

# HARM REDUCTION Communication

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## Letter from the Editor

**This special double-issue of *Harm Reduction Communication* has two central themes: hepatitis C (HCV) and personal narrative.**

From 2004 to 2010, I worked on a research study investigating acute hepatitis C infection among younger injection drug users. In addition to conducting HIV and HCV testing, the study team was especially committed to creating environments that promoted safer injection through the integration of HCV awareness into the community dialogue and norms. We did our best to actively challenge stigma by discussing drugs and drug use openly and honestly – acknowledging the good parts with the not so good parts; we encouraged conversations about real life injection practices so that we could, in turn, tailor prevention messages; we recognized the reality of injecting in public bathrooms and did what we could to support safety under those circumstances; and we defied the notion that HCV is an inevitability if you inject drugs. In light of that experience, coupled with exciting developments in the HCV world, dedicating this issue of *Communication* to HCV made perfect sense.

**Jon E. Zibbell** kicks things off by building on Greg Scott's arguments from *Communication 16* with a critical look at hepatitis C prevention. He challenges the harm reduction community to move beyond traditional prevention strategies and messages that have over-emphasized the syringe as the primary vehicle for HCV transmission and makes a strong case that, while there is much to learn from our experience with HIV, HCV is a different beast that will require unique and nuanced messaging. **Heather Lusk** (who was one of the first people to teach me about HCV back in 2000) moves us from prevention to HCV counseling, testing and referral (HCV CTR). Heather is a brilliant educator and her "harm reduction how-to" for HCV CTR is both informative and very practical.

Back when the issue was first taking shape, I was talking with our Policy Director, Daniel Raymond, who suggested I collect some personal stories from people about their experience with HCV treatment and I was immediately sold on the idea. I was fortunate to connect with the New York City Hepatitis B and C Stories Workshop where **Donald Davis** told me about going through two treatment attempts before successfully clearing HCV and about the broader impact having HCV has had on shaping his career. Another member of the Stories group, **Paul Bolter**, also went through several treatment attempts, and while none were successful at clearing HCV, they were helpful in moving him to a deeper understanding of harm reduction and self care. **Gordon H. Peters** reminisces about his early days of injection and considers himself among the lucky ones, both because he learned about syringe exchange early and cleared his HCV with treatment. Another contributor who prefers to remain anonymous shares a beautiful piece written in the midst of depression and internal struggle that highlights how daunting it can be to try and access HCV treatment given both internal and external barriers.

Some of my first interviews were with **Peer Educators** at an HCV treatment and support group that has been integrated into a methadone program in the Bronx with the goal of addressing some of those internal and external barriers to treatment. The Peers had nothing but praise for this treatment model and I remember leaving the interviews with a spring in my step, inspired and hopeful about being able to share more about it in this issue. In case you find yourself as inspired as I was, **Alain Litwin**, **Irene Soloway** and **Frank Medina** have provided a great resource for starting your own group! Finally, long-time AIDS activist

**Lynda Dee** discusses what's on the treatment horizon with the new non-interferon-based therapies and tells us about her relatively painless experience clearing HCV in a clinical trial of the new medications.

Next we move onto advocacy where we're happy to introduce Harm Reduction Coalition's Hepatitis C Advocacy Manager, **Hadiyah Charles**. Hadiyah explains that she has witnessed a different level of stigma since focusing her efforts purely on HCV and issues facing drug users, despite having worked on HIV and viral hepatitis for nearly a decade before joining our team. Writing from the perspective of a woman of color who grew up in the Virgin Islands, she also explores the role of race, class, power and privilege in HCV advocacy.

Sadly, the hepatitis C and harm reduction community lost a great champion this year with the passing of **Michael Carden**. Our harm reduction family has lost far too many friends and loved ones to pay tribute to each one individually, however, Michael was a great advocate for people who use drugs and an important part of the HCV community, so it felt relevant and timely to include some thoughts and memories from the people who loved him in this issue. I feel incredibly lucky to have worked with Michael for several years and to call him my friend. That experience working with Michael, witnessing his struggles with drug use, and mourning his death from overdose are all parts of the reason why I felt so compelled to print the words of **Donald Grove** and **Allen Kwabena Frimpong** about harm reduction in the workplace. Donald generously let me print his very personal thoughts about living and practicing harm reduction within organizational structures that are driven by hierarchy, power, and the false distinction

of impersonality. Allen's response to Donald builds on the discussion and draws connections to social and racial justice, oppression, and trauma.

Continuing on the theme of personal narrative, we have two articles that explore relationships to violence. **Maria** talks about her experience with intimate partner violence and the link with hepatitis C. **Tessie Castillo** and **Robert Childs** from the North Carolina Harm Reduction Coalition share interviews and stories from several current and former sex workers who describe varied perspectives on violence while outlining systems and policy changes that are needed in order to better protect sex workers.

In *Communication 16*, Denise Cullen and Alice Bell wrote about the need for increased access to naloxone; in this issue we carry this message forward and highlight the great strides being made in overdose prevention by presenting a model for integrating overdose prevention into drug treatment settings. This is a groundbreaking program and we're thrilled to be able to feature it here (even if we couldn't give proper credit due to bureaucratic red tape).

Plus, **Roxanne Saucier** introduces a new section to *Communication*: Reviews! Roxanne explains why the new report, *Protecting Your Privacy in an Age of Electronic Medical Records* written by Corinne Carey and Gillian Stern for NYCLU, is such an important resource in light of the ever-shifting health care landscape. Are you interested in contributing to the new Reviews section? Write to me at [publications@harmreduction.org](mailto:publications@harmreduction.org)!

Lastly, I want to extend huge thanks to all of the contributors in this issue. I appreciate your patience, your attention to detail, your willingness to take risks, and your great generosity in sharing your stories.

—EMILY WINKLESTEIN, EDITOR



These figures paint a harrowing picture of an epidemic running roughshod over people who inject drugs. Any virus that has a prevalence rate upwards of 70% in a given population should give us great pause. Yet, the fact that PWID make up a majority of those at risk for infection means that, like HIV, the pause may linger for much too long. Be that as it may, it's still quite possible that the lessons learned from HIV/AIDS can help prompt a national response to the hepatitis C epidemic, one that can avoid the types of political moralism that stymied America's reflex to AIDS during the 1980s and 90s.

In the early days of the AIDS epidemic, as countries faced the initial threat of an unknown contagion, many states supported the forced quarantine of HIV-infected persons as an effective tactic to prevent future spread of the disease. With AIDS, however, the practice of *cordon sanitaire* came to be seen as a dubious response for two reasons: First, although AIDS is a fatal disease, HIV, the virus that causes it, is not, which means there is the likely potential that a long time period will elapse between when a person first acquires the virus and when that person may die from AIDS-related causes. And second, HIV is not a communicable, airborne contagion, but bloodborne, so besides unprotected anal and vaginal sex, drug injection with a contaminated syringe, blood and organ transplants, and semen donation, it's not easily transmitted.

Fortunately, these discoveries led to a rather straightforward set of interventions for preventing future infections, whereby screening organ, semen, and blood donations, offering safer sex education, expanding condom distribution and increasing access to sterile syringes were found to significantly reduce the number of infections, especially as people began to think and act differently with regard to their sex and drug using practices. While these characteristics make

prevention—rather than containment—an effective and relatively inexpensive strategy for protecting civil society from HIV/AIDS, they also make it unlike any other modern disease epidemic; that is, until HCV enters the picture, presenting a myriad of analogous characteristics. Here are nine of them:

1. Both HIV and HCV are not communicable, airborne contagions, but blood borne, and thus acquired through an exchange of contaminated blood;
2. There are currently no vaccines for the prevention of either infection;
3. Both viruses have prevention, i.e. harm reduction, as the primary strategy to reduce individual exposure;
4. Both diseases have treatment regimens that are limited by high costs and the demanding effects of anti-viral therapy;
5. Both viruses disproportionately affect PWID and as such are not democratically acquired;
6. Both viruses have needles, syringes and preparation equipment (e.g. cookers, filters, water, etc.) as transmission vectors;
7. Both viruses can retain their infective capacity on injection equipment (under the right conditions) for extended periods of time;
8. Both viruses have a protracted time period between when a person is first exposed to the pathogen and when the onset of symptoms arrive from a subsequent illness;
9. Both viruses are disproportionately acquired by groups that are independently unpopular.<sup>5</sup>



Contrary to HIV's fleeting lifespan, infectious quantities of HCV were detected on inanimate surfaces for more than two weeks after initial contamination. Shared injecting surfaces that are not routinely sterilized, even when blood may not be visible, may act as vectors of transmission. While heating drug solutions can decrease viral infectivity of HCV, it generally takes between 80-95 seconds of heating to have such an effect. Photo: Greg Scott

With these factors in common it seems plausible that tactics proven to reduce injection-related HIV transmission – like making sterile syringes more easily accessible – could have comparable results with HCV. This logic is based on three decades of scientific research establishing an inverse and causal relationship between increased syringe access and decreases in new HIV infections; a correlation most succinctly demonstrated by a substantial drop in injection-related HIV prevalence from more than 50% to less than 10% in regions with syringe service programs (SSPs). In the teeth of such evidence it's easy to understand why researchers have started to examine whether SSPs can be just as successful in preventing HCV as they have with HIV.

**The foremost lesson to be drawn from comparing viruses is that HCV presents a unique set of behavioral risks for PWID by its ability to transform every piece of injecting equipment (syringes, cookers, filters, rinse water, mixing water, alcohol swabs and tourniquets) into a primary transmission vector.**

At this point, however, it is still an open question. A few *bona fide* studies have demonstrated reductions in HCV incidence due to SSPs while many other, equally reputable studies have found little or no effect. This wooliness notwithstanding, what is unequivocally true is that HCV prevalence has now surpassed HIV across all prevalence studies: recent data indicate that *HIV* prevalence among PWID is between 1% and 10% while *HCV* prevalence ranges between 30% and 70%. These results, it is sobering to say, clearly demonstrate that successes in the field of HIV prevention have not translated to HCV as comparable and reproducible outcomes have yet to be observed.

Hope persists, however, and appears in the form of studies reporting increased effectiveness when prevention efforts focus attention on preparation equipment *in addition to syringes*. The possibility that the sharing of cookers, filters and water play a formative role in HCV transmission (more than they do with HIV) is particularly instructive because it highlights the potential for there to be significant differences in how HIV and HCV function outside the body. The fact that HIV needs an airtight environment to survive – it can live only momentarily in the open air – is the principle reason why the syringe, with its hermetically sealed barrel, provides an ideal environment for HIV. It is also why HIV prevention efforts have hitherto focused on syringes as the riskiest of all transmission vectors.

Regrettably, this syringe-centered logic has had a tendency to identify the sharing of preparation equipment as being less risky than syringe sharing (and thus of lesser concern) on the basis that cookers and filters do not provide a closed enough environment for HIV to subsist for more than a few moments. But when HCV is figured more heavily into the equation, this 'hierarchy of risk' will perhaps need to be modified seeing that scientists have recently demonstrated significant differences between HIV and HCV's infective capacity. If accurate, these differences may account, in part, for why HCV infections exceed HIV across all prevalence studies.

### **The Exceptional Virulence of HCV**

Ever since its official discovery in 1992 (formerly categorized as *non-A/non-B* hepatitis) scientists have characterized HCV as a virulent and easily transmissible pathogen. This is mainly attributed to the fact that it is ten times more concentrated in the blood than HIV and thus more effectively transmitted when any infected blood is involved. To investigate transmission capacity and the manner in which HCV behaves on injection equipment, researchers have begun to simulate the way syringes, cookers and surfaces are used in the drug preparation process. And the preliminary results are striking.

Contrary to HIV's fleeting lifespan, infectious quantities of HCV were detected on inanimate surfaces for

more than two weeks after initial contamination. Like many viruses, HCV is gradually inactivated when outside the body but the presence of heat has been shown to speed up the inactivation process and negatively impact its lifespan. When heating HCV in a spoon, for example, viral infectivity started to decrease when the solution reached 112 °F and was only below the detection limit when the solution reached 136-144 °F; though it generally took between 80-95 seconds of heating to have such an effect.<sup>6</sup> On inorganic surfaces, infectious quantities of HCV were found for up to seven days after initial contamination and were reported to remain infectious under certain conditions for as long as sixteen days.

The high probability of HCV transmission has also been attributed to the virus's potential to remain infective in both needles and syringes for protracted periods of time. With syringes, HCV virus has been shown to survive in the barrel of a syringe for up to 63 days. High dead-space syringes (HDSS), in particular, are especially worrisome<sup>7</sup> due to their capacity to retain over 1000 times more blood *after rinsing* than low dead-space syringes (LDSS).<sup>8</sup> The continued use of HDSS, when seen from the angle of prolonged infectivity, may contribute to why HCV infections resulting from contaminated syringes are estimated to be 5 to 20-fold higher than HIV.

When researchers compared syringes to preparation equipment, however, they reported differences that, if accurate, are quite astounding. Researchers discovered that infectious levels of HCV in syringe barrels tended to be *lower* than levels found on surfaces and cookers, suggesting a greater possibility of becoming infected through the use of contaminated preparation utensils and surfaces than through a tainted syringe. The decisive insight here is that preparation equipment, when coming in

contact with infectious blood, may serve as viral reservoirs and be directly associated with HCV transmission *even when using a sterile syringe*.

### A New Kit for Every Hit

Up until this point I have insisted on the importance of identifying both similarities and differences between HIV and HCV on grounds that our experience with the former can help inform our understanding and response to the latter. Even so, the fact that there is a high prevalence of HCV and a low prevalence of HIV, simultaneously, and within the same population, highlights the importance of narrowing in on their differences, particularly when trying to grasp the gravity of our present day situation. Before proposing a few suggestions for how to modify existing safer injection (SI) protocols, let's recap the above-mentioned differences between HIV and HCV so as to remind ourselves of the implications they have for how we design SI protocols intended for HCV prevention.

- HCV infections resulting from exposure to a contaminated syringe is estimated to be 5- to 20-fold higher than HIV transmission.
- HCV has been detected in syringe barrels two months after contamination.
- While a syringe barrel is a hermetically sealed and friendly environment for bloodborne viruses to thrive, infective levels of HCV were found to be *lower in the barrel* than on cookers and surfaces.
- While HIV is compromised quite rapidly by low temperature heat, HCV-contaminated solution needs to be heated for almost a minute-and-a-half and reach temperatures of 144°F for infectivity to be at undetectable levels.

- While HIV's survival on inanimate objects is short-lived, HCV has been shown to survive on cookers and surfaces for up to sixteen days after contamination.

The foremost lesson to be drawn from comparing viruses is that HCV presents a unique set of behavioral risks for PWID by its ability to transform every piece of injecting equipment (syringes, cookers, filters, rinse water, mixing water, alcohol swabs and tourniquets) into a primary transmission vector. In effect, the combination of protracted infectivity and environmental stability has the potential to transform the entire injection episode into a substantial risk factor since the setting itself contains a plethora of mandatory equipment that can harbor and transmit HCV.

Now, suggesting we need to expand the boundaries that circumscribe "the risk environment" is not intended as hyperbole, nor is it meant as a 'doom and gloom' scheme to scare people straight, but instead posited as a reasonable explanation for why there is such a high prevalence of HCV among former and current injectors. If this hypothesis is indeed accurate – even a little bit – then it's essential for PWID to be aware that *the reuse of contaminated cookers, filters, swabs, tourniquets and water can lead to the acquisition of HCV even when using a sterile syringe*. It also highlights the need to incorporate preparation equipment into the "safety" equation and to modify our current SI protocols accordingly. Both efforts will require incorporating HCV's behavioral risk profile into SI protocols

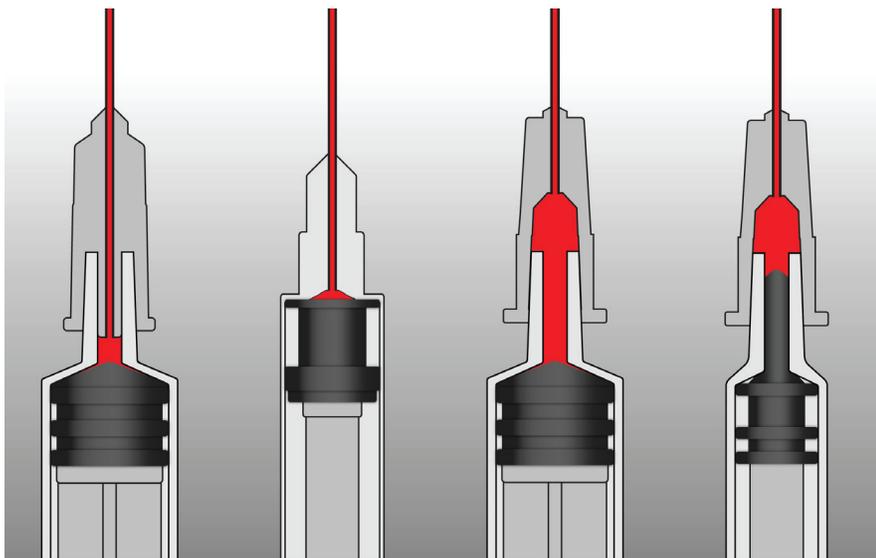


"A new kit for every hit": It is important for prevention education to include information about HCV's behavioral risk profile and the specific hazards involved when sharing preparation equipment.

originally based on HIV's risk profile. Since there has yet to be a collective attempt to update existing protocols, let me propose, in what follows, a few suggestions to initiate this effort.

First and foremost, the syringe itself needs to be dethroned as the *principle* source of infectious contamination for the sole reason that it is manifestly not true. Instead, the risks accompanying the sharing of preparation equipment need to be considered on par with the risks associated with sharing syringes; otherwise, SSPs that continue to prioritize syringes will be less effective in reducing HCV infections than programs that place an equivalent importance on preparation equipment. Many programs spend copious amounts of time discussing

**Many programs spend copious amounts of time discussing syringe types and injection angles but deliberations on preparation equipment are often just a point to the shelf accompanied by the directive: "take what you need."**



Illustrations of dead space in common needle and syringe designs. Dead space increases with barrel size, needle length and needle gauge and is significantly greater in syringes with detachable needles. See note 7 for an extended definition of dead-space. Artwork courtesy of William Zule, DrPH, licensed by Creative Commons.

**A non-judgmental approach should never prevent workers from being frank and forthright when discussing injecting techniques with participants nor should it impede them from suggesting safer and more efficient ways to inject.**

syringe types and injection angles but deliberations on preparation equipment are often just a point to the shelf accompanied by the directive: “take what you need.” To complement the discussion surrounding syringes, service workers need to talk to their participants about HCV’s behavioral risk profile and the specific hazards involved when sharing preparation equipment. “A new kit for every hit” is an appealing catchphrase to popularize this effort.

Next, SSPs should explain to participants the health benefits of using LDSS. Harm reduction workers can explain that HDSS pose significantly greater risks and strongly suggest the use of LDSS whenever possible. This style of interaction is consistent with the non-judgmental ethos that characterizes the harm reduction philosophy. Being tolerant and open-minded towards a participant’s drug use, i.e. “meeting them where they’re at,” is intended to help service

workers conceptualize and discuss a person’s drug use without sneering at their rationale or having contempt for their way of life. But a non-judgmental approach should never prevent workers from being frank and forthright when discussing injecting techniques with participants nor should it impede them from suggesting safer and more efficient ways to inject.

It is entirely acceptable for service workers to have straightforward discussions with program participants about their injection practices so long as both parties are committed to similar goals, like reducing the chance of acquiring bloodborne infections, avoiding bacterial infections and abscesses, maintaining healthy veins, etc. Stated somewhat differently, there is a substantial difference between confronting participants about their drug use in a haughty and contemptuous manner on the one hand, and having candid and pointed discussions on the hazards of certain injection techniques

on the other. However, when having these discussions it’s important to keep in mind that a person’s decision to use a specific type of syringe is not always the result of individual choice but influenced by geography, culture, drug type, resource access, solution requirements, etc. Here in the U.S., for instance, PWID generally use fixed-needle syringes, most of which are LDSS, though with drugs requiring solutions greater than 1ml, such as speedball, steroid, or pill injections, PWID have been shown to employ – and need – high volume, high dead-space syringes.

Third, HCV’s lengthy infective period provides further evidence for the need to expand syringe access as SSPs have been shown to reduce the circulation time of syringes, i.e. the amount of time the average syringe remains in circulation before it is disposed of or exchanged, by twenty days. This, along with the fact that IDU is the primary ‘motor’ of HCV incidence, are just two more reasons why SSPs should be supported and expanded at the state and municipal level.

Fourth, safer injection education needs to tailor injection messages to PWID based on their drug-of-choice and the drug using trends of their social networks. These protocols must be flexible enough to adapt to the particular circumstances under which people acquire, prepare and inject their drugs while also being able to account for the limitations that paltry resources and milieu place on their ability to perform hygienic injections. To see why, it is useful to look at prescription opioid injection insofar as pill injections provide a window into how drug-type affects the drug preparation process



SI messages must be both evidence-based and applicable to real life situations. Photo: Greg Scott

and the choice of injecting techniques.

Preparing prescription pills for injection requires more water than is typically needed to dissolve powdered (white or brown) heroin or even black

effective, nevertheless bodes ill for risk reduction for the reason that multiple solutions – when brought back together to make a singular, robust shot – yield a more voluminous final measure (>1ml) and often require the use of syringes with capacious barrels, most of which possess high dead-space. PWID need to appreciate the complexities associated with injecting pills and recognize the risks involved when sharing mixing water and HDSS during the preparation process.<sup>9</sup>

The fifth is the need to educate participants on the high prevalence of HCV-infected persons already in the general population of PWID and to explain why this increases the likelihood of becoming exposed to HCV

be mindful of the potential harms that can result from equipment sharing, it is important to note that *HCV infection is certainly avoidable and by no means inevitable*, especially when PWID are armed with knowledge and unsparing about not sharing injection equipment.

And lastly, we need to draw lessons from our experiences with HIV/AIDS and develop prevention strategies from the level of personal experience. (The early history of AIDS activism where drug injectors provided clean needles to fellow injectors to the dissatisfaction of health departments is a case in point.) After all, PWID were central to the development of SI protocols designed to prevent HIV transmission and their insights were decisive in making sure injection messages were appropriate to the actually existing conditions on the ground. So clearly, involving PWID will help ensure that HCV-based protocols are both effective and practical. But we also need protocols whose practicality and efficacy can be tested, replicated and documented. The requirement that protocols be evidence-based and field tested highlights the key role that scholarship and scientific research need to play in the development process. The lessons ethnographers have acquired from observing *in situ* injections should be combined with drug user acumen and fused into a set of practical and effective recommendations for how to intervene – or not intervene – in people's injection practices.

This deliberate mangle-mangle of science and experience is critical if SI protocols are to be both evidence-based and applicable to real life situations. To get PWID to truly amend their injection techniques, it is essential, as Greg Scott reminds us, that SI recommendations be region specific and relative to the material conditions under which people inject their drugs. For Scott, this means supplanting a

**The challenge to creating realistic and effective interventions is to figure out how to incorporate what we know about HCV – that it's an insidious and hearty virus and really easy to transmit – into prevention messages that take into account the unpredictable and inhospitable realities of the street.**

tar. This is due to the fact that many tablet formulas include an assortment of "inactive" ingredients as binding agents, and with opioids these often include additional contents for controlling release or preventing diversion (or both). When mixed with water these inert ingredients have a tendency to coagulate the solution, turning it into a gelatinous and unwieldy concoction: the mixture turns gooeey, filters are easily clogged and the solution becomes impossible to draw up with a 1ml, fixed needle, insulin syringe. To prevent such a misfortune, folks will often divide up pills (in crushed, powdered form) and prepare multiple solutions – by adding more water and less powder to each share – in an effort to produce a less viscous and more manageable solution. This process, albeit

when sharing injection equipment. Tragically, many injectors perceive HCV infection as ubiquitous amongst their peers and many go so far as to see it as an inevitable outcome, a consequence of injecting. It is important to recognize that this belief is not the result of specious thinking given that 7 out of 10 PWID, in some regions of the country, have been exposed to the virus; and since the chance of injecting with an HCV-infected partner is now greater than the likelihood of injecting with someone who is HIV-positive; and because a person can be exposed to HCV from just one instance of equipment sharing. All these factors, in totality, are what contribute to the overall perception that "everybody has Hep C." While PWID need to understand this state of affairs and

one-size-fits-all model of SI for what he describes as *micro-interventions*: behavioral interventions that are place-based and take into account the systemic barriers and limitations posed by real life situations. This ecological approach to injection-related harm not only enriches our understanding of the public health challenges we face, but its pragmatic application furnishes us with the tools to confront the HCV epidemic head-on.

