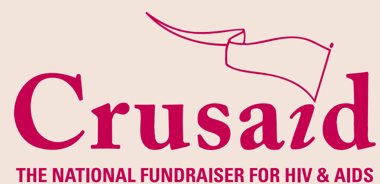
Poverty and HIV

Lessons from the Hardship Fund



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4. Foreword

Poverty and ill-health are problems that go hand in hand, often creating a vicious circle of deprivation. As a Shadow Secretary of State for both Social Security and Health, I was increasingly aware of how true this was for many people in Britain. Sadly, this is even more the case today. It is especially so for those with long term and chronic health conditions such as HIV.

While many people appreciate the global impact of HIV and the way it has devastated many African economies – and threatens more – far less attention has been given in the UK to the personal impact HIV can have upon individuals closer to home. Many people living with HIV find that they must cope with not only the virus, and the stigma and discrimination that often go with it, but unexpected economic consequences also.

Problems can range from the sudden impact of an unexpected HIV diagnosis causing homelessness, loss of job or even domestic violence, to the long term impacts of ill-health – debt, depression and difficulty in coping with medication. Each of these can have an impact on a person's health and that ill-health, in turn, causes further economic problems for them.

Whilst the real remedy for these problems lies in long term changes – fighting prejudice, supporting people to maintain employment or find new skills and the improved management of HIV – often quite small things can help to prevent a further slide into deprivation. The Hardship Fund, founded by Crusaid in 1987 and now managed by Crusaid with Terrence Higgins Trust, Elton John AIDS Foundation and MAC AIDS Fund, exists to help with these small but often pivotal expenses.

This publication sets out some basic facts about the poverty faced by people with HIV in the UK, the ways in which poverty and HIV interact and the role of the Hardship Fund in tackling some of the problems. It does this alongside real life stories of how individuals living with HIV have benefited from the Hardship Fund, often using small amounts of money to make a real difference to their futures. It is a story of problems, challenges, and of some of the ways in which we can address them.

Rt Hon Chris Smith
MP for Islington South & Finsbury
Patron of Crusaid and Trustee of Terrence Higgins Trust

6. The Hardship Fund: key facts and key changes

The Crusaid Hardship Fund, in partnership with the Terrence Higgins Trust, Elton John AIDS Foundation and MAC AIDS Fund, helps individuals across the UK to cope with poverty and HIV. The Fund provides small grants for basic necessities, ranging from transport to a hospital appointment or basic food and clothing, to items such as washing machines. Every application is assessed by social workers and by Crusaid, to ensure that only those in greatest need are assisted – and that funding is not available from any other source.

- Last year (2002) the Hardship Fund gave out almost three quarters of a million pounds (£723,714) – an increase of 47% in just two years.
- In total there were 4,195 awards of money to 3,183 people in 2002, compared to 2,691 awards to 1,960 people in 2000.
- People using the Fund need to do so more often than in the past; in addition to the general increase in the numbers of people applying, the number needing to apply twice within a single year has almost doubled between 2000 and 2002, from 408 to 808.
- Different groups of people living with HIV are using the Fund more; gay men receiving help increased by 14% over the past three years, while those born in Southern Africa increased by 38% and those originally from Latin America almost trebled (from 270 to 798).
- Average weekly income of applicants to the Fund has decreased dramatically over the past few years, from £93.79 a week in 1999 to £65.08 a week in 2002. Data for 2003 suggests that this downward trend continues, with an average weekly income for applicants so far of £57.21.
- More women are applying to the Fund for help than ever before, with 2,064 awards in 2002 compared to 1,176 in 2000. Levels of awards to men and women are now almost equal, and women are experiencing similar levels of deprivation to men; female weekly income is running at an average of £57.98 in 2003 compared to £56.26 for men.
- People applying for help with debt relief, either for general debt or for housing debt, increased from 13 in 2000 to 103 in 2002.
- Although funding provided for "white goods" (washing machines, cookers, etc.) has fallen over the past three years, funding for essentials such as beds and basic household repairs has almost doubled in the last three years from £11,982 to £20,638.

Terrence Higgins Trust

Terrence Higgins Trust was set up in 1982 in memory of one of the first people to die with AIDS in the UK. It is now the UK's leading HIV charity, and one of the largest in Europe. People with HIV are involved with the charity at all levels and THT has centres across England and Wales, with over 250 staff and more than 800 volunteers.

