

Take Control, Learn and Connect: weekend workshops for people recently diagnosed with HIV

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Introduction

For many people, receiving an HIV diagnosis is a worrying and confusing time. Reactions can range from shock, anger, guilt, shame and disappointment through to denial or even a nonchalant acceptance that the infection was somehow inevitable. Some recently diagnosed people have reported to us at Positively UK that they felt a sense of relief, particularly if they had been diagnosed HIV positive after a period of ill health. Self-stigma is commonly reported among people living with HIV and this may be particularly high among those recently diagnosed [1].

Whatever the reaction, one thing that is common at the start of a person's HIV journey is the need for information, reassurance and support. Nearly all recently diagnosed people have questions about their health, treatment, who to tell, and how to prevent transmission. Some may need to meet others with the same experience to be reassured that they can continue with life.

How someone manages, and the support they access and receive in the first weeks or months of a new diagnosis may inform their subsequent adjustment and acceptance of living with HIV. This in turn will influence how well they live with the condition, impacting on their adherence to medication, engagement with services, mental health, ability to disclose their status to others and relationships.

Providing support and interventions at this early stage of diagnosis has long been recognised as beneficial to the client. Support groups and recently diagnosed workshops have been available since the early days of the epidemic. These interventions are often the first point of referral made by clinicians, HIV nurses and health advisors.

The BHIVA Standards of Care for People Living with HIV [2] and BHIVA Standards for Psychological Support for Adults Living with HIV [3] state that: 'Access to HIV-appropriate emotional, psychological and peer support services is particularly important for people as they adjust to their diagnosis.'

Through our nearly 30 years of providing support, mentoring and advocacy at Positively UK, we have learnt that connecting people living with HIV to their peers is an effective and powerful way of enabling

them to accept their diagnosis and to live full and healthy lives.

Take control, learn and connect

Positively UK is contacted almost every day by newly diagnosed people seeking support. We also receive a number of referrals from clinics across the country looking to link their patients to peer support. In 2014, and in response to this need, we developed a workshop programme for recently diagnosed people: Take Control, Learn, and Connect (TLC).

Take Control, Learn and Connect
Weekend workshops for people recently diagnosed with HIV

Take Control of your HIV.
 Learn how to get the support you need.
 Connect with other people living with HIV.

Receiving an HIV diagnosis can be a worrying and confusing time. Our two-day workshops are a great first step in helping you manage and live well with HIV.

The workshops will take place on the following weekends in London. Lunch and refreshments will be provided

+ 26–27 September 2015 (held at Dean Street)	+ 22–23 August 2015
+ 28–29 November 2015	+ 10–11 October 2015
	+ 30–31 January 2016

To find out more visit positivelyuk.org/tlc
 and to book a place email tlc@positivelyuk.org
 or call 020 7713 0444

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we are positive

The programme of workshops is funded by the Elton John AIDS Foundation and 56 Dean Street, Chelsea and Westminster Hospital NHS Foundation Trust

TLC is based on the Positive Living for Us (PLUS) programme developed by the San Francisco AIDS Foundation [4].

We recognised that there were many excellent programmes for recently diagnosed people being run in the UK; for example: Terrence Higgins Trust's

Newly Diagnosed Gay Men's Group [5], George House Trust's accredited Newly Diagnosed Course (Understanding HIV and the Holistic Health Approach) [6], and the Bloomsbury Clinic's Newly Diagnosed Course [7].

Many of these run over a 4–6 week period, risking people dropping out before course completion due to the substantial commitment required from the participants. We also felt that the involvement of people living with HIV (PLWH) in the development and facilitation of the workshops needed to be a central element. Therefore TLC was developed to run over one weekend, led by four facilitators, all of whom were living with HIV.

The pilot programme, which ran over four weekends in 2014, showed a high acceptance of this model. The evaluation indicated a high retention rate, with 98% of all participants completing the workshop. In 2015, following the successful pilot programme, Positively UK received funding from the Elton John AIDS Foundation to continue the programme and run six workshops between July 2015 and January 2016.

The series of workshops was promoted widely across London sexual health and HIV clinics, on the Positively UK website, and via social media. This was supported by presentations to clinic staff in specific clinics that were reporting a significantly high number of new diagnoses per month.

