

August 2011



Fluctuating symptoms of

HIV

Findings of an anonymous online survey conducted by NAT (National AIDS Trust)



NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We campaign for change.

Executive SUMMARY

Contents

- 3 Executive summary
- 4 Introduction
- 5 Main fluctuating symptoms
- 6 Fatigue, exhaustion or lack of energy
- 8 Depression and anxiety
- 9 Gastro-intestinal problems
- 10 Insomnia and difficulty sleeping
- 11 Neuropathy
- 12 Multiple symptoms
- 14 Impact on work and daily life
- 16 Work
- 18 Daily life
- 20 Conclusion
- 21 Recommendations
- 22 Appendix A: about the survey
- 24 Appendix B: the survey

SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

Our vision:

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection.

Our strategic goals:

All our work is focused on achieving four strategic goals:

- effective HIV prevention in order to halt the spread of HIV
- early diagnosis of HIV through ethical, accessible and appropriate testing
- equitable access to treatment, care and support for people living with HIV
- eradication of HIV-related stigma and discrimination.

In February and March of 2011, 265 people living with HIV responded to an anonymous survey about symptoms they experience which fluctuate over time and the impact this has on their daily life.

The most commonly reported fluctuating symptoms were:

- **fatigue, exhaustion or lack of energy (57%)**
- **depression or anxiety (55%)**
- **gastro-intestinal problems (such as nausea, vomiting and diarrhoea) (48%)**
- **insomnia or difficulty sleeping (46%); and neuropathy (nerve pain) (33%).**

These symptoms can be the result of HIV infection, HIV treatment, or both, but many respondents were unable to identify the cause of their fluctuating symptom(s), or were not certain that these were directly linked to their HIV (20-45%, depending on the symptom).

Frequency, predictability and duration of symptoms varied greatly among the respondents.

Many people with one fluctuating HIV-related symptom also experienced another symptom, either on a constant or fluctuating basis. Fatigue was especially associated with other symptoms, with the majority of those reporting fluctuating depression or anxiety, gastro-intestinal problems or insomnia also experiencing fluctuating fatigue.

The experience of these fluctuating symptoms is a cause of real distress for some people living with HIV and creates significant barriers to work, daily living and social participation. These impacts must be considered in assessments for welfare benefits and social care.

Respondents indicated that they would like greater opportunities to discuss the impact of HIV-related symptoms with those involved in their clinical care.

Clinical and scientific studies are needed to determine the prevalence of these symptoms among people living with HIV and how best to manage them.

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INTRODUCTION

Main fluctuating SYMPTOMS

In January 2011, NAT (National AIDS Trust) was invited to join a working group on how the impact of fluctuating conditions, such as HIV, could be more accurately assessed in claims for Employment and Support Allowance (ESA), the chief out-of-work benefit for people with illness, disabilities and long-term conditions.

The working group was brought together by Professor Malcolm Harrington, as part of his independent review of the Work Capability Assessment (WCA), the assessment for ESA.¹

NAT had previously made representations to Professor Harrington's review about how the fluctuating nature of HIV-related symptoms meant that key barriers to work were not captured by the WCA. However, more thorough research was needed in order to make evidence-based recommendations on how the WCA could be improved to more accurately assess the impact of fluctuating conditions, including HIV. An initial literature review found that there was a real gap in scientific research on variability of these symptoms (there are reasons for this gap, which are discussed in Appendix A).

In the absence of such literature, NAT launched an anonymous online survey of people living with HIV to better understand how those who do have fluctuating symptoms experience these and the impact the symptoms have on their capacity for work and their daily life.

This study did not attempt to establish the prevalence of fluctuation among people living with HIV, but via an opportunistic survey it did gather extremely valuable information about how fluctuating symptoms and side-effects of treatment are experienced by people living with HIV, and the impact on their lives. It is clear that these symptoms have a real impact on quality of life for those that experience them, and that this is an issue that is very important to people living with HIV. These initial findings are compelling in their own right - and are very relevant to the benefits assessment processes which the study was designed to inform - but they also strongly make the case for further scientific studies into how fluctuation is experienced by people living with HIV.

For more information about how the research was conducted, see [About the survey](#) at the end of the report.

Of the five types of symptom that the survey asked specifically about the most commonly reported fluctuating symptom was fatigue, exhaustion or lack of energy, at 57% of respondents.

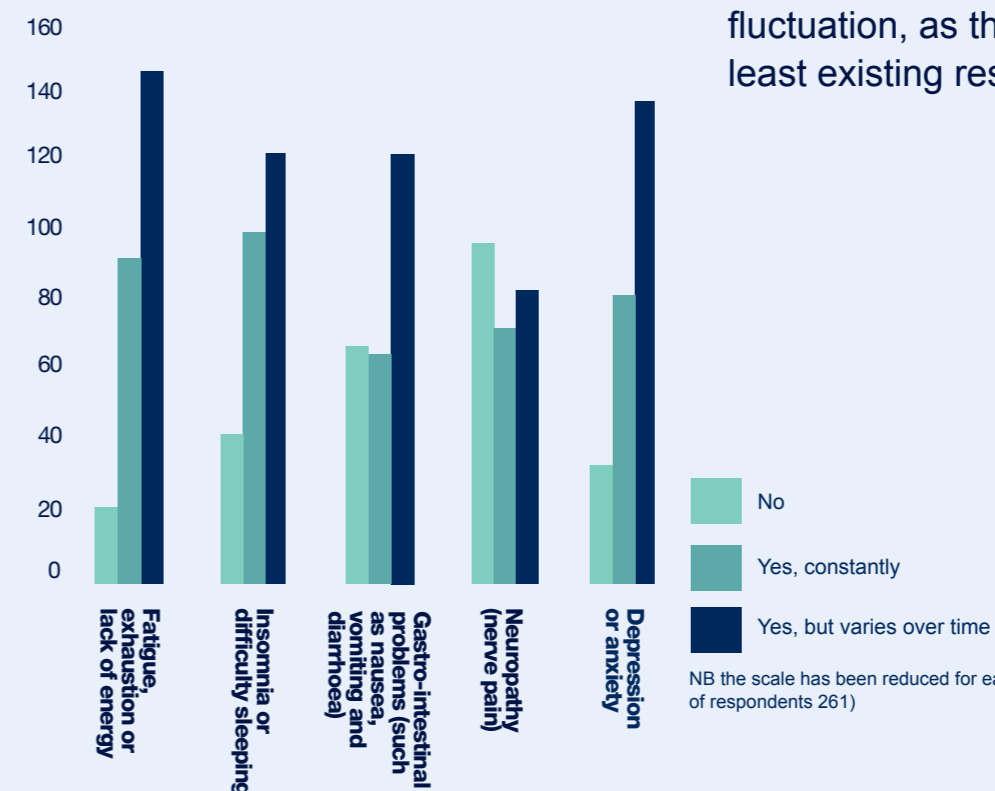
This was followed by depression or anxiety (55%), gastro-intestinal problems (such as nausea, vomiting and diarrhoea) (48%), insomnia or difficulty sleeping (46%) and neuropathy (nerve pain) (33%).