THT's objectives are to reduce the spread of HIV and promote good sexual health; to provide services which improve the health and quality of life of those affected; and to campaign for greater public understanding of the personal, social and medical impact of HIV.

Services include:

- THT Direct – a national telephone helpline and email service offering information, advice and support on all issues relating to HIV and sexual health
- Publications covering a wide variety of issues related to HIV and sexual health
- Targeted health promotion campaigns for people at risk of and living with HIV
- Counselling and emotional support
- Peer support for people living with and affected by HIV
- Specialist legal and financial advice
- Lobbying and campaigning for the rights of people with HIV

Crusaid

Crusaid is the national fundraiser and leading independent grant maker for HIV and AIDS in the UK. Recognised nationwide as a charity that efficiently disburses the monies raised through the generous support of our donors, Crusaid is determined to make a lasting difference to the quality of life of people living with HIV and AIDS living in the UK and overseas, allowing them to obtain and retain dignity, health and independence.

As well as running the Hardship Fund, Crusaid manages both a domestic and international project programme and supports vaccine research.

The national Hardship Fund has assisted almost one quarter of the HIV positive people diagnosed in this country, and has just disbursed its 25,000th grant.

To fund this and many of our other projects, Crusaid relies on the support of our donors, benefactors and partners; providing a community-based response to the HIV/AIDS epidemic. With more people infected and affected by HIV/AIDS than ever before, the calls for our help have never been greater.

8. HIV discrimination:

the facts

Two recent national surveys of people living with HIV in the UK show widespread experience of discrimination against people living with HIV. In *What do you need? (Sigma Research, 2002)*, the largest survey ever undertaken of people with HIV in the UK, 20% of respondents had experienced discrimination in the previous 12 months. Discrimination on the basis of HIV status was the most reported, with 68% (1,238) of respondents having experienced this kind of discrimination in the previous 12 months.

The *National Consultation of people with HIV on the National Sexual Health and HIV strategy (Terrence Higgins Trust/UK Coalition)* undertaken in the previous year, found that almost 80% of people with HIV had experienced some sort of discrimination or prejudice in the years since their diagnosis. Over half of them had experienced this from friends. Shockingly, around 45% of people experiencing discrimination said they had done so at the hands of health professionals, with GPs and dentists being named most frequently.

Recent surveys have also shown that some people with HIV are more likely to experience discrimination than others, and this may well be due to "multiple discrimination", where someone's gender, sexuality or race comes into play alongside their HIV. A survey of 435 African people with HIV in the UK found three times greater experience of discrimination than white people with HIV in the UK *(Project Nasah, Sigma Research, 2003)*. Another survey of people with HIV in London found that black people with HIV were more than twice as likely to be unemployed as white people, despite having broadly similar qualifications *(Erwin J et al., Pathways to HIV testing and care by black African and white patients in London: Sex. Transm. Inf., Feb 2002)*.

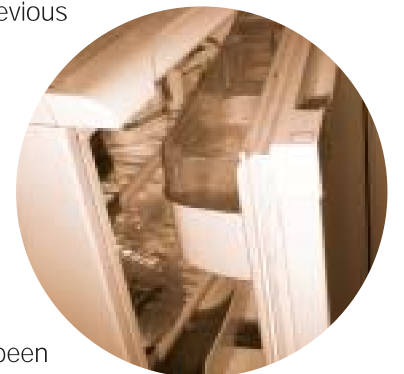
the experience

Mark, 37 and single, had lived all his life on a housing estate in the North East. Recently, his mother died and he applied to take over the tenancy of the property they had lived in.

During the process of transferring the tenancy to him, the local authority sent a letter mentioning his HIV diagnosis to the wrong address. The person who received the letter copied it to local residents and placed further copies of it on lamp posts around the area, making Mark's HIV status completely public. This resulted in serious and ongoing physical and emotional abuse for Mark as people tried to drive him from the neighbourhood. At the height of the problem, both anti-gay and anti-HIV graffiti were daubed on his door and walls, and tins of paint were thrown through his windows, damaging many of his belongings.

Although at first the local authority refused to do anything beyond apologising, eventually a transfer was offered to a safer flat in a new town. However, Mark was only given 14 days to move in and was told that he could not get a Social Fund grant, despite being on benefits, because he was still paying off a previous amount loaned after earlier damage to his flat.