The two-day workshops have four objectives:

- To provide education about the virus and treatment options (*Take Control*)
- To provide opportunities for participants to get questions answered by experts and others living with HIV (*Learn*)
- To provide a safe and supportive space for recently diagnosed people living with HIV to meet with peers and to network (*Connect*)
- To introduce participants to the range of services for PLWH

Over the weekend, participants gain a deeper understanding of HIV, increased knowledge of treatment and care, and most importantly the chance to engage with other people, all of whom will help open the door to living well with HIV in new ways.

The workshop covers the following topics:

- The science of HIV
- Understanding HIV treatment
- Transmission and treatment as prevention (TasP)
- Disclosure and talking about HIV
- Sex and relationships
- Managing stigma
- Getting the most from your healthcare provider

The workshops are delivered using a variety of teaching methods. A mixture of large group discussion, small group work, presentations, work in

pairs and interactive exercises are used throughout the two days to provide a range of ways for participants to engage fully with the programme that suits their learning needs.

In line with Positively UK's ethos of peer support, the workshops are led by staff and volunteer peer mentors, all of whom are living with HIV. This approach also meets the recommendation in the BHIVA Standards for Psychological Support for Adults Living with HIV [3] which state that: '*PLWH should play a role in the provision and dissemination of information about HIV and HIV services to other PLWH, as well as providing peer support, advice, advocacy and means of engagement.*'

All peer mentors who facilitate the workshops have experience of providing one-to-one peer support. They have also completed our core peer mentor training and have received or are working towards an Open College Network Level Two qualification in peer mentoring. In addition all facilitators receive a day's training in group work facilitation skills.

Hearing about the experience of other people living with HIV can be a very powerful way of helping recently diagnosed people come to terms with their diagnosis. Throughout the weekend, participants are encouraged to share their personal stories and the strategies they have used with each other. A central part of the workshop is the facilitators sharing their stories. This has proven to be one of the most popular sections of the weekend for participants, many of whom have never interacted with another HIV-positive person. It gives them an opportunity to hear about HIV from a new and authentic perspective.

Facilitators talk about when and how they learnt they were HIV positive, the challenges they have faced and overcome, and the opportunities HIV has given them. This section is focused and facilitators talk specifically about their experience of:

- Finding out
- Starting treatment
- Disclosure and talking about HIV
- Accepting an HIV diagnosis

After each presentation, participants work in smaller groups to explore issues in more detail and discuss their personal experiences.

Some time is given over to guest speakers, including a treatment advocacy specialist who delivers a session on the science of HIV, understanding viral load and CD4 cell count, starting and managing treatment. Participants are also given time to have their specific questions about treatment answered in an interactive way. A community nurse specialist also attends to talk about the healthcare system and how to get the best out of HIV services, primary care and pharmacy.

Each day closes with a mindfulness meditation exercise and group affirmation. Participants are

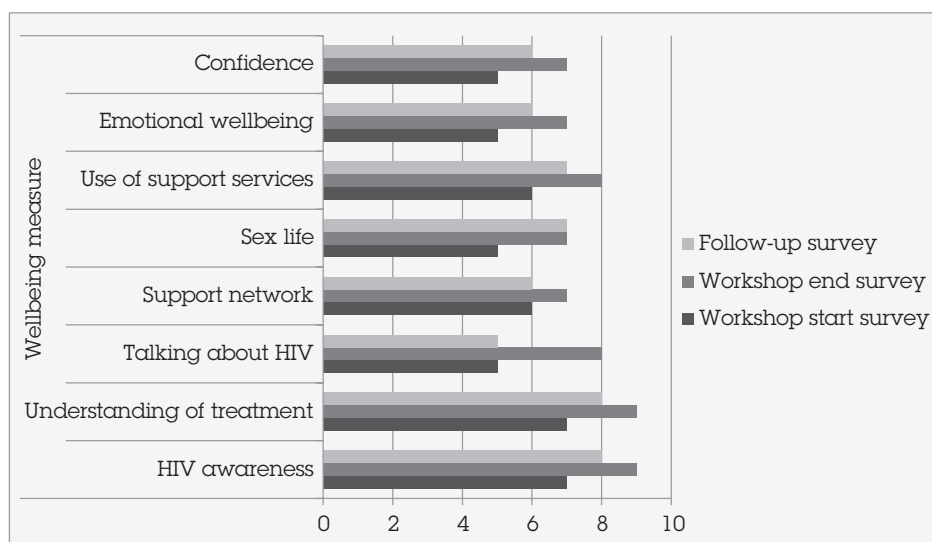


Figure 1: Impact of recently diagnosed workshop on participant wellbeing.

encouraged to exchange contact details and to attend Positively UK's services and groups.