## Conclusion

*Out of the crooked tree of humanity  
no straight thing can ever be made.*  
—Immanuel Kant

The fact that people inject many types of substances under different conditions with varied resources and by way of personally unique tactics makes the process of generating a universal set of SI protocols an arduous and challenging undertaking. The eminent philosopher, Theodor Adorno, once warned that it is ideologically dangerous to think in universal terms when evaluating human behavior since the development of any social phenomenon is a product of an antagonism between what is universal to the human condition and what is particular to specific polities, cultures and individuals.

For our purposes the universal is categorized as the “total hygiene model of safer injection” and defined as a set of techniques derived from a strict interpretation of HCV’s behavioral risk profile, and the particular is classified as the actually existing conditions under which people inject their drugs, meaning the real life circumstances that serve to limit people’s capacity to pull-off sterile injections. The inherent tension between these two poles is what makes it dangerous to assume that hygienic outcomes can be achieved merely by ‘teaching’ PWID to perform an explicit number of steps in the proper order; because, following

Adorno, the assumption rests on a disregard for the very factors that prohibit such an outcome from happening.

Ethnographic research teaches us that most people who inject drugs do so under circumstances well beyond their immediate control. Whether this concerns a lack of privacy, the threat of getting caught, persistent police presence, a lack of resources, or other outside influences, there are countless factors that can limit a person’s ability to perform hygienic injections. When these obstacles are taken into account, drug using behaviors normally considered precarious and irresponsible can, under certain conditions, be regarded as entirely rational and measured. Sadly, traditional injection messages tend to ignore these real life situations and the restrictive affect they have on people’s injection practices.

So here is the paradox that confronts us: On the one hand we need to design SI protocols based on the way HCV acts on injection equipment so we can interrupt the potential for contamination and prevent transmission, but on the other we need to identify the limitations people face in real life situations and recognize how these barriers impede their ability to administer hygienic injections. The challenge, then, to creating realistic and effective interventions is to figure out how to incorporate what we know about HCV – that it’s an insidious and hearty virus and really easy to transmit – into prevention messages that take into account the unpredictable and inhospitable realities of the street. Such an effort will no doubt require that we get out of the office, the classroom, or the clinic and head out into the street to further engage PWID in conversations about their drug use so we can better understand their health needs and pleasure-seeking goals. This is the first step toward making sense of people’s drug using practices.

In the meantime, though, we need to act, as the situation before us is

critical and requires a rapid and deliberate response. Broadly speaking, we need to come together as harm reductionists to figure out how a wide spectrum of injecting techniques can be incorporated into a set of SI recommendations that can be employed in diverse locations under varying circumstances and still be able to achieve meaningful results. I have described at length elsewhere how PWID,<sup>10</sup> by employing the skills acquired from years of injecting, have been serving their communities as “hit doctors” and teaching their peers how to inject more safely and with greater effectiveness. It is in this role (as injection experts) that PWID have been central to the development of HIV-based safer injection protocols – and with HCV it should be no different. Concerned dopefiends need to be key players in coming up with techniques to inject more safely in an era of endemic HCV, as they are in the most favorable position to gather evidence for such a breakthrough. After all, their health and the health of their junkie comrades depend on it. On this front, let’s hope the past is predictive.

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<sup>†</sup> Dr. Zibbell was a visiting professor of anthropology at Skidmore College during the writing of this manuscript. The arguments and conclusions in this essay are therefore his and do not represent the Centers for Disease Control and Prevention.

## Notes

1. I would like to acknowledge Dr. Greg Scott for making me aware of the moniker “beyond the point.” I promised myself, long ago, that I would no longer use gratuitous point slogans in my writing. But given how poignantly this one captures the essence of my argument when used literally, I found myself unable to resist. I hope readers accept this explanation and afford me a well-deserved mulligan for contributing to the pungent overuse of a word that is, as Shakespeare put it in *Macbeth*, “full of sound and fury yet signifying nothing.”
2. HCV is the most common bloodborne infection in the United States with an estimated 4.1 million Americans (anti-HCV) infected and 75-80% of those living with chronic HCV infection (see Armstrong et al. 2006). That this number represents an epidemic is self-evident when compared to the estimated 1.2 million persons infected with HIV.
3. See an earlier edition of this journal for a series of engaging essays on injection-related HCV prevention, care and treatment (*Harm Reduction Communication*, Summer 2002, 14: 23-37).
4. Quite recently, in certain rural and suburban regions of the country, HCV infections have increased significantly within networks of young persons (aged 20-29 years) who inject drugs together. Lower HCV prevalence among younger injectors (10-36%) illustrates the need for prevention strategies designed specifically for freshman dopefiends given that the probability of being exposed to HCV increases every year after the transition to injecting. Perhaps the suppositions presented in this article can shed some light on the reasons why neophyte injectors are being increasingly exposed to hepatitis C.
5. What I mean to suggest here is that since drug injecting and gay sex were socially and politically demonized well before the onset of both HIV and HCV, people’s ability to sympathize with those most at-risk for infection is always already poisoned by the moral judgments of society.
6. This means that a person preparing an injectable solution would need to heat that solution for approximately a minute-and-a-half just to inactivate the virus to make it safer for injection. I lament suggesting that the majority of PWID would resist such a practice as most heroin injectors heat their solution for as little time as possible – if at all – in order not to “boil away” the drug from the solution. Nevertheless, the use of constant heat might be employed in ways that do not ‘compromise’ the drug and this should be explored when developing safer injection protocols specifically designed for HCV.
7. All syringes retain small amounts of fluid when the plunger is fully depressed. Researchers have described this area, the space where this fluid remains, as its “dead-space.” More specifically, the term “dead-space” refers to the space between the tip of the syringe, i.e. the hub of the needle, and the needle itself. Syringes have different degrees of “dead-space” depending on whether needles are fixed or detachable. Syringes with detachable needles are often referred to as *high dead-space syringes* (HDSS) since they contain a relatively high degree of space between the needle and the syringe tip, whereas *low dead-space syringes* (LDSS) refer to syringes with permanently attached needles and therefore very little (dead) space between the needle and the syringe. Researchers have discovered that HDSS retain small amounts of fluid in the “dead-space” when the plunger is fully depressed, while LDSS only retain fluid in the needle itself when the plunger is fully depressed and thus retain significantly less. “Experiments have shown that 1-ml high dead-space insulin syringes with 26-gauge 0.5-in. detachable needles retain approximately 84\_1 of fluid with the plunger fully depressed. In contrast, 1-ml low dead-space insulin syringes with 28-gauge, permanently attached needles retain approximately 2\_1 of fluid” (Zule, W.A., Ticknor-Stellato, K.M., Desmond, D.P., Vogtsberger, K.N., 1997. Evaluation of needle and syringe combinations. *J. Acquir. Immune Defic. Syndr. Human Retrovir.* 14, 294–295). This is a striking 82 point difference! For more on syringe types and the correlation between HDSS syringes and bloodborne viral transmission, see *World Health Organization/HIV AIDS Programme, Guidance on Prevention of Viral Hepatitis B and C Among People Who Inject Drugs*. July 2012, <http://www.who.int/hiv/topics/idu/>; and Strauss, K., van Zundert, A., Frid, A., Costigliola, V., 2006. Pandemic influenza preparedness: the critical role of the syringe. *Vaccine* 24, 4874–4882.
8. The use of HDSS has been shown to substantially increase a person’s chance of becoming HCV infected. Zule and Bobashev’s (2009) study in North Carolina, for example, found an independent association between a history of sharing HDSS and HCV prevalence among PWID. Their observations are consistent with experimental studies in HIV. (Zule WA, Bobashev G. High dead-space syringes and the risk of HIV and HCV infection among injecting drug users. *Drug Alcohol Depend* 2009 100:204–213). For a similar analysis see: Abdala N, Stephens PC, Griffith BP, Heimer R. Survival of HIV-1 in syringes. *J Acquir Immune Defic Syndr HumRetrovir* 1999; 20:73–80.
9. Making multiple solutions also increases the number of preparation steps that transpire during the injection episode, which, in turn, has been shown to increase the number of contamination points that may occur during the injection episode. For an informative discussion on this topic, see Greg Scott’s essay in the previous issue of this journal. (*Harm Reduction Communication*, 2011, issue 16)
10. Zibbell, J. Caught between the Hard and Soft Arms of the State: A conceptual apparatus for situating the formative role of drug user organizations in national policymaking and service delivery – a commentary. *Substance Use & Misuse*, 2012, 47(4): 558-565.

# Opioid Overdose Prevention

To Empower or Not to Empower, That is the Question!

ANONYMOUS

**I never thought in a million years I would use that kit you gave me, but a friend of my son came to my house last night... He fell to his knees in front of me... I ran and got my kit... I saved his life. I need another kit!**

If you have any fear or doubt about implementing an Opioid Overdose Prevention program, hopefully I will change your mind.

I work in a New York State operated addiction treatment center (ATC), bureaucracy is our middle name. Any new or improved programs most often require mounds of paperwork to be submitted and approved at numerous levels before it can be born into existence. I was not dissuaded by the probability of paperwork when I began my quest; I was taking a leap of faith and knew that whatever it took, I would be able to help save lives. Now, for the past two years, I have been given the opportunity to implement a very successful Opioid Overdose Prevention program here within our facility.

Two years ago I was asked by our Administration to review the Overdose Prevention Program that was being widely discussed in the perimeters of addiction treatment. At that time I had been a Registered Nurse for 16 years but was new to Addiction Treatment. I had very limited knowledge of the impact that deaths from opioid overdoses were having on us as a society and even more eye opening was the effect it was having on my local community.

However, I knew firsthand how one overdose death had affected my life and the lives of my entire family having lost my 18-year old nephew to an opioid overdose 6 years prior. I still remember the morning I received the call from my Mom. She was so devastated and sounded so empty; she simply stated “\_\_\_ is dead”. The last 8 years have given witness to all of the following in our family: divorce, another opioid overdose (thankfully reversed), (1) nervous breakdown, treatment for severe depression and anxiety, (1) prison sentence and the relocation of most of my family members. I know these events to be a directly related to the unintentional overdose death of my nephew.

So, when I inquired about the Overdose Prevention Program being offered by the Harm Reduction Coalition and was given the green light to develop a program within our facility, I jumped at the opportunity. To this day I feel this was an act of divine intervention.

Although our administration was in support of implementing an Overdose Prevention Program, it did not come without speculation and naysayers. Even though I work in an Addiction Treatment Center, and we offer 24/7 Rehabilitation from all addictions, it does not exempt us from judging of people who are addicted. I began to receive many anxious visits from employees who were very fearful of dispensing syringes to “drug addicts” as well as some who worried about jeopardizing treatment when clients handle syringes and are instructed on how to draw up naloxone for injection.

One seasoned counselor stated, “Aren't you afraid this will stir up cravings?” Another professional stated, “We're going to give addicts syringes? What is the liability of that?” Yet another wanted to know “why we were going to support addicts who will go out to use again and giving them kits to reverse their overdose?”

At first, I was taken aback by these comments from my peers; but I had to take a step back and look at them as individuals just like the rest of us. We all have personal experiences and histories that form our opinions. So to those who had concerns about cravings I responded that the benefits of implementing an overdose prevention program far outweigh the risks associated with cravings.

To the others who had concerns about giving syringes to addicts, I said that for about \$4.00 Walmart will sell anyone a bag of 10 syringes no questions asked, no prescription. Why? Because clean syringes help prevent the spread of disease among IV drug users. I reassured my co-workers that



the syringes supplied in the Opioid Overdose Prevention kit will be given to the client on the day of discharge as they leave the building eliminating the possibility of syringes being in the rehab community. And to the question of liability, the Good Samaritan Act<sup>1</sup> protects individuals from liability.

Lastly, in answer to the question of reversing one's own overdose, it is highly unlikely that anyone would be able to reverse their own overdose because when someone overdoses from an opioid they do not know it is happening. In an opioid overdose the person stops breathing and becomes unconscious. Therefore, they are unable to seek or provide help for themselves.

Many people continue to hold negative or moralistic opinions, or absorb the many messages we are fed by society in general about drug use. It is the portrayal of the "drug addict" in our society that supports this misconception and causes our culture to lose the ability to show empathy towards those who have become addicted. Therefore, we continue to harbor negative opinions about this epidemic. This misconception rises from the belief that the people who use drugs or become addicted to drugs must be uneducated, non-working, homeless,

"vagrants" who don't want help. This could not be further from the truth.

I see the young father who was injured on the job, the young mother who has multiple injuries from an abusive partner, the seasoned nurse who worked 25 years on her feet, lifted a patient and injured her back, the grandfather who slipped on the ice, and broke his leg and hip, etc. etc. etc. These people described above are all hard working, independent, tax-paying individuals with multiple levels of education and life experiences and yet became addicted to opioid pain medication. But, unfortunately the need for the opioid overrides all rational thoughts. These people thought they could manage this on their own. They all dwelled in the river of denial to avoid seeking help due to the image associated with drug use and addiction treatment. This image is supported by our society. And even people who may have less education, are unemployed, homeless, or are otherwise struggling, still deserve the right to stay alive. Today if someone is in need of treatment for drug abuse they are widely believed to have a personal weakness and not a disease. Too many people wait until they lose nearly everything or often times, everything that is

important to them, due to the fear of seeking treatment.

The scenarios above are not isolated events. Any one of us could be one injury or sickness away from addiction becoming our own reality.

Our Opioid Overdose Prevention Program has been up and running successfully for two years now and that fear and doubt encountered in the beginning has been replaced by the jubilation experienced each and every time I receive a call from a former client who reports they saved someone's life. It doesn't get any better than that!

To date I have received 13 phone calls from former clients who have used their overdose prevention kit. All 13 callers reported their kit was successful in saving someone's life. The calls go something like this:

*A breathlessly speaking female, "Hello, I never thought in a million years I would use that kit you gave me, but a friend of my son came to my house last night bragging about how he just shot 10 bags. He fell to his knees in front of me and then on his face! I was so scared! I ran and got my kit, I had to shoot him twice, and he's 32 years old and the father of three kids. I saved*

his life. I need another kit! I can't believe I saved his life!

A young man speaking quietly, "Hey remember me? I got a kit from you. Do you need a police report to give me another kit? I had to use it this mornin'. My nephew was dead! Why would my Uncle give him dope, I want to kick his F----g --ss! Crying now, the young man states, "I am so glad I had the kit!" "He came around when the ambulance came but they had to shock him twice! Oh my GOD!" How can I get another kit?

A young girl left this voice mail: "Hello, I need another kit. I saved a girl's life this weekend!" "Someone had another kit but they only had one dose, so I used mine and the girl came back! Call me back!"

Every time a call is received reporting a successful opioid overdose reversal, I know I have spared another family unmentionable pain and sorrow.

## Every time a call is received reporting a successful opioid overdose reversal, I know I have spared another family unmentionable pain and sorrow.

### Getting Started Was Simple

Getting started was as simple as making a phone call to Bill Matthews RPA-C, Opioid Overdose Prevention Program Coordinator at Harm Reduction Coalition in New York City. Bill explained the program in full and offered to provide an in-service at our facility (even earning CEU credits). The in-service offered training (to all employees who attended) in the use of the overdose prevention kit and provided attendees with their own prescription for naloxone. The training supersedes any trepidation about the misuse or mishandling of syringes. In addition to the staff workshop, Bill

walked me through the process of becoming a trainer and a distributor of overdose prevention kits so I could train future staff and get kits directly into the hands of our participants.

The policies and procedures are simple, basic, common sense practices. To implement an Overdose Prevention Program with naloxone distribution, an MD, NP, or PA must be designated as the Clinical Director to write orders and write prescriptions. Another person is designated as the Program Director to manage the program, order supplies and track the use and distribution of the kits. We were able to edit and adapt policies sent to us from Harm Reduction to fit our practice and ensure the safe storage of all supplies that are required.

I currently facilitate two opioid overdose prevention groups weekly. These groups are offered to all staff as well as all persons admitted to the ATC regardless of their substance of choice upon admission. The groups, although offered on a strictly voluntary basis, are very well attended. Since the inception

of our program, I have trained approximately 700 persons to identify an opioid overdose, call 9-1-1, perform rescue breathing, and administer naloxone (Narcan®) using an intramuscular syringe. We get great feedback on the groups; one client stated, "This group is the most valuable group I have ever attended in rehab."

### No Time to Wait

As reported in the CDC Grand Rounds report on January 13, 2012: Opioid overdose is an epidemic in the United States, citing one overdose every 19 minutes in 2007; the data from that report is already 5 years old and we

know that the situation has only gotten worse.<sup>2</sup> Prescription drug abuse is being reported as the fastest growing drug problem with two groups targeted as most at risk: people who legally use prescribed medical opioids and those who use prescription opioids without a prescription or medical need.

With Opioid overdose deaths at epidemic proportions, why would anyone harbor doubts or fears about a program with proven success in preventing deaths from this disease? If we had a kit to reverse deaths from cancer, how many of us would question the distribution of that kit?

So – if you have had any fear or doubt about implementing an Opioid Overdose Program, I hope I have changed your mind. The life of someone you care about may be depending on it.

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*The author of this article has chosen to remain anonymous in order to bypass the bureaucratic nightmare that is the approval process for publishing by state employees. If you are interested in learning more about this program or would like to start an overdose prevention program where you work, please contact Bill Matthews, RPA-C at Harm Reduction Coalition: [matthews@harmreduction.org](mailto:matthews@harmreduction.org).*

### Notes

1. New York State Assembly Bill Number So4454 protects people from being arrested for personal possession of drugs, paraphernalia or underage drinking when they call for help to save the life of someone experiencing drug overdose. [http://assembly.state.ny.us/leg/?default\\_fld=%0D%0A&bn=So4454&term=2011&Summary=Y&Actions=Y&Votes=Y&Memo=Y&Text=Y](http://assembly.state.ny.us/leg/?default_fld=%0D%0A&bn=So4454&term=2011&Summary=Y&Actions=Y&Votes=Y&Memo=Y&Text=Y) (accessed September 25, 2012)
2. CDC. CDC Grand Rounds: Prescription Drug Overdoses — a U.S. Epidemic. *Morbidity and Mortality Weekly (MMWR)* 61[01], 10-13. 1-13-0012.

# Building a More Inclusive and Effective Hepatitis C Counseling, Testing and Referral Model

HEATHER LUSK

**Client-centered counseling embodies many of the same tenets as harm reduction: meet people where they are, be non-judgmental and maintain a neutral stance, offer options, not directives and actively listen to people's stories.**



With the new rapid test, everyone who is ready will get their results 20 minutes after collecting the sample, so the counseling can be much more focused on the impending results. Photo: CHOW Project

"I already got that!" Kara responds to me after I inquire if she'd like to take the new rapid hepatitis C antibody test. I encourage Kara to come over and talk with me so I can learn more, because experience has taught me that with hepatitis C testing, it isn't always as simple as it seems. Upon discussion with Kara, it turns out that while she had a positive hepatitis C virus (HCV) antibody test, she has never gotten a confirmation test to determine if she is currently living with the virus, or whether she has cleared HCV. When I explain to her that up to 1 in 4 people who test antibody positive end up getting rid of their HCV, but still have antibodies, Kara seems interested, but says she needs to go meet up with someone right now and that she'll be back later. I make a mental note of where Kara is along the spectrum of HCV testing so I can re-visit this when Kara is ready to take the next step, knowing finding an affordable and accessible viral load test for HCV for her will be the next challenge.

The recent Institute of Medicine report on Hepatitis and Liver Cancer

found that less than 25% of people living with HCV were aware of their status. The subsequent Health and Human Services Viral Hepatitis Action plan released in 2011 prioritized increasing hepatitis B and C screening to prevent some of potential long-term consequences of chronic viral hepatitis. Twenty years after the first generation of HCV antibody tests, we welcome a new point-of-care rapid hepatitis C antibody test with results ready in 20 minutes and vast advances in the treatment of HCV. Unfortunately, there has been little progress in the resources available for hepatitis C counseling, testing and referral (HCV CTR) over the same time period, but harm reduction programs continue to strive to increase access to HCV CTR for their participants.

Despite the lack of monies dedicated to HCV CTR, many programs have pieced together testing programs over the years which have provided some lessons on how to support people in learning their HCV status — and in how to follow-up once finding out the test results. Many of us have heard horror stories about people learning they have HCV over the phone by an uncaring provider, or those who have been told not to worry about having HCV, or especially for active users, that it is an automatic death sentence. These experiences underscore the importance of spending time not only with people who are receiving HCV CTR, but also with those who already know their HCV status as they may need additional information, referrals or support too. Client-centered counseling has been found to be effective, when time permits, both before and after performing sample collection or the test. Client-centered counseling embodies many of the same tenets as harm reduction: meet people where they are, be non-judgmental and maintain a neutral stance, offer options, not directives and actively listen to people's stories.

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## Conducting a Rapid HCV CTR Session

1. Build rapport and provide an overview of the test, explaining exactly what it will (and will not) test for
2. Gather informed consent and collect the test sample
3. Explore HCV risks and circumstances
4. Develop a realistic behavior change action plan
5. Disclose test results
6. Explore meaning of results, answer questions and provide participant-driven support
7. Share referrals and any additional educational materials
8. Summarize and explore next steps

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While not everyone will choose to engage in counseling, it offers an opportunity for those who are ready to explore their feelings, beliefs and behaviors as they relate to hepatitis C.

### Basics of HCV CTR

Whether actual counseling occurs with HCV CTR or not, there are some basic areas that should be covered when testing someone to ensure the participant has basic knowledge of HCV and what the results of the test means. Starting with HCV transmission, it may be helpful to ask the person what they know about how HCV is transmitted. Without spending too much time, it is important to have a mutual understanding so that when exploring risks, you are both on the same page. Hepatitis C is spread through blood-to-blood contact and can live outside the body for up to 4 days (one study found

up to 63 days in a syringe). Having a written risk assessment for counselors to use or for testing participants to self-administer is helpful. Everyone agrees that people with a history of injection drug use, those with a blood transfusion prior to 1992, and health-care workers with a known exposure should be tested. What about people with a potentially unsterile tattoo or body piercing? What about non-injection drug users? How about people having sex with someone who is living with HCV? While these categories may not fall under formal recommendations, many feel there is enough evidence to encourage testing for people who may have been exposed to blood through other means. Another community, baby boomers born 1945-1964, were recently highlighted in the newly updated CDC hepatitis C screening guidelines because HCV is four times more prevalent among people in this age group and universal testing for this group makes sense. Having the HCV CTR program develop some guidelines on who should be tested based on risk will help front-line staff discuss risk and help make testing decisions. Having a standardized risk assessment also allows the program to collect some data on those being tested. In many harm reduction settings, it may be easier to offer testing to all participants as resources allow.

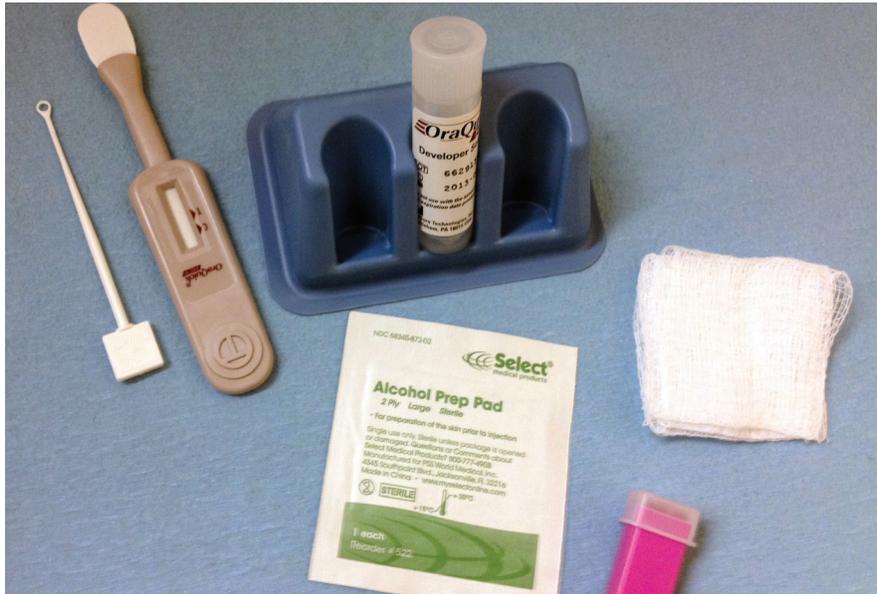
In addition to understanding the risks for hepatitis C, people getting tested need to understand the HCV antibody testing process, the window period and the various possible test results in order to truly give informed consent. Since the test that looks for hepatitis C virus (HCV RNA or PCR) is very expensive, the HCV antibody test is first used as a screening test. If the person being screened has ever had HCV, antibodies will still be present in the blood so a blood sample is taken to look for antibodies. While it can take up to six months for antibodies to show up after someone is newly infected

with HCV, this “window period” more often averages 8-9 weeks. This is important if someone has had a recent risk, as repeat testing should occur 6 months after the last risk to make sure enough time has elapsed for antibodies to appear. The concept of antibodies is very important to understanding the HCV test results because as Kara learned, someone may still have HCV antibodies but no longer have the virus. Therefore, a positive antibody test means that the person has had HCV — and probably still does, but needs a viral load test to see whether s/he is currently infected with HCV. As mentioned, 15-25% of people who test HCV antibody positive will no longer have HCV despite having the antibodies because the body’s immune system was able to clear the virus even without treatment. A negative HCV antibody test means the person does not have hepatitis C, but may still be

**Everyone born  
between 1945–1965  
should be tested for  
hepatitis C!**

in the window period if there was a recent risk. It is important that people understand the possible test results before the test result is disclosed to them because some people, especially if the test is positive, may be in shock and unable to process new information as easily. While counselors may clarify other information during the session, it should be based upon the participant’s needs and not a laundry list of information which may be confusing or overwhelming. Answer the person’s questions but share information as simply as possible and focus on their needs and issues.

