

Our+Care OC

A newsletter created by HIV-positive individuals for people living with HIV



This issue of the Our+Care newsletter is about you, as clients/patients¹, being an advocate for your own health. Studies show that individuals who are actively engaged in their health care have better health outcomes². When you are in charge of your own health, you will get the most out of health services. The intent of this newsletter is to provide tips on how to be an active participant in your health care. Keep reading to find out more!

3 Ways to be a Self Advocate

1. Be part of the decision-making process.

When you go to your appointments, share your opinions on your health or treatment plan. If you are unsure about what you are



supposed to do, let your doctor know. If you have a suggestion for your doctor, share your ideas. Don't be scared to tell your doctor what you think or how you feel about your health.

Sometimes, clients see providers as authority figures and may not want to speak up. However, it is important that you let your doctor know what your thoughts and opinions are on your health.

2. Ask questions. Doctors are a great source of information, so if you have any questions about your health plan, make sure you ask them questions. Bring a notebook with your questions or put them in your cellphone.



Ask yourself:

- Do I understand the information they gave to me?
- Do I know what my lab results mean?
- Do I know what my viral load is?
- Do I know what my next steps are?
- Do I know the name of my current medications?

If not, ask your doctor these questions. By learning more about your health status, you can better advocate for your needs. If the information provided to you is confusing or hard to read, ask someone to explain it to you. You can also contact a case manager to help you with these questions.

3. Talk openly and honestly about HIV with your doctor(s).

Do not feel embarrassed or worried about hearing bad news from your doctor. Talking to your doctor will make things better and help with any concerns you may have. The more information you give to your doctor, the better he/she can help improve your health. If you have a primary care doctor and an HIV specialist doctor, make sure they both know your current care plan. Talk to your doctor about how you are monitoring your viral load (VL) numbers.

Your doctor may be able to help you with having an open dialogue about HIV with other important people in your life, such as family and friends.

A visit with your Primary Care Doctor...

Remember to tell your PCP your medications changed...

Thanks! This is great info. It looks like your VL has gone down with the new medications.

Here is a copy of my VL that I got when I saw my HIV specialist.

I think the change in meds caused my VL to decrease.



¹ For this newsletter, clients and patients are used interchangeably.

² Hibbard, J. H., & Greene, J. (2013). What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health affairs*, 32(2), 207-214.

Advocating

HIV advocacy has a long history that began since the beginning of the HIV epidemic. Since the 1980's, individuals, regardless of their HIV status, have come together to promote the needs for people living with HIV disease (PLWHD) and reduce HIV-related stigma.

There are many opportunities for clients and providers to get involved in advocating for the needs of PLWHD in Orange County.

1. Attend local HIV advocacy meetings. Some agencies have an HIV advocacy committee that talks about important issues that impact the PLWHD community. These committees are often open to PLWHD, providers of HIV services, and people who are interested in supporting the HIV community. (See table for some of Orange County Advocacy Groups.)

2. Be part of an HIV Planning group. In Orange County, the HIV Planning Council (Council) is in charge of identifying goals and strategies for Ryan White funded services. The Council is a planning group composed of service providers, PLWHD, and other knowledgeable individuals in the field of HIV. Being part of the HIV planning process is a great way for you to provide your input to help meet the goals of reducing new infections and meeting the needs of those living with HIV in Orange County. For more information on the Orange County HIV Planning Council, please visit <http://ochealthinfo.com/phs/about/dcepi/hiv/council> or call (714) 834-8399.



3. Attend community events. Year-round, various fundraisers, galas, and community events bring awareness to the HIV community. By attending HIV-related community events, you are showing your support and advocating for individuals living with HIV. You can contact a local AIDS services organization for upcoming events or go to the HIV Planning and Coordination website:

<http://ochealthinfo.com/phs/about/dcepi/hiv/events>



Orange County Advocacy Groups
<p>HIV Client Advocacy Committee Who: People Living with HIV Disease When: 3rd Monday of the month at 6:00pm. Where: Santa Ana For more information, call: (714) 834-8399</p>
<p>AIDS Services Foundation Client Advocacy Committee Who: People Living with HIV Disease (Interested individuals must register first by calling the number below) When: 1st Wednesday of the month Where: Irvine For more information, call: 949-809-5706</p>
<p>Needle Exchange Who: Opened to everyone interested. When: Every Monday at 7:00pm. Where: Location alternates between Orange and Irvine. Call or email to confirm. For more information, call (714) 794-5643 OR email staff@ocnep.org</p>
<p>Shanti Ambassador Program Who: Opened to everyone interested. When: Contact admin@shantioc.org Where: Laguna Hills For more information, call: (949) 452-0888</p>

Other Advocacy Resources
<p>Harm Reduction Coalition advocates for harm reduction strategies such as: syringe access, overdose prevention, access to quality healthcare and reduction of stigma. For more information, please visit: http://harmreduction.org/our-work/policy-advocacy/</p>
<p>Positive Justice Project focuses on the decriminalization of HIV. For more information, please visit: http://www.hivlawandpolicy.org/initiatives/positive-justice-project</p>
<p>Positive Women's Network USA advocates for changes that improve the lives of women living with HIV by including women in policy and decision-making roles. For more information, please visit: https://pwnusa.wordpress.com/</p>
<p>National Minority AIDS Council advocates normalizing discussion about race within the HIV movement, reducing new HIV infections, and retaining people of color living with HIV in care. For more information, please visit: http://www.nmac.org/</p>

ORANGE COUNTY HIV QUALITY MANAGEMENT COMMITTEE



Our+Care OC is a project of the Orange County HIV Quality Management Committee and HIV Consumer Advocacy Committee. The HIV Quality Management Committee works to increase the quality of Ryan White services. For more information about the committee, please call (714) 834-8063. If you have feedback or suggestions for future newsletters, please contact **Mindy He** at MHe@ochca.com.

