Help Wanted

POZ asked readers: How have HIV groups helped you? Here are edited excerpts from an opinion piece posted on POZ.com titled "Help Wanted" that spotlights both positive and negative responses.

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"Yes, they helped me in more ways than one. If it had not been for them, I don't know where I would be today. Twenty-five years later, I can say they saved my life with things like acupuncture, mental health counseling, case management services, education, dentist referrals. I'm healthy and undetectable 26 years after my diagnosis."

"The help I received for HIV medication came in the form of a reduction in cost from the manufacturer passed on to the pharmacy, with insurance taking care of the rest as I met the deductible. I needed to find a therapist. Found no one at first. Now I'm paying for therapy myself. That's the extent of any so-called help."

"To be honest, they changed my life. I have a son who is 18. He is HIV negative. When I was pregnant with him, they put me on an HIV medication to prevent me from passing on the virus to my son. I have been undetectable for years."

"Though it has been a struggle at times, I have remained self-sufficient, not using assistance from any groups. It is important to me that those resources are not used unless absolutely necessary. These resources are limited. So using any of them will make them no longer available for someone who may need them more."

"I have been homeless for years. Asked for help but never received any real assistance. I have heard of people living with HIV who have gotten help. The excuse I get is that I have not lived in the area, so no assistance is possible. I tried to get disability, but nothing. They are just keeping their quota of applications so the funds can keep coming, but no help offered."

“I am so very grateful for the help I receive. They have a program that covers monthly insurance premiums as well as co-payments on doctor visits, prescriptions and hospital stays. I have qualified for and used this service since they first implemented it. It is income-based. I could not afford these costs without this help. I feel certain my health would’ve suffered greatly if not for this program. I honestly don’t know what I would do without it. I believe it is partially funded through the Ryan White CARE Act.”

“I am now in my first own place after being homeless since 2017. At the time of my diagnosis, I immediately started researching social service agencies that might help. The first tool I used was the POZ Health Services Directory. I got mental health, transportation, housing and health care in six cities and across two states since then. Case managers helped. Infectious disease doctors and other providers treated me. Currently, my housing and housing case management are provided by Ryan White funds disbursed through my local AIDS service organization. I couldn’t be more grateful to be a recipient of these services and funds.”

“I have been living with HIV for 30 years and have worked in HIV for many years as well. I recently went on disability and moved. I have found the local AIDS service organization to be less than helpful. I had to call my case manager several times and threaten to call the state Ryan White program and file a complaint just to get referrals to two support groups. I know my way around these services. I would hate to think how a newly diagnosed person is able to deal with these nonresponsive agencies.”

“HIV groups helped me by making me more confident about myself and making me aware that as long as I take my medications, then I will be fine.”

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