



How Are Early Members of ACT UP Adjusting Today?

A new study assesses the long-term impact of AIDS activism, including trauma, loss, posttraumatic growth and a belief in change.

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AIDS activists who were members of the AIDS activist group ACT UP New York from 1987 to 1992 and who participated in a recent study reported that the experience “dramatically contributed to positive growth, which they still experience 25 years later. The vast majority reported an enhanced sense of self, confidence, belief in change and their ability to influence events.”

The research, published in *AIDS Research and Treatment* under the title “Trauma and Growth: Impact of AIDS Activism,” assessed current rates of posttraumatic stress disorder (PTSD), depression, substance abuse and posttraumatic growth.

Authored by Judith G. Rabkin, Martin C. McElhiney, Mark Harrington and Tim Horn, the full article is available for free at [Hindawi.com](#), a publisher of peer-reviewed journals. As the report notes, it’s the only study that has examined the long-term influence of AIDS activism on the participants.

Researchers interviewed 102 men (40 percent are HIV positive) and 23 women involved in ACT UP (AIDS Coalition to Unleash Power) during its peak years, 1987 to 1992 (the group is still active in New York and across the globe). Some of the results include:

- 17 percent reported current symptoms suggesting PTSD, slightly above the range in general population studies.
- 8 percent reported symptoms consistent with depression, with higher rates for the men living with HIV.
- 93 percent of the respondents reported an enhanced sense of self, belief in change and empowerment; this was independent of concurrent PTSD or depression.

The researchers also explored “unit cohesion,” the idea that being part of a close-knit tribe or community, especially during a time of crisis, such as a war, can have a positive, protective effect. For example, when participants were asked “In what ways was ACT UP a positive experience?” 79 percent cited “social ties.” Similarly, many said what they most miss about ACT UP is the “loss of network.”

Another area of discussion was loss. “Loss refers not only to the deaths of friends and fellow ACT UP members,” the authors write, “but also to loss of the spirit, the focus and the support of ACT UP membership in its peak years. Respondents also spoke of loss of a sense of purpose, of relevance, of friendships and connection, the excitement and stimulation, the sense of community after the ACT UP years.”

The study concludes that “AIDS activists recalled their ACT UP years as ‘the best of times, the worst of times.’ Dramatic personal growth was often accompanied by lingering sadness, unresolved grief and, for some, loss of perceived life purpose. However, the community bonds within ACT UP played a central and protective role, enabling most members to move forward and lead productive lives.”

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