If the testing participant is open and time permits, this can be a good opportunity to explore more about current risks for hepatitis (or even



Left: An OraQuick® HCV testing kit set up. Right: A reactive OraQuick® HCV test displays lines in both the C and T zones, while a non-reactive test would only display one line in the C Zone. Photos: CHOW Project

HIV/STDs) and what, if anything, the person is ready, willing and able to change. With the new rapid test that takes 20 minutes once the sample is collected, there is often plenty of time to explore how the person is feeling and to develop an action plan of small steps for incremental change. This discussion, like all aspects of HCV CTR, will be more effective when conducted from a harm reduction perspective. What is the participant most concerned about? What are some options for reducing harm? These discussions will be helpful regardless of the result. If someone is negative and still has potential risks in their lives, developing an action plan may support the person to stay negative. For those who test positive, these discussions can lay the foundation for identifying next steps and also, if appropriate, can be helpful when discussing prevention and the importance of not engaging in distributive sharing which could result in passing hepatitis or HIV. In addition to exploring the participant's interest in behavior change, it is essential

to begin to explore how the person is feeling about their impending test results and what, if any, support or services would make an effective referral. If the sample is collected via blood draw, it also creates an opportunity to discuss safer injection techniques and modeling of proper alcohol swab use and other techniques.

Conventional HCV CTR leaves a period of up to two weeks (or longer) between when the pre-test discussion is had and results are given to the participant. Therefore, exploring how the person will cope with the wait as well as how to access results once they are available is important. With the new rapid test, everyone who is ready will get their results 20 minutes after collecting the sample, so the counseling can be much more focused on the impending results. Regardless of whether using a rapid or conventional HCV antibody test, when disclosing the results, follow the client's lead. When the person is ready, state the results in a neutral tone and pause, letting the results sink in. Meet the client where they are — happy, relieved, scared, angry or disengaged. Provide the space for them to react however they need to, give support as appropriate and ask a few questions to determine next steps.

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## Giving Positive Test Results: Main Messages

- **Support:** Provide participant-driven emotional support as needed.
  - **Confirmation:** Explain the importance of a follow-up viral load test to confirm the antibody result
  - **Vaccination:** Encourage vaccination against hep A/B and provide referrals to testing sites when possible
  - **HCV 101:** Provide basic hepatitis information, offering educational materials that can be read later
  - **Liver Health:** Explain basic strategies for taking care of one's liver
  - **Don't panic:** Help people understand that they have options and time to make treatment decisions.
-

With negative results, the goal is to hopefully support the person in staying negative by reinforcing their efforts in staying safe. For many people who inject drugs, HCV may feel inevitable and yet it can be empowering for someone to envision that they can prevent acquisition by having access to sterile equipment and building skills in negotiating and using as safely as possible. Exploring the context around their use may identify areas to focus on. For example, in our syringe exchange program our recent research found the prevalence of HCV in participants under 30 was 17%, while the prevalence in those over 30 was closer to 70%. We use this data, along with individualized risk data, with those who test negative to reinforce that what they are doing is effective and to keep on doing it. For those who have experienced a recent risk for HCV and may still be in the window period, a reminder to get tested again in 6

**It is important that people understand the possible test results before the test result is disclosed to them because some people, especially if the test is positive, may be in shock and unable to process new information as easily.**

months may be helpful. For most who test negative, it is a huge relief and this can especially be true for those whose risk for HCV was in the past. Unlike HIV, there are many people who test for HCV and are not currently at-risk but may have a risk far in their past. A negative result in this context can be

particularly joyful because there is no longer a worry since there is no current risk. At the same time, when someone with a distant risk tests positive, it can be particularly overwhelming as it may seem to have come out of nowhere.

For those of us conducting HCV CTR with people who inject drugs, we've given a lot of positive HCV antibody test results, but that doesn't make it any easier. While I've conducted hundreds of HCV tests, I still remember my first time conducting HCV CTR when 11 of the 13 people I tested came back positive, and I disclosed 8 positive results in just a few hours. Many years later, I use this when training others to conduct HCV CTR as a reminder about how important it is for us, as the provider, to get support and take care of ourselves and each other because of the intensity of disclosing positive results to others. When setting up or managing testing programs, consider the impact of the results on the participant and on the counselor. Ensure enough time is available not only for the person testing positive to have the space they need, but that the person giving the results has time afterwards to get support or regroup as necessary.

That being said, during a positive results disclosure session it should be all about the person testing positive. As mentioned before, give the result and then pause to allow the person to absorb the information. Provide the space so the person can react however they need to. Some may need emotional support, some may want information, some may have already suspected and take it in stride, some will be devastated, and some won't want to talk with you. Meet them wherever they are and follow their lead but make sure to cover a few important aspects. Make sure the person understands what testing HCV antibody positive means and doesn't mean. Remember Kara – she thought her positive test meant she definitely has HCV. This

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## What about Hepatitis B Testing?

Hepatitis B testing is recommended for:

- People born in a country with >2% prevalence
  - Pregnant women
  - People who inject drugs
  - Men who have sex with men
  - People living with HIV
  - The only option for hepatitis B testing is a blood draw and many community-based sites don't have resources to offer this test on site – refer out if necessary.
- 

is a common misconception, so it is important to explain the need for another confirmatory test to see if the person is still living with HCV or has resolved it like up to 25% of those infected. This is particularly important for active injection drug users because if the person has resolved the infection and yet thinks they are positive, they may engage in behaviors with other HCV+ folks that could cause them to be re-infected. Linking the person to a physician or health center to get the viral test is one of the most important follow-up steps for those testing antibody positive. Sharing some basic information about HCV, the liver and what it means to be living with HCV is important, as is making sure the person is vaccinated against hepatitis A and B. Answer the person's questions but be aware not to overload them with information. Having easy to read educational materials is important as some people will be in shock and unable to absorb everything in the moment, but may want to read more about hepatitis later. When available, share information about local hepatitis resources,

such as support groups or clinics that specialize in HCV. Some may want to discuss treatment options – but for many this is a premature conversation until the results of the viral test are available. Depending on the person's most immediate concerns, this could range from getting a doctor's appointment to how to disclose their status to others, or perhaps not wanting to talk at all. While you can provide a safe, non-judgmental and compassionate space for someone to receive this potentially life-changing information, you cannot control how the person will behave or react, which is one of the reasons harm reduction is so effective – focus on the process, not the outcome.

### **Making the Most of HCV CTR**

The model of HCV CTR presented here is very flexible and may be as short as 5 minutes with testing participants who don't have the time or interest in engaging longer. Spending time at the front end of the testing program developing risk assessment forms, policies, educational materials, referral lists and other structures will support the people on the front line to have everything they need to meet the client where they are. Training on client-centered counseling, harm reduction-based behavior change, hepatitis transmission, testing and care information and local resources is essential to ensuring testing participants get what they need out of the testing process.

There are many resources available to testing program coordinators and those who conduct HCV CTR with several new best practices on the horizon. In addition to the Harm Reduction Coalition

hepatitis materials (<http://harmreduction.org/issues/hepatitis-c/>), the Hepatitis C Support Project (<http://www.hcvadvocate.org>) has fact sheets on the hepatitis C antibody and viral load tests, a brochure on "Testing Positive, Now What?" among other helpful publications. The National Alliance of State and Territorial AIDS Directors (<http://www.nastad.org/>) has been collecting information on which states offer HCV CTR and many are willing to share best practices. Check with your local Adult Viral Hepatitis Prevention Coordinator (<http://www.cdc.gov/hepatitis/Partners/AVHPC.htm>) who may have resources to share and may be able to connect you with other local partners. Many harm reduction programs also have lessons learned that you can query about on the harm reduction listserv (<http://drcnet.org/mailman/listinfo>). The CDC's Division of Viral Hepatitis has some resources on-line and will be releasing not only new HCV screening guidelines this year but also HCV CTR recommendations and resources. Finally, the rapid hepatitis C test is changing the landscape of HCV screening and Orasure (<http://www.orasure.com/>) has detailed instructions on the use of this device.

In many ways, 2012 has seen an increased focus on hepatitis C testing. The Department of Health and Human Services held a hepatitis testing consultation in February. The new hepatitis C screening guidelines were released and 10 million dollars appropriated to CDC specifically for viral hepatitis testing which was allocated through a competitive proposal process. More and more research is concluding that

too few people with hepatitis C know their status and screening needs to be increased. More hepatitis C treatments are coming down the pipeline that give people living with hepatitis more options with a higher cure rate, and developing technology like the rapid test makes it easier to ensure people get tested, get their results and are linked to care. Harm reduction programs have always been on the cutting edge of viral hepatitis activities because of the disproportionate impact of hepatitis C on people who use drugs. More than ever it is important that harm reductionists ensure the needs of people who use drugs are considered as these national policies are developed and implemented locally. We all know the challenges of accessing hepatitis C care and treatment for people who currently use drugs or have a history of drug use, despite the fact that these individuals are at the core of this epidemic. Together, we can advocate for a more inclusive and effective model of HCV CTR which helps prepare and empower people to learn their hepatitis C status and arms them with the information and tools necessary to make informed choices about next steps.

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*Heather Lusk is the executive director of the CHOW Project, Hawaii's statewide harm reduction and syringe exchange program. She had been working in viral hepatitis and harm reduction for over 18 years.*

### **Notes**

1. <http://www.cdc.gov/hepatitis/c/cfaq.htm> (accessed September 28, 2012)

# Finding My Niche

DONALD DAVIS



My name is Donald Davis. I was diagnosed with hepatitis C, I remember very distinctly, in December of 1991. I used to donate plasma on a weekly basis. I was using drugs at the time and I knew that I could donate plasma, get money, and buy drugs at least twice a week. So, they started testing for hepatitis C and they called me at home one day and said that I needed to come in and see the doctor. I went in and the doctor told me I had hepatitis C. [They explained] that I couldn't donate plasma any longer, that I couldn't donate blood any longer, and I said okay because I was just happy that it wasn't HIV. I knew that I had got my hepatitis C from injecting drugs. I started injecting drugs back in 1975.

I went home and I thought about it for a while and I really didn't know what hepatitis C was. So I went to my doctor and *he didn't really know what hepatitis C was*. All he said was that the medication is expensive and so we will just monitor it. He admitted that he didn't know that much about it and because I didn't feel any symptoms or I didn't feel sick or anything – I forgot about it and obviously he did too because he never said anything else to me about it.

## Getting Hepatitis C Treatment

I did the treatment (with a new doctor), but had to do it twice. I was diagnosed in 1991 and I didn't start treatment the first time until 1998. The first time I took treatment I was taking non-pegylated interferon and ribavirin. I took three injections a week. About half way through, the depression started setting in – I got really depressed. I wouldn't say I was suicidal, but maybe some ideations came about. So a friend took me over to the hospital. They put me on one antidepressant first and that made me feel high, so they switched me over to Zoloft® and I felt better with that.

Six months after I finished with the treatment, when I went back for my blood work, the virus was still there. So my doctor said that the new *pegylated* interferon was coming out soon. I had a lot of trust in [my doctor] and so I started treatment with the pegylated interferon four, or maybe six, months after [finishing the first round of treatment]. This time, they put me on the antidepressant *before* I started. The injection was just one day a week and the pills were every day. There weren't as many severe side effects – the side effects were minimal compared to the three times a week. I was able to

function better and when I finished treatment I was undetectable. I went back six months later and I was still undetectable, and I have been undetectable ever since. I haven't seen the doctor since 2003 right before I moved to New York.

## Key Messages for People Thinking about Hepatitis C Treatment

Having hepatitis C prompted me to start a support group at the HIV agency I was working at. I started doing workshops and presentations on hepatitis C and having hepatitis C. Having been cured for hepatitis C has motivated me to work with two different groups: African Americans who don't believe that they can be cured for hepatitis C and the elderly – and by that I mean the "baby boomers". I'm a baby boomer myself. I know there are a lot of my friends who have hepatitis C and they may not know it, some may know, but it just depends if they've ever gotten checked for it. I look at the number of people who are baby boomers and they are just finding out that they have hepatitis C and they have to stop and think back to what they did back in the 60s and the 70s. So, it's impacted me in a way where I

found my niche – as far as work goes – because I work strictly with hepatitis C. I do testing, I do a support group, and I do some consulting work for a pharmaceutical company specifically about hepatitis C.

From my own experience and from listening to what I hear people say over the years – especially with the age groups I'm working with – I hear African Americans say 'That cure doesn't work for us' or 'That medication doesn't work for us.' I say, 'Yes – it does. It can. Be patient – try the medications,

try and deal with the side effects.' Some people can and some people can't manage the side effects, but at least try the medication. And for baby boomers – think about what you did in the past and if you can't remember anything – still go and get tested.

## Hepatitis C, Harm Reduction and Domestic Violence

MARIA

**I want to get that  
message out – you can  
have love and intimacy  
and have hepatitis C.**

**M:** So my name is Maria. I was raised in a poor drug-addicted community, and my life has been about having relationships with men who were users and family members who were users. I was also present for the crack epidemic... and what it did to my community. So, substance abuse has really been a big deal in my life, and because I'm street smart and know how to negotiate and survive in poor communities, I felt very comfortable within the harm reduction community. My introduction, the first [harm reduction] agency I went to was in the Village [in Manhattan]. I started going because I wanted to go to a place where I would feel supported and where I could be myself. I'm Latina. I had just been diagnosed [with Hepatitis C]. I knew I was smoking weed, and I wanted to continue smoking weed, and I felt like the harm reduction community really understood and would understand, and keep it real in terms of giving me the information that I needed in order to make a decision about whether I was going to stop using, stop smoking, or smoke less or whatever. I wanted to feel comfortable and not judged. And I felt that way. I also felt like I understood, because I had loved ones who were struggling with issues around using.

**EW:** It sounds like, from what you were saying earlier, you've been witness to some of the many harms related to drug use... that you've experienced firsthand

some of the devastation that can be associated with drugs.

**M:** Right... the loss of jobs and families and futures and all of that. A man who I know loved me more than anything... you know... *could not stop using*. And, he eventually died because of substance use and alcohol. So I know how difficult it is for people to stop using.

So – I felt good [about going to the harm reduction agency]. A lot of them were exchanging needles and I wasn't going there to get needles. I was going there to be a part of a group that understood that I wanted to keep smoking weed. I wasn't feeling judged, but I did feel like I stood out a lot because of the way I was dressed or whatever. But it was a good experience because even though I was employed, I still could not afford Reiki, or acupuncture, and I couldn't be in a group [anywhere else] where I could be myself and talk about smoking weed. I got good resources and I could come and go. It was a good experience. But, I did leave thinking that I wished the harm reduction community embraced working people, the working class – although poor, but the working class. That was why I stopped going.

**EW:** It's interesting because in the last issue of Harm Reduction Communication there was a conversation between two drug user organizers talking about stigma. They talked about how even people who are stigmatized,

such as drug users, are not immune to stigmatizing other people who are different in whatever ways.

**M:** Right. I would walk in there and I couldn't care less whether you took a bath or not or whatever. I went in there and I sat down in the room and I loved it. They had incense going, there was acupuncture and nice chairs and everybody was nice. And, another thing that was different was that it was in the Village, so there were a lot of white participants, you know? Which was kind of different for me – but I was cool with it. I wanted to be there, because they were down...you know, hippies, baby boomers...it was good.

**EW:** *It sounds like there were a lot of pieces of your experience that were really positive, but your critique is also important and valid.*

**M:** I noticed another thing too. I didn't really understand, and I didn't feel comfortable, that harm reduction locations were always hidden – in the back of some highway or whatever. I went to a couple of them and they were always hidden, where nobody could see them. They were stigmatized from the community. It was as if they were throw-aways: "Let's hide this community... we are going to give them services, but we are going to put them where nobody can see them."

**EW:** *There is actually a phrase used to describe that: "Not In My Back Yard" (NIMBY).*

**M:** Well – to make a connection, it's the same thing with domestic violence shelters for women. I've seen communities come out and rally against safe housing for women who are victims [of domestic violence].

**EW:** *It's true. Do you want to speak more about the connection between hepatitis C and domestic violence, intimate partner violence?*

**M:** Yes. I have two children and both of their fathers were heroin addicts, and used for many years. Those were very abusive relationships. A lot of the abuse was sexual, economic, emotional abuse. So, some of the stuff I talk about is coercive sex and the times I was coerced into having unprotected sex, and doing sexual acts that I didn't really want to do. Really, who is to know that I didn't get infected [with hepatitis C] because of one of those incidents of violence and sexual abuse? There were also times when they told me they were not using, that they had gone to treatment and I believed them – when in fact they were still using and had not completed treatment. So, that could also have been one of the ways I was infected with hepatitis C. Really, it could have been anything – I had a blood transfusion, I used drugs, I experimented with intravenous drugs, I sniffed cocaine. But, those are some of the connections, and having done work around violence against women for so long, when I talk about hepatitis C, I also incorporate these issues because women can get infected because of sexual assault and abuse in their intimate relationships.

**EW:** *That's an important connection. Even with hepatitis C prevention messages – we often hear messages around controlling your own injection or the space where you are injecting or with other messages about sexual risk prevention – but it's so important to think about different relationship and power dynamics. If you're in a relationship that's abusive or there are power dynamics that interfere, you may not have the same kind of control over your own personal safety and the way that you take care of yourself. That's really important. I don't think it gets talked*

*about a lot and while it can impact any relationship, it often impacts women in particular.*

**M:** I just have a lot of memories. This happened a lot of years ago and a lot of it is kind of shaded, but I just remember a lot of sexual abuse. For example, I remember having to subject myself to certain acts because someone had promised to help me financially with a birthday party for my little boy. I didn't have the money to give the party and this person had promised to take care of the cake and the food and I kept asking him when he was going to get it. Eventually I had to have sex with him, in the way that he wanted it, so that he could provide for that party that I had already promised my son. I didn't want to disappoint my son. I remember having to do that, and that's a person who had died of hepatitis C. So, I remember that and I just want to get the word out about [domestic violence].

But, I also want to use the opportunity to talk about how hepatitis C is a blood-to-blood infection and it's difficult to get hepatitis C through sex. I want to get that message out because there is a lot of hope in that. You can have a healthy, intimate, loving sexual relationship with a partner as long as you are informed and you can talk it over with your partner. It's always best to use condoms – but if you happen not to, you don't need to get crazy and think you are infected and bug out.

**EW:** *Right. It's all about the blood.*

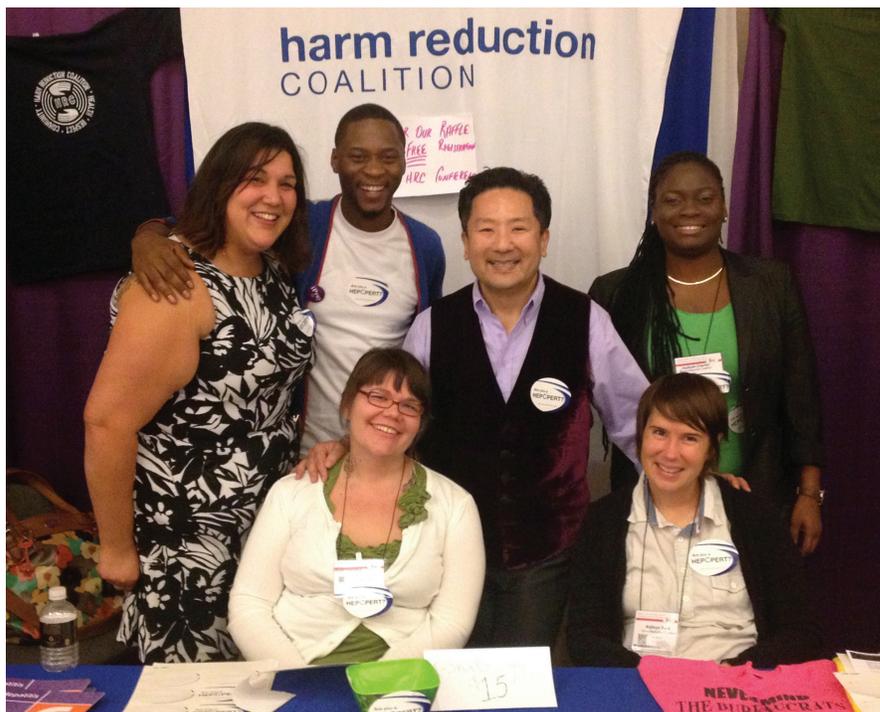
**M:** It's all about the blood. I want to get that message out – you can have love and intimacy and have hepatitis C.

# “You’re doing what?!”

Notes from a  
Hepatitis C Advocate

HADIYAH CHARLES

Harm Reduction Coalition staff, with Paul Kawata from National Minority AIDS Council, wear HepCpert stickers at the US Conference on AIDS, September 2012. The HepCpert Campaign was launched at the conference in order to further bridge HIV/AIDS and HCV advocacy.



One never really knows where life will take them. After working in the HIV advocacy field for many years and having recently completed a Master of Arts in Women’s Health, I’m now working on hepatitis C (HCV) advocacy at Harm Reduction Coalition. As the HCV Advocacy Manager, I’ve had an interesting time adjusting, not so much to the work – advocacy is my passion – but more so in adapting to the intense stigma that continues to plague drug use and diseases related to sex and drugs.

I came to the HCV field by way of HIV advocacy. While studying in Boston MA, Rebecca Haag, Executive Director of AIDS Action Committee, offered me an opportunity to organize and revive a defunct statewide viral hepatitis coalition. I was super excited because this position gave me the chance to learn about and focus my efforts on another infectious disease, while still utilizing my organizing skill set. I enjoyed working on viral hepatitis and saw it as an opportunity to engage communities of color on health issues other than HIV that also disproportionately affect them.

When I returned to NYC I wondered what was happening locally around viral Hepatitis. I knew that the Department of Health and Human Services had recently released their strategic plan, *Combating the Silent Epidemic of Viral Hepatitis: Action Plan for the Prevention, Care and Treatment of Viral Hepatitis*<sup>1</sup>, and I thought surely New York State and City were doing something to incorporate the *Action Plan’s* agenda items. My research ultimately led me to Harm Reduction Coalition. Luck would have it that they were hiring for an open HCV position! I applied and was hired. I was thrilled to have opportunity to engage in hepatitis work once again.

My experience working on hepatitis was very different in Massachusetts where I had organized broadly around viral hepatitis, including hepatitis A, B, C, D and E. At Harm Reduction Coalition, my advocacy work focuses primarily on hepatitis C. My first thought was, “Fabulous! I can concentrate on Hep C!” Of all the hepatitis viruses, HCV affects Black people more than any other race (though, such is the case with too many diseases). Initially it did

not occur to me that I would be advocating on behalf of people who inject drugs or had a history of injection drug use. To be honest, prior to working at Harm Reduction Coalition, I hadn’t really given much thought to my personal feelings about injection drug use or drug use at all for that matter. However, as the Hepatitis C Advocacy manager my job is to advocate for drug users’ health. For many people, providing funding or creating policies that ensure adequate drug user health is a tough pill to swallow.

