [...] 'Oh, it's the cannabis',*

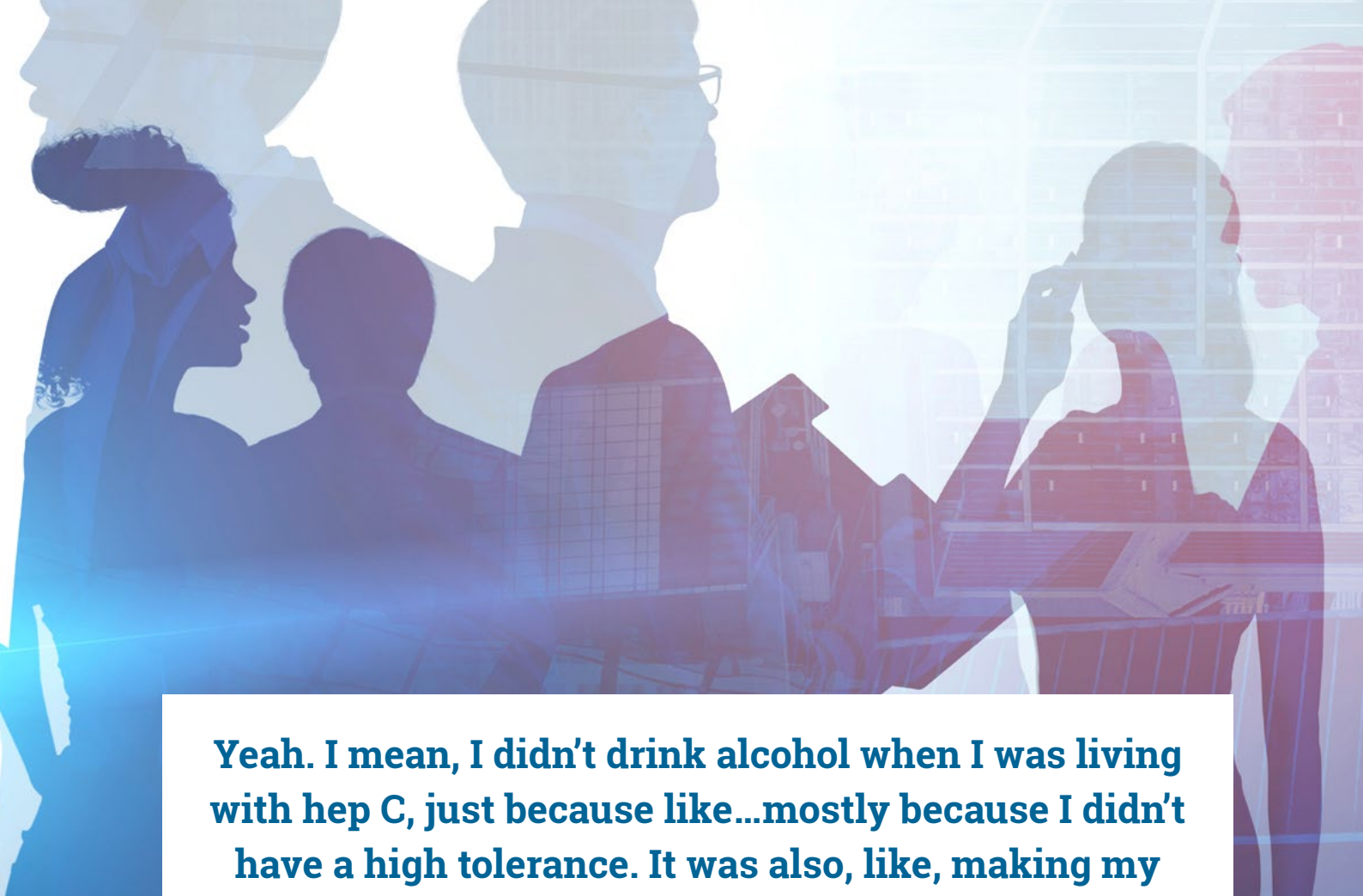
*and actually, no, cannabis doesn't give me anxiety, it's the alcohol. So, I just don't really drink, because I don't like the anxiety after it.*

Another common theme in our interviews was the need to continue managing other ongoing health issues after being cured of hepatitis C. For several participants, hepatitis C had been only one of a range of serious health issues they had to manage.