Evaluation methodology

Positively UK evaluates the impact of these workshops on their participants through the use of a standard wellbeing measure used by the organisation to measure the impact of most of its services. This involves a self-completed survey of eight questions covering the key aspects of living with HIV, each one being scored between 1 and 10 where 1 is poor or low and 10 is good or high. Participants are asked to complete this on arrival immediately before the workshop starts, and again immediately before departure on day two.

The eight wellbeing measures used are as follows:

1. HIV awareness
2. Understanding of HIV treatments
3. Disclosure and talking about HIV
4. Support network – i.e. family/friends/social life
5. Sex life – i.e. negotiating safer sex/understanding of sexual health and transmission risks
6. Using support services – e.g. sexual health, counselling, peer support
7. Emotional wellbeing
8. Confidence

In March 2016, a follow-up survey of those who participated in four workshops between August 2015 and January 2016 was conducted to measure the longer-term impact of the intervention on people's wellbeing, using the same wellbeing measures. The survey of 53 participants elicited a 26% response rate.

Results

The results in Figure 1 illustrate the impact on participant wellbeing as a result of the intervention. What can be seen is that during the workshop, participants move up an average of two points on most of the eight wellbeing measures. The follow-up

survey, conducted between two and seven months after the workshop (depending on which workshop they attended) indicates that whereas wellbeing has dropped across almost all measures compared to the workshop end survey, the scores still remain higher than when participants arrived at the workshop. The exception to this is the measure around 'Talking about HIV' which has dropped back to its starting score.

As part of the evaluation we asked participants how they had heard about the workshop. The majority of participants had seen a leaflet or poster in their clinic and self-referred. A smaller number reported that the workshops had been suggested to them by a health advisor or nurse.

Most of the participants who attended the workshops received their HIV care in clinics in and around central London, with a significant proportion from 56 Dean Street, Chelsea and Westminster Hospital. However, a few participants travelled from Birmingham, Derby and Hertfordshire for the workshop as they were unable to find similar provision locally.

Conclusions

The results lead us to two key conclusions.

Firstly, the immediate impact of the workshops is very positive and many participants feel the experience as quite transformative. One comment received from a follow-up survey participant illustrates this well:

It is difficult for me to express the impact the recently diagnosed workshop had on all aspects of my life. Before I went I felt like my life was finished, I couldn't see any future for myself – the workshop turned everything around for me. I will always be thankful to the facilitators. After that weekend I was able to make positive choices based on the information I picked up – over the last couple of months I have managed to pick up my life and actually feel excited about my future. I feel like a

worthwhile person again and this is really thanks to the weekend workshop. I do not exaggerate the crucial role these workshops play for people newly diagnosed. The workshop gave me hope for the future and gave me tools that have empowered me to take an active role in my health and medication choices. 'Thank you' just doesn't seem to say everything I want to express to the staff and facilitators working for Positively UK.

The second conclusion is that despite the impact the intervention has in the immediate and short term, once people settle back into life and the daily reality of living with HIV, these gains do not appear to be maintained at a similar level over the longer term, even if wellbeing overall has improved compared to when they started the workshop. This is not entirely surprising; we know that support needs are ongoing after a diagnosis and that also for many PLWH a wide range of other issues may be impacting on how that person is able to deal with a diagnosis. What the results do show is that the issue of disclosure and talking about HIV remains one of the most difficult issues for people, and indeed we know this from our wider work with clients at Positively UK. Having the confidence to disclose our status, to cope with the stigmatising nature of the condition and the impact this has on self-esteem, relationships and how our care is managed remain extremely challenging for PLWH, despite the huge advances in treatment and clinical care. The following survey comment is apposite:

I still can't tell people I meet on dates or anything, I don't feel confident enough to own my status and I'm afraid of rejection. I know this will come with time though and the

rejection thing is me in life in general so the HIV has become another reason to be rejected.

In final conclusion therefore, the weekend workshops have been shown to provide an essential platform from which newly diagnosed people can start to build a healthier future for themselves but they are not a panacea; ongoing social, emotional, informational support and engagement with other people living with HIV is required to ensure that these benefits are sustained in the long term.

References

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