Unfortunately, many people think that people who use drugs could care less about living healthy lives. In fact, some of my friends simply could not understand why I would want to advocate for legislation that would ensure access to quality healthcare for people who use drugs. Really, one friend actually said, “Hadiyah, you’re doing what?! Advocating for drug user rights, yo – drug users have no rights!” I was shocked. I just couldn’t believe that my friend felt this way, but the response was eye opening. I’m convinced that advocates have untraditional ways of processing what is vs. what isn’t – but

that's what makes us tick right? I've realized that I have a super liberal approach to a great deal of things. I essentially exist in my own small, private, liberal Hadayah world. Just the other day another friend exclaimed that there was just no way that he would ever kiss an HIV+ person!? I just couldn't believe it. But – I digress.

For a few days, I couldn't stop thinking about my friends' reaction to my work. I just couldn't understand why folks would want to deny anyone – addicted to a substance or not – access to tools that would help them lead healthier lives. I mean, it's really no one's business how anyone else decides to live. The more engaged I became in the issues around hepatitis C, the more I realized that while I understood hepatitis from a clinical standpoint, I didn't have a clue about street drugs and drug use.

I decided to take a step back and assess my own thoughts about drug use. Growing up in the Virgin Islands, saying "NO to Drugs" was translated as: don't smoke weed. Well, that message didn't resonate because everyone smoked... everyone. Just like everyone drank alcohol. When I moved to the mainland, I found that the same

was true. Everyone I knew used some drug or another on a functional, regular basis. It is not right, nor is it fair, for anyone to deny those that have seemingly "indulged" more than others, access to healthcare. I've always been intrigued at human beings' ability to judge others as though they've never done ANYTHING that would warrant some sort of "righteous" judgment.

As I said, I've found that working on HCV is much different than advocating around HIV because HCV primarily affects injection drug users (IDU) – some of the most marginalized, oppressed people in our society. While HIV and HCV both affect IDU, HCV has not affected white men in the same way that HIV did. You see, if it were not for gay white men, it is unlikely that people living with HIV would have many of the benefits they have today. While the story of AIDS activism in the early 80s and 90s is obviously more complex than I can go into here, gay white men had the wherewithal to advocate for themselves; despite facing their own stigma and discrimination, they also had access to – and were accustomed to – a certain level of economic and racial privilege simply because they were white and

male. Current and former drug users are more likely to be lower-income and, simply put, are busy working on meeting their immediate needs (food, shelter, avoiding withdrawal, etc.). They often have fewer resources, fewer allies and little to no political clout. As a policy advocate, I'm meeting with legislative staffers, who in some cases – just like my own friends – have no compassion for people that use drugs. None. That is, unless I'm talking about people that live and look like they do. It is unfortunate that I find myself having to highlight the IDU epidemic in suburbia in order for legislators to consider increasing funding for HCV or drug user health services in general for that matter.

Contrary to what we would like to believe, certain communities here in America have little choice about the way they live their lives. I recently read a letter to Janet Bodnar, editor of the July edition of Kiplinger's personal finance magazine. I was floored when I read about her son Peter's reaction to "labor-force refugees" – hopeless folks who migrated from Portugal, Spain, Italy and other European countries to Australia in hopes of finding "good jobs". Peter spoke about how "resigned to their fate they were/are." Peter explained that, "they shrug their shoulders because they have no hope of changing the situation and no control over their future." He hopes "that never happens in the States." Peter is a 23-year old, non-black man who had the privilege to work and live abroad. He encountered people his age from other countries who had to leave their home country in order to find employment. What Peter witnessed and heard from his "labor-force refugee" friends was in many ways very similar to what many low-income young people experience right here in these United States. Subpar education, discrimination, constant harassment from the police, and little to no opportunity because many low-income Americans

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Renaissance Baltimore Harborplace Hotel  
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**While the story of AIDS activism in the early 80s and 90s is obviously more complex than I can go into here, gay white men had the wherewithal to advocate for themselves; despite facing their own stigma and discrimination, they also had access to – and were accustomed to – a certain level of economic and racial privilege simply because they were white and male.**

feel as *The Roots* articulated in their song, *Now or Never*:

*But my role is cast before I even audition for it. So I don't really see an end to my vice. It's just false reformation, no end of my strife. Feel the evil overpowering; you can go ahead throw the towel in.*

Many young people from marginalized communities feel like there is absolutely no way they could ever make it in America. That – coupled with the war on drugs *and* on poverty (dare I go there) – leaves too many members of our communities forced to live what could be considered an absolutely hellish existence.

It's easy and convenient to overlook the poverty, racism and discrimination that exist in our own back yard. Systems are designed to keep certain populations oppressed (and hidden) – schools, jails, prisons, banks – it's actually all part of a plan that benefits the few at the cost of the many. We know that prisons and jails are overwhelmed with men of color, many of whom are locked up for non-violent drug offenses. The school to prison pipeline is eating away at our very existence. When people of color apply for business or home loans, we are routinely denied for this or the other reason. We see, and we internalize, that as people of color, our lives have little to no social value. We know this. And, I'll tell you – the Dr. Martin Luther King quote:

*"Of all the forms of inequality, injustice in health care is the most shocking and inhumane"* – is the TRUTH.

So, with Hepatitis C, the odds are way off. Let's just review some of the facts:

- The CDC 2010 prevention budget allocated less than \$30 million for Viral Hepatitis. That budget includes hepatitis A, B, C, D, E. In that same 2010 prevention budget, the CDC allocated \$728 million for HIV, even though there are five times as many people infected with HCV as with HIV.
- This past February, an *Annals of Internal Medicine* published report revealed that in 2007, hepatitis C killed 15,100 Americans, compared to the 12,700 HIV-related deaths.
- Roughly 4 million people in the United States have chronic hepatitis C; many have been infected for 20-30 years and are now facing serious complications. That 4 million does not include homeless, incarcerated and immigrant populations.
- Hepatitis C-related liver disease is now the leading cause for liver transplants.
- African-American men in the Baby Boomer generation have the highest infection rates of any major demographic.

The bottom line: Much more needs to be done to educate legislators, funders, the general public *and* health professionals about this "silent killer". Hepatitis C, like HIV, *is a health issue* – it should not be viewed as a moral issue. As an advocate, I'm constantly challenging stigma and discrimination related to drug use and hepatitis C. So, whether I'm meeting with legislators emphasizing money (i.e. how much HCV treatment and care cost the state and city, etc.), speaking to current injection drug users in the spirit of harm reduction (i.e. meeting them where they are at, urging them to take advantage of syringe access programs, etc.), or urging medical professionals to offer HCV screening (CDC now recommends that ALL baby boomers get screened) – the bottom line remains the same: people at risk for hepatitis C have a right to resources and tools that can prevent infection and those who are living with hepatitis C have a right to quality, affordable care and treatment.

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*Hadiyah Charles worked as an advocate and grassroots women's health activist for 12 years, working closely and extensively on policy and advocacy issues for women living with HIV/AIDS, their families, and communities. Hadiyah was recently recognized as a Champion of Change as part of President Obama's Winning the Future Initiative.*

#### Notes

1. Available online at [http://www.hhs.gov/ash/initiatives/hepatitis/actionplan\\_viralhepatitis2011.pdf](http://www.hhs.gov/ash/initiatives/hepatitis/actionplan_viralhepatitis2011.pdf) (accessed October 2, 2012)

# I Would, If I Could, If I Should.

ANONYMOUS

**It is so very easy to lose  
yourself in a city so big...**

About four years ago, in one of the newer subway cars, lit up so much you feel like you are in a fish bowl, I sat across from a poster with a man's face, part of it looked, well, like a burnt marshmallow. It said something like: If your face looked like your liver you would get treatment. No how... where ... or when. Gee thanks. I would, if I could, if I should.

A lot of stuff in a short time led me to that point in life-less-ness, 3 ½ years of stuff, not nice stuff ... I put my dog of 12 years to sleep, saw the second plane hit the World Trade Center and worked next to the city's Medical Examiner's office, where, for years, they identified the remains of 9/11 victims... I began to drink vodka, insane amounts of vodka ... one, then the other person I worked for moved on, job got too hard, job got sabotaged, job got too easy, got no job ... pre- then full-on menopause, which became disruptive then destructive ... short term, followed by working memory, began to fail ... poor long-term memory since childhood ... my brain was being fried; sunlight hurt, florescent lights hurt ... I was thirsty all the time ... physically getting weaker ... had no emotional control ... my closest and dearest friend had been using me but I had no clue and out of the blue he publicly dumped me ... already a loner I isolated myself, no social support, no friends ... the craziness of speed abuse. It is so very easy to lose yourself in a city so big ... Bursitis so bad I had to take crosstown buses ... Hep C diagnosed, high titer w/some liver damage ... abdominal surgery: It's damn hard to get out of the hospital when you have no one to pick you up ... quit drinking ... immediately started sleeping ... then crying ... crying, ridiculous public displays of emotion ... low self-esteem, no self-esteem ... so soooooo tired ... crying ... 3 ½ years ...

Most likely I got the virus in my mid 20's, but I hoped that I got it later in my

30's when I worked on AIDS research projects with infected blood. So I figured I had time, that odds were against successful treatment but better drugs were on the way. All alone I started to "fix" my apartment look into other jobs, career changes and school. I tried to be self-employed. Initially found good dental care at schools but later had my gums mangled by a practicing hygienist. I was successfully evaluated for a clinical trial, but for some mysterious reason was not included. I looked into other ways to get medical care but was only able to find mental health care [later]. I bounced back and forth between chemical energy and pathetic lifeless recovery from the drug use from mid-2003 to mid-2007. Finally I stopped. My life, myself and my apartment were in embarrassing disrepair and remain so to this day. I had no sense of time and when I could make myself go out in the light what I saw had no dimensions [literally]. I went deeper into deep depression.

Less than a 1½ ago I got a dog, quit smoking and cut way down on caffeine. I already ate right and walked a lot. I then got some mental health care, and have even gone to a Hep C support group. Age, drug and alcohol use or lack thereof, loss of estrogen, chronic infection, the ever popular stress and so on ... any, some or a combination have taken their toll ... it's hard to know. I still remain unemployable on so many levels. I can't afford insurance and I am afraid to gamble with what little savings I have on anything other than current living expenses.

I may have come a long way ... I'm clean, sober and able to read and day-dream again but I am still sitting on that train, sooooo tired with my side hurting looking at the man with the burnt marshmallow face wondering if I should and how I'm supposed to get treatment and pay my rent at the same time. One thing is for sure, I need a dog.



# Remembering Michael Carden

1971–2012

Michael Carden passed away on April 9th. Michael was a strong, passionate advocate for harm reduction and the health needs of people who inject drugs. He worked as Project Director at SUNY Downstate Medical Center and Weill Cornell Medical College, where he managed studies of acute HCV infection in young injection drug users and multidisciplinary integrated care linking syringe exchange program participants to HCV treatment. He was a leader in hepatitis C advocacy in New York, and chaired the board of directors of two of New York City's leading syringe exchange programs, New York Harm Reduction Educators and Washington Heights Corner Project. He was also active in research advocacy through the Hepatitis C Advisory

Board and a member of the National Viral Hepatitis Roundtable (NVHR) Steering Committee member.

Michael was smart and wise, kind and funny, and well loved. His humor and generosity made him a good friend; his compassion and insight made him a skilled harm reductionist; and his intelligence and dedication made him a valuable advocate and ally.

At its heart, the harm reduction movement is a close-knit family of dreamers, radicals, and outsiders, tempering anger with hope, fighting stigma and marginalization with love. Michael was a beloved member of our family; he touched the lives of countless people, and his loss is deeply felt.

– Daniel Raymond

*Let me respectfully remind you,  
Life and death are of supreme  
importance.*

*Time passes by swiftly and  
opportunity is lost.*

*Each of us should strive to awaken.  
Awaken! Take heed, do not  
squander your life.*

– The Evening Gatha, Zen Buddhism

I read this at Michael's funeral. Not because he was a religious man. But because he did not squander his life. He looked. He loved. He lived. In spite of great darkness, he loved. No matter what, we never have to squander our lives. Thank you Michael. I miss you and love you.

– Wyndi Anderson

You truly was a champion of the people Michael. I still recall the times when you worked at Citiwide where the majority of the participants only spoke Spanish and how despite the language barrier somehow you was still able to connect with them. I witness how you truly gave of yourself in a really genuine way to give a hand to anyone who walked through them doors seeking help. The people of the south Bronx will miss you and never forget you. Love you my brother. Rest in peace until we meet again.

– *Edwin Santiago*

Michael was that one person I could ask those unaskable questions to. He was my go-to for the confusing, confounding, emotionally charged and complicated life and work dilemmas that are too humiliating to air to usual confidants. He had a knack for the 'been there done that' shrug. I think of Michael when dealing with participant and participant-staff issues at WHCP. I remember once talking at a Board meeting about how we were having a hard time managing our participant telephone which was being used to loudly secure drugs or money. While Board members looked pained and concerned, Michael said something along the lines of 'So what? If they don't use your phone they'll just use the one right outside.' Everyone, including me was dumbfounded. I measure WHCP's successes against what Michael would have wanted, what he would have thought was just or right. Michael was my compass, a navigation trick to weave me through the day. I feel lost without him.

– *Jamie Favaro*

Michael was always helping me out in my post-opiate dark days between 2005-2008. Come summer 2009 I had the chance to return the favor. Michael had stopped using and was single and lonely. I introduced him to Tino Fuentes. To my surprise Michael and

Tino became fast friends. For a short time we became the 3 musketeers. They would come watch me do comedy at Bowery Poetry Club's Monday night open mic; the remainder of the week would be spent hanging out at Mars Bar (Michael would sip cokes).

I frequently had Michael in hysterics with tales of mad comic routines: mass public fellatio practiced upon whippersnappers and dental clinics on vaginal teeth cleaning. He had a great laugh, which I will always miss. Sadly we drifted apart after the summer ended. I had fulfilled a role not unlike the one he had earlier fulfilled for me. Then it was time to move on. I will always cherish that summer we spent together.

– *Paul Cherashore*

I always will remember Michael's kindness and his courage: he was not afraid to care about people or to witness and face many letdowns and ugly things in life. I trusted him implicitly: he didn't lie about things most people do. He had a deep, razor sharp intellect and lots of emotional intelligence. Usually Michael had a very serious expression on his face; he was thoughtful, and spoke quietly. His wild sense of humor came as a delightful surprise. Michael would send me the most ribald and ridiculous texts at meetings, while his expression remained solemn. He looked as if he was getting a stream of very important work-related messages and trying to handle them with discreet urgency.

There are so few people that can do what Oscar Wilde suggested we should aim for: amuse or feed or shock people. Michael did all three. I miss him a lot.

– *Tracy Swan*

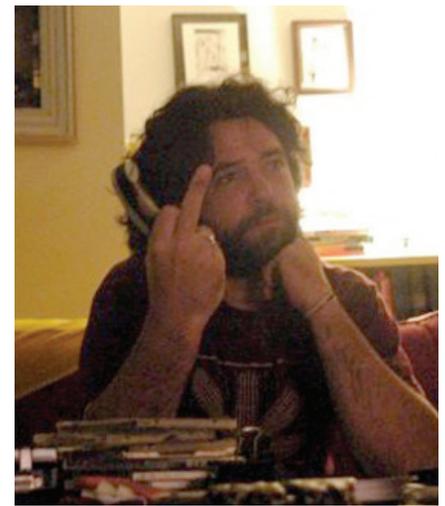
This is so fucking hard to write. Not because I don't have lots of nice thoughts and memories of Michael. Despite it taking a minute for us to warm up to each other, I'm so fortunate that we did get close. He was an important friend who I trusted a lot. While

many of our conversations found us working out tough issues—both his and mine—there was almost always laughter somewhere along the way and lots of kindness. Michael's gentle honesty and interest in *really* understanding allowed me to talk to him about things I didn't talk about with pretty much anyone else. I miss Michael's laugh... he had such a great laugh. I miss his hands... shaking as they smoked a cigarette or typed away at his computer. I miss his awkward silence that sometimes made me uncomfortable. I miss knowing that he's around... that I might run into him at a meeting unexpectedly and get a great hug. But, it's hard to write this because it just really sucks that he died. It sucks that he was struggling— with his demons and his drug use. And it sucks that Michael died of an overdose— and knowing that no matter how hard we work, and no matter how careful we are, sometimes there are still accidents. I miss you so much Michael... thanks for being my friend... xo

– *Emily Winkelstein*

I never met someone that was so caring and willing to help other people and fight for them anyway he could. Michael will be forever on my mind. He changed and saved my life. When medicaid turned me down he went to the drug companies for me to receive my treatment. He helped me through my HCV treatment and helped me get clean. My treatment was rough but I think it would've been worse if I didn't have Michael in my life. He became a close friend that was there 24 hours a day, I would call him in the middle of the night to talk about my problems. I still want to pick up the phone and call to this day but not about problems but to tell him how great my life is and I am happy. Thank you Michael for everything you have done for me!

– *David Pierog*



Michael and I thought we hated each other at the beginning, but it turned out that we just didn't know better. He became one of my closest friends and, without judgment, saw past the walls to the vulnerable core. He was honest and open and sometimes too smart and perceptive for his own good. His wicked sense of humor (delivered without even a smirk) left you rolling on the floor if you knew him and shocked and stunned if you didn't. I still find myself picking up the phone to share something that happened or to ask him for advice. The harm reduction movement lost an important voice and mind in April, and I lost a piece of my heart.

— Carolina Lopez

Like many of my friends and acquaintances in that era of my life, one of my first encounters with Michael involved him loading a syringe and handing it to me. The only difference was that when Michael did this, he handed me a syringe containing a new lease on life, while *EVERY SINGLE* other occasion this occurred I was being handed the same ol' gloom and doom. Michael was tasked with overseeing my interferon treatment for Hepatitis C.

Although we were introduced in a formal, professional context, Michael and I discovered similar tastes in terrible, noisy music, amongst other

things, and over time a bond formed between us two quiet, (slightly) misanthropic curmudgeons. At the time of his passing, I considered Michael my best friend amongst those that I've met since living in NYC. We both had the same habit of making plans only to break them, and saying "let's get together soon" (which we rarely did) every time we ran into each other; I'm glad that we had this in common, as I'm sure someone's feelings may have gotten hurt otherwise.

I could go on and on, but in summation I'd just like to say that I feel very fortunate that I was able to be part of Michael's life, even if it was for a very short time. He was a rare breed and we won't see another like him any time soon.

— E

The first time I met Michael he came to my rescue with a hug. I had recently entered the world of hepatitis C advocacy. We were both attending a community meeting with the NYSDOH. Acronyms were being tossed around as if they were everyday language. Not understanding them and lacking the confidence to say so left me feeling daunted and quite frankly stupid. My frustration grew until I could not stand it anymore so I said loudly "this all sounds like M O U S E to me." When the meeting ended I left quickly to

avoid conversation. I smoked a cigarette outside in an effort to calm down and regain my composure. Michael seeing that I was shaken walked up to me and offered words of encouragement. Again, new to advocacy and feeling very inexperienced, I started crying. Not one of my finest moments, but one I will never forget. No sooner than the tears started falling did Michael gently hug me. No thoughts of awkwardness, no hesitation. This is how Michael approached life with deep compassionate and genuine sensitivity. I will never forget my dear friend, he will live on in my heart forever.

— Shari Foster

Michael Carden and I worked together for 8 years, running a radical, revolutionary, successful intensive case management program that he developed that delivered integrated multidisciplinary hepatitis C care, including antiviral treatment, to active drug users. I have never worked so closely, shared so deeply, or learned so much from another person. Michael was talented, smart, and dedicated. The breadth of his skills and knowledge was matched only by their depth. He had a deep understanding of policy, research and the treatment of both substance use and hepatitis C. He understood addiction scientifically but also possessed the ability to connect

with people in a deeply human manner, while remaining objective enough to help them through their struggles. He understood the science of behavior change, and was skilled at helping people take difficult and challenging steps that they wanted but had been unable to make. He understood hepatitis C, its natural history, its medical evaluation, and the risks and benefits of the variety of treatment options. He understood the complications of treatment and how to help people manage

them. He understood how to provide information that would be absorbed and understood and support that was nourishing. He understood the medical aspects of addiction and its complications and was equally comfortable in medical and community settings. He understood how to design and conduct research that would make a difference. He understood policy, politics, and how to effect change. Michael showered love and generosity on those he came in contact with. He was gentle,

caring, generous, funny, passionate, courageous, stubborn, loving, and wise. He was sensitive, earnest, tenacious, wicked smart, and intensely committed. I have never trusted anyone so completely, nor felt a loss so deeply. Michael was a hero. His spirit will live long in the hearts and work of the many whose lives he touched. He left us bereft and heartbroken. Somehow we will recover and continue the work he cherished. Somehow we must.

— Brian Edlin

## Don't Let Fear Prevent You from Living

PAUL BOLTER

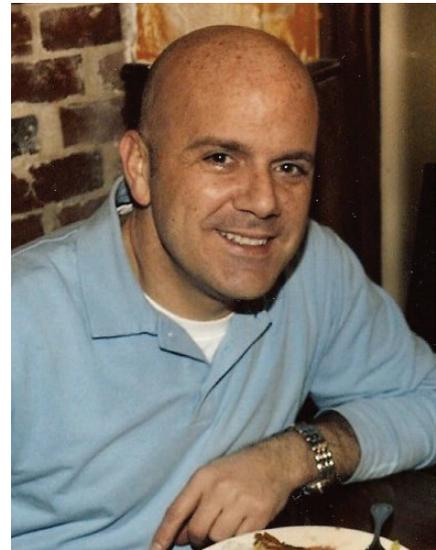
I was diagnosed with hepatitis C in March of 2001, almost by accident. At the time, I was consistently very tired by mid-afternoon and needed to take naps after work. I was experiencing issues with my primary care provider because I couldn't get him to listen to me about the way I was feeling physically, so I decided to get a second opinion. I was given a name of a new doctor and she was very pro-active. After listening to my past history and asking questions to get more information, she took action to try and get to the root of things. Neither of us could understand why at my age I was so worn-out. She decided to test me for hepatitis C, and gave me comfort while waiting for labs and other test results to return.

Back then, the Health Department in Boston mailed out the results of these tests but I actually got a call from my doctor while I was reading the letter. I didn't have a lot of time to panic or get crazy. By the time we hung up, I had another appointment

with the best liver specialist in Boston and I thought about what to do next.

The irony was I had just been hired as the Hepatitis C Specialist for the City of Boston and was in the process of learning about this virus when, BAM! I get my diagnosis. I was stunned at first because after being healthy for so long, I immediately thought I was no longer healthy and that I was in trouble. It was extremely overwhelming for someone who is always "in control".

One of the biggest challenges I faced had to do with stigma. When I found out I had hepatitis C, I had issues disclosing my diagnosis with family and friends. The majority of the people in my life had never heard of hepatitis C and many weren't able to understand it. Immediately after disclosing, my phone started to ring less and even with the people I was used to speaking to daily, I found myself having weekly conversations that were brief at best. My family was also hard to educate and, given the culture I was born in, I wasn't really surprised. Once again, I found myself trying to make others feel okay and comfortable with my diagnosis and yet I continued to receive less support. At the time I was diagnosed, I had been attending a 12-step program for 11 years and I thought that was



**So with my clients, I would often support them in various harm reduction models but as an addict myself, I didn't think that harm reduction worked for me.**

enough in terms of taking care of my addiction. But after my diagnosis, I was taught a few things about something I thought I was an expert on: harm reduction. I was a substance abuse counselor working with addicts who were still struggling and often couldn't stop using drugs for more than a few days at a time. So with my clients, I would often support them in various harm reduction models but as an addict myself, I didn't think that harm reduction worked for me. As I was starting treatment I met with my provider and got schooled on ways to practice harm reduction while living with this diagnosis.

I started treatment and things got more difficult. I had been told that the side effects may be bad, but I wasn't as prepared as I thought I was. The smartest thing I did at the time was to join a support group and share my experiences with others, as well as with a medical provider that was able to answer my many questions. I learned that my diet needed some attention and that I had to limit my iron intake. Most importantly, it was time to quit smoking cigarettes. I wasn't interested in quitting but I knew it would be a good thing to attempt it. So my provider gave me a prescription for the nicotine patch and taught me some

things to prevent giving in to the cravings. Within a month I was smoke free!

Looking back on the various tools I was given throughout treatment – many of which are the same tools I would give my clients – I was amazed they actually worked for someone like me. Applying healthy options with my diet has kept my cholesterol and blood pressure perfect. Remaining smoke free has improved my skin and activated my senses even more than before, and I'm less winded. Instead of 2 large coffees a day I have 1 medium coffee in the morning and I go to the gym regularly which increases my energy and keeps my spirit up.