Dave (male, 65, experience with both DAA and interferon-based treatment) described concerns shared by several participants when he explained that he had other health conditions still needing treatment.

*I do have an old back injury, but that's not going to change. It's being treated, I am living with it. I am doing physio for it, so yes, I need a hip replacement, but other than that, I am quite healthy. My dental health, my teeth are looked after quite well. I regularly see the*





**Yeah. I mean, I didn't drink alcohol when I was living with hep C, just because like...mostly because I didn't have a high tolerance. It was also, like, making my liver, that was already under pressure, having to work, and, like, I got a really bad taste and kind of a bit of a reflux when I was drinking alcohol. So, when I [was cured of] it, I was like, 'Oh, cool. I can drink again now.' [...]** What I realised is that actually, like, **alcohol causes me anxiety...**

**ROHAN (NON-BINARY, 38, EXPERIENCE WITH BOTH DAA AND INTERFERON-BASED TREATMENT)**

*optometrist every two years and get an update for my glasses. I went through physio for my back and stuff, and I exercise quite regularly. I do my exercises reasonably regularly [...] I look after my health. I don't drink a lot. I am not using IV drugs. I will have a joint at a party [but] I won't go looking for it. I am in the process of giving up smoking again.*

Carol (female, 58, repeat diagnoses, experience with DAA treatment) was cured of hepatitis C but described still needing to pay attention to her diabetes and diet.

*I have a little bit of trouble in my legs, but [...] that's] part of being type 2 diabetes [...] I still do what I was doing then [during treatment]. I try and walk, I've got a [dog], so we walk every day [...] I still like to eat a little bit of... like, you've got to live, you know what I mean? There's no point in eating fruit and vegetables and being depressed because you would feel like you've got no quality of life [...] It's just listening to your tummy and doing what's best without sort of going overboard. At the moment, we are carving out cheese. Like, I had a little run on cheese, and I find cheese*

*with a high fat content, it's got to go. Milk chocolate's got to go.*

**Participants varied in how they approached life after treatment, but many described paying greater attention to diet and exercise, and more generally prioritising their health and wellbeing. While treating hepatitis C was a priority for many, other persistent health issues were also a concern that required ongoing management and care following cure.**



## Reflections on life after hepatitis C

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# Testing and support after treatment

Most participants did not report ongoing liver problems or the need for regular tests for their liver health. However, for some, ongoing testing and support was a feature of everyday life following treatment. Some of these tests were due to long-term hepatitis C-related matters such as monitoring of liver health, including liver disease and cirrhosis. For others, regular blood tests were undertaken due to the ongoing risk of acquiring hepatitis C again.

Post-treatment healthcare was delivered through general practitioners, liver specialists, and other health professionals. Terence (male, 34, experience with DAA treatment) explained that his doctor encouraged him to have regular liver monitoring and gave him information about reinfection and support.

*My doctor was very good with that stuff and encouraged me to get a liver function test at least every 12 months. Yeah, he gave me some information and, yeah, sort of invited me back anytime I needed any further assistance or information. [He said] that I could come back and then also sort of went through the whole, you know, 'Just because you've [been cured of] it, it doesn't mean that you can't catch it again' sort of thing. Like,*

*[he said,] 'If you return to injecting drug practices or put yourself in other high-risk situations, yeah, you can still contract the virus. Like, the treatment doesn't give you any immunity to it.' So yeah, they were good in that aspect.*

In contrast, some participants described little testing after treatment. Chris (male, 60, experience with DAA treatment), for example, explained that he 'didn't really have any other [tests or follow-up]' after his cure was confirmed. He also explained that he had to initiate all follow-up tests related to his hepatitis C.

While tests confirmed that Lou's (female, 40, experience with DAA treatment) liver was healthy, she described wanting more information than she received about issues to consider after being cured.