Some participants also used the free text box to report other variable symptoms. Commonly mentioned symptoms included joint pain, muscle pain, skin sensitivity/rashes/fungal infections and migraines. Less frequent HIV-related conditions mentioned included lipodystrophy and vertigo.

Participants emphasised fluctuation both with regards to when symptoms are experienced, as well as variation in the severity of symptoms.

As illustrated in Chart 1, the survey asked both about symptoms that fluctuate, and those which are experienced constantly by respondents. However, this report will focus on the findings in regard to fluctuation, as the area where there is the least existing research.

Chart 1:
HIV-related symptoms
Do you experience any of the following symptoms? If yes, please say whether the symptoms are constant or whether they vary over time



¹ Following wide-ranging concern about the accuracy and suitability of the WCA, the Government in 2010 announced that there would be five annual independent reviews with the aim of recommending improvements to the WCA - Professor Harrington chaired the first year and at the time of writing was chairing the second. The working group was chaired by the MS Society. The other members of the group were Arthritis Care, Crohn's and Colitis UK, Forward MS and Parkinsons UK.

FATIGUE, EXHAUSTION OR LACK OF ENERGY

Fatigue can be defined as a general feeling of tiredness that does not really go away, even after someone has been able to rest.² Studies into fatigue among people living with HIV suggest a prevalence of between 33% and 88%.³

Over a third of respondents (36%) to the survey said that their fatigue was constant, and only 8% said they experienced no fatigue.

“Tiredness or fatigue occurs when I do more than normal - this means, for example, spending some time every day doing voluntary work. I am far more tired than I ever used to be. Also anxiety and depression seem to be related to exhaustion, but the exhaustion is not related to the sort of activities that would leave normal people exhausted. You are just more vulnerable if you are HIV positive.”

40% of those who experienced fatigue that fluctuated over time believed that it was caused by both their HIV infection and treatment. However, more than a quarter (29%) said that they did not know what caused their fatigue.

“I quite often felt I'd 'hit a brick wall' when untreated, I wouldn't always know when that was going to happen and needed to rest when it did. Fatigue hit more often when dealing with diagnosis and starting / changing treatment.”

Very few could always or mostly predict when fatigue would hit them, with the most common experience being that fatigue was 'sometimes' predictable. A theme in comments was that certain levels of activity were associated with fatigue.

The vast majority of this group also said they experienced depression and anxiety, either constantly (20%) or on a fluctuating basis (70%).

“The fatigue has gone on for months now and when I have it I am quite incapacitated and have no choice but to limit, stop or cancel plans to do things.”

As with all symptoms there was a wide range of experiences relating to the duration of fatigue. Participants reported both the minimum and maximum duration of their fatigue. The most commonly reported responses indicated that fatigue would last between 3 hours to a day when less severe to over a week in bad cases.

“Fatigue is always there, lurking, so if I do anything for more than an hour it begins to kick in.”

Three quarters of participants with fluctuating fatigue had experienced it at least three times in the past month.

Elliot's⁴ experience

I usually feel really tired in the middle of the afternoon. If I'm working then I have to force myself to stay awake to get through the day and go to bed for maybe an hour or two when I get home. If I'm home then I normally have an afternoon nap for maybe one or two hours.

I need at least eight to nine hours sleep every night otherwise I find it more difficult to function during the day, it's mainly when I don't get enough sleep overnight that I feel more lethargic during the afternoon. However, my physical strength is definitely reduced and I think it is a side effect of the medication.

I have lost a lot of muscle from my arms and legs and now find that my elbows take a lot of the weight when I'm carrying heavy bags etc. This can lead to severe pains in the joints. Doing housework and anything physical takes me much longer than it used to and I seem to have to spread my housework over a few days rather than getting everything done in one day as I was able to do when I was healthy.

I've not had any time off sick in my current job and I've been in my current post for 16 months now. I've had a lot of depression recently, however, I've managed to continue working.

² i-base. 2010. *HIV and your quality of life: a guide to side effects and other complications*. November 2010.

³ Carter, M. 2010. Fatigue remains common in people with HIV, and often connected with social factors and mental health issues. *aidsmap* 10 June 2010. <http://www.aidsmap.com/Fatigue-remains-common-in-people-with-HIV-and-often-connected-with-social-factors-and-mental-health-issues/page/1439035/>

⁴ All quotations were provided anonymously to the survey. As no identifying personal information was collected, non-gender specific pseudonyms have been used.

DEPRESSION AND ANXIETY

People living with HIV are disproportionately affected by mental health problems including depression and anxiety.⁵ Depression and anxiety are also major barriers to work for people living with HIV.⁶

“Living with HIV is stressful, due to high levels of anxiety and awareness of the way the disease is stigmatised in society. It is hard to say whether the symptoms are as a result of the virus or of the stress of living with the virus.”

Some respondents to the survey reported that their depression or anxiety had existed prior to their HIV diagnosis, though it had increased since they had been living with HIV. 42% of respondents said they didn't know the cause of their depression or anxiety.