The Hardship Fund located a specialist gay removal firm which would transfer what was left of Mark's belongings to the new flat with discretion. Nobody on his old estate knew where he had moved to. The Fund also bought him a new fridge to replace the previous one, which had been damaged by the vandals. Total cost was £350.



Mark has now settled into his new home. He has made friends and been able to start work and get off benefits. Living in a more supportive environment has helped him to rebuild his confidence in people and to be more positive about his diagnosis and his future. For a small amount of money and a little emotional support and advice, Mark effectively has a new lease of life.

10. Child support needs:

the facts

There are currently around 1,000 children living in the UK who have been diagnosed with HIV. Many thousands more are affected by their parents or brothers and sisters having the virus.

HIV can affect a child's life in many ways beyond the possibility of illness. For many families, when to tell a child that they have a life threatening condition is a major concern, especially if they may have to have treatment. Living with HIV can also affect a child's access to a good education and to healthcare services. The possibility of losing a parent, or caring for them through illness and death, can also have a direct psychological impact. *(Lwin R, Melvin D, Journal of Child Psychology and Psychiatry, vol. 42, no. 4, May 2001)*

The Hardship Fund is available to both adults' and childrens' needs, and the amount awarded specifically for childrens' items rose by just over 20% between 2000 and 2002. Figures from the Child Poverty Action Group (CPAG) show that in 1999/2000 there were 4.3 million children living in poverty in the UK (defined as below half of average income after housing costs). This represents a third of all children in the UK, a dramatic jump from the 10% of children living in such poverty in 1979.

Over a third of the 1,821 people with HIV surveyed by Sigma Research for *What Do You Need?* said they found their household bills difficult to meet, and CPAG statistics show that families report greater likelihood of poverty than single people. This is matched by the Hardship Fund's experience over the past three years, with awards to cover personal debts rising from £1,761 to £8,366 and awards to cover ordinary living expenses rising from £187,734 to £420,511.

the experience

Sarah is a professional, middle-aged woman living in a small community in the Midlands, who adopted two young brothers. One of the children had HIV and began to attend a local hospital in order to maintain his health.

Unfortunately, one of the therapists discussed the child's case in the public hospital dining room, within earshot of someone who knew the family. The visitor spread the story, and within a short time the Headmaster of the child's school refused to allow him into the school. The boys changed schools, but a teacher in the second one again refused to have him in her class. Matters became so heated in the neighbourhood that local residents besieged the family home one night, causing Sarah and the children to flee for their safety to a local café dressed only in their nightclothes.

In order to provide a safer environment for the children, Sarah had to move to a new city away from her friends and her good job. She began to seek work and found somewhere to live, but the children were extremely traumatised, crying constantly and having trouble eating and sleeping.

Sarah managed to find a specialist facility which would provide child counselling in this kind of situation, but had used most of her personal savings to fund their relocation. Although the treatment itself was funded, the associated costs of travel and accommodation were not. The Hardship Fund stepped in and paid the associated costs for a two-week intensive counselling programme for the family. In all, this cost £400.

The family have told the Fund that this support was invaluable in helping them rebuild their lives. Although the children have emotional scars that may never heal, they now feel safe in the new environment and able to move on with their lives.

12. Problems faced by asylum seekers:

the facts

Many people in the UK are unaware of the reality of life for people who come here seeking asylum. Applicants receive only 70% of the minimum normal income support level. Currently children under 16 receive £33.50 per week, adults get £37.77 and a couple £59.26, for everything they may need. Those who leave their allocated accommodation for any reason (including violence or abuse, or to be nearer to specialist healthcare) lose even this support.

Since the introduction of the 1999 Immigration and Asylum Act, many asylum seekers with HIV have been dispersed to areas where the medical services have little experience of their particular needs, such as treatment for pregnant women or for children. Some have been asked to travel back to London to access specialist services, although they receive no special funds for this.

In a recent national survey of people with HIV in the UK, those with the lowest incomes were those seeking leave to remain in the UK, who had to survive on vouchers and whatever social support they could find. Many of these people wanted to work in order to earn money but could not do so because of Home Office regulations. *(What do you need? Sigma Research, 2002)*

Despite claims of the opposite in the press and by politicians, migrants actually make a net contribution to the UK's finances. In 1999/2000 migrants in the UK contributed £31.2 billion in taxes and consumed £28.8 billion in benefits and state services. This is roughly equivalent to saving the country an extra 1p on the basic rate of income tax. This is, of course, only one aspect of the economic contribution that migrants make to the UK. There are wider benefits which migrants bring, through their skills and experience, and by setting up new businesses and creating new jobs, for example. *(The migrant population in the UK: fiscal effects, Research, Development and Statistics Directorate, Home Office, 2002)*

the experience

Viola is a 28 year old woman who came to the UK seeking political asylum after she saw her two children killed and her husband tortured during a civil war. A local official helped her leave in order to save her own life, but by the time she arrived at the airport in the UK she collapsed with exhaustion from the trauma. As part of the medical attention she received after this, she was tested and found to have HIV.