*I said, 'So what do I need to do from here? Do I see you again in a few years? What happens?' And he was just again, that dismissive, 'No, everything is fine, don't worry about it again, everything's fine.' [...] Yeah, it would be helpful to know certainly about, you know, any signs or symptoms of anything changing. It would be helpful to know if, you know, if there were any screening programs that would be recommended to me. It*

*would be helpful to know what is best practice in terms of, you know, the ongoing management of somebody who's had the illness for so long. I feel like I don't know much about that. I feel like all of that information is geared around, yeah, how to prevent yourself from getting it again through safe needle use, yeah.*

**For some participants, blood-borne virus and liver testing and management of chronic health issues were ongoing features of post-cure life. Notably, for others, the support they received after treatment did not provide enough information about life and health after cure.**

## Reflecting on life after treatment

Of the people we interviewed, being cured of hepatitis C affected their lives in different ways. For some, being cured was a significant event connected to a range of other shifts in their lives. For others, cure was less significant, as many other aspects of their lives remained the same. Together these experiences indicated that while treatment is an important event for many, it addresses only one of a range of issues and concerns in life for people affected by hepatitis C.

Being cured of hepatitis C was 'life-changing' for Marty (male, 65, experience with both DAA and interferon-based treatment). He said he had a success story to tell others, and since completing treatment he had been doing formal advocacy work with a hepatitis advocacy organisation.

*From that day when the virus was cured, that was life-changing, because I had a story to tell others of success [...] I went to a federal inquiry into living with hepatitis [C] in Australia. After I told my story, a politician called Ken Wyatt<sup>1</sup> came straight over to me, shook my hand,*

*gave me a hug, he's a Koori fella, [and] gave me his card [...] Then, I went down to Canberra during this time. I saw Sussan Ley<sup>2</sup> personally. The Pharmaceutical Benefits Advisory Committee<sup>3</sup> came up to Sydney to see me, not to have a cup of tea or see her [Sussan Ley], to see me [...] When you've got the Pharmaceutical [Benefits] Advisory Committee coming up from Canberra to see me, you know, there's a bit of ego there, but there's also a bit of authenticity for me, you know, like, 'Fuck! You know, these people are interested in me, you know, interested in my story.'*

Colin (male, 44, experience with both DAA and interferon-based treatment) explained that his life has changed significantly since being cured of hepatitis C. For him, being cured meant he felt able to pursue an intimate relationship, and it was also connected to a range of other positive changes in his life.

*I hadn't had any intimate partners for a long time, because I lost a partner when I was 20 and wasn't in a relationship, actually, had nothing for*

*about 18 years, you know. And then with the hep C, I just thought I was just dirty, you know what I mean, and it was too much of a risk. Like, I had it in my head [that] it was too risky, and stuff like this or whatever, to transmit it on to a partner, and no-one deserves that sort of thing, you know. Getting it off your back, like, I guess as far as intimate partners [go], like, I need connection in my life with someone, you know. I need to share my life with someone, and that made that hell of a lot easier to, I guess, go and pursue that. And I think my family have only been back in my life probably four or five years, you know, and they have definitely... like, they have seen the change and the effort that I put in, you know what I mean. I have worked incredibly hard to get to where I am at.*

Since completing treatment, Dave's (male, 65, experience with both DAA and interferon-based treatment) life has changed in several significant ways. He spoke about getting involved in a campaign promoting hepatitis C treatment, but also said that he continued to face other health issues.

<sup>1</sup> Ken Wyatt is a former assistant minister for health in the Australian Government.

<sup>2</sup> Sussan Ley is a former minister for health in the Australian Government.

<sup>3</sup> The Pharmaceutical Benefits Advisory Committee is an independent expert body providing advice to the Australian Government about which drugs and medicinal products should be listed on the Pharmaceutical Benefits Scheme and subsidised by the government.



*I have made a lot of connections with people who I'd never thought would [meet] in my life, and a lot of that has come through working [on a campaign to increase treatment uptake]. I am meeting politicians [...] I am talking to people about sort of expanding drug treatment facilities. I am a team leader of a group of people with lived experience who are part of the campaign. I am also co-editor of [...] a newsletter [for a service... I also edit a [...] Facebook page [on treatment]. None of that would happen if I hadn't stopped using [drugs], and none of that would have happened if I hadn't sort of [been] cured [of] hepatitis C [...] Yeah, getting rid of hep C and putting down the IV drug use has greatly changed my life [...] I realised how old I am, you know. There is not another 50 or 60 years in front of me. I am sort of going to have to accept that, you know, and my body is sort of breaking down. I am going to need another hip replacement in a few years' time, on the other hip. I have a back injury [...] I crushed a lot of vertebrae in my back, but I can work around that sort of stuff, you know [...] My life has changed completely.*

Terence (male, 34, experience with DAA treatment) explained that while being cured had a positive impact, it occurred at the same time as a series of other positive shifts in his life.