“I feel very depressed given the future as a “limited treatment options” patient.”

⁵ NAT. 2010. *Psychological support for people living with HIV.*
<http://www.nat.org.uk/Media%20library/Files/Policy/2010/Psychological%20support%20July%202010%20updated.pdf>

⁶ NAT. 2010. *Unmet disability, unmet needs.*
http://www.nat.org.uk/Media%20library/Files/Policy/2011/Unseen%20disability%20unmet%20needs_2.pdf

“Depression and anxiety are related to the stress of living with HIV and the impact it has had on my life, which includes financial problems, relationship problems and mobility problems and sometimes acute pain through neuropathy.”

Only one in five felt that their depression or anxiety was predictable, and 7% said that they could never anticipate when it would hit them. This uncertainty may be expected to further compromise mental wellbeing.

“I have ups and downs of anxiety and resulting depression. Again not sure if HIV-related as I am otherwise healthy.”

A third of respondents said that depression and/or anxiety hit them for a minimum of a week at a time. Over 90% of those who said that depression and anxiety fluctuated for them had experienced one or both at least once in the past month.

GASTRO-INTESTINAL PROBLEMS

Out of all the fluctuating symptoms, respondents with gastro-intestinal (GI) problems were most likely to state that these were a side-effect of treatment, with 29% citing this as the cause. A further 45% attributed their symptoms to a combination of their HIV infection and their treatment.

“I hate feeling sick more than anything else and when I have diarrhoea it is difficult to go places where I do not know if a toilet will be nearby enough.”

Diarrhoea is listed as a side-effect of almost all HIV medications and is one of the most common side-effects of treatment, although it only affects a minority.⁷ Nausea and vomiting are also associated with some drugs, and with adjusting to new treatment.

The link to treatment (and in some cases, types or quantity of food consumed), lent some predictability for some respondents, with around a quarter reporting being able to predict these ‘mostly’ or ‘always’.

⁷ i-base. 2010. *HIV and your quality of life: a guide to side effects and other complications.* November 2010.

For those who are not able to predict when fluctuating GI problems would affect them, though, these symptoms are the most difficult to negotiate socially, with a real impact on work and daily life.

Respondents with fluctuating GI problems were also very likely to report fluctuation of other symptoms: neuropathy (47% of those with fluctuating GI symptoms), insomnia (52%), depression or anxiety (62%), and fatigue (66%).

Responses to the questions on the duration of GI symptoms were spread out fairly evenly, but the most common responses were that the symptoms lasted a minimum duration of “more than a couple of days” and a maximum duration of “less than a week.”

“Explosive toileting has lasted for up to a month at times - despite following a very controlled diet designed to maintain healthy weight and combat effect of diabetes.”

The frequency of GI symptoms also varied greatly, with similar proportions saying they had had problems one to two times (32%), three to five times (33%) and more than five times (30%) in the past month.

INSOMNIA AND DIFFICULTY SLEEPING

Sleep disturbance, including difficulty falling asleep, waking during the night or very early in the morning, can have serious knock-on effects for concentration, memory, cognitive functioning, communication and mood.

Not surprisingly, among the respondents to the survey fluctuating insomnia was commonly associated with fatigue, either on a fluctuating (66%) or constant (27%) basis.

“ I have become used to adapting to poor sleep and functioning on less rest time.

Almost half of the respondents with variable sleep problems (45%) did not know the cause, and only a small proportion (18%) could reliably predict when they would be affected.

“ [I have] sleepless nights due to pain.

“ My lack of sleep is very unpredictable which is more of a problem, as even when I am very tired my sleep can be disturbed so I am still very tired the following day. I usually get a couple of nights a week when I do not sleep well.

More than a third had had problems more than five times in the previous month. 43% noted that in bad cases, their sleeping problems could last for more than a week. This can be expected to have serious consequences for their capacity to perform even basic daily tasks.

“ I am unable to focus on work, feeling like I have jet lag.

NEUROPATHY

Neuropathy (nerve pain) was a common side-effect from some of the early HIV drugs. It can also be caused by HIV itself.

“ Nerve pain can be a bummer, it creeps up sometimes when you least expect it - how can you sit in the cinema or theatre and enjoy a performance and at the same time stifle the scream when a red hot poker is stuck in your lower limbs?

It was the least commonly reported symptom in our survey, but can have a dramatic impact on quality of life. The experience of neuropathy ranges from numbness or tingling to severe pain in the hands and feet (in particular).

In NAT's survey, 23% of respondents with fluctuating neuropathy said that it was caused by their HIV, compared to 21% that attributed it to treatment and 30% to a combination of both.

“ Peripheral neuropathy means that my feet are always sore - they can get very painful at night (enough to keep me awake); or after standing/walking for more than say 15 minutes. Nothing seems to help.

This group was also most likely to say that they experienced another symptom on a constant basis - for example, 38% reported constant fatigue and 39% constant depression or anxiety.

“ As a result of the neuropathy I experience permanent numbness as well as burning sensations, cramps in my feet lasting for hours, acute unpredictable stabbing pains in the soles of my feet and shooting pain up my legs. This is not predictable but affects my ability to do a range of personal care tasks and activity including household chores and paid employment. The other annoying thing about the neuropathy is that it comes and goes in severity, no warning and never predictable.

One in five said they could never predict when neuropathy was going to affect them. There were two main dimensions of fluctuation reported: whether neuropathy was at all present; and when present, the severity of the discomfort experienced.

A third of respondents with fluctuating neuropathy said that they were affected for a minimum of a week in any one episode.

MULTIPLE SYMPTOMS

The findings also show that many people who experience one fluctuating symptom will also experience another symptom, either on a constant or fluctuating basis.

Even when a range of lower-level health problems are experienced simultaneously, symptoms can combine and interact to have an impact on everyday life which is greater than sum of their parts.