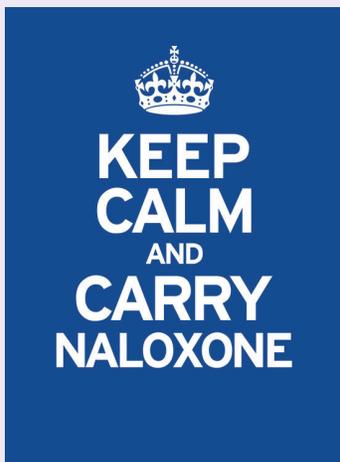
I learned many lessons during this time and as difficult as it was, I stuck things out – many times alone – but I remained compliant with my treatment regimen. After 6 months it was determined that I was not responding to the treatment and I discontinued it all together. A few months later I tried a few other studies and after about 3 months in those studies we realized they weren't really helping much either. Recently, I was fortunate to try a study for non-responders, and although I didn't respond to this latest round of treatment, I feel good about trying and not being too disappointed in the results. I have hope today and

I'm sure there will be something for me soon.

Nonetheless, things are great now. Almost 12 years later my disease has not progressed, I am in great health and my career in this field has only flourished – all because I decided not to let stigma, ignorance and fear get in my way. I got the best healthcare I could have imagined and for that I am truly grateful. I still have what I call "Hep C days" when I get little physical reminders that the virus is still present in my body, but today I know how to respond to these reminders with calmness and patience. There is nothing wrong with me. I am grateful that I know my diagnosis because I am able to understand things about my body more clearly and it gives me back the control that was taken away at first. Don't let fear prevent you from living.

---

*Paul has been working in the HIV/HCV field for nearly 20 years. He was awarded Employee of the Year from Boston Public Health Commission for Outstanding Performance and is currently employed at Harlem Hospital in New York City as a Hepatitis C Clinical Health Educator.*



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# Impersonality and Drug Use in the Harm Reduction Workplace

DONALD GROVE with a response from ALLEN KWABENA FRIMPOG

*The thoughts that follow were originally written on a harm reduction list-serve across a couple of posts. There had been some recent back-and-forth on the list about strategies for managing recovery and abstinence within harm reduction workplaces and, while much of what was shared was insightful and interesting, I found the following comments from Donald Grove (Parts I and II) to be especially moving, authentic, challenging and important. I've also included an insightful response from Allen Kwabena Frimpong (Part III) that continued to move the discussion forward.*

— Emily Winkelstein, Editor

## Part I: Framing Dialog about Drug Use in the Workplace

We harm reductionists still carry the traditional stigmas, and we also have a whole new set of stigmas based on whether the way we do our work is “authentic harm reduction” — the new magical paradigm that reverses the old stigmas. So if an employee is struggling with abstinence, where does the dialog begin? How do they ask for help? Particularly, how do they ask for help when they are aware that the help they need might actually mean leaving their job? Stigma enters the picture and cuts both ways. The employee is a “conniving manipulator” for not asking for help, and the employer is “not really practicing harm reduction” because they didn’t rush forward and offer an excellent solution. Of course, it’s not that simple, but that is how it tends to get gossiped about in the harm reduction community. And we do gossip about all of this.

And why do we gossip? Honestly, I think it is a way of mediating not only just how few tools we have, or just how little understanding we have, but also just how much we see what is happening and don’t know what to do about it. So we vent and gossip. And we accuse and ridicule. I’m not above this at all. I’ve been smack in the middle of it for over 20 years. We need to begin to look at that gossip and see what it tells us about our expectations, aspirations and oversimplifications. And what it tells us about our feelings of helplessness. Really.

Gossip is also a way of mediating our grief. And grief is often the operative factor in our raising questions about drug use in the work place. Too much so. At conferences, discussion on grief and discussion on questions of use within agencies are often forced into the same time slot. I think the issues are closely tied, but that we as a group don’t know how to differentiate between them well in our dialogs. Grieving often gets expressed as rage

and accusation. At conferences, the forums where we speak about these things are often serving multiple purposes, and those purposes wind up competing. Again, I am not above any of this. How often have I used ideology as a substitute for self-examination because I was overwhelmed by the presence of death or profound suffering?

Also — and this is risky — how ready are we to recognize that the questions about “drug use in the workplace” are not just about labor but also about management and boards of directors and visionary founders? Does one policy fit all? We can talk about some of it with relative safety, because it appears to be about “personnel”. But some of it is very, very dangerous to discuss, because acknowledging what is happening could shut an agency down. 20 years down the line, and I still don’t know how to bring that one up.

I completely agree that the dialog is necessary; I also think that harm reduction programs have a responsibility to begin the dialog and to keep it going. But, too often, we have this monolithic way of speaking about workplaces and policies that assumes there are graceful answers. There aren’t. In my opinion, we haven’t even developed the ability to ask the right questions yet. What’s more, we need to look at our own humanity for what it is: confused, gossiping, ridiculing, using, struggling, feeling, overwhelmed. LEARNING.

## Part II: Impersonality and Drug Use in the Harm Reduction Workplace

People who know me know that I can say a lot. And this is no exception. I’ve struggled with how to say this. I don’t know any other way to say what I need to say, so here it is, warts and all. It starts kind of cerebral, but it doesn’t end that way.

The idea of “impersonality” is huge in the American workplace. For most of us, we are supposed to leave our personal

lives behind and function in specific, impersonal ways in the work setting.

A strong illustration of this – from outside the Harm Reduction world – is the question of childcare. Within homes there is nothing impersonal about children and, much as we try, addressing their needs can't happen on a fixed schedule. But for many workers, particularly for women, they are supposed to completely separate their "personal" roles as parents from their jobs. The expectation is that one's responsibilities in taking care of children should have no impact on one's job. This places workers, particularly women, in a vulnerable position: Don't let your personal role as a caregiver have an impact your work, or you could lose your job. This push for impersonalization goes well beyond childcare into many parts of our lives; and it isn't just true of Walmart, it's true in all kinds of workplaces: police departments, church offices, banks, schools, construction companies, and harm reduction agencies.

Another aspect to impersonality is the role of hierarchy. Non-profit and for-profit companies alike have a legal framework of incorporation, which identifies responsibilities within a hierarchy. Within the hierarchy, the personal meets the impersonal. The structure is assumed to be impersonal (fixed and objective), but when the systems fail or problems occur, there is blame directed at *the individual* (variable and subjective) – and that is personal. Either the Executive Director was personally responsible, or the Supervisor was personally responsible, or the Employee was personally responsible, and the hierarchy itself is "impersonal".

My own view is that "impersonality" is a cultural myth, like gender. It has its positive side, or function, but really, we don't stop being human when we do work for pay. And the idea that we should leave our personal lives at the door is a huge source of pain and

**And why do we gossip? Honestly, I think it is a way of mediating not only just how few tools we have, or just how little understanding we have, but also just how much we see what is happening and don't know what to do about it.**

frustration (and oppression) for many people precisely because it isn't a real distinction, yet is still demanded of us. We are expected to have two selves, one that encompasses everything in our lives (including our work), and one that leaves everything but work out of the picture, subsequently demanding a self that is defined purely by the functions of the workplace. We have cultural systems that insist that the ability to differentiate between "personal" and "job" is a normal part of maturity. Those cultural systems also assume this workplace-impersonality to be universal. It should be as true for farmers and fishermen, and bankers and harm reduction workers.

I think it's fair to say that harm reduction challenges these structures and assumptions at some basic levels. We usually prefer to hire people with direct personal experience of the need for harm reduction (i.e., current and former drug users). But we are often required to use employment structures that are hierarchical and therefore, that mythic impersonality is also required. There is a cultural expectation that both the employer and employee can move in and out of that impersonality as needed.

There is also a sharp contrast between the impersonal workplace and a model of working with drug users that explicitly challenges authority. This is something I don't really feel there is much clarity about. We want workplace policies that support both employee and agency stability, but we have difficulty approaching questions of hierarchy and impersonality, particularly because as people we have differing approaches to these ideas. We

also have differing capacity to address questions of hierarchy at all. Race, gender, poverty, histories of incarceration, etc., all play into how likely or able people will be to question the hierarchies or the structures of impersonality. But the structures are there, either way. And whether we like it or not, those structures are supported by systems of violent oppression. I'm just sayin'. Can we get things done within this structure? Yes we can. But let's not forget the power behind the structure, and how we are compelled to shape our ends in response to that power.

The other side of impersonality is much more difficult. We work within a philosophy that supports the idea of drug user autonomy. We challenge ideas that say drug users are incapable of critical thought about the risks and harms of their drug use. We challenge the belief that drug users are failed humans. We challenge stigma. And we challenge the system of cultural entitlement that allows drug users to be dismissed solely on the basis of their drug use, without consideration of other present factors, such as systemic racism and poverty.

But we also tend to use a model for understanding drug use that identifies a point at which drug users may lose critical capacity, may lose their autonomy in relation to their drug use. A point at which it is no longer the person who is acting, but a disease, or some other, somehow impersonal force. (Since when is disease really impersonal?) In my own personal experience, both as a user and as a person living among active users, this is actually a natural part of my understanding of what is going on. Maybe it is part of the system

of stigma that I want to separate Joe from Joe on drugs. But I do. Not in all cases, but I do.

I think this is where it gets really difficult. We see our co-workers use; we see them – ourselves – high on the job, sometimes genuinely incapable

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of doing their work. And that incapacity doesn't begin or end with work. No matter how much we want to impersonalize the workspace, the user is living a life outside of that workspace where their drug use is also having an impact on their ability to raise children, manage parole, stay housed, etc. Taken within this context, the idea that the workspace is impersonal is not only incredibly dangerous and harmful, but also political. Is it also harmful to depersonalize the drug use? "It's not Joe, it's his disease." Who draws the line? It's a line that negates the autonomy of the user. It's still a line I draw, sometimes, with pain and confusion.

I give this analysis because this is how I approach the question of "drug use in the harm reduction workspace." It's not happening in an impersonal vacuum. It's happening in my life, everyday. In my real, highly personal life. I need help to understand the functions of the hierarchies, the functions of the impersonalization, the functions of differentiating between user autonomy and user incapacity because of what is happening in front of me, everyday, to people I know, love and admire. I see executive directors and supervisors blamed and accused

for not supporting the users, I see users blamed and accused for not being forthcoming about their needs or incapacities. I see users asking the harm reduction community as a whole, "How come no one said anything when I picked up and nearly died?" And I see users in a state of total meltdown angrily rejecting the suggestion that their drug use may be part of their meltdown.

It just doesn't look impersonal to me. It looks super, super personal. I am dissatisfied by the presence of hierarchy, and it's cautious, legalistic structures of responsibility and blame. What I see are people whose lives are going down the toilet. It is impossible to predict who is going to die next. And it is very hard to tell where to set my boundaries, when often where I set them may be the difference between life and death. If not life and death, then the difference between dignified well being and humiliating destitution within struggling and oppressed communities.

Drug users are often living in a state of continual repeated trauma; we are battling with, or conceding to, continual deep personal loss. And we experience that loss and that trauma not just as individuals but also as members of families and communities. But what about when that loss is someone else's, not my own? I have seen loss happen to others again and again. I have watched people fall apart, struggle, suffer and sometimes die, again and again. That is a trauma too. And I struggle to judge which matters more – doing triage in a world of competing traumas. This is what the people in harm reduction agencies often face. Each trauma is supposed to stand alone, and be addressed on its own terms. But that isn't possible in this world, at this time.

I say this because this is what I actually bring to the table: "You failed, I failed, because x or y were neglected." I try to be detached and impersonal, but scratch the surface and this is what it looks like. In order to move

forward and work with others, I need some sense of detachment from this experience, but that detachment can't simply be to say, "It's not personal". It IS personal, AND I also need detachment. And it is personal for all the people I work with, as well. Some of us are better at navigating this than others, but we all bear the scars – the scars of enormous loss, the scars of enormous blame. This is the way things are. This is what I see.

I don't question that there are things that can be done within the structures as they are. I don't want the perfect to be the enemy of the good. But that hierarchy is not impersonal, the workplace is not impersonal. And we haven't worked out how we relate institutional structures to the shifting capacities we have as drug users. And this is how it looks to me personally.

– Donald Grove

### **Part III: A Response**

Thanks for this Donald! I started to research and write about the complexity of this from a racial justice and harm reduction frame in a webinar called, *A Need for Racial Justice in Harm Reduction: Where a Racial Justice Agenda Matters*<sup>1</sup>.

I would also add it's not just hierarchy, it's also the autocracy that comes with hierarchy when people are not given the opportunity to consent to decisions that actually impact them in very personal ways – whether harmful or not. This is why, at this point, I don't expect to receive support from hierarchal/autocratic structures that operate from a place of impersonality. It's disingenuous. Rather, I find support from outside of them, and outside the context of the impersonality; others are not always that fortunate.

These dynamics result in a violation of people's rights. Organizations that exist in these traditional social service or hierarchal/autocratic models are inevitably going to have harmful consequences – intended or

**Race, gender, poverty, histories of incarceration, etc., all play into how likely or able people will be to question the hierarchies or the structures of impersonality.**

unintended – where trauma *will* show up, *will* reproduce various kinds of oppression, and *will* go unmitigated. The inability and unwillingness to “meet people where they are at” is a manifestation of liberal privilege. That privilege – and its entitlements – blinds people to the realities and burdens “other” people (HIV positive, people of color, womyn, LGBTQ, etc.) are forced to carry when their rights are continuously violated. In this case, it happens when workplace spaces promote principles that are antithetical to the very practices they are promoting (i.e. health promotion among people who are using drugs and/or are HIV positive, etc. and management models of “dealing with people”).

It’s the personal relationship that people have to their wisdom, gifts, talents, and skills in a place and space that holds the intent for people to be labor intensive. *There are personal reasons for why people do the work they do.* This is why people can use

impersonality as a tool of oppression. It allows those who continuously break consent to then question and invalidate peoples’ lived experiences in their many identities and capabilities from within an environment that sets them up to fail; this is especially true when there are false expectations about how the institution *ought* to be supporting them since they are about harm reduction. Further, impersonality allows people not to act instead of actually navigating the oppression in ways that can mitigate harmful behavior in workplace spaces. We need a harm reduction approach that explores the relationship between how we engage with non-profit system structures, practices, and cultures and the labor we produce within these spaces that also addresses the trauma that we experience both inside and outside of these spaces. This is a really DOPE and much needed conversation that should be continued!

– Allen Kwabena Frimpong

*Donald Grove has been involved in harm reduction advocacy and service delivery above and under ground in New York City for over 20 years. He is currently an independent contractor.*

*Allen Kwabena Frimpong is an independant consultant and an apprentice of the Art of Hosting/ Participatory Leadership practice. He centers his work on transformative justice in communities whose journey is to be in collective self-determination and liberation. Allen currently works as the Program Manager for Living Cities, Integration Initiative site in Newark, NJ.*

**Notes**

1. Background material is available online at <http://harmreduction.org/our-work/training-capacity-build/capacity-building/community-consultation/racial-justice-harm-reduction/>



**Did you know:**

- About **25%** of individuals infected with HIV in the US are also infected with HCV?
- About **80%** of injection drug users with HIV infection also have HCV?
- HIV coinfection more than **triples the risk** for liver disease, liver failure, and liver-related death from HCV?

Harm Reduction Coalition has launched a new **hepatitis C advocacy campaign** aimed at strengthening the relationship between the HIV and HCV advocacy communities. Get involved and learn more at **[harmreduction.org](http://harmreduction.org)**!

# “We’re All in the Same Boat”

## Stories from a Hepatitis C Treatment Empowerment and Support Group

*Back in early 2012, my colleague Dale Simmons and I had the privilege of visiting a meeting of the Hepatitis C Peer Educator Group at the Albert Einstein College of Medicine Methadone Maintenance Treatment Program. At Einstein, HCV care and treatment are integrated into Methadone Maintenance treatment program services. Participants can receive HCV treatment within an innovative weekly group format, which provides provider consultation and medication assistance, peer support, education, discussion and even advocacy to address common barriers to successful treatment. Patients who have undergone treatment at Einstein are eligible to become Peer Educators with the Hepatitis C program.*

*Several Peer Educators agreed to take part in interviews to share their experience having HCV, taking HCV treatment and being part of the group treatment model. The interviews were recorded and have been transcribed here. For more background info on the group and for tips on starting your own group, see page 42.*

*Thanks to Dale for helping with the interviews and special thanks to the entire team at Einstein, including Lauren Cockerham-Colas, MPH, Alain Litwin, MD, MPH, Irene Soloway, RPA, Robert Roose, MD, MPH, Sheila Reynoso, BS and especially to the peers for sharing their stories.*

– Emily Winkelstein, Editor

### ANTHONY

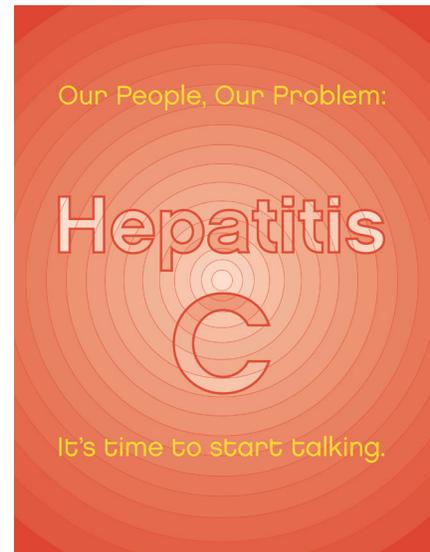
*Anthony is 58 years old. He was diagnosed with hepatitis C in 2008 and went through 72-weeks of treatment with interferon and ribavirin shortly after being diagnosed. Treatment was successful.*

**HRC:** *Please tell us a about your experience having hepatitis C and going through hepatitis C treatment.*

**A:** *Let's start from the beginning. I noticed something was wrong when I was working on construction. I noticed that I started getting tired quicker and running out of energy faster. I*

*just didn't feel right. So, I spoke to Irene [the RPA] and she asked me if I wanted to get tested for hepatitis C. I was a little hesitant, but she chased me around for at least a year and a half, and thank God she didn't give up! Finally ... I got tested for HIV and hepatitis C. The results came back and Irene told me I have good news and bad news: the HIV is negative, for hepatitis C you're positive. I had mixed feelings but I was glad that I'd done it because at least I knew and could deal with it. I was fortunate enough that right after I got tested and found out that I had hepatitis C, I started treatment.*

*The first couple of weeks, I didn't feel any side effects – it didn't bother*



This poster, created by the Hepatitis C Harm Reduction Project, is available in English and Spanish at [harmreduction.org](http://harmreduction.org).

*me. But, once the medication got into my system, I came down with the nausea, anemia, irritability, and I was getting anxiety attacks and panic attacks. I had always been nervous and always got [panic attacks], but before treatment I was always able to sit down and calm myself and they went away. Once I started treatment, they came closer together and stronger. So I spoke to Irene and she prescribed a 2-week supply of Klonopin and then I had to see the psychiatrist. It seemed to help and I don't like to overmedicate, but – it was the only way I could get rid of them.*

**HRC:** *Did you ever taught of stopping treatment because of the side effects?*

**A:** No – never. Going to treatment one-on-one, where it's just you and the doctor – I don't think I would have been able to. The main thing is the support group. It was 16 of us, all of us in the same boat, and if you were going through a rough patch, you had people to talk to. It was amazing how we all bonded and plenty of times people wanted to walk out, and we weren't going to let that happen. My friend, Ivan, who I went 72 weeks with, there were many times he wanted to stop and I'd tell him, "Look, we went 48 weeks already. So, if we have to do another 25 to get healthy and maybe save our lives – what's the big deal?" By that time, we had gone through side effects and sometimes they were bad and sometimes they didn't bother you. It depended on the day.

**HRC:** So, what does it mean to you, having been able to clear the virus? What does that mean to you?

**A:** It means so much. It means that I got rid of something that was eating away at my liver – something that, if I didn't take treatment, would've eventually killed me. I just feel good having done it, having gone through it, and being undetected now – I feel like I got a new lease on life.

Now, I'm a peer educator and I talk to people; they tell me if they've been tested, if not I tell them to get tested and at least find out. Once you find out, if you're negative – great. If you're positive, now the ball's in your court. You've got the option to treat it or not.

**HRC:** Looking back, is there anything you now know, or that you've learned since you finished treatment, that you wish you had known before?

**A:** I wish I would've done [treatment] earlier. People make a big deal about getting tested, but like I said, if I had known how it was going to go, I would've done it much earlier. You hear

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people say, "Oh, yeah, I tried the treatment and in 2 months I had to stop because I was so sick, I had no energy, I felt so sick, etc." But everyone is different – there is a list of side effects and if you look at that list, right away you would say no – I can't do this. But you're not going to get all the side effects.

**HRC:** What is a message you would like to give to people living with hepatitis C and who are thinking about treatment?

**A:** Get treatment.

**HRC:** What is a message you would give to doctors who are treating people with hepatitis C?

**A:** Try to be as compassionate as possible because some people do go through rough times.

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## IVAN

*Ivan is 56-years old. He found out that he had hepatitis C in 2001 and has tried treatment three times.*

**HRC:** When did you take treatment and for how long each time?

**I:** The first time I tried treatment was in 2002. I only lasted there for about a month because of the side effects. After about the third week I started throwing up in the morning and since the clinic only had hours on Tuesdays for hepatitis C, I went to the emergency room. They didn't know what to do, so I wound up just dropping [treatment]. Then it tried it again about a year later

and it was pretty much the same thing.

Then, here in the program, Irene was talking about starting a group [treatment] process, and since she's here five, six days a week, I did it. When I started waking up nauseous, she gave me pills. The next thing that started bothering me was being tired and she had something for that too. Those were basically my main concerns – everything else I was able to deal with. I was able to do 72 weeks.

**HRC:** So you did 72 weeks – was it successful?

**I:** No. [The hepatitis C] came back. It was good after we finished, I was undetectable, but 6 months later it came back. When I first started, my viral load was four and a half million and when it came back it was only at two hundred seventy thousand – which is a big change. What I like to tell people is that when I first got into it, I was always feeling tired and bloated and I couldn't eat the way I used to and, even though [the hepatitis C] came back up on me, I feel fine. I'm still able to eat and I don't feel tired and I'm doing pretty good.

**HRC:** Can you tell me a little bit more the things that helped you get through treatment this last time?

**I:** The group – we'd come in and get our treatment and we'd talk about what the week was like. We met every Thursday, once a week, for an hour or an hour and a half. We talked about the changes we went through and you'd get different ideas on how to deal and,

at least, you get to vent about whatever you were going through, which was real good.

We wound up being close. The group started out with about 18 or 20 people and only 2 people walked away from it. The rest of the people either had to stop because of medical issues or they completed it. And most of the people cleared. It's only me and, I think, one other person that didn't clear it. But, with the new medications my chances are even better.

**HRC:** *Can you talk about the different experiences you've had with doctors?*

**I:** There were some, when I went to the clinic, where it felt more like.. how can I put it... it was like a factory – the way you were treated. It was just “do this, do that” and there was never any real tightness. Here, we have a group process and we get to know each other, it's more personal and it makes a big difference in dealing – you feel like you have somebody to help you. Whereas with the clinic thing, if I didn't take care of everything before I left, I would have to wait a week before I saw anybody to help me. It made me feel like nobody really cared.

**HRC:** *Did you experience any stigma related to hepatitis C or drug use at any period throughout your process?*

**I:** Oh yeah. When I first started going to clinics, there were a lot of times they would want to know if you were using, and if you said you were, they weren't that interested in pushing you forward because they didn't think that you would continue to go to the groups or take the medications like you're supposed to. Whereas, with this group, Irene always states that whether you are using or not, you can always come and get your medicine. She is special – she makes a big difference.

**HRC:** *When treatment was getting hard, what kept you motivated... what kept you going?*

**I:** The group – always talking. Anthony and I both wound up doing 72 weeks and he was my partner. A couple of times I wanted to stop and he wouldn't let me; a couple of times he wanted to stop and I wouldn't let him. It helps to have the group because it gets hard – it does get hard.

What I think is scarier is...I went to see a guy who had hepatitis C and he had decided to try and get treatment but it was too late. He was talking about how there was nothing they could do and he was just waiting to die. There's no way I want to be like that.

You know, I tell people to take this medication while you can because it gets to a point where they can't do anything – and you don't want to get to that point. A lot of it is fear – people are afraid of the side effects. I was one of them. But, when I found out that there were ways to fight them and that you can deal with [the side effects] – it's worth it. I tell you – even though [the hepatitis] came back, I'm glad I took [treatment].