*I suppose emotionally I felt better [once I was cured]. Physically, I would probably say yes, that [the cure] contributed [positively], but I was going through a lot of changes in lifestyle as well at the time. Yeah, when I [was cured of] the virus, that was a huge emotional baggage lifted*

*from my shoulders [...] I also] probably just start[ed] to make better choices in life. Yeah, that's about it really [...] I decided to go and study instead of work. Typically, I'd worked in the meat industry and labouring and stuff like that, so yeah, it was pretty big for me. I didn't really go to high school, probably got a Year 7 education, and I decided around that time in my life that education was something that I wanted to pursue, so yeah, I signed up for a course at university.*

In contrast, Sean (male, 42, repeat diagnoses, experience with DAA treatment) said his life had not improved a great deal since being cured of hepatitis C.

*[My life hasn't changed], not because of not having hep C, no [...] My life isn't that great, and I couldn't give two shits whether I have it or not, you know. Yeah, I've got a pretty bleak outlook, you know [...] I've just got a lot of stuff going on. You know, [my ex-partner], she's my wife, I'm married to her, and I don't even know where she is [...] No idea where she is. I just know that she's a mess and I can't find her.*

While Gracie (female, 65, experience with DAA treatment) said that her life had not changed dramatically since completing treatment, she was glad to be cured of hepatitis C and felt relatively content.

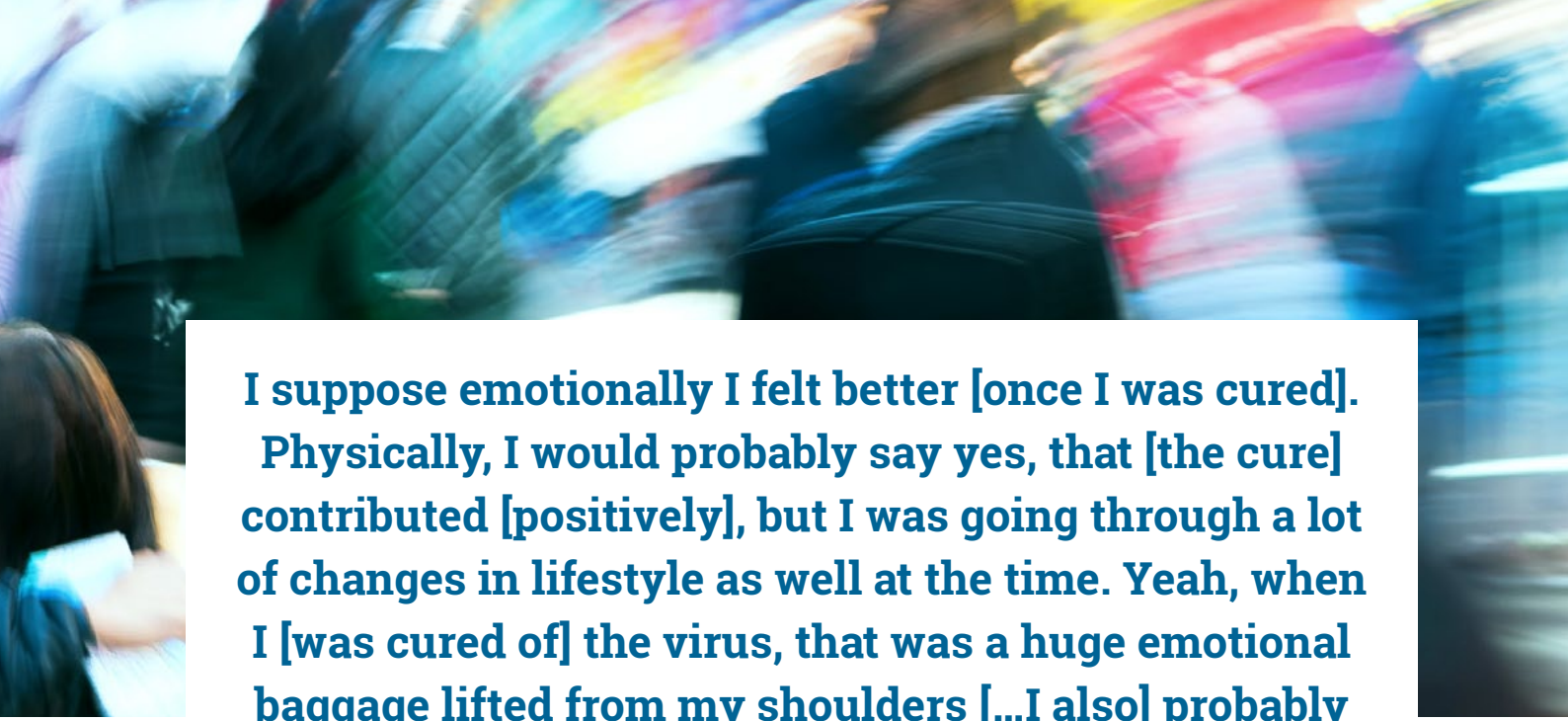
*I struggled with hep C for 20 years, and miraculously the new medication worked with me, but I struggled sometimes in those 20 years, especially when I was thinking about entering sexual relationships and stuff about disclosure and whatever [...] There's nothing I really want to do that hep C... if I was a young woman and sexually active, this would've*