Figure 1
Respondents with fluctuating fatigue – most common other fluctuating symptoms

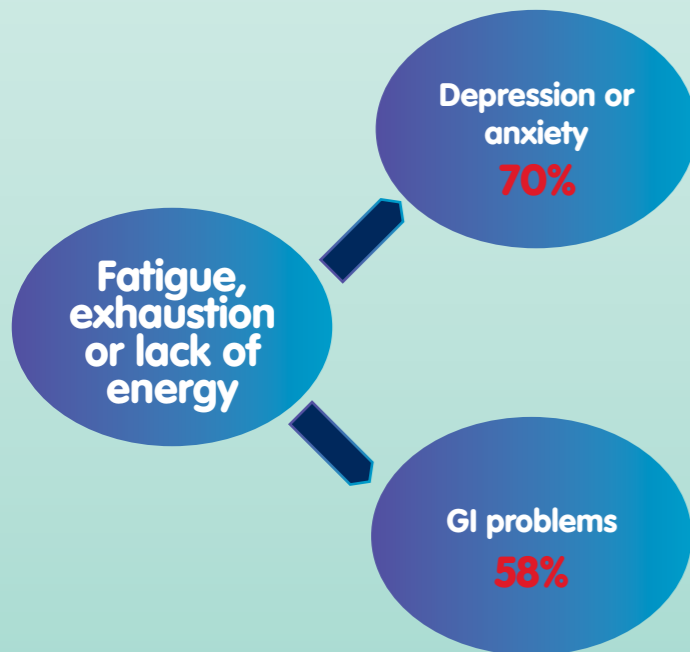


Figure 2
Respondents with fluctuating depression or anxiety – most common other fluctuating symptoms

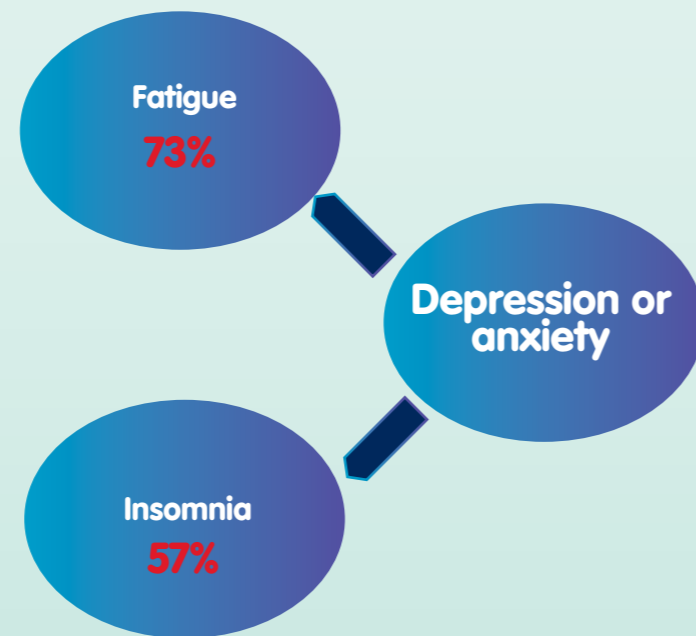


Figure 3
Respondents with fluctuating GI problems – most common other fluctuating symptoms