**HRC:** *What is a message that you would give to other people who are thinking about going on treatment?*

**I:** Do it! Find a good place that you will be comfortable with and my suggestion would be, if you can find a group, do it that way because it makes a big difference – it's more personal. But, take the treatment because you never know when it's too late. Find out where you're at – it's better to know where you're at than not to know.

**HRC:** *What is a message you will give to doctors who are treating people for hepatitis C?*

**I:** I would say to some of the doctors, to be more compassionate towards

**A lot of it is fear – people are afraid of the side effects. I was one of them. But, when I found out that there were ways to fight them and that you can deal with [the side effects] – it's worth it.**

individuals and explain the process better. Because for a lot of people – if you don't know what you're doing – people just hear different things and they wind up going to the streets – that's where people hear most stuff. So, I think communicating better with your patients would be a big change in the way things are done.

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## **BOBBY**

*Bobby is 61 years old. He found out that he had hepatitis C in 2001 and started treatment with interferon and ribavirin in September 2011. At the time of this interview, he had been on treatment for 15 weeks.*

**HRC:** *How has the treatment been going so far?*

**B:** After 8 weeks, I was symptom free and my blood work seems to be improving every time I get my blood checked.

**HRC:** *Why did you decide to start treatment when you did?*

**B:** When they first told me I had hepatitis C, it wasn't “so bad”. It was bad – but they told me I'd have to address it “one day”. I worked my whole life, I worked in construction and they told me to try and find some soft easy work, but you really can't in construction and I wasn't feeling that bad. I figured as long as I keep my blood work up everything would be fine so I just passed it

off for over ten years. I didn't feel too bad. Until I got to 60 years old, and due to stress and the economic situation in the country now, I retired. It was time to address my hepatitis C. My count started to get higher and my platelets started to drop so I addressed my situation then, in September 2011.

**HRC:** *Can you tell me a little bit about your experience with hepatitis C treatment?*

**B:** Well, being that I didn't have insurance – I lost it when I retired – I qualified for a program called HepCAP<sup>1</sup>. At that time, when I got into it, I was the only patient on a methadone program with hepatitis C that was approved. I had HepCAP to take care of my medical needs – my biopsies, blood work, medications, seeing my doctors, etc. So that was a very big issue. I felt pretty proud and happy that I could do this, and maybe open the door for other people with no insurance, so I wanted to give a good show for it. I put everything that I possibly could into my treatment and I wanted to take it seriously.

I have a very good relationship with Irene. I've known her for over 10 years. She always wanted me to take the treatment, but I always had to work or was busy and couldn't do it. The treatment, the doctors *and* the staff are all part of the support group. The support group itself, I'm very happy with it. I was never really too comfortable going to any kind of support group in the years. I was using drugs from the 1960s up until, well – for a long time. I used to have all sorts of therapeutic groups and group encounters and I never went to them – I didn't like going to them. But when I came here and most of the people were my age and we were all in the same boat being on methadone, and it was all being handled through the clinic, I felt more relaxed. I was able to open up and feel safe that I could talk my problems out, if I had any problems. Or, I could help

somebody else. I was always there to give somebody a good word if they needed it or needed information.

**HRC:** *When treatment gets hard, what keeps you motivated to continue?*

**B:** Just staying healthy, addressing the issue, and getting it done. Like I said, I made a very big commitment to myself and I just look in the mirror and say, 'Bob, if you want to be around another 10 years or so, 20 years, address this now.' So far it hasn't gotten to the point where I've had to walk off treatment like I've heard other patients have. The side effects have been minimal. In the beginning they were a little rough, but after 5 or 6 weeks I started to feel better, and then after 8 weeks I was symptom free.

**HRC:** *Did you get a biopsy?*

**B:** Yeah, I got a biopsy in early September. That was a trip. It's a whole other story. The day I was scheduled for the biopsy we had a hurricane, Hurricane Irene – that's my doctor's name. I had to cancel it because I couldn't get into the city. So I rescheduled for the following week and through hepatitis C counseling here, they were able to get me an escort – somebody I knew for a long time, somebody from the fellowship here, and I had no problems. The staff was nice, the hospital was nice, the nurses, doctors – everybody was fine, I had no problems.

**HRC:** *How has your mental health been throughout treatment?*

**B:** Pretty good. I get a little bit irritable at times. Depression – not so much. I don't really think I'm depressed, just a little anxious. I went through a period where I thought I might need some kind of sedative or something but I went against it and decided to just knuckle it out and address it.

**HRC:** *What would a cure or a sustained viral response mean to you?*

**B:** It would do a lot for me just to feel healthy again because I am getting older. I'm 61 – it would definitely be a boost for me. I'd feel 100% better not having the cloud around my head that I have hepatitis C or that my liver is damaged. I could even address other health issues I have or just try to stay as healthy as I possibly can.

**HRC:** *What is one message would you like to give other people living with hepatitis C who are thinking about getting treatment?*

**B:** Go through the treatment – take it. No matter what it takes, no matter what you hear about side effects, do it – because it's a step in the right direction. There's always another medication you can take to combat the side effects, there are support groups, and why live with the possibility that one day you might not even be able to go through a biopsy because you're just beyond help.

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## JEANNETTE

*Jeannette is 54 years old. She first found out that she had hepatitis C in 1999. She successfully cleared hepatitis C after 48-weeks of treatment with interferon and ribavirin in 2009.*

**HRC:** *Can you tell me a little bit about your experience with hepatitis C treatment?*

**J:** Well when I found out [I had hepatitis C], I wanted to get treatment. It didn't bother me, but I wanted to get it over with. So when I did the treatment, I was great – no side effects, no nothing. I got hepatitis C through a blood transfusion, that's how I caught it in the '80s.

I think the support was useful – the group therapy. We would always look

forward to group. Every week we would look forward to that. My doctor was Irene – she was good. I don't have any complaints. The treatment was good – I'm still trying to tell people about it now, to get treated. I didn't have any problems with nothing (*laughs*)! I used to ride bikes while I was in treatment.

**HRC:** *You started treatment 10 years after you were diagnosed?*

**J:** Right. I was trying to start treatment for a long time before that but I didn't have insurance, so that's why I did it when I did.

**HRC:** *What message would you like to give people living with hepatitis C and who are thinking about starting treatment?*

**J:** That they should get treated for one. And two, that not everybody's the same. Like for me, I didn't get any side effects, but not everybody's the same. But I would want everybody to get treated...to go through with it. Just do it.

**HRC:** *What is a message you'd like to give doctors who treat people with hepatitis C?*

**J:** The only thing is patience. They should also learn more about it.

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## FERNANDO

*Note: Fernando's primary language is not English. Some minor editing has been made for clarification of his comments. Whenever possible, the text has been left unedited.*

**HRC:** *How old are you and when did you find out you had hepatitis C?*

**F:** 34 years old. The first time that I used drugs and needles I knew I would be infected because I was living in Puerto

Rico. Puerto Rico has a lot of problems and dangers for hepatitis C. I think 90 or 95% of people at risk in Puerto Rico have hepatitis C. My first time using needles, I used with a friend and I enjoyed the drug with him using the same needle. I knew he was infected, but I had a problem with the drugs and I wasn't thinking [about hepatitis C], I was thinking, *'I'm sick and I don't want to feel bad.'* So, the first time I injected I know I was probably [infected with HCV], but I took a hepatitis test about one year later, when I was maybe 26 or 27 years old, and I was positive.

When I found out I was positive, my family tried to find out where I could take the treatment, but in Puerto Rico I needed insurance to cover the treatment. It's very expensive and I couldn't take it there. Years later, I got into a treatment program for the drugs. I have one daughter and I want to see her grow, and I don't want her to see in me a bad example. I needed to change my life so I made a decision to come to New York to try and change my life. But I don't have family in New York and at first it was difficult for me. I've been in New York for 6 years. It difficult, but now I can do it because when I stay here, I am clean. I had one year clean, but then I started to use drugs again. I lost my job. Later I got on a methadone program. In the methadone program I was told that I am positive with hepatitis C and they asked if I want to take the treatment. I said yes, sure. I took the treatment for one year and it has been one year and half since I am done with the treatment. During the treatment, I felt good all the time. I didn't have any side effects. The treatments were good. After the first three months they checked my viral load and I was undetectable. Before the treatment, my viral load was 7 million plus, maybe ten million, 12 million, I don't know.

**HRC:** *What does it mean to you to have cleared hepatitis C?*

## Hepatitis C Support Groups For Drug Users

### FACILITATORS MANUAL

This guide was developed with the collective input of syringe exchange participants and service providers actively involved in hepatitis C support groups throughout New York City. The guide offers facilitators practical suggestions and creative tools for managing support groups with current and former drug users. Available in English and Spanish at [harmreduction.org](http://harmreduction.org).

**F:** I am feeling good because it's a new opportunity for a longer life.

**HRC:** *If there was one thing that you wanted to say to people who are thinking of starting hepatitis C treatment, who were maybe unsure, what would you tell them?*

**F:** Not to be scared. I recommend everybody who has hepatitis C take it because it is the opportunity for a longer life, not everybody has the opportunity. In Puerto Rico many people don't have the opportunity, I got lucky that I stayed here and I took the treatment. Many people want to take it, but can't because they don't have the money or don't have something.

**HRC:** *Is there anything else you want to make sure people know about hepatitis C or hepatitis C treatment?*

**F:** I want to say, go to the doctor. This sickness is very silent. It's that silent sickness. You may be sick and after 20

years, maybe it's too late. No matter if you are using drugs, maybe you have sexual contact or whatever, you might be sick. Everybody – everybody needs to take the test, to verify how you are. If you are positive, don't be scared.

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## RICHARD

*Richard is 47 years old. He found out that he had hepatitis C in 1994 and later cleared it with ribavirin and interferon.*

**HRC:** *When, and for how long, did you take treatment?*

**R:** I started treatment [for the first time] in about 1999. I took it for four months and couldn't handle it so I stopped. I got anemia and, without supervision or blood work or groups, I couldn't handle it so I dropped out. Then I met Irene and she had a group that I liked a lot because it helped me cope with my mental health and my anemia – because I used to get the suicidal thoughts. The group helped me out with a lot of the problems I was going through – from depression, to itches, to the anemia, down to my bowel movements. [Treatment] was horrible, but I stuck through it. Right now I'm undetected and I really was one of the patients that had everything on the list of the illnesses. But, I stuck through it and knew I could manage it. It was harder for me without the support group.

**HRC:** *So the treatment was successful?*

**R:** Yes, I'm undetected. I'm also HIV positive. They're both undetected. It's hard to take all those pills and be undetected. If you're not on the right regimen, and you don't have groups to help you out, it's very hard to keep off both HIV and HCV because there are so many pills. I'm proud of myself because I made it through both treatments. They're going to check my

blood in 6 months to make sure the hepatitis C doesn't appear again.

**HRC:** *Can you talk more about your experience with hepatitis C treatment?*

**R:** I kept putting [treatment] to the side. Irene came and she asked me, but I kept ducking her because I had a bad experience the first time. But I said I can't be with this pain all the time – I wanted to do something about it so I could continue living. I decided to get back on treatment and finish it.

When I first started I was skeptical, like, "I don't wanna' do this, I don't wanna' do none of this!" I knew it was going to be a lot of time and effort. I was scared. I didn't think it was going to work. But if I *could* do it, I could help somebody else to do it – that's what I got out of it most of all. There are a lot of people out there who say, "I'm not gonna do it, the medication makes me sick." I was one of them. I feel that the groups are very helpful – without the groups, I don't even think I'd do it. You need someone there to help you, to trade information on how you feel. For me, it got more out of me to help other people. If they were scared, I could show them that I've been through it and you shouldn't have to be scared. You've got peers that can help you go through it.

**HRC:** *You said when you started treatment you were skeptical of it. What made you take your medication?*

**R:** I'm HIV positive so it was easier for me. I was already on a schedule for my HIV medications, so it made it easier for me to take the HCV medications. I never missed any medication because I knew if I missed the HIV meds, it's not gonna work, so I felt the same way for the HCV medication.

**HRC:** *When treatment got hard, what kept you motivated to keep taking it?*

**When I first started I was skeptical, like, "I don't wanna' do this, I don't wanna' do none of this!" ... But if I could do it, I could help somebody else to do it.**

**R:** The groups, positive thinking, I got into exercising and cooking. I try to help people – that's one of my goals. If they have [HCV], I try to convince them that the treatment isn't that bad. But, you could get liver damage if you keep doing nothing about it. Mainly it's the positive thinking and especially exercising. If I didn't exercise I'd feel really shitty because of all that medication. It's not that easy, but if you motivate yourself, you can do it.

**HRC:** *What does a "cure" or a sustained viral response to HCV mean to you?*

**R:** It means a lot. It means longer living for me, healthy living. I need to take care of myself if I want to live longer, because before I didn't care about those things. It was also a mental health turn in my mind – I'm three years drug-free and it feels good.

**HRC:** *What is one message you'd like to give to other people living with hepatitis C thinking about treatment?*

**R:** It works. Don't be scared, because I've been through it.

### Notes

1. HepCAP is a program to provide care and treatment to uninsured individuals who have chronic Hepatitis C. The program is offered through the NYS Uninsured Care Programs. HepCAP does not pay for HCV medications, however HepCAP patients may receive their medications through medication assistance programs.

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## **HCV Empowerment Groups: Support, Education, and Advocacy**

ALAIN LITWIN, MD, MPH

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FRANK MEDINA

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*This handout was initially created for a presentation at the Centers for Disease Control.*

In a collaborative effort between methadone maintenance treatment program clients and staff, we have developed a multifunctional group of support, education, and advocacy. This group had a natural evolution which began with supportive and educational activities, and ultimately led to group advocacy efforts.

Initial educational sessions focused on the steps involved in pre-treatment evaluation of HCV including interpretation of hepatitis C viral load and genotype tests, and the importance of the liver biopsy. The group helped to destigmatize the liver biopsy and interferon-based therapy. The support component evolved through group discussion of individual experiences with the evaluation and treatment process. These verbalized experiences allowed the group to identify barriers in HCV evaluation. Consequently, the group became motivated to address these barriers through advocacy activities. The group also engaged in efforts to raise community awareness about HCV. These support, education and advocacy groups empower clients have a voice within their own treatment programs and in the community. Furthermore, these groups have the potential to influence adherence to treatment as participants share their

individual successes in the HCV evaluation and treatment process with the group and these verbalized experiences become powerful motivators for others to engage more actively in their own treatment.

### **Components and Development of HCV Empowerment Groups**

**Group facilitators:** Our group was originally facilitated by two clinic staff members who had a clinical relationship with most of the group members. While this need not be an essential aspect of the relationship between the group facilitator(s) and the group participants, the clinical relationship can be a powerful component in these groups. Positive feelings (e.g., of support, healing and safety) in the clinical relationship may promote the transfer of similar expectations to the group setting. These positive feelings encourage clients not only to consider a first meeting but also to remain actively involved in these groups. Facilitators serve different roles in the group: They clarify misconceptions about the disease and treatment; promote a sense of safety; reinforce educational messages and supportive behaviors among members; and help identify supportive partnerships. The facilitator serves as a role model for members as they emerge as co-leaders. Over time, clients will emerge as co-facilitators.

**Raise awareness of HCV in the clinic or program setting:** HCV is the leading cause of death in our clients, and is a potentially reversible disease. Beat the HCV drum! Discuss HCV at staff meetings. Post news articles, flyers, and informational materials in a dedicated area in your clinic and start a HCV bulletin board and literature rack. Create a formal or informal portfolio of interesting materials gathered by group members.

**Become an expert on HCV, even if you aren't one now:** A group leader must develop expertise on the subject: This means knowing enough about HCV to teach the basics and to help dispel myths about the disease.

**Identify leaders:** Every clinic has clients who have leadership abilities and experiences. Some are already recognized as leaders (e.g. Patient Advocacy Committee leaders); others will emerge in the course of meetings and projects. Opportunities to identify leaders include asking members to volunteer with the recruitment and orientation of new members, setting up and cleaning up the meeting space, speaking at and facilitating meetings. Encourage leaders to accompany patients who have less social support to medical procedures and make hospital visits. By acknowledging leaders for their work, others are motivated to step forward in leadership roles. A culture of self-help and education is developed.

**Link individual recovery and treatment to group goals:** Fighting back against the HCV epidemic is achieved when individuals make steps towards their own work-up and treatment: Acknowledge these accomplishments in the context of the group's evolution. The group progresses when an individual within the group progresses.

**Promote group identity:** Coming up with a name and mission statement as a group process will enable group members and clinic staff to take ownership of the group. Encourage members to design logo, flyers and slogans. Take a meeting to post a large sheet of paper on the wall, and write down mission statement ideas as they are expressed.

**Look for opportunities for advocacy:** Engaging in individual and group hepatitis c advocacy efforts can be a motivating force in itself, resulting

in patients addressing longstanding health and addiction issues with a new focus. Advocacy work can include local petition campaigns, staffing hot lines, information tabling. Simple advocacy projects can become pivotal movements within the community.

**Create a galvanizing event:** Find or create an event in your community that will focus the group's creativity, talent, and energy. Consider a local liver walk, fundraiser, street fair, petition campaign, picnic or conference: Creating a splash early on will heighten the groups profile, attract members and supporters, raise awareness of the issue, and create leadership opportunities. Group members will begin to think "out of the box" and interact in new ways. Patients who are not ready to confront their individual issues may be more likely to participate in a group event. It is also an opportunity to interact with like-minded groups, form alliances, and receive recognition and publicity.

**Advertise for your support group through multiple venues:** Create or recruit others to create attractive, informative and attention getting flyers. Flyers are necessary props; however personal recruitment is essential to bring in members. Enlist your core leaders in this task. Make sure announcements for HCV support groups are made at other clinic groups and activities. Interoffice email sent to staff announcing upcoming groups and asking for assistance in group recruitment.

**Every group is an event:** Attendance at meetings may vary, and if attendance dwindles it can affect group morale. Emphasize that every meeting is an event (even if two people attend, that meeting can precipitate life changing action steps) Emphasize positive aspects of all meetings, and share outcomes of previous meetings in future groups.

**Consider all administrative issues:** Work with clinic administrator, interceptors, and nurses to avoid disruption of clinic services. This is especially important when large groups meet and adjourn: Make sure staff time is protected so patient care does not suffer and solicit the support of fellow staff members for coverage.

**Document everything:** Keep flyers, attendance lists, newsletter articles, etc. documenting what you are doing: This is your group's history, and could be the basis of soliciting donations or grants.

**Create a HCV Peer Education Program:** Peer education naturally evolves out of the empowerment group. As group members become knowledgeable about key HCV issues and develop ways to communicate about these issues, develop a simple, but formal program to train peer educators. You can ally with other HCV organizations to deliver a curriculum leading to peer education certificates.

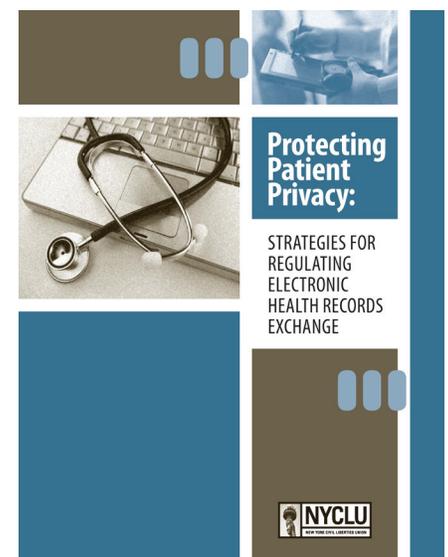
## Review: Protecting Your Privacy in an Age of Electronic Medical Records

ROXANNE SAUCIER

Imagine that a decade ago you went to counseling for your college drinking problem – today you've been sober for ten years. Now you're going to your dentist to get some teeth pulled. You don't think your drinking history is

relevant to your dentist, but because he has access to your electronic medical records, he can see information about your past passion for the hard stuff. You're worried that now he won't give you adequate pain treatment – what if he labels you as a "drug seeker"?

Or, say you shoot dope. You trust your primary care physician and confide in her about your drug use – she's great – she prescribes you naloxone to prevent overdoses and helps you with abscesses. Now you're going to an eye doctor because your vision isn't as good as it used to be. You think your drug habit should have no bearing on your eye exam, but you find out that your new eye doctor can see your entire medical record, including your drug use history and the therapy you went to



Download the report at [http://www.nyclu.org/files/publications/nyclu\\_PatientPrivacy.pdf](http://www.nyclu.org/files/publications/nyclu_PatientPrivacy.pdf)

years ago when your best friend died. Is it just your imagination, or is the eye doctor acting gruff and unfriendly?

These are the types of issues that the New York Civil Liberties Union raises in their new report *Protecting Patient Privacy: Strategies for Regulating Electronic Health Records Exchange*.

Today, medical records are going electronic all over the country. Hard copies of doctors' charts and electronic charts stored in individual doctor's

**NYCLU cautions that if patients don't feel like they have control over what information is shared, they are less likely to feel comfortable being frank with their doctors about issues that carry stigma.**

computers are being converted into a comprehensive network of integrated, searchable databases. The NYCLU report focuses on New York State, but the ultimate goal of policy makers is to create a health information network that links records across the nation—and the concerns the report raises are relevant to electronic systems across the country.

As the report points out, there are benefits to our medical records being kept electronically. Our many providers have the potential to better coordinate the care they give us; there could be fewer medical errors and misdiagnoses; and in many ways it's more convenient. The downside is that the current system doesn't allow enough patient control.

It used to be that you could decide if you wanted to authorize your doctor to get copies of records from specific providers – or even to tell your

doctor about other providers in the first place: Your podiatrist didn't have to know that you see a therapist or that you had an abortion. And when sending your records to your podiatrist, your primary care doctor was able to copy only the relevant sections. This isn't the case in New York State's "all or nothing" approach to electronically sharing medical data.

NYCLU cautions that if patients don't feel like they have control over what information is shared, they are less likely to feel comfortable being frank with their doctors about issues that carry stigma. They're also more likely to opt out of the electronic medical records system – or refrain from seeking health care at all – due to these concerns. This would be unfortunate, because it would mean that people with the most privacy concerns will likely be underrepresented in data compiled to analyze public health – which could in turn mean flawed assessments of public health problems – and potentially less funding for actual needs.

The report provides ten recommendations to reform the system, and the NYCLU continues to advocate for these policy changes in New York State. In the meantime, here are a couple things you should know:

When providers join what's called the Health Information Exchange (HIE), information about each of that provider's patients is automatically linked to a search system that permits others who have access to the network to identify patients in the network. (Others with access may include labs that process medical tests, the hospital system where your doctor works, the hospital's record management company, and your insurance provider). Identifying information might be demographic (like an address) or it could be a unique patient identifier. Your informed consent won't be sought at this stage. You should ask your providers if he or she is already

enrolled or plans to enroll in one of these exchanges.

Your informed consent *will* be sought before other providers can access information about you in the HIE if you are in New York or a state with a system like New York's. You will be presented with a consent form saying that you agree to allow that provider to access your medical information. But beware – that release form is often provided with all the other paperwork you fill out when you arrive at a doctor's office, so it can be easily overlooked. If you don't want to share everything in your medical history with that provider, you can decline to sign the form. If your doctor pressures you or tells you that he or she won't provide you with treatment, you should complain to your local department of health or contact your state's ACLU chapter.

New York law allows adolescents to seek certain treatment (like reproductive health care and mental health treatment) without parental knowledge or involvement. Many health information exchanges completely exclude the medical records of minors between the ages of 10 and 18, because the current systems aren't nuanced enough to shield this protected information from parents who wish to obtain their child's medical record.

For more about New York State's current system and recommendations for reform, read the full report at [http://www.nyclu.org/files/publications/nyclu\\_PatientPrivacy.pdf](http://www.nyclu.org/files/publications/nyclu_PatientPrivacy.pdf).