*been a massive improvement in my life, but I'm not, I don't care, and everything's cool.*

Kylie (female, 46, experience with DAA treatment) said that while being cured of hepatitis C made her 'happier', she still faced drug use-related discrimination due to her appearance and residence.

*It's funny, I've always been skinny but I'm a lot skinnier now, because I can't have a lot of weight on my legs because of injuries [from a car accident] and, like, my son's friends say to him – I don't even look like I take drugs – but they say to him, 'Oh, your mum is still on drugs, she's so skinny' [...] It's upsetting a little bit, like, that he has to deal with things like that, but he said it comes with the fact that as soon as you say you are in the housing commission house, everyone is supposed to be on drugs in [a] housing commission house, which is bullshit.*

**Our findings show that the effects of hepatitis C cure emerged differently for people depending on life circumstances, how long they had been living with hepatitis C, the concerns they dealt with in their lives and the challenges of stigma and discrimination. For some, cure was a significant event connected to an improved sense of self, confidence and optimism about the future. For others, it was less significant, because stigma, discrimination and material concerns were still present and requiring management. While treatment was significant for many people we interviewed, it does not address all the issues and concerns experienced by people affected by hepatitis C.**



**I suppose emotionally I felt better [once I was cured]. Physically, I would probably say yes, that [the cure] contributed [positively], but I was going through a lot of changes in lifestyle as well at the time. Yeah, when I [was cured of] the virus, that was a huge emotional baggage lifted from my shoulders [...I also] probably just start[ed] to make better choices in life. Yeah, that's about it really [...] I decided to go and study instead of work.**

TERENCE (MALE, 34, EXPERIENCE WITH DAA TREATMENT)

## Reflections on life after hepatitis C

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# Concerns about the future

Many of those we interviewed described the ways their experiences with hepatitis C and treatment shaped their thoughts about the future. As noted, several participants explained that while they had been cured of hepatitis C, they had ongoing concerns about their health. Offering a different perspective, some people interviewed said that hepatitis C was not an ongoing concern and that they rarely thought about it any more.

While being cured of hepatitis C was a positive experience for many, for some participants, such as Regina (female, 69, experience with DAA treatment), the long-term health effects of hepatitis C remained a concern.

*Yeah, it was a big relief. It really was. All of a sudden, I felt like I wasn't dying but, of course, there's always the worry of the ongoing effects. You know, developing liver cancer or something. There's always that slight worry, but I try not to worry [...] I think*

*I've got cirrhosis, if I remember, a bit of cirrhosis, but nothing to worry about. From the minute that I was diagnosed with hep C, I haven't had a drink. Not that I was a big drinker, but I've not had a drink of alcohol since.*

Others worried that cure was only temporary or incomplete, and that hepatitis C might affect them again. Some said that they worried the virus might re-emerge in their bodies or 'come back' spontaneously, while others thought about reinfection because they injected drugs.

According to Chris (male, 60, experience with DAA treatment), since finishing treatment he had been more 'careful' in how he managed his injecting, to minimise the risk of reinfection and to look after his health.