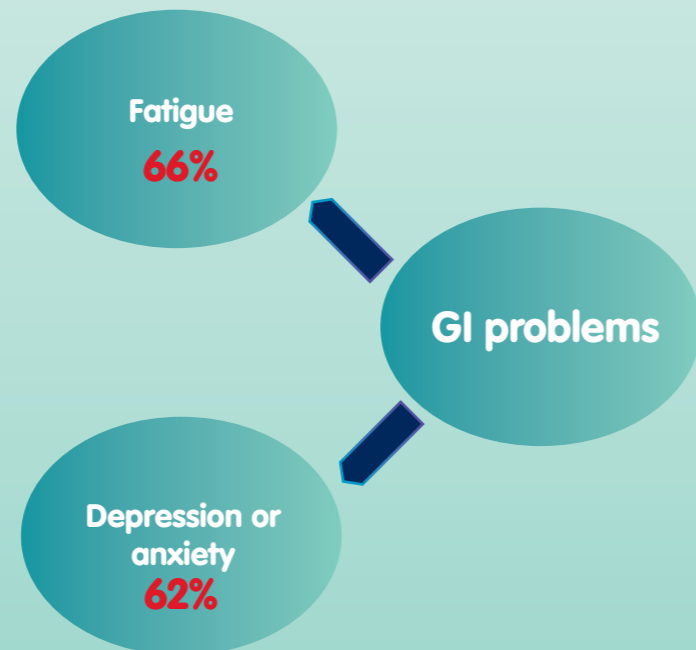


Figure 4
Respondents with insomnia – most common other fluctuating symptoms

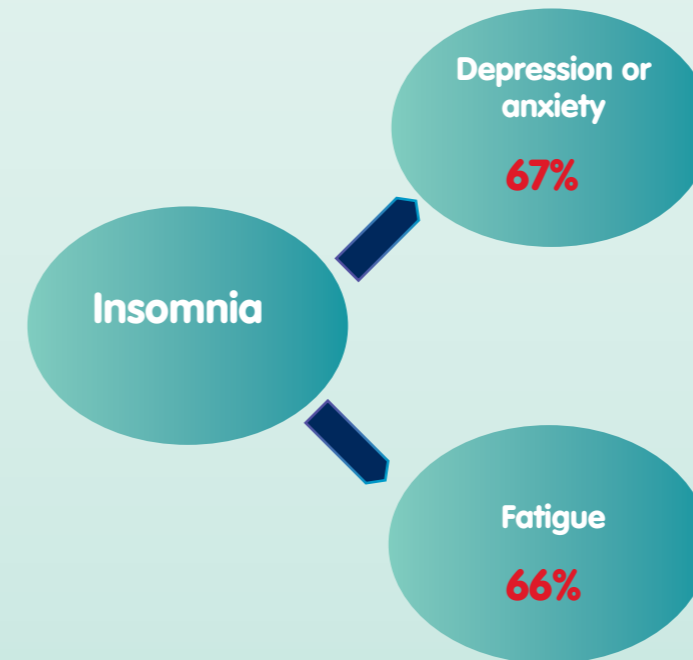
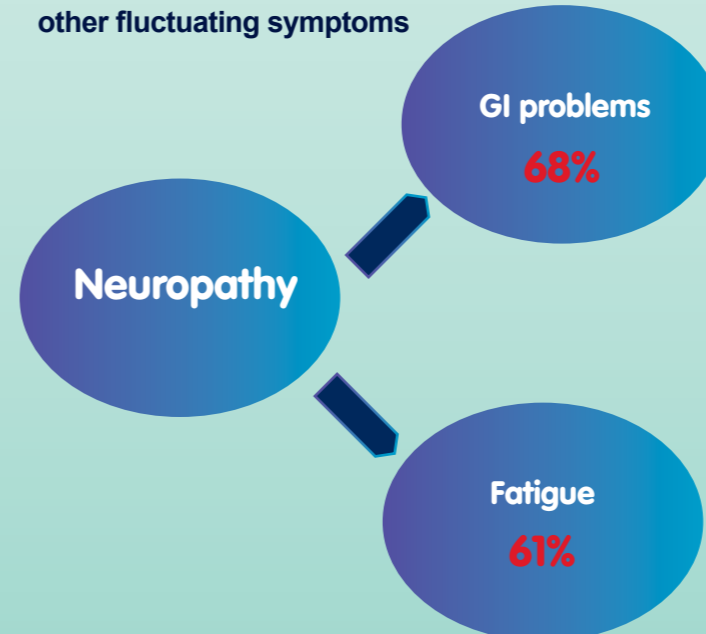


Figure 5
Respondents with neuropathy – most common other fluctuating symptoms



Figures 1 to 5 illustrate that for many people with HIV will experience more than one fluctuating symptom or side-effect of treatment. It can also be safely assumed that there are direct interactive relationships amongst some of these combinations – for example, insomnia and fatigue.

What is also striking is the frequency with which fluctuating fatigue is cited alongside every other fluctuating symptom. Fatigue has a serious impact on physical and mental functioning, but can appear more 'vague' than the other symptoms and side-effects described, and with less obvious options for treatment.

Responses to the survey also showed that fatigue was problematic socially because it is an imprecise concept – people are less likely to consider 'feeling tired' as being as serious a health problem as neuropathy, for example. Yet both have a debilitating impact, as illustrated by the comments to the questions on work and daily life.

Impact on WORK AND DAILY LIFE

The survey was created with a view to gauging the impact that fluctuating symptoms had on daily life for people living with HIV. The responses given on the specific symptoms shed some light on this - in particular, the frequency with which respondents said that they did not know the cause of their symptoms.

The feeling of being 'in the dark' about these daily health challenges appeared for many respondents to have an impact on mental and emotional health, confidence and self-esteem.

I can't honestly say whether the symptoms are specifically HIV-related or not. Some of them may be age related, some lifestyle and some due to other medical conditions. However I think it is more than likely that the gastro symptoms are related to HIV treatment.

There were also several free-text comments provided which indicated that some people living with HIV wished to discuss their experience of fluctuation more with those involved with their clinical care.

The doctors don't seem to bother with the neurological problem so with one excuse or another they look only about HIV.

The high response rate to the survey and detail provided by many respondents in the comments section (sometimes for every question), made it clear that these are issues that are very important in the lives of people living with HIV, but there are not always opportunities for these experiences to be heard.

It's difficult to 'decide' whether my health issues are HIV related, treatment related, or age related... as such it's often hard to decide the appropriate action to take, and to who to turn to for advice or treatment

Over 20 years living with HIV I've learnt to know my body and feel when something is wrong or not with my health, but sometimes the doctors make doubt about my feelings.

Generally doctors don't care, and the public don't notice HIV at all any more.

Thanks for conducting this survey - I was beginning to think that "we" should all be fit and well since party politics and busy clinics effectively decided as such.

Ali's experience

Exhaustion and fatigue are a constant daily battle. Medication often contributes to disturbed sleep patterns/vivid dreams which lead to waking un-refreshed and still tired. I recently caught a bacterial infection which caused severe bloating and stomach cramps - the doctor said it would normally clear within a few days but the healing process can often take longer when HIV positive/on medication. This particular complaint took about 7-8 days to pass.

Being HIV positive often affects self-esteem and confidence and has directly contributed to choices surrounding my personal ability at work, etc. Unemployment and underachievement often trigger feelings of low self-esteem. Many HIV drugs (including mine) can cause sudden mood swings and feelings of depression. Social factors contribute to this as well - issues surrounding disclosure to friends/family/work often lead to increased stress levels and anxiety.

Work situations can be very complicated and awkward - I often tell my employers my status but people often think you are 'taking advantage' when you have a day off (perhaps due to fatigue or a particularly bad night or just a general feeling of being unwell) only to return the next day seemingly happy and healthy on the outside. This makes me feel guilty about putting my health first and I will often go to work when I know that I really should rest - feeling guilty about resting and recovering is a big part of my life!

WORK

Around 40% of respondents said they were not currently in work. Fluctuating neuropathy (49%) and GI problems (46%) were most associated with not working.

Respondents were asked, “On how many occasions in the past 4 weeks have the symptom(s) significantly affected your ability to work?” They were asked to include “any occasions when you have gone to work and found it much more difficult than usual, as well as times you have had to call in sick, or change your working hours.”

“ I work from home together with my partner and between us we manage my symptoms and ability to work as well as the work-load I undertake.

The most frequent disruption due to fluctuating symptoms was reported by those with variable fatigue, with half of those currently in work reporting at least three such occasions over the past month.

“ I am a student and have had to miss lectures due to symptoms.

“ I have just started a job, I am 3 days in after being out of work for a year and a half....I am knackered but happy to be working, keeping my mind occupied but worry about being able to cope or remember simple tasks....