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*Roxanne Saucier is a consultant working on advocacy for harm reduction and human rights of people who use drugs. She is a former program officer at Open Society Foundations' International Harm Reduction Development Program.*

# From HIV Treatment Champion to HCV Treatment Pioneer

An Interview with LYNDA DEE

*It's an exciting time for hepatitis C treatment. New medications have already increased treatment success rates and it's very likely that within just a couple of years, interferon-based HCV treatment will be a thing of the past. It's not at all unrealistic to say that a cure for HCV (... a cure for all, not just some) is on the horizon. Pharmaceutical companies are conducting clinical trials with non-interferon-based therapies and as they move into Phase 2 and Phase 3 of their trials, there will be more opportunities to get involved sooner rather than later, especially if you're hooked up with care at a good university-based hospital. For those who would rather wait until after FDA approval of the new medications, it may still only be 2-3 years out.*

*Lynda Dee is a long-time AIDS activist who found out that she was HCV positive about 6 years ago. She knew that interferon-based treatment wasn't for her, and she also knew that if she looked in the right places, she could get hooked up with a non-interferon-based clinical trial. After doing her research to find the protocol that made the most sense for her, she began a 24-week clinical trial with Pharmasset 7977 (a nucleotide analog polymerase inhibitor) and BMS [Bristol-Myers Squibb] 790052, (an NS5A inhibitor). She cleared the virus after 21 days and is still undetectable today — 36 months later.*

*I talked to Lynda about her experience with the new drugs.*

— Emily Winklestein, Editor

**EW:** *You have a unique perspective — having been outside of the clinical trial world [as an AIDS advocate] as well as having your own experience now with the new drugs. I'm curious to hear your thoughts — what do you think is most important for people to know about the new drugs based on that unique perspective?*

**LD:** Let me just give you a little bit of background. I've been an AIDS activist for about 25 years, and I am very familiar with what people with HIV go through — what's going on with clinical studies, changes in trial design and

dealing with the FDA, NIH and all the drug companies. So, when I got into HCV advocacy — I had years of experience and it really isn't that much different. Obviously, there are scientific and funding differences, but dealing with a drug company and dealing with the government is about the same. Unfortunately, we have not been able to get a lot of government funding for HCV. That's a huge difference.

Anyway, I "had" HCV. I was diagnosed about 6 years ago. I was an intravenous drug user in my late teens, early twenties and I stopped doing drugs more than 30 years ago. I mean



in those days — I'm 59 years old now — we just started to hear about non-A, non-B hepatitis. I did contract hepatitis B within in the first six months of using IV drugs — just like most people did. But I was 18 years old, so I cleared it pretty quickly. Years later, I tested negative for HIV. So, I thought I had dodged a bullet, especially since my husband died from AIDS complications in 1987.

I'm a pretty strong dog — I didn't have any issues with my hepatitis C, *until* I was diagnosed with cancer in 1996. My ALTs were elevated, not terribly, but they weren't right. I was on

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chemotherapy and I had had prior liver disease, so nobody really thought anything of it. I think that my own body probably would have kept the HCV in check if it hadn't been for the chemotherapy. But who knows?

I've been in remission since 1996 but I never got stronger – I never really got back to my old self. I would go to the doctors and they knew my history; I would complain that if I did a little bit of exercise by mid-day I'd feel like I had a fever, really sick and all wrong – where was my stamina?

Finally, after years of complaining – you know, they don't pay attention to women especially when you talk about being tired and not feeling right... and, if you had my schedule, you'd be tired too...but, this was different than a good, honest tired...this was feeling sick from doing the same amount of exercise that I had been doing for years – so finally, quite a few years later, my primary care doctor finally tested me for hepatitis C and there it was! I was like, "I can't believe this!" I really thought that I was in the clear.

I had breast cancer. And while I was an HIV advocate, I didn't know anything about cancer. I read as much as possible in the short time I had to make decisions. I was a community advocate for NCI's ECOG (Eastern Cooperative Oncology Group) after my treatment, just like I was in the ACTG (AIDS Clinical Trials Group). But I really wasn't well informed before my treatment, and with cancer, you've got to

be treated right away. You can't fool around. And what I learned about my treatment, I learned that the hard way. Because I didn't have the time to get to know what I was able to learn about HCV, I ended up with probably too much chemo, too much radiation and definitely too many lymph nodes removed. I decided that this would never to happen to me again. Of course, I can't reiterate too strongly that you may have the luxury of more time with HCV to get to know what's up, and you really don't with cancer. Nevertheless, I learned a very valuable lesson.

I got involved with HCV advocacy not long after I was diagnosed. I learned about the new drugs and I was certainly interested in the new HCV pipeline. I learned about the many interferon side effects. I always say that if I got any more anxious or depressed, I would be out in the street with a machine gun! Interferon was not for me! I am not right to start with. I believe that most people that use drugs with any frequency have chemical imbalances. They're looking for something to make them feel right. From what I learned, I knew that interferon would make me feel all wrong while I was taking it and that I would probably continue to experience anxiety and depression even once treatment was completed.

I made sure that I educated myself. Luckily, I was very plugged into both HIV and HCV advocacy; and luckily there has been an explosion of new HCV drugs. So I got myself to Hopkins. They saved my life when I had cancer – and my advice to everybody is to get yourself to a university-based hospital, the best one you can find in your vicinity. Their doctors are really more cutting edge and if you can get to an infectious disease doctor who knows his/her stuff instead of a hepatologist, you might be better off. Many ID docs are much more used to dealing with our communities, and they're

not so pompous. Many hepatologists think they know best, don't entertain patient questions well and don't see the value of patients being engaged in their care. Of course, that doesn't go for every hepatologist in the world, I'm generalizing here. I think they're just not yet used to dealing with patients in the same way HIV experienced infectious disease docs are. Believe me, the ID docs thought we were from Mars in the very early days of the HIV epidemic.

My advice to people is this: if you have access to a university hospital based infectious disease doctor or group that's experienced in HCV care, knock on their door! I think Hopkins has a great model in that they don't refer you to a hepatologist unless you're in need of a transplant. Hopkins has a lot of experience in dealing with people with HCV infection and with people who are also co-infected with HIV.

By the time I started looking for HCV protocols, I was really ready to start treatment. I had literally gotten to a point in my own saga that I was thoroughly exhausted most of the time. After doing even 5 to 10 minutes of exercise, I felt sick. I couldn't walk up a flight of stairs without huffing and puffing like I was 90 years old, and my memory was gone. I couldn't remember anything and I've always prided myself on having an excellent memory.

Before enrolling in a protocol, I did my homework. I found out what interferon sparing regimens were available. I knew many people in both the HCV scientific and advocacy communities, including a Pharmasset doc who told me all these fabulous things about PSI 7977, then owned by Pharmasset, now owned by Gilead and now known as sofosbuvir. But you have to take what industry says with a grain of salt because they love to use you to promote their drugs. I looked into the data, talked to my doctor and the principal investigator of the study at Hopkins, both of whom I knew well and trusted. I was able to find information online and

discussed it with other HCV activists.

I decided on a combination protocol that included sofosbuvir, which is a nucleotide polymerase inhibitor, and BMS [Bristol-Myers Squibb] 790052, now known as daclatasvir, which is an NS5A inhibitor. They're once-a-day drugs and they barely have any side

**My advice to people is this: if you have access to a university hospital based infectious disease doctor or group that's experienced in HCV care, knock on their door!**

effects compared to the current three drug combination standard of care, interferon, ribavirin plus one of the recently approved protease inhibitors, Incivek® or Victrelis® – though I did have some side effect issues and I'll talk about that in a minute.

Interestingly, my trial design was the same design we championed for heavily treatment-experienced HIV patients. I ended up benefiting from my own work. It was an amazing feeling and still gives me goose pimples. I'm very grateful to have had access to such a progressive protocol. Everybody received new drugs. There was no placebo control. The trial was not blinded, so we knew what we were taking from jump street. We also received our viral load results in real time. Initially, the protocol required me to be at the study site every day for the first two weeks. After two weeks my visits were bi-monthly, then monthly. It was a real commitment, but I got access to these new drugs 3 or 4 years before FDA approval and wide availability to the public. It was well worth the effort.

One arm of the study included sofosbuvir monotherapy for five days with daclatasvir added thereafter. The

second arm included both drugs taken together at study initiation. The third arm added ribavirin to both drugs from the onset. Patients in all three arms received drugs for 24 weeks. I was really wringing my hands about whether or not I should take just two drugs if I got randomized to that arm? Were two drugs going to be enough? We know a lot more now than we did when I started the protocol. I had a doctor friend who was willing to give me ribavirin under the table if I wanted it.

But after reviewing the data, I saw the slope of decline in HCV in both sofosbuvir and daclatasvir and I thought, "I think these two drugs together can do the job." I talked to HCV community advocates and the Protocol Chair. He said that he thought the one drug was the real deal and it was just a question of what it should be combined with. He thought these two drugs would be sufficient and that the real question was whether 12 weeks or 24 weeks of therapy was necessary to eradicate HCV. So, I felt confident enough to proceed without using ribavirin. And, I didn't want to cheat. I agreed to participate and I really wanted to stick to my part of the bargain. That being said, I must admit that I was also very confident that these two drugs would do the trick.

As luck would have it, I got randomized to the two-drug arm and didn't have to suffer through any ribavirin side effects. I had a 4 million viral load count when I started the protocol and was undetectable in 21 days! I have been undetectable ever since, both at week 24 and 36 after completion of treatment.

**EW:** *Wow – that's incredible!*

**LD:** Incredible! I have Genotype 1A, which is the hardest to cure and a CT polymorphism, which is not the worst, but it doesn't usually respond well to interferon. Because of these factors, I was afraid that the two drugs wouldn't

be enough – but here I am, cured! Now, the sofosbuvir Genotype 2 and 3 Phase 3 trials are 12 weeks in duration. Gilead hasn't decided yet what to do for the Genotype 1 trials, they're waiting for more data to decide whether the length of the Phase 3 trials will be 12, 16 or 24 weeks.

As far as side effects are concerned, for the first two months, it was like taking nothing! I mean, nothing was wrong with me – and I get everything. I'm a slow metabolizer. Drugs usually work well for me, but I get every side effect known to man. And I mean nothing, nothing happened to me! Then, after about two months I started to get dizzy – and I don't mean dizzy like when you get up from a chair– I was *really* dizzy. I travel a lot for work. Once when I was traveling, I was late and tried to jump into the shower and almost fell. The room felt like a swinging pendulum, everything was going sideways. It was really scary. I ended up taking Dramamine®, the drug they give you for motion sickness. I tried other drugs first, but they made me really drugged out. Dramamine® wasn't as bad because I could cut it in half. But I was still drugged out and for two or three months I was miserable. It was like being hung-over. I thought, "I'm getting off this Dramamine®."

When I did stop taking the Dramamine®, I felt better immediately. I think the Dramamine® might have been worse than the protocol side effects after a while. The dizziness seemed better – I wasn't seeing that horrible swinging pendulum. And I noticed that I felt worse when I was traveling, when it was much harder to take good care of myself.

Anyway, I got through it. The last month, mercifully, I didn't have to go out of town. I was really glad to be finished with the trial. Because it was the phase 2 trial, I was required to show up very frequently and to have a lot of blood draws, EKGs and physical exams– which is nothing really, when

you think about the requirements of some HCV protocols. I didn't have to get a biopsy. I had access to amazing new treatments years before FDA approval. All things considered, when you think about interferon regimens, this regimen was a breeze! I didn't miss a day of work. And I'm cured after only 24 weeks of once a day treatment!

**EW:** Yeah, it's really incredible! Can you speak a little about the implications around access for people who use drugs, in particular, moving forward?

**LD:** I think it will be good for a number of reasons. Number one, interferon makes you feel like you're jonesing – who wants to feel like that? And, you're using needles – using a needle is also like a bad flashback to the past. So, I mean, hello...? If you have those old tapes in your head, you could be right out again. Just having to use a needle is bad enough without also feeling like you're jonesing. That prospect really scared me. I mean, I haven't used intravenous drugs since the 1970s, but when I smell a match – OK, I know nobody uses matches anymore, but when I even think about the smell of a striking match, the process of injecting drugs immediately comes to mind. I can only imagine what it would feel like to have to use a needle once a week for 48 weeks, number one, and number two the thought of jonesing is as vivid in my mind today as it was 30 years ago. I didn't want to get anywhere near it, let alone all the psych side effects – anxiety, depression and all the rest. Who needs to be all mentally out of sync when you're sick as a dog to boot, from the other side effects related to the current standard of care?

I think the implications for people that use or have used intravenous drugs – or any drugs for that matter – are huge. I mean, I've been in the program<sup>1</sup> for 20 years and I've watched people come in and out of the rooms. I would venture to say that 90% of

them are probably bipolar to some degree. When you think of the mental and physical side effects you will experience for as long as 48 weeks on the current standard of care, the new drugs are amazing. It's really unbelievable! Real progress!

**EW:** It sounds like a world of difference. Do you think FDA approval is two years out?

**LD:** Well it could have been. But Gilead bought Pharmasset and is now refusing to continue to study daclatasvir with sofosbuvir. Both drugs will be approved individually. But the combination has only been studied in 44 people with Genotype 1. All 44 were cured- that's a 100% SVR rate! Nevertheless, insurance companies might refuse to reimburse for the combination and doctors may want more patient data before prescribing

**People are going to have to look out for the best trials available for them and jump on them once they have carefully considered their options and the study drugs as well as the study design.**

the combination. It's a real nightmare. Gilead promised the community that they would continue to collaborate with other companies. They have gone back on their word so that sofosbuvir can be combined with a line-up of all Gilead drugs instead of drugs owned by other companies. They are going to clean up! God knows what they will charge for the all Gilead combination! If their HIV prices and price increases are any indication, we are in for a real Gilead greed game. And now everyone has to wait at least an additional year to have access to interferon sparing, sofosbuvir containing regimens because of Gilead's greed. A lot of really sick people who don't have the luxury of waiting a year will now have

to be subjected to using the current standard of care with all its horrible side effects. It's not like there aren't thousands and thousands of other patients who will have time to wait for the all Gilead combination. It's really sickening! Gilead CEO John Martin is already a millionaire many times over. When is enough, enough!

**EW:** What do you think what about any potential insurance and payment issues for widespread access?

**LD:** Well, once these drugs are approved, they will be accessible to some. But the degree of accessibility depends on the cost of the drug. The new healthcare insurance trend is higher premiums and co-pays with less coverage. If these drugs are priced too high, accessibility may be a real issue. Insurance companies may institute prior authorization requirements.

That means you and your doc may have to jump through a lot of hoops before you can actually get the drugs. I am a member of the Fair Pricing Coalition. We do our best to make the companies price drugs "reasonably", whatever that means! But, in our country, companies are allowed to charge what the market will bear – and until the whole system blows up, that's what is going to continue. Gilead is one of the worst offenders, taking the highest and most frequent price increases of all the HIV drug companies and recently pricing its new HIV 4-in-1 drug combination off the charts. If their HIV pricing history is any indication of how they will act in the HCV arena, we're in for a lot of trouble. Until

the government is ready to deal with the excesses of the pharmaceutical industry, this is how it is going to be. Most of our elected officials are bought and paid for—and the pharmaceutical industry is one of the highest bidders. It's really disgusting.

But — the good news is that many interferon-sparing protocols are available, and that's another good reason to get hooked into university-based care where most of the trials are conducted. People are going to have to look out for the best trials available for them and jump on them once they have carefully considered their options and the study drugs as well as the study design. Not all trials are as progressive as my trial. I've been in a lot of meetings with a lot of different HCV companies. We all know that there is a flood —of these new drug combinations. Many are interferon-sparing regimens — and everybody knows there are *thousands and thousands* of people who are just waiting for these regimens to become widely available. We're beating on the companies to try to get them to provide early access, for people with extensive liver damage who can't wait till 2014. The good news is that hepatitis C is slow moving and a lot of people will be able to wait for the new interferon sparing regimens. Unfortunately, many cannot wait and will need to use the horrible current standard of care in the meantime.

**EW:** *What do you think harm reduction organizations can do to support people who are living with hepatitis C around treatment and getting more involved with advocacy?*

**LD:** Well, the bottom line is: information is power. If you don't know the facts, you could be stuck with some podunk doctor who doesn't know what's up. You could be advised to treat now with the rotten current standard of care, when in fact, it might be perfectly reasonable for you to wait

for the new drugs if you are carefully monitored in the interim.

I am also Co-Chair of the Maryland Hepatitis Coalition and you know, we're in the trenches and it's very hard to get people engaged — it's not like HIV, it's not as desperate a situation for many people. So many people are disenfranchised and from underrepresented communities. But that shouldn't stop anybody. Everybody has problems and issues. Get out there and help yourself and others! Some of us are old and tired and have been doing this for years, and we need help from the many people who are just hanging out and wondering, "Well, what should I do?"— Get informed and get your ass to work! That's what I say. I'm the "just do it" girl. We could use some help and the way to help is to learn and to get involved.

**EW:** *What avenues would you suggest for people who are reading this and want to get involved in HCV advocacy?*

**LD:** First, get informed. There is so much information online. Check out [natap.org](http://natap.org), [hcvadvocate.org](http://hcvadvocate.org), HIV and Hepatitis.org and [treatmentactiongroup.org](http://treatmentactiongroup.org). The National Viral Hepatitis Roundtable is a great viral hepatitis national policy organization, advocating for people with both HBV and HCV. Check out their website at [www.NVHR.org](http://www.NVHR.org). Or get involved locally. I know there are a lot of local hepatitis organizations that would love to have people help them do so many things.

Every year we get involved with the Maryland State Legislature — this year we going to try and get a testing and counseling bill passed. We don't even know how many people have hepatitis! Get tested — and urge your friends to get tested so we know how many people are actually infected with HCV. We have no idea of the actual number and how much money to ask for — not that there is a lot of extra money floating around. But if we knew the actual prevalence of HCV, we would have a

stronger argument for more money for care and treatment.

Get involved nationally or locally and if you like it, then stick with it — that's what I did. I got involved in HIV locally and thought, "Wow, I'm good at this, I can do this, I can be helpful" and here I am 25 years later — having learned so much about national policy, drugs and drug pricing, clinical trials and all the rest. I didn't learn it all in one day, I wasn't this fierce on day one, but it will happen, one step at a time.

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*Lynda Dee is an HIV and HCV activist and was a co-founder of AIDS Action Baltimore in 1987. She works with academia, industry and government to expedite ethical drug development, to provide access to life-saving medications before approval and to ensure reasonably drug prices and price increases.*

*Ms. Dee has served on national and local HIV and HCV boards and committees. She has been a member of various FDA Antiviral Drugs Advisory approval panels and has been a member of many NIH Advisory Boards, including, NIAID, the Office of AIDS Research, and the NCI. She has also served on many HIV and HCV industry community advisory boards and has been a member of many community organizations, including the Treatment Action Group and the Hepatitis Community Advisory Board. Ms. Dee is also a current member of the HIV and HCV Fair Pricing Coalition, the AIDS Treatment Activists Coalition and the Maryland Hepatitis Coalition.*

#### Notes

1. Alcoholics Anonymous/Narcotics Anonymous

# Violence and Sex Work in North Carolina

Interviews with North Carolina Sex Workers

TESSIE CASTILLO  
AND ROBERT CHILDS



Former sex worker Nyjhiee "Juicy" Mugler, in the video, *Former Sex Workers and Advocates Talk about Condom Use*, produced by NCHRC. Available online at: [vimeo.com/49649959](https://vimeo.com/49649959)

Sex work is a risky business, particularly in the South where stigma abounds and resources for sex workers rarely exist. In the South, sex workers have few opportunities for economic liberation, a high incidence of violence, and greater risk for diseases such as HIV and hepatitis C. Condoms are not as prevalent due to moral stigma against "safe sex" and "helping prostitutes," and violence prevention mechanisms such as bad date lines only exist in limited areas. But despite risks of violence and other dangers, men, women and people of transgender experience continue to enter the sex industry for different reasons. In this

**Setting aside any moral discussion on whether sex work is "right" or "wrong," we cannot deny the basic humanity of sex workers.**

article we hear the stories of several North Carolina sex workers, including April and Stephanie, two women who entered the trade because of drug addiction. Then there's Jennifer, who started sex work due to the difficulty of finding traditional employment as a transgender person, and Hawk, a

former male sex worker who got into the industry for its economic benefits. Lastly, Jill was forced into sexual slavery as a teenager, and then decades after she escaped, returned to the sex industry due to rising medical bills and economic hardship.

The stories of each of these sex workers are numerous and diverse; they come from different socioeconomic backgrounds, different genders, different life experiences, and they entered the sex industry for very different reasons. Some view sex work as a positive experience, others wish they had never started. Yet there is a common thread that unites them all, one of vulnerability to violence. Due to the illegality of the sex trade, as well as the stigma against it, violence against sex workers often goes unreported and unpunished. All but one of the sex workers interviewed had experienced extreme violence: rape, stabbings, beatings, even slavery, and each one described the difficulty, or even impossibility, of reporting such events to the police or seeking treatment at hospitals.

Setting aside any moral discussion on whether sex work is "right" or "wrong," we cannot deny the basic humanity of sex workers. They too should have the right to a safe

existence free of violence and fear. And though it is often difficult to understand sex work, why people do it, and how they survive, there is a desperate need for public awareness, as violence and murder continue to abound against those who have few legal or social protections.

## Getting into Sex Work

People get into sex work for lots of different reasons. April, a 29-year-old sex worker from Durham, North Carolina, started at 25 because of a drug addiction. "I was addicted to lots of shit, mostly dope," says April. "I made money boosting (stealing) clothes, shoes, makeup. I'd walk into a store, take anything I wanted and pepper spray anyone trying to chase me. One night I was at a hotel with a friend when he told me about backpage.com [Internet site for escort listings]. He said 'You wanna make some real money?' and I did because I needed more dope. I made a lot of money off Backpage. Guys like me because I have red hair."

April's story of drug addiction leading to sex work is common, and also shared by Stephanie, a former sex worker from Asheville, North Carolina. "I started sex work through addiction to crack cocaine," she says. "It was not

a choice to do sex work. I can remember the first time a drug dealer told me he would give me a crack rock if I would have oral sex with him. I remember thinking, 'I don't want to have oral sex with this dude,' but I did want his dope, so I did it with every ounce of me."

Other sex workers turn to the industry primarily for economic reasons. Explains Hawk, "With gay men some of them go through a stage where they end up working in the [sex] industry, especially when people are thrown out of their homes or [separated] from their families... that is sometimes the easiest way or the only way to make the kind of money they feel they need to live in an urban environment."

Jennifer also went into the sex trade for economic reasons, though her experience was very different from Hawk's. "I am a trans feminine person who transitioned early in life," says Jennifer. "I started [sex work] basically to survive... my legal name [didn't always] match up with my presentation, so finding a job was very difficult and [sex work] turned into side money until I figured out I could support myself with it."

Sex work has been in the news a lot lately because of the increase popularity of the anti-trafficking movement. However, as Jill can tell you, there is an enormous difference between forced sex trafficking and consensual sex work. "I started out as a sex slave," says Jill. "One day I was in the mall and this gorgeous guy walks up to



Sex worker and advocate, Jill Brenneman in the video, *Sex Worker Violence Prevention*, produced by NCHRC. Available online at: <https://vimeo.com/37758509>

me. He looked like my teenage crush Lindsey Buckingham, lead singer of Fleetwood Mac. He came up to me and sweet-talked me... he picked out that I was a homeless runaway, that someone must have hurt me, and he was very sympathetic... He told me he ran an entertainment agency and that I seemed intelligent and beautiful and smart... I jumped at the chance because I wanted to get off the street and work... he took me back to the basement of his house] and he raped me and hit me with some kind of whip hundreds of times... until I agreed to work for him. He told me I was going to work as a pain submissive, a pain slut."

After three years of slavery, Jill escaped when the trafficker was arrested on unrelated charges and rebuilt her life as an airline stewardess.

Then due to an expensive medical condition, she lost her job and her health insurance. "I went back into sex work in my forties... It came down to needing money for rent, so I posted on Backpage and started working as an escort, which was a very different scenario than as a coerced teenager because as an escort I can screen my clients and control, to some degree, my environment. I needed the money... I advertise in various venues and work for myself as an independent."