Viola was placed by the authorities in a shared bedsit with someone she had never met before, and had to keep her HIV a secret for fear of their reaction. She was given £27 worth of vouchers each week and a small amount of cash, for all her food and personal needs. She knew nobody in the UK and did not know where to turn for help.

After 18 months – which is quite swift for the asylum system – the Home Office agreed that she would be in extreme danger if she was returned to her country of origin and granted her leave to remain. Unfortunately, this meant that they immediately withdrew the vouchers, as she was no longer an asylum seeker. It took Viola three months to negotiate her way through the benefits system in order to get any other money for food and support. She had to leave the bedsit, and the local authority found her a bed in a hostel but could not give her money.

Viola needed money simply to eat enough to survive, and to get through the weeks until the benefits system responded. The Fund, initially through emergency payments and then in a more systematic way, was able to provide small payouts of around £20 a week to cover her absolutely basic needs so that she could live with some dignity until then. Total cost to the Fund was only £250, but it made all the difference to Viola.

Since the Fund's intervention, Viola has been able to stabilise her life. She has found a cheap bedsit of her own, is managing on basic benefits and has begun to be able to adhere to medication which controls her HIV.

14. Anti-gay discrimination:

the facts

A 1996 survey of 4,200 lesbians and gay men about homophobic violence and intimidation in the UK showed that one in three gay men had experienced violent attacks. A similar number had been physically harassed and 73% had been verbally abused because of their sexuality. *(Mason, Palmer, Queer Bashing: A national survey of hate crimes against lesbians and gay men, Stonewall, London, 1996)*

Gay men, in contradiction of many public stereotypes, earn less on average than their heterosexual counterparts. The average salary in 2001 for a heterosexual man in the UK was £24,000, whereas for a gay man it was £22,000. Scotland has the biggest under-employment of gay men, followed by Wales and the North West of England. These figures correlate broadly with higher incidences of homophobic attacks in more deprived areas of the country. According to the 2001 Lesbian and Gay Census, gay men in less economically developed environments are more vulnerable to homophobia.

A 2001 survey of gay men in England also showed that poor health was associated with both poverty and unemployment. Retired and unemployed men (who were most likely to have a lower income) were least likely to describe their health as good and most likely to report illness. *(Gay Men's Sex Survey 2001, Sigma Research)*

the experience

John is a young single gay man who lived in a small community in the North West and worked for his family. He had kept his homosexuality secret from his family for fear of confrontations and travelled a long way from home to meet other gay people.

However, John started to become regularly ill and take unavoidable absences from the family business. Eventually, he was diagnosed with HIV during a bout of pneumonia and his family were told. They stopped visiting him for the rest of the month he was in hospital, and John suspected that this was due to his HIV.

On his arrival home from hospital, he found that all his possessions had been moved into the garage and he was not allowed to enter the house. However, the family told him that it was not the HIV that concerned them; they would not accept his "being queer". John had to find a bed and breakfast to convalesce in, although he tried to maintain contact with family and friends. However, his family had told all his friends about his homosexuality and HIV. As a result, the man who had been his closest friend beat him so badly that he ended up back in the hospital with a broken collar bone.

John needed to move to a new town and was found supported housing but, because he had a small amount of savings, he could not get any help from the benefits system when he moved and had to spend all his money on furniture and carpets. The Hardship Fund, which had helped to find him the housing, gave John a small grant to cover the costs of his removal. Despite everything that had happened, John wanted to maintain contact with his family and so, once he was settled in his new home, the Fund also paid for a visit to them with a professional family counsellor to try and re-establish communication. The total cost to the Fund was £350.

Although things will not be easy for John with his family, he has finally been able to talk to them on his own terms and from an independent perspective. He has also found that being in a secure and more open environment has helped him to maintain better health and manage his HIV.