Table 1 Respondents in work - impact of fluctuating symptoms on work

| On how many occasions in the past 4 weeks have the symptom(s) significantly affected your ability to work? | | | | | |
|--|-----|-----|-----|-------------|-------------|
| Fluctuating symptom | 0 | 1-2 | 3-5 | More than 5 | No response |
| Depression or anxiety | 37% | 30% | 15% | 15% | 4% |
| Fatigue, exhaustion or lack of energy | 11% | 40% | 25% | 25% | 0% |
| Neuropathy (nerve pain) | 40% | 34% | 4% | 20% | 3% |
| Gastro-intestinal problems | 39% | 30% | 11% | 14% | 5% |

Protections for people living with HIV against discrimination in recruitment and employment have been significantly strengthened with the introduction of the Equality Act 2010.⁸

Research has also shown that most people living with HIV in employment don't find that their health is an issue at work.⁹

However, even though people living with HIV have the right to reasonable adjustments at work and a working environment free from harassment and discrimination, there can be challenges in practice.

HIV is still not a well-understood condition among the general population,¹⁰ and employers' attitudes may not reflect the reality of living with HIV today.

The ongoing stigma associated with HIV means that people living with HIV who have experienced prejudice may be hesitant to disclose their status at work, even though this means they are not able to access all their entitlements to reasonable adjustments at work.¹¹

While all people with disabilities are entitled to reasonable adjustments – such as flexible hours or some leave for a clinic appointment - their success in managing their health and treatment needs around their work demands is often determined by the understanding shown by their employer and colleagues.

“ Of course I can predict that the bowel movements will be looser if I haven't eaten little and often ... but when I don't want to eat, I just don't want to eat period. How do I predict when I'm going to be tired and want to sleep all day - and when I know I want to sleep all day I try not to because I won't sleep at night ... or will I? How do you work round this kind of thing unless you work for yourself or have an extremely understanding employer? Sometimes it gets down to “what's the point?” because working only makes you even more fatigued it would be easier not to work at all.

8 NAT. 2010. *HIV @ Work*. <http://www.nat.org.uk/Media%20library/Files/Policy/2010/5180-NAT-A5-HIV-Work-Employees.pdf>
 9 NAT. 2009. *Working with HIV*. <http://www.nat.org.uk/Media%20library/Files/Policy/Our%20thinking/Employment%20summary%20report%20-%20FINAL%20August%202009.pdf>
 10 NAT. 2011. *HIV: Public knowledge and attitudes*, 2010. http://www.nat.org.uk/Media%20library/Files/Communications%20and%20Media/HIV_awareness_report_2011DOWNLOAD.pdf
 11 NAT. 2009. *Working with HIV*. <http://www.nat.org.uk/Media%20library/Files/Policy/Our%20thinking/Employment%20summary%20report%20-%20FINAL%20August%202009.pdf>

DAILY LIFE

Respondents were asked about the impact on their daily life, including social occasions, exercise and leisure, getting out of the house, shopping, preparing food, basic housework and personal care.

“The exhaustion and depression combine to make it difficult to do things that are a part of every day life. I do not feel like leaving the house unless I have to, which is why I do voluntary work to ensure that I do get out of the house. However, I do leave things until it is essential to do them - for example, I may put washing on but then take two or more days to actually hang it out.

Those with fluctuating fatigue were most likely to say their symptoms had “significantly affected” their daily life - 95% said that this had happened on at least one occasion in the past four weeks, and 38% had been affected more than five times in that period.

“Activities such as preparing food, shopping and basic housework affect me ...I find that I can't remember a lot of things I've done or have to do. I lack motivation.

Those whose neuropathy fluctuated also reported a high number of disruptions to their daily life, with 37% reporting more than five occasions in the past four weeks when they had been significantly affected by their symptoms.

The responses to the questions about daily life illustrate clearly that the social dimensions of these fluctuating symptoms are the most distressing for those that experience them.

“Fatigue combined with Peripheral Neuropathy is the most debilitating side effect of HIV/HIV medication, mainly because it occurs randomly. This random occurrence affects my day to day lifestyle as nothing can be planned with any certainty. Work, relationships, holidays ... everything becomes a lottery as to whether it can be completed. This makes an already complicated life more difficult.

Disclosure is not only an issue in a work context – some people living with HIV may not feel able to talk to their friends or family about their HIV.

“[I am] putting things off due to lack of energy. Not going out as I don't want friends to think I am not enjoying myself when I'm just very tired.

Even where disclosure has not been an issue, many respondents talked about the reaction of others, some clearly feeling that they let down their friends and family by not feeling reliably well.

The nebulousness of some of the symptoms, lack of information about the cause and unpredictability of the impact can lead to a sense of weariness about constantly ‘spoiling’ social occasions with last-minute health problems. This feeling of being ‘socially awkward’ in turn can lead to isolation from even basic social interaction.

“Lately more and more I have the tendency to isolate myself, not to have to face my family and friends. I have a hard time to accept them seeing on me that I am totally unhappy without being able to help me. I'd rather stay at home, not showing myself.

Kerry's experience

My doctors are reluctant to implicate ARVs in any symptoms (at least to my face), but I know that ARVs cause some of the problems, even the very minor ones, like neuropathy.

Some of my symptoms begin when I've been doing anything for more than an hour, sometimes longer - in short, I have no stamina. Anxiety, or just over-stimulation, makes them worse because I have an over-active nervous system too, for which I've taken beta-blockers since I was 18.

Fatigue is always there, lurking, so if I do anything for more than an hour it begins to kick in. I have no stamina and so never leave home for long. I have to carefully plan my shopping and cleaning etc. so I can do it all in stages.

It takes four or five toilet visits over the course of each morning and early afternoon (at least) to adequately clear my bowels. If something interferes with my very solitary routine or with my digestive tract (which it often does) then I get irritable bowel syndrome, sometimes agonisingly so.... Socialising is very uncomfortable.

Whilst I want to work a regular job in order to re-engage the wider world, the huge gap in my CV, plus the looming economic climate, more than likely means that when my time on incapacity benefit comes to an end I'll end up in an uninspiring job that is not only unsuitable for my physical health but that leaves me bereft of energy to continue the kind of work upon which my mental health depends.