*So, I think when you are in your twenties, when you're young, you think you are invincible. You have*

*lots of energy, nothing is going to be a problem, you just take risks. You don't even know. But with the training I have had from my job and the life experience, I am going to be much more careful, and I don't want [my injecting] to be [a] compuls[ion] or an anxiety, but I do want it to be a safe practice. [I want to maintain] clean living and clean health and clean practices around risky things like taking drugs.*

**For some participants, the experience of undergoing treatment for hepatitis C produced uncertainty and concern about the virus returning, and about ongoing health effects. For others, it meant hepatitis C was no longer an issue or part of their lives.**

# Conclusion and recommendations

The experiences and perspectives reported here suggest that while hepatitis C cure is important, a range of issues and support needs persist and must be addressed to allow for improvements in life in general after treatment.

Our data indicate that many participants still actively engage with the legacy of hepatitis C by managing their health, diet and wellbeing, and for some, by adjusting injecting and hygiene practices to minimise the risk of reinfection. While most participants did not report ongoing liver or health problems following cure, some did have concerns and support needs that were not adequately addressed by health professionals.

For some of our participants, treatment was not considered significant or life-changing but was nonetheless associated with positive changes in health, employment and social relationships. For others, especially those who had lived with the virus for a longer period, concerns lingered about its impact on their health or its potential to return in the future.

## Key recommendations based on these findings

- Health professionals should offer ongoing testing and support following cure to assist patients in managing liver health or ongoing liver damage into the future, and to provide opportunities for addressing reinfection.
- Peer-based education networks and peer support mechanisms should be embedded in the development of post-treatment support and service models to strengthen pathways and linkages to care amid ongoing stigma and discrimination.

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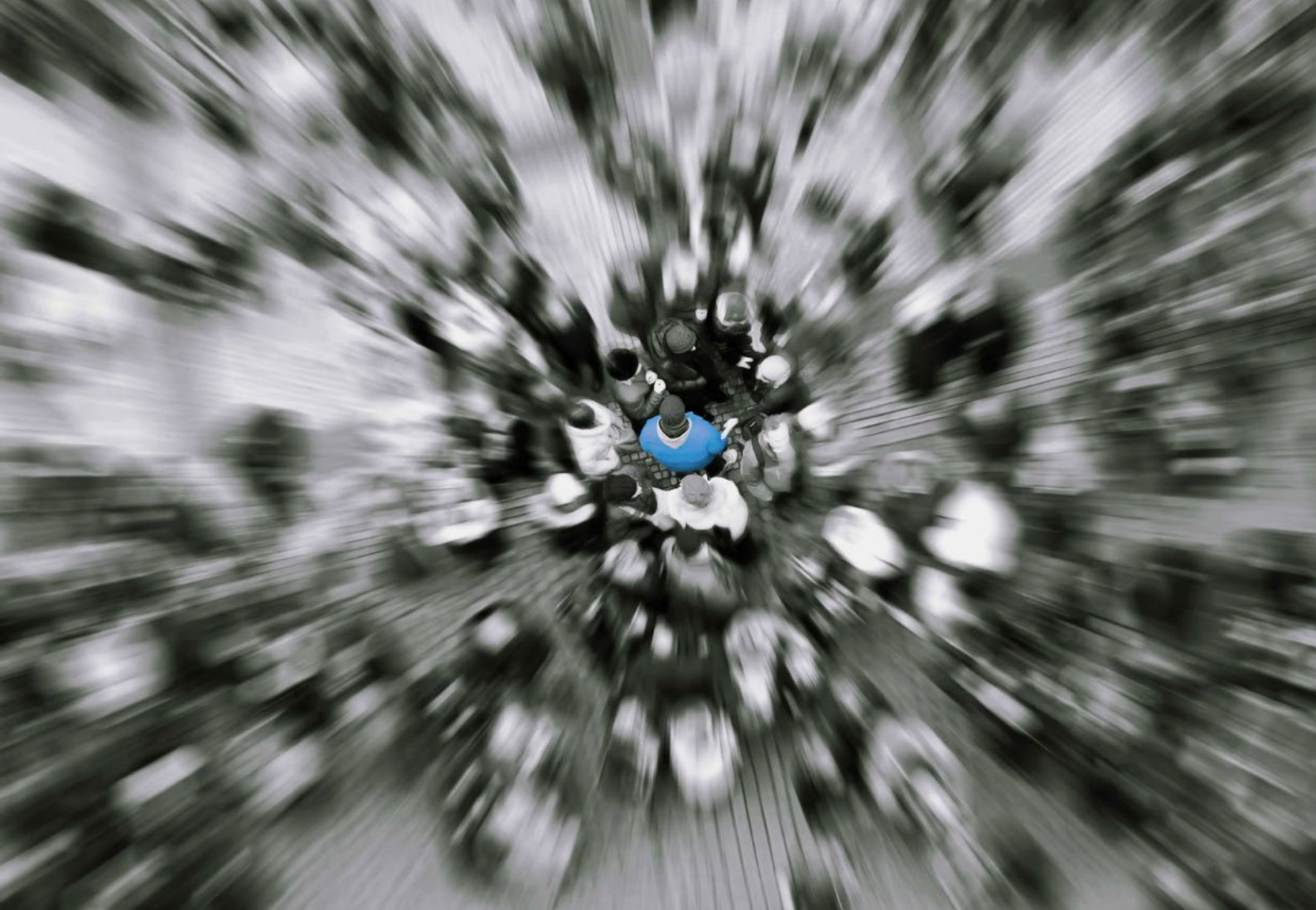
# Appendix 1: Participants