16. HIV ill-health:

the facts

Before the introduction of new and effective HIV treatments in the mid 1990s, low income, unemployment and poverty were associated with an increased risk of disease progression and death *(Hogg R et al., Lower socio-economic status and shorter survival following HIV infection, Lancet, 1994).* A study published two years after the introduction of combination therapy suggested that this difference in risk had disappeared for those with access to the drugs, whatever their socio-economic circumstances *(Ledergerber B et al., Poverty and prognosis of HIV infection in Switzerland, AIDS, 1998).*

However, a study published in 2003 showed people with HIV living in poorer areas of San Francisco were more likely to progress to AIDS than those living in wealthier districts, and linked this directly to access to treatment and care *(McFarland W et al., Low socio-economic status is associated with a higher rate of death in the era of highly active antiretroviral therapy, San Francisco, JAIDS, 33: 96-103, 2003).* The study adds to a growing body of research suggesting that socially disadvantaged patients are less likely to access treatment in a timely fashion, with factors such as poorer healthcare, lower levels of education and inadequate adherence often to blame.

Many people do not realise that around 500 people a year still die from HIV-related factors in the UK, despite treatment being available. In a recent study of deaths at a major London hospital *(Ashby J, Changing patterns of mortality in the age of HAART, 9th Annual Conference of the British HIV Association),* 14% of people died within three months of starting treatment because they were diagnosed very late. In all, 55% of the deaths surveyed were despite the person being on treatment.

Figures from the Public Health Laboratory Service in 2001 showed that nearly 25% of people diagnosed that year in the UK were already at an advanced stage of HIV (had CD4 counts below 200). This was more likely amongst heterosexuals; overall, gay men on average had a CD4 count of 310 when diagnosed, while heterosexuals had a count of 230 – significantly lower.

There is clear proof that disabled people are particularly at risk of poverty because of extra disability-related costs and low incomes. About a third of disabled people spend more on transport and 45% spend more on heating than non-disabled adults, while household incomes are around 20% to 30% lower for people living with a disability than without *(Poverty: the facts, Child Poverty Action Group, 2001).*

the experience

Michael and Grace are a married couple with two children, living in London in a small one bedroom flat on a total of £86 a week income. Both of them have HIV, but were only diagnosed after Michael became very ill. This means that Michael has an AIDS diagnosis, and has already had several bouts of serious illness, leaving him almost blind in one eye and housebound in the small flat.

Grace has to act as her husband's carer in addition to looking after the two children, neither of whom has yet been tested for HIV. To add to the difficulty of this situation, Grace's own health is not always good and she is intermittently too unwell herself to be able to manage the entire household. However, at other times she is well enough to manage, and the family were keen to maintain as much of their independence as possible in the circumstances.

One of the ways in which they could do this was for Grace to pre-cook a number of meals whenever she had the energy, to be stored and reheated when she felt too unwell to cook from scratch. Their low income does not allow them the everyday luxury available to many others of buying precooked ready meals in those circumstances.

However, the family's income is so low that they were unable to afford to buy the equipment which would make this scheme possible. The Fund therefore bought and delivered a fridge freezer to store the meals for as long as needed, and a microwave oven to reheat them. Total cost to the Fund was £275.

Since getting the fridge freezer and microwave, Michael and Grace have been able to plan, store and eat balanced and affordable meals. This has helped them to maintain their precarious health, and also to maintain the family independence that is important to them.

18. Housing problems:

the facts

Poor or costly housing can be a significant drain on the resources of HIV positive people in the UK. In a national survey of people with HIV in the UK, a quarter (141 out of 567) of all respondents who were experiencing financial difficulties reported rent or mortgage repayments as a cost that was difficult to meet *(What do you need? Sigma Research, 2002).*

In particular, African people with HIV have been shown to be seven times more likely to have problems with housing and living conditions than white people living with HIV in the UK *(Project Nasah, Sigma Research, 2003).*

In a recent study, investigators in New York found that unstable housing was associated with poor adherence to HIV treatment. In total 435 people with HIV who were accessing anti-HIV therapy were followed for three years, with half of the cohort being African American. Five factors which may impact on adherence were assessed (drug use, stress levels, housing status, belief in the efficacy of treatment and alcohol use). Whilst all the factors above impacted upon adherence, it was a lack of stability in housing which most significantly increased the odds of non-adherence. *(Tesoriero J et al., Stability of adherence to highly active antiretroviral therapy over time among clients enrolled in the Treatment Adherence Demonstration Project, JAIDS 33: 484-492, 2003)*

the experience

Rose is a 37 year old woman with two children, who has been on a local authority waiting list for housing for more than a year. She is often unwell, and has been unable to get a job because of this. Despite her having HIV and having care of the children, she is not classed as a priority for housing.

