

U.K. Survey: 'Fluctuating' HIV Symptoms Affect Work Ability and Daily Living

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["Fluctuating" symptoms](#) are common among people living with HIV and have the potential to disrupt day-to-day living, including the ability to work, according to a survey conducted by the United Kingdom's National AIDS Trust (NAT) and [reported](#) by aidsmap. The variation and unpredictability of the symptoms, which include fatigue, insomnia, depression, diarrhea and neuropathy, tend to be as much of a problem as the symptoms themselves.

Much like the U.S. Social Security Administration's recent efforts to better understand disability and the need for income benefits among people living with HIV amid today's antiretroviral therapy options, the United Kingdom's Work Capability Assessment and its Employment and Support Allowance (ESA) benefits are also under review, notably for their inflexibility when it comes to accommodating diseases associated with fluctuating symptoms.

The NAT survey involved 265 people living with HIV, all of whom completed an online questionnaire about various HIV-related symptoms during the previous six months.

It is not surprising, the aidsmap report notes, that in a study inviting people to self-report, the majority of the respondents had at least one of the symptoms on the list. The most common was fatigue (57 percent), followed by depression or anxiety (55 percent), gut-related problems (48 percent), insomnia (46 percent) and neuropathy (33 percent). "More significant," the aidsmap report adds, "was the fact that more people experienced these symptoms as fluctuating rather than constant."

Roughly 40 percent of the respondents were unemployed. In many cases, the symptoms were significantly affecting respondents' ability or willingness to work.

In other cases however it was clear that fluctuating symptoms—as compared with constant symptoms—were significantly affecting people's ability or willingness to work. One question on the study asked, "On how many occasions in the past four weeks have your symptoms significantly affected your ability to work?"

A quarter of people with fatigue, 20 percent of those with neuropathy and about 15 percent of

those with depression and gastrointestinal problems reported that, during the previous four weeks, their symptoms significantly affected their ability to work.

NAT recommends that more research needs to be undertaken into these common, fluctuating symptoms and that HIV organizations—at least in the United Kingdom—should raise awareness among employers, and among HIV-positive people themselves, about the importance of making reasonable adjustments at work to enable people living with HIV to continue their employment.

In terms of the ESA benefits, NAT recommends that qualifying evaluations take into account “the full range of barriers fluctuating symptoms present to participation in work and other daily activities,” including their unpredictability and the fact that they come in combination.

“Assessment should consider the impact of fluctuation and the cumulative impact of multiple, lower-level symptoms on people living with HIV,” they comment.

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