CONCLUSION

There is no doubt that HIV is a complex condition, and that knowledge about HIV and how to treat it has improved dramatically in a very short space of time. However, as improvements in treatment options have allowed people living with HIV to live longer, healthier lives, it is important to keep in mind that for some people HIV-related health problems will always make life more complicated. This report has focused on the impact of fluctuating and often unpredictable symptoms, which has not yet been considered in scientific research into HIV-related symptoms and side-effects of treatment.

The responses to NAT's survey revealed that fluctuating symptoms are a cause of real distress for some people living with HIV and place significant barriers on work, daily living and social participation. Fatigue stood out as the most common symptom, and was frequently experienced alongside all the other symptoms addressed in the survey. The cumulative effect of multiple symptoms and side-effects, even at a lower level and only on an occasional basis, can be physically, mentally and/or emotionally debilitating. However, even the least reported symptom, neuropathy, was experienced on a fluctuating basis by a third of respondents in this survey.

It is now vital to establish, through further research, the extent to which the experiences identified in this study are present in the

UK HIV positive population in general. The challenges associated with researching fluctuation over a period of weeks or months have already been acknowledged. However, there are alternative research designs possible, such as asking patients to keep diaries of their symptoms. NAT urges those involved in HIV research to consider these questions and the impact of fluctuating symptoms on quality of life more generally in future research on HIV treatment and care.

The findings also suggest some more immediate actions. It is clear from survey responses that fluctuation around HIV is not a simple matter of experiencing good health on some days, and worse health on others. Participants were not merely experiencing 'blips' in otherwise consistent good health. The variation and unpredictability of their symptoms was often as much of a problem as the symptoms themselves. It is therefore essential that this true impact of fluctuation be properly taken into account when assessing the needs of people living with HIV in relation to benefits, social care, and accessing employment.

In addition, it was very clear from comments made by participants that there is a need for greater consideration of the impact of fluctuating symptoms within clinical care relationships. Increasing opportunities for discussion of these issues will help improve patients' wellbeing, as well as add to healthcare professionals' knowledge of the extent to which HIV-related symptoms are an issue for their patients, including their ability to adhere to treatment.

RECOMMENDATIONS

1

More scientific and clinical studies are needed around: the most common fluctuating symptoms associated with HIV; the prevalence, severity, frequency, predictability and duration of these symptoms; and how best to support people living with HIV in managing symptoms and side-effects of treatment.

2

Assessments for disability and illness-related benefits such as Employment and Support Allowance and Personal Independence Payment should take into account the full range of barriers fluctuating symptoms present to participation in work and other daily activities. In addition to the current focus on the frequency and severity of symptoms, assessments must also consider the impact of unpredictable fluctuation and the way in which multiple, lower-level symptoms can combine to have an impact that is greater than the sum of their parts.

3

At present, high eligibility thresholds prevent many people with HIV from accessing social care, even when they have clear health-related support needs. Assessment criteria should consider the impact of fluctuation and the cumulative impact of multiple, lower-level symptoms on people living with HIV.

4

Clinics should consider how to increase opportunities for discussion between patients and clinical staff about the impact of fluctuating symptoms and side-effects of treatment. This could include discussion within existing appointments and in additional sessions with specialist nurses and health advisors.

5

Organisations who support people living with HIV should continue to work to raise awareness among employers and people living with HIV of the right to ask for reasonable adjustments at work, to help people with fluctuating HIV-related symptoms to find and retain employment.

Appendix A:

ABOUT THE SURVEY

The survey was developed by NAT with input from experts in HIV-related symptoms and side-effects. Resources such as the i-base guide *HIV and your quality of life*¹² were also referred to in drafting the survey and interpreting the responses. The questions focused on four dimensions of fluctuation: the type of symptom, predictability, duration and frequency. The full list of questions can be found in Appendix B.

NAT considered existing quality of life scales in the development of the survey questions, such as the MOS-HIV questionnaire.¹³ However, there were no previous studies to draw upon which sought to collect information about the specific fluctuating health issues which people living with HIV report as being the main barriers to work and participation – such as fatigue, gastro-intestinal problems and depression. One of the main reasons for the gap in research in this area is the challenge of capturing information about fluctuation over a sufficiently lengthy period of time to be meaningful (at least four weeks).

Most studies about quality of life are based on patient recall. However, it is not usually considered good research design to ask participants in a scientific study to recall detailed aspects of their health from longer than a week ago.

As this was an initial, non-scientific survey with the aim of capturing how fluctuation was experienced by people living with HIV and the impact on their life – as opposed to the extent to which particular symptoms were experienced by HIV positive people overall – NAT decided to move away from this usual best-practice approach.

Respondents were asked to recall aspects of their health in the previous four weeks.

This time-frame was chosen as a compromise. Ideally, we would learn about fluctuation over a three or even six month period, but it was unrealistic to expect respondents to be able to report accurately about their health over these longer periods. One of the free-text questions at the end asked respondents to consider their life over the past six months, and this longer time-frame is reflected in some of the quotations presented.

The survey was self-administered, with participants able to choose to respond to all or only some questions. Likewise, every question had an optional open text box, so that respondents could include as much or as little personal detail as they felt comfortable with sharing.

The online survey creator SurveyMonkey was used to allow people living with HIV to respond to the survey anonymously. NAT is aware that the use of an online tool limits the population of possible respondents to those that have access to the internet. However, it had the advantage of reaching many respondents quickly, and in a low-cost way. NAT also asked HIV support organisations to encourage their clients to fill in the survey – some will have been able to offer IT facilities to assist with filling in the survey. In the space of a month,¹⁴ 265 people participated in the survey (although not all responded to all questions).

The survey was titled “NAT survey: HIV-related symptoms”. There was no mention of fluctuation in the title, to reduce the likelihood that only those who experienced variability in their health would respond.