Rose was in receipt of £127 a week altogether in benefits, but the only private rented accommodation she could find to live in cost the family £51 a week more than housing benefit would pay her. On top of this disparity, the local housing benefit department took more than three months to process her claim, leaving her to build up arrears of more than £500 altogether which became increasingly difficult to pay off. The landlord, unaware of her HIV, was unable to understand why she could not get work of some kind to pay off the debt and Rose did not want to tell him about her HIV for fear of being made homeless.

Because of the difficulties with the landlord, and unaware of anywhere she could get support, Rose began to avoid him by taking the children and staying out of the house from early morning until late in the evening. This caused her health to deteriorate until she collapsed and was forced to spend two weeks in hospital, causing her children to be placed in temporary care. The hospital social worker contacted the Hardship Fund on her behalf.

The Fund, sharing the costs with a children's charity, cleared Rose's debts with £300. This eased her situation enough for her to leave hospital with a clean slate and start to tackle her problems, including reorganising her finances and her housing situation. This enabled her to bring the children home and reunite the family.

20. Mental health and HIV:

the facts

Mental health problems and HIV are often associated. This is both because poor mental health may be sometimes implicated in poor decision making around sexual health risks, and because living with any long term, incurable, life threatening condition is liable to affect a person's mental wellbeing.

Mental health problems such as depression have regularly been associated with low adherence in HIV-positive adults and adolescents. This is related anecdotally by doctors and people living with HIV, and proven by researchers *(Singh N, Squire C, Sivek C, Determinants of compliance with antiretroviral therapy in patients with HIV: prospective assessment with implications for enhancing compliance, AIDS Care 1996;8:281 and Murphy DA, Wilson CM, Durako SJ, Antiretroviral medication adherence among the REACH HIV-infected adolescent cohort in the USA, AIDS Care 2001;13(1):27-40).*

HIV-positive people who have problems remembering, learning or understanding as a result of their illness are less likely to adhere to their treatment regimen than people living with HIV without such difficulties *(Hinkin CH et al., Medication adherence among HIV-positive adults: effects of cognitive dysfunction and regimen complexity, Neurology, 59: 1944-1949, 2002).*

In a major study of 1,668 women receiving HIV care in the USA, women with HIV who also had poor mental health were found to be less likely to access HIV treatment. Poverty was also widespread amongst this group. The researchers stated that "efforts to enhance women's access to mental health services may increase their use of HIV treatments. Given the complexity of some regimens, and their reliance on near-perfect adherence for efficacy, it is unlikely that women struggling to cope with serious psychiatric disorders and other emotional difficulties will successfully initiate complex multi-drug regimens". *(Cook JA, Effects of depressive symptoms and mental health quality of life on use of highly active antiretroviral therapy among HIV-seropositive women, Journal of Acquired Immune Deficiency Syndromes, 30:401-409, 2002)*

the experience

Marcel is a single man who has been living with HIV for more than a decade. Although, physically, he remains relatively well, he has had a number of episodes of clinical depression linked to his HIV diagnosis, including several attempts at self-harm. He also has mild schizophrenia, which is kept under control by drugs. In addition he has had some problems in going out in public.

Because of these and other mental health issues, Marcel had difficulty in the past in managing his health and taking the HIV treatments he needs at the regular intervals prescribed.

Due to these problems, Marcel had already had to change treatment programmes twice in order to replace drugs that would no longer work for him. His benefits allow him to pay for a private carer, and Marcel realised that this would be the most appropriate person to help him manage his treatments. With only a limited number of treatment options, which gain in complexity as each drug fails, this was increasingly important.

The Hardship Fund helped Marcel to identify and pay for a short programme of residential weekends which were known to be sensitive to the needs of people with poor mental health and which specifically supported better management of treatments. The Fund also found another charity which would pay for his carer to attend with him, thus allowing them to learn about the treatment programme together. Total cost to the Fund was £400.

Although Marcel still continues to need regular supervision and to live a somewhat chaotic lifestyle, since the programme his carer has been able to work with him to manage the treatments better. Between them, they are working to ensure that Marcel has a better chance of making his limited treatment options last as long