### **Trouble with Law Enforcement**

Sex work is a risky and dangerous job, but because of the illegal nature of the job, most of the sex workers interviewed said they couldn't go to the police when acts of violence were committed against them. Because clients or "tricks" know that sex workers are unlikely to go to the police, and if they do, police often don't believe them or report the crime, they can commit acts of violence, rape and even murder with little consequence. Also, prevailing societal attitudes and myths about sex workers such as "those people deserve it" or "prostitutes can't get raped" allow violent crimes to go unpunished while society turns a blind eye. As Hawk explains, "sex workers are not considered valued members of society so we

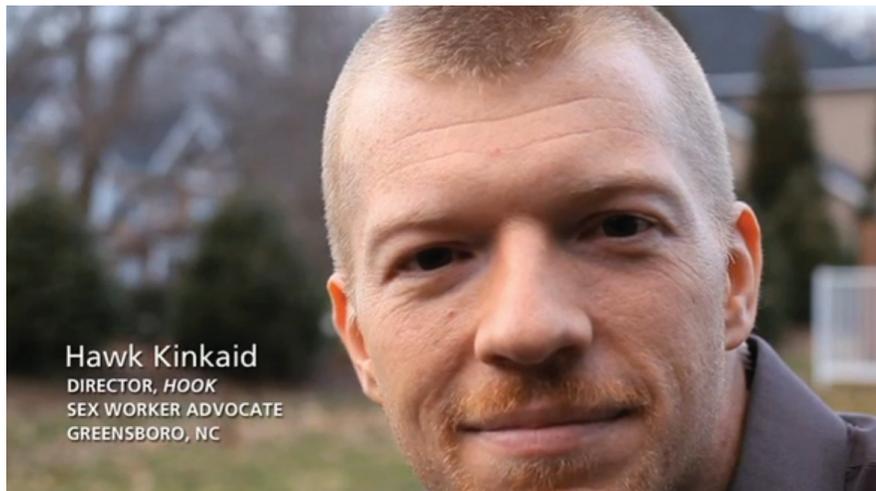
**I went back into sex work in my forties... It came down to needing money for rent, so I posted on Backpage and started working as an escort, which was a very different scenario than as a coerced teenager because as an escort I can screen my clients and control, to some degree, my environment. I needed the money... I advertise in various venues and work for myself as an independent.**

don't know overall number of violent cases. They go unreported and don't make the news."

April describes her experience with violence and her attempt to report to the police. "One time a client held me hostage in his house...he told me, 'bitch, you ain't going nowhere' when I tried to leave and he stabbed me in the leg with a butcher's knife. I had to jump from the second story of his house naked. I called the police. Basically they said if they had to write a report, I'd get arrested. So I didn't ask them to write a report."

People of transgender experience are even less likely to receive help from law enforcement. "I was raped 15 years ago," says Jennifer. "He pulled out a razor blade and said he would kill me. I fought and got him out of my house and called the cops...They wouldn't even take me to the hospital because their mindset was 'Oh, it's just a faggot trying to fool somebody.' That was not the circumstance."

Of all sex workers interviewed for this article, only Stephanie reported positive experiences with the police. However, she too left most violent crimes unreported. "I've been dragged out of the car, left on the side of the



Sex worker advocate and Director at HOOK, Hawk Kinkaid, in the video, *Sex Worker Violence Prevention*, produced by NCHRC. Available online at: <https://vimeo.com/37758509>

open for predators. "One time I had a call with a high profile Dallas businessman. When he got to where I was doing the end call he told me to get on my knees and he kicked me in the stomach and threw me on the bed... he tied me to the bed and told me not to look at him and said he was going to hit me 200 times with a bamboo stick and if I broke out of the restraints, which were Velcro, he was going to start over and I had to count. At 143 he hit me hard enough that I pulled out of the restraint and he started over. He kept

Dallas businessman...the only people protected by criminalization are the predators and violent men. It creates a class of people who have no right to seek protection."

### Difficulty Seeking Hospital Treatment

Besides difficulty reporting violent crimes to the police for fear of arrest, sex workers often face similar hurdles when seeking hospitalization or treatment for rape or wounds. Often it's difficult for sex workers to find non-judgmental care. In some cases the hospital staff will call the police when they learn that the patient is a sex worker.

For sex workers of transgender experience, hospital visits can be a nightmare. Jennifer explains, "[As a transgender person in the hospital] you have bias and prejudice from support staff down to the janitors mopping the floors. Once word gets out that there is a transgender person in the hospital, everyone wants to come see. I was in the hospital to take care of getting raped and all the sudden I was under a microscope and getting ridiculed for my truth."

April's experiences have been similarly negative. "I've been in the hospital lots of times. They treat you like shit,

**...the only people protected by criminalization are the predators and violent men. It creates a class of people who have no right to seek protection.**

road, smacked, beaten, gotten bloody noses. My throat was slit one time. I've been cut and raped, but all that didn't matter as long as I was able to get high. I didn't report any kind of abuse because I felt in my mind that I asked for it and that I deserved it, you know...I don't think that now. No matter what you do not deserve to be beaten, stabbed and left for dead."

Jill has been speaking and writing for years about sex worker criminalization and how it leaves the door wide

telling me he was going to beat his slave until I submitted...He covered me from the back of my knees to my breasts in jet black bruises. There were open wounds. At the end he thought it would be funny to leave me tied to the bed and he shove my panties and the money he paid me in my mouth.

"Because of criminalization I had no recourse. I didn't even go to the hospital because I couldn't explain what had happened...with the police it would be my word against a high profile

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## April's Story

When I was growing up Mom nodded off all the time [on opiate pills] and in the morning I'd find her lying on the floor or wherever she'd passed out high the night before... My father was drunk all the time, my mother high on pills, so my brother and I raised ourselves. I learned to cook for myself when I was three and got myself up to get ready for school at age five. [My brother and I] were abused mentally a lot, and my Dad abused us physically too. We terrorized the neighborhood. We played with knives and ripped the shingles off houses.

I had my first baby at fifteen. I'd had such a shitty life growing up that I swore I wanted my kids to be better off than me. I stayed in school and worked. I was smart and wanted to make something of myself. But when my son, Jamie, was two and a half he was diagnosed with autism. I was so upset, angry at God. I dropped out of school. I was about nineteen then and I had my own cleaning business with seven women working for me. A co-worker introduced me to dope. When I shot up for the first time I thought 'Shit, I've been looking for this my whole life.' My mother and grandmother were addicted to opiates. I was born addicted.

When I did heroin I stopped crying

all the time about my son's autism and I didn't feel stressed when I was high, so I did it more and more often. Then things started to get bad. I got two DWIs in the next five years and went to prison for 18 months. When they put me in jail I was dope sick for three weeks and couldn't even walk. I felt like I was going to die. I was throwing up and shitting all over myself in my cell.

Under North Carolina law if you are locked up for more than a year they take away your kids. They took Jamie away. My second son, Gabriel, was born when I was in prison. I was handcuffed and shackled all through the birth. I only saw my baby for 15 minutes before they took him away.

When I got out of prison I was clean and had saved up some money to start my life over and try to get my kids back. When I found out I couldn't get my sons back I went crazy and started using heroin again.

A few months [after I got out of jail] I went to the doctor for a physical and they told me I was seven months pregnant! I was scared because I'd been using the whole time and hadn't known I was pregnant. I went to a prenatal clinic to talk to the doctor about it and he said basically, that if I tried to get off heroin the baby would die from withdrawal. I signed up for a

methadone clinic to try to get off heroin without hurting the baby.

When Alexandra was born I only had her for three days before she was taken away too. Since the state had already taken the first two kids, they automatically took the third also. Since then I've been blitzed all the time over the pain of losing my children. I needed to take stronger doses of heroin just to not be dope sick. Also the father of my last two kids, the love of my life, got deported. So in just a few short years I lost everything: my children, my lover, my business and wound up living back with my mother who abused me as a kid and is still addicted to pills.

I was at a hotel with a friend when he told me about Backpage [an internet site for escort listings]. He said 'you want to make some real money?' That's how I started sex work at twenty-five. I've been a sex worker for four years now and an addict for ten. My addiction is so bad I sell my body to pay for it. I never thought I would end up like this.

I want to get clean. My Dad is clean seven years now. I'm going to try to live with him and start my life over. Mostly I want to find my kids. I hope they have a good life now.

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like you're worthless. They won't even give you pain medication." Refusing pain medication is common in hospitals, especially when staff believe they are dealing with a drug user who may abuse the medications.

Sarah Danforth, co-founder of the Asheville Sex Worker Outreach Project, describes her experience bringing an injured sex worker to the hospital. "I took a woman to the hospital in November who had a couple different

injuries but also had been sexually assaulted. She was a woman who was homeless and did sex work. She had some pretty serious infections, and I knew that she didn't have a place to stay that night... She had a really serious infection in one of her hands. She had a lot of cigarette burns, she had a lot of bruises all over, and they wouldn't keep her overnight. And I was there with her in the ER for eight hours talking to every nurse and

doctor, saying 'this person needs to be here overnight, they need to have a chance to get stable and to heal from these injuries'... But the ER doctors didn't keep [her]."

Not all doctors and hospitals mistreat sex workers and it is possible to find nonjudgmental care. Access to care can depend a lot on location. "It's easier in urban areas than in rural to access a doctor who would understand," says Hawk. "Even clinics who



Participants gathered at the *Sex Worker Summit in the South* that took place in December 2011 to draw attention to the issues facing sex workers and to provide risk reduction education, violence prevention tips and harm reduction supplies.

provide services for gay men tend to be loose in their understanding or support of the [sex] industry, which doesn't necessarily encourage men to get health care or speak openly with their doctor about issues."

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## Get Involved to Prevent Sex Worker Violence

- Visit the websites of organizations and projects mentioned in this article to see how you can help:  
[sexworkerswithoutborders.org](http://sexworkerswithoutborders.org)  
[nchrc.org](http://nchrc.org)  
[hips.org](http://hips.org)  
[ourvoicenc.org](http://ourvoicenc.org)  
[hookonline.org](http://hookonline.org)  
[transhealthcoordinators.org](http://transhealthcoordinators.org)
  - View and share NCHRC's videos on sex worker violence prevention: <http://vimeo.com/user6734193>
  - Check out the Asheville Sex Worker Project on facebook
  - Get involved in the International Day of Violence Against Sex Workers
- 

## Do Sex Workers Practice Safe Sex?

Safe sex is another difficulty for many sex workers. Most people know about the importance of condom use to prevent the spread of HIV, STIs and other diseases. But realistically, are sex workers willing and able to practice safe sex? The experiences seem to vary widely. Some sex workers are in better control of their clients and can negotiate condom use. Others have little control over what happens to them, even in terms of their own safety. As Cindy Clay, Executive Director of Helping Individual Prostitutes Survive (HIPS) in Washington DC explains, "People's ability to do risk reduction depends on what power they have in a relationship."

Hawk explains that in some circumstances, abstinence from unprotected sex is not realistic. "[Gay male sex workers] live in a different cultural environment. Gay men and MSMs (men who have sex with men) generally get access to condoms when they need them...access is not so much the issue, but the conversation around use is a difficult scenario."

Another barrier to safe sex is the fear that condoms can be used as evidence of prostitution in court. While this practice does not occur

**People's ability to do risk reduction depends on what power they have in a relationship.**

everywhere, there is ample documentation of instances in which police have arrested people on prostitution charges for carrying multiple condoms, and certainly the fear of arrest deters many sex workers from carrying condoms. As Sarah Danforth of the Asheville Sex Worker Outreach Project explains, "There are certainly lots of condom bowls around town. But I think that people don't always feel comfortable carrying more than a few condoms because the police can use that as a way to target them. If they're already in an area where prostitution is known to happen and they've got more than a few condoms on them, that gives the police justification to arrest them."

Of the sex workers interviewed, Jill was the only one who reported being able to practice safe sex all the time. "Certainly I have had clients who try to push boundaries," she explains. "They'll offer \$50 more to have unprotected sex or try to slide the condom off or pop a hole in the end, at which

point I cut off the session. I won't play with that."

Others had more difficulty with condom use. "I didn't always practice safe sex, not when I was high and didn't care," says Stephanie. "Condoms weren't always available and honestly I didn't care. I was on a death mission and as long as I got high nothing else mattered."

April illustrates a fairly common practice of 'selective safe sex'. "I had safe sex most of the time, but I had some regulars that I didn't use condoms with."

Says Jennifer, "I would like to think that everyone practices safer sex. Was I always able? Realistically, no. Sometimes the people I was dealing with didn't want to use condoms. I had a couple incidences where a man put a condom on his penis and turned away to take it off. Or sometimes the condom allegedly broke and they would bareback it. You have to be cautious of that, keep your eye on what is going on."

## Resources for Sex Workers

The situation might seem bleak for sex workers. As long as sex work is criminalized, sex workers will suffer predator violence and may have difficulty reporting incidents to the police or seeking medical treatment. But it's not all bad news. Increasingly, nonprofits and civic organizations are stepping up to address these issues. The North Carolina Harm Reduction Coalition (NCHRC) recently held a summit on sex work in the South to draw attention to the issues facing sex workers and to provide risk reduction education, violence prevention tips and harm reduction supplies. NCHRC works statewide on sex worker outreach, risk reduction education for medical and service providers, and safety and empowerment classes for sex workers.

The Sex Worker Outreach Project in Asheville, North Carolina, is trying to "educate the larger community

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## Tips for Sex Worker Safety

- Trust your instincts. If anything raises a red flag, walk away. You don't need the money that bad.
- Use the buddy system: let someone else know where you are and what to do if you don't come home on time. You might have a safe code to text to a friend if you need help. If you get into a car, call out the license plate number to a friend, even if no one is there.
- Taking "candy" (i.e. drugs and alcohol) from strangers is dangerous. Drugs and alcohol, especially from someone you don't know, don't mix well with sex work.
- Stay in well-lit areas or places where people could hear you scream.
- Set your price higher rather than lower, even if you lose some business. More dangerous clients tend to go for lower-priced girls because they know they will jump for the money.
- Report crimes to a bad date sheet if there is one in your area. Check the date sheet before you go out looking for tricks.
- Stay in control. Set clear time limits and guidelines about what you will or won't do. If the client has the upper hand, the situation could turn violent and you may also lose the ability to use condoms or to prevent rape.
- Separate your personal life from your work environment. Have a support system of people who know you are in the industry and can understand the challenges.
- Wear clothing you can run in.
- Screen your clients before you agree to work with them. Some recommended websites are: [Providerbuzz.com](http://Providerbuzz.com), [Datecheck.com](http://Datecheck.com), [Verifyhim.com](http://Verifyhim.com) and the National Escort Blacklist.

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that sex work is a part of life," says co-founder Sarah Danforth. "[Sex workers] deserve to have the tools of their trade with them so they can continue to do their job and live safely and protect other people." The Sex Worker Outreach Project also links sex workers to different agencies that can help with supportive housing, recovery groups, schooling, or pursuit of alternative employment. Also in Asheville, North Carolina's first bad date line, "Kelly's line" was established in late 2011 to help sex workers report violent crime and "bad dates" anonymously to police and also to other sex workers. Kelly Lane Smith was an Asheville sex worker whose body was found in pieces in 2005 after a violent date.

Several sex workers interviewed

for this article have started programs of their own to assist their colleagues still in the business. Jennifer is the founder and director of Trans Health Coordinators in Asheville. Her program helps educate doctors, support staff and caregivers on the needs of transgender people, as well as provides free HIV screenings and condoms to sex workers.

Jennifer also works to educate the public on the experiences of transgender people. "So many people equate transgender with sexuality. They think if you dress up, you're looking for something. It is not a sexual thing if I am wearing a short skirt... Transgender people are regular people...but for some reason if I have a penis and wear a skirt I am a freak or gay or looking for

something. A lot of work needs to be done to change people's mindset."

Hawk founded Hook Online, an internet resource for men in the sex industry. "[Hook] is about occupational education for people who choose to work in the industry. It's really important for them to learn from others to [ease] the learning curve a bit. If they choose to do [sex work] we want to make sure they do it with both eyes open and also set an end goal."

Jill speaks about her experiences as a trafficked person and also as a consensual sex worker at events all over the country to raise awareness about violence against sex workers and the harms of stigma and criminalization. "Human trafficking is a terrible thing," she said. Whatever can be done to fight that should be done, but consenting sex work is not human trafficking. Making us into criminals and arresting

us does nothing to protect us from predators or to protect sexual slaves. It's just a political ploy for grandstanding and funding and to make the community feel safer from prostitutes." (Read an extended version of Jill's story at [harmreduction.org](http://harmreduction.org).)

Stories of sex workers drawing on their experience to bring resources and hope to others are inspiring. Their action is a call to the rest of society to end this senseless violence and to bring consequence to the thousands of predators who go unpunished each year. Stephanie sums up the situation nicely. "When I hug a lady who is strung out on crack and weighs 97lbs I love her, because I remember what it was like for me and how I craved somebody to tell me it was going to be OK... I just hope that what I do makes a difference somehow, someday."

*Tessie Castillo (Writer) serves as Harm Reduction Coordinator for the North Carolina Harm Reduction Coalition, (Raleigh, NC). She works with drug users and sex workers to improve their health index through non-judgemental care and to combat stigma.*

*Robert Childs, MPH (Editor) is the Executive Director of the North Carolina Harm Reduction Coalition (Chapel Hill, NC) and was just named one of five people who made a difference in HIV in the USA in 2011 by [thebody.com](http://thebody.com). Robert oversees and participates in all of the agency's operations, harm reduction advocacy, direct services and resource development.*

## Recent Harm Reduction Coalition Publications

For more information, visit [harmreduction.org](http://harmreduction.org) or call 212-213-6376 x12.



### Peer-Delivered Syringe Exchange Toolkit

This toolkit provides insight and lessons learned from peer delivered syringe exchange programs. It gives an overview of points to consider in starting new programs and seeks to generate new ideas for revising and improving existing programs.



### Harm Reduction Communication #16

This issue marked the relaunch of Harm Reduction Coalition's unique news magazine with a celebration of our 2010 National Conference. It features articles on a range of topics from safer injection to prescription pills and overdose prevention to stigma — plus much more!



### Guide to Developing and Managing Overdose Prevention and Take-Home Naloxone Projects

This manual is designed to outline the process of developing and managing an Overdose Prevention and Education Program, with or without a take-home naloxone component.

# Luck Junky... I Survived

GORDON H. PETERS

I began shooting dope in 1982. I had no idea what I was doing and remember I got my wings from a beautiful Russian girl I met in a bar. I learned how to cook, filter and hit my vein...though not great at it at first, I could hit myself with one hand tied up after only a few attempts.

Buying dope on the Lower East Side was always easy...no more difficult than buying a pack of reds in the local bodega. Getting clean works...that was always a challenge. It seemed like I was always buying works from some creepy dude on a street corner and they were always used. I knew something about HIV and knew I did not want to contract it...I learned from a street hooker to clean my works with bleach (to this day I love the smell of bleach). Then, one day we heard about a group of people giving out free works on the street...I thought, no way...this is another scam...or the cops are just trying to round up a bunch of junkies. Lo and behold it was this group of humanitarians trying to save the world...I ended up as part of the world they saved. They went from a group of people strolling the street and educating us on the use of clean needles to opening up a storefront on Avenue C and 3<sup>rd</sup> Street. It was safe and easy: Bring in a dirty set of works and they'll give you a free set...alcohol wipes, cotton, even condoms. Yes – they explained to me the ideas of staying disease free and I began to understand how my behaviors as a heroin addict could go far beyond my injecting drugs.

**If I can help one person understand the value of taking precautions no matter what their choices are and help them live a disease-free life, then I know my experience has helped someone or something.**

## Hepatitis C & Interferon Treatment

Though I had been sober for almost 19 years and did not die of HIV or AIDS...didn't get shot for robbing or stealing, didn't kill myself when filled with self pity...I did at some point in my life contract HEP C. This must have happened either through sex (which is highly unlikely) or prior to my visits to the LESNEP.

I learned of my HVC status early in my sobriety. Having received health insurance through my employer I began to visit a doctor annually. The first thing I told him was that I was a recovering IV drug user. He ordered some blood tests and discovered my ALTs and ASTs were elevated. After further tests I was referred to the Liver Center at Beth Israel Deaconess Medical Center in Boston, Massachusetts (BIDMC) where I began a very long relationship with a group of physicians, nurse practitioners and clinicians. We discovered that I was in the early stages of fibrosis and was told that with my newfound sobriety I should not have any problems for many years. Approximately 10 years and a few liver biopsies later, the fibrosis increased and was determined to be at a stage 3-4. It was May 2010 when I began the treatment with interferon and ribavirin.

I was a bit concerned because of the stories I had heard from others regarding the potential side effects of interferon treatment – from depression, to loss of energy, to low red blood cell count. How was I going to continue to live my life...work, marriage, home, friends and take 11 months for

treatment...? The staff at the BIDMC Liver Center worked very closely with me and we discussed all of my concerns. We dealt with the fear of depression by going on a mild antidepressant (Wellbutrin) 4 weeks prior to my treatment. I also went on a drug... (I can not remember the name) that would help manufacture hemoglobin to address potential loss of energy due to anemia. We also determined that I would inject the interferon Friday evenings, to minimize loss of time during the week. I did not mind giving up weekends for a year if it meant I would continue to have an effective lifestyle Monday-Friday. Though I did experience loss of energy and slept through most weekends – I made it through the treatments. I completed treatment in April 2011.

Fortunately, I am now considered completely cured of the hepatitis C. Though I have had some complications due to some additional unforeseen events – I am at peace with my life and am well aware that I would have been dead a long time ago if I had not been given the opportunity to obtain clean syringes. Some people may read this and think, "...but you still got infected with hep C." I would say, "I sure did...but no HIV, no AIDS, 20 years of an amazing experience and now an opportunity to be of service in a way that fills my heart." If I can help one person understand the value of taking precautions no matter what their choices are and help them live a disease-free life, then I know my experience has helped someone or something.

# Harm Reduction Communication

Fall 2012, Number 17

## Editorial Policy

*Harm Reduction Communication* aims to:

- Provide a forum for the exchange of practical, “hands on” harm reduction techniques and information
- Promote open discussion and reflection on theoretical and political issues of importance to harm reduction and the movement
- Inform the community through resource listings and announcements of relevant events
- Document the struggles, experiences and lessons of our movement as a tool for strategy-building
- Ensure that our history is not erased.

*Harm Reduction Communication* is a product of the harm reduction movement – it is not written by Harm Reduction Coalition, but by the people on the ground making harm reduction happen. In our editorial role, the Harm Reduction Coalition is committed to presenting the views and opinions of people who use drugs, former users and people in recovery, people accessing medication-assisted treatment, people living with HIV or hepatitis C, sex workers, incarcerated or formerly incarcerated persons, outreach and front-line workers, and others whose voices have traditionally been marginalized or ignored. We aim to provide an outlet for exploring harm reduction issues in an honest and critical way – with full respect for the messy, complex, vulnerable, dynamic, hopeful and inspiring nature of what we do and how we do it.

Since a large part of harm reduction is about casting a critical eye toward the thoughts, feelings, and language we have learned to have and use about drugs and people who use drugs, Harm Reduction Communication assumes that contributors choose their words as carefully as we would. Therefore, we do not change ‘addict’ to ‘user’ and so forth unless we feel that the author truly meant to use a different word, and contributors always have last say.

The views of contributors to Harm Reduction Communication do not necessarily reflect those of the editorial staff or of the Harm Reduction Coalition. Any part of this publication may be freely reproduced as long as the Harm Reduction Coalition is credited.

**Please write with your comments, feelings, and responses — we want to hear from you.**

If you would like to submit an article, or photos or artwork, we would be happy to look at your material. HRC gives a voice to communities that are ignored by conventional media: people who use drugs, people of color, individuals who are living with HIV or Hepatitis C, and lesbian/gay/bisexual/transgender individuals. If you have never written something for publication, assistance is available: just ask for it. You can call the editor at 212 213 6376, or include a note with your submission.

Send submissions or correspondence to [publications@harmreduction.org](mailto:publications@harmreduction.org), or by mail to: Editor, Harm Reduction Communication, Harm Reduction Coalition, 22 West 27th Street, 5th Floor, New York, NY 10001



## About the Harm Reduction Coalition

[harmreduction.org](http://harmreduction.org)

The Harm Reduction Coalition is a national advocacy and capacity-building organization that promotes the health and dignity of individuals and communities impacted by drug use. Harm Reduction Coalition advances policies and programs that help people address the adverse effects of drug use including overdose, HIV, hepatitis C, addiction, and incarceration. We recognize that the structures of social inequality impact the lives and options of affected communities differently, and work to uphold every individual's right to health and well-being, as well as in their competence to protect themselves, their loved ones, and their communities.

Harm Reduction Coalition promotes the use of harm reduction as an alternative to traditional coercive and punitive drug policies and approaches. Harm reduction is a set of practical strategies that reduce negative consequences of drug use, incorporating a spectrum of strategies from safer use, to managed use to abstinence. Harm reduction strategies meet drug users "where they're at," taking a nonjudgmental stance to addressing conditions of use, along with the use itself.

**Harm Reduction Coalition works to fulfill its mission through five core programs:**

- Capacity building assistance and training to both organizations and individuals on issues relevant to drug user health and well-being, harm reduction service provision, and organizational and professional development.
- Policy analysis and advocacy at the local, regional, national and international levels.
- Overdose Prevention Projects that provide education and training on overdose prevention and response.
- Publications, reports, and other topical materials to communicate critical knowledge, skills and education.
- National and regional conferences, community forums, and coalitions.



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