Participant information	Number
<b>Gender</b>	
Men	27
Women	21
Trans women	1
Non-binary	1
<b>State</b>	
Victoria	31
New South Wales	29
<b>Age</b>	
30-39	10
40-49	21
50-59	9
60-69	8
70-79	2
<b>Type of treatment</b>	
DAA treatment	19
Interferon-based treatment	9
Both DAA and interferon-based treatments	9
No treatment experience	13
<b>Employment status</b>	
Working or studying	15
Not working or studying	31
Retired	4

Participant information	Number
<b>Education level</b>	
Incomplete secondary	22
Complete secondary	12
Post-secondary	6
Tertiary	10
<b>Cultural and ethnic background*</b>	
Australian	32
Aboriginal Australian	5
New Zealander	2
North African and Middle Eastern	1
North American	1
North-West European	2
Southern and Eastern European	6
Southern and Central Asian	1
<b>Sexuality</b>	
Heterosexual	41
LGBQ+	9

\* Reporting of cultural and ethnic background follows the Australian Standard Classification of Cultural and Ethnic Groups (ASCCEG), developed by the Australian Bureau of Statistics. Cultural and ethnic background was classified according to a combination of self-reported group identification with particular cultural or ethnic groups, the participant's birthplace and their parents' birthplaces. For example, if one parent was born overseas and the other was born in Australia, as was the participant, and they identified as 'Australian', their background is classified as 'Australian'.





## Appendix 2:

# Articles in press and under review

### Hepatitis C cure as a 'gathering': Attending to the social and material relations of hepatitis C treatment

Farrugia, A., Fomiatti, R., Fraser, S., Moore, D. Edwards, M., Birbilis, E. & Treloar, C. (2022). Hepatitis C as a 'gathering': Attending to the social and material relations of hepatitis C treatment. *Sociology of Health and Illness*. <https://doi.org/10.1111/1467-9566.13467>

Since the advent of direct-acting antiviral hepatitis C treatments, widespread enthusiasm about disease elimination has emerged. This article examines experiences of hepatitis C treatment and cure in this period. Mobilising Fraser and Seear's (2011) approach to hepatitis C as a 'gathering', we analyse cure not as a biomedical phenomenon but as a social and material event. To do so, we take a Science and Technology Studies-inspired approach to analyse three complementary cases drawn from an Australian project on experiences of hepatitis C, treatment and cure. First, we analyse the ways a friendship between two women combines with adjustments

to treatment access to produce a gathering that makes cure possible. Second, we analyse the forces that gather and distribute responsibility when cure does not occur in a context shaped by oversimplified treatment logics. Third, we analyse a gathering of relations in which hepatitis C lingers, thereby limiting cure's possible transformative effects. We argue that, even in an era defined by highly effective medicines, hepatitis C cure is not necessarily straightforward, but an unpredictable gathering constituted by a fragile coalescing of social and material forces.

## Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment

Fomiatti, R., Farrugia, A., Fraser, S., Moore, D., Edwards, M., Birbilis, E. & Treloar, C. Post-crisis imaginaries in the time of direct-acting antiviral hepatitis C treatment. (Under review)

Until the recent introduction of direct-acting antiviral (DAA) medications, the only available hepatitis C treatments were lengthy and onerous interferon-based therapies, with relatively weak success rates. While experiences of interferon-based treatment have been well-documented, including the role of their side effects in impeding treatment uptake, there is a need to better understand how the experiences of the 'old' treatments shape contemporary treatment experiences. This article uses the concept of 'post-crisis' developed in critical scholarship on HIV/AIDS (Kagan, 2018), and recent theorisations of 'curative time' (Kafer, 2013), to explore the relationship between contemporary treatment experiences and the legacies of interferon-based therapies. In mobilising these concepts, we trouble linear temporal logics that take for granted distinctions between the past and present, old and new, and cure and post-cure, and draw attention to the fluidity of time and the overlapping co-constitutive terrains of meaning that shape treatment

decisions and experiences. Drawing on 50 interviews with people affected by hepatitis C, we argue that the curative imaginary of DAA treatments – that is the temporal framing applied to hepatitis C in which cure is expected and assumed – is shaped by the logic of crisis. Here, knowledge of and the possibilities for the new treatments and living with hepatitis C remain tethered to crisis accounts of interferon. Unlike HIV/AIDS, in which the disease itself was figured as crisis, many participants described interferon-based treatments as the crisis: as worse than living with hepatitis C. While the new treatments were widely described as simple and easy, we argue that treatment is not so straightforward and that the crisis/post-crisis relation is central to this complexity. We conclude by considering the significance of these post-crisis enactments for understanding the recent plateauing of DAA treatment uptake, and reflect on how post-crisis futures of hepatitis C 'cure' need to address the ongoing constitutive effects of interferon-based treatments.

## Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era

Fraser, S., Moore, D., Farrugia, A., Fomiatti, R., Edwards, M., Birbilis, E. & Treloar, C. Exhausted practical sovereignty and lateral agency: Non-uptake of treatment for hepatitis C in the antiviral era. (Under review)

With the advent of highly effective antiviral treatment for hepatitis C, many people have undergone treatment and been cured. Others, however, have not undergone treatment, even where it is free and readily available. Australia's aim of eliminating the disease by 2030 means this group are of concern to researchers, health professionals and policymakers. This article draws on 50 interviews conducted for a research project on treatment experiences to examine treatment non-uptake in Australia. Informed by Berlant's (2007) work on 'slow death', it analyses experiences of non-uptake to explain the dynamics at work in such outcomes. The analysis is divided into three parts. First, participant Cal describes a lifetime in which hepatitis C, homelessness and prison have shaped his outlook and opportunities. Second, Evan describes intergenerational drug

consumption, family contact with the prison system, and an equally long history with hepatitis C. Finally, Rose also describes a long history of hepatitis C, complex struggles to improve life, and contact with the prison system. All three accounts illuminate the dynamics shaping treatment decisions, calling to mind Berlant's slow death as a process of being 'worn out by the activity of reproducing life' under conditions that both demand self-management, and work against it. In concluding, the article points to Berlant's distinction between 'epidemics' and 'endemics', arguing that its politics apply directly to hepatitis C. In doing so, it highlights the need to address the criminalising, pathologising capitalist context of 'attrition' (Berlant) that wears out lives even as it fetishises autonomy, responsibility and choice.



La Trobe University proudly acknowledges the Traditional Custodians of the lands where its campuses are located in Victoria and New South Wales. We recognise that Indigenous Australians have an ongoing connection to the land and value their unique contribution, both to the University and the wider Australian society.

La Trobe University is committed to providing opportunities for Aboriginal and Torres Strait Islander people, both as individuals and communities, through teaching and learning, research and community partnerships across all of our campuses.

The wedge-tailed eagle (*Aquila audax*) is one of the world's largest.

The Wurundjeri people – traditional owners of the land where ARCSHS is located and where our work is conducted – know the wedge-tailed eagle as Bunjil, the creator spirit of the Kulin Nations.

There is a special synergy between Bunjil and the La Trobe logo of an eagle. The symbolism and significance for both La Trobe and for Aboriginal people challenges us all to 'gamagoen yarrbat' – to soar.

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