However, the email sent with the survey to promote it among HIV organisations included reference to the fluctuating conditions working group, so this effect may still have occurred. In addition, it is

likely that the reference to ‘symptoms’ in the title would have engendered more interest from people with HIV who do experience health problems than those who do not. Finally, we can assume that more generally, a survey of this kind will appeal more respondents with problems to report.

However, while it can be safely assumed that the respondents to the survey were more likely to experience some form of HIV-related symptoms of treatment side-effects than the HIV positive population generally, this does not reduce the strength of the findings in terms of describing the impact that these experiences have on the quality of life of this group. There is limited commentary provided on the findings as there is a limited ability to generalise from this group of respondents to all people living with HIV. Instead, the discussion of the findings places particular weight on the individual experience of fluctuation, with the inclusion of many quotations and some case studies of participants in the survey.

¹² Available online at <http://i-base.info/guides/side>

¹³ The Medical Outcomes Study HIV Health Survey (MOS-HIV) is a brief, comprehensive health status measure developed in 1987 that has been used extensively in studies of HIV. <http://www.jhsph.edu/mos-hiv/index.html>

¹⁴ The timing of the survey was constrained by the external deadline set upon the work of the fluctuating conditions working group.

Appendix B: THE SURVEY

About your symptoms

This survey is about HIV-related symptoms that vary over time. It will ask about any symptoms you experience that are not constant, but change over time.

NAT (National AIDS Trust) is conducting this survey to help us advocate for HIV positive people. We want to make sure that people who have these types of symptoms are properly assessed for illness and disability-related benefits.

Only answer the questions you want to. But, if you decide not to answer all of them, please click through to the end and click “done” - otherwise your responses won't be saved.

Thank you for your help and your time.

1 Do you experience any of the following symptoms? If yes, please say whether the symptoms are constant or whether they vary over time.

| | No | Yes, constantly | Yes, but varies over time |
|---|----|-----------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | |
| Insomnia or difficulty sleeping | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | |
| Neuropathy (nerve pain) | | | |
| Depression or anxiety | | | |

Other symptoms - are these constant, or do they vary?

2 What is the cause of the symptom(s)?

| | HIV-related | A side effect of HIV treatment | Both HIV and my HIV treatment | Don't know | I don't have this symptom |
|---|-------------|--------------------------------|-------------------------------|------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | |
| Insomnia or difficulty sleeping | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | |
| Neuropathy (nerve pain) | | | | | |
| Depression or anxiety | | | | | |

Other causes - please explain.

Predictability of symptoms

3 Can you predict when the symptom(s) are likely to occur?

| | Always | Mostly | Sometimes | Hardly ever | Never | I don't have this symptom |
|---|--------|--------|-----------|-------------|-------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | | |
| Insomnia or difficulty sleeping | | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | | |
| Neuropathy (nerve pain) | | | | | | |
| Depression or anxiety | | | | | | |

Other - please explain.

Duration of the symptoms

4 What is the MINIMUM amount of time you experience the symptom(s) in any one episode?

| | Up to 3 hours | 3 hours to 1 day | 1 - 2 days | Over 2 days but less than a week | A week or more | I don't have this symptom |
|---|---------------|------------------|------------|----------------------------------|----------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | | |
| Insomnia or difficulty sleeping | | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | | |
| Neuropathy (nerve pain) | | | | | | |
| Depression or anxiety | | | | | | |

If you said 'a week or more', please specify.

THE SURVEY

5 What is the **MAXIMUM** amount of time you experience the symptom(s) in any one episode?

| | Up to 3 hours | 3 hours to 1 day | 1 - 2 days | Over 2 days but less than a week | A week or more | I don't have this symptom |
|---|---------------|------------------|------------|----------------------------------|----------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | | |
| Insomnia or difficulty sleeping | | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | | |
| Neuropathy (nerve pain) | | | | | | |
| Depression or anxiety | | | | | | |

If you said 'a week or more', please specify.

Frequency of symptoms

The next two sections will ask you how often symptoms have affected you in the past 4 weeks. Answer as best as you can remember.

6 On how many occasions in the past 4 weeks have you experienced these symptoms?

| | 0 | 1-2 | 3-5 | More than 5 | I don't have this symptom |
|---|---|-----|-----|-------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | |
| Insomnia or difficulty sleeping | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | |
| Neuropathy (nerve pain) | | | | | |
| Depression or anxiety | | | | | |

If you said 'more than 5', please specify.

7 On how many occasions in the past 4 weeks have the symptom(s) significantly affected your ability to work?

Include any occasions when you have gone to work and found it much more difficult than usual, as well as times you have had to call in sick, or change your working hours.

| | I'm not currently in work | 0 | 1-2 | 3-5 | More than 5 | I don't have this symptom |
|---|---------------------------|---|-----|-----|-------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | | |
| Insomnia or difficulty sleeping | | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | | |
| Neuropathy (nerve pain) | | | | | | |
| Depression or anxiety | | | | | | |

If you said 'more than 5', please specify.

8 On how many occasions in the past 4 weeks have the symptom(s) significantly affected your daily life?

Include any occasions when you have gone to work and found it much more difficult than usual, as well as times you have had to call in sick, or change your working hours.

| | I'm not currently in work | 0 | 1-2 | 3-5 | More than 5 | I don't have this symptom |
|---|---------------------------|---|-----|-----|-------------|---------------------------|
| Fatigue, exhaustion or lack of energy | | | | | | |
| Insomnia or difficulty sleeping | | | | | | |
| Gastro-intestinal problems (such as nausea, vomiting and diarrhoea) | | | | | | |
| Neuropathy (nerve pain) | | | | | | |
| Depression or anxiety | | | | | | |

If you said 'more than 5', please specify.

THE SURVEY

Other comments

This final section will ask you to explain your symptoms in your own words.

9 **Think back over the past 6 months. How have changing symptoms related to your HIV or HIV treatment affected your daily life, including work?**

Provide as many details as you like about:

- types of symptoms
- how often these occur
- if you can predict when symptoms will affect you
- how long the symptoms last

10 **Please give any other comments about how you are affected by HIV-related symptoms that vary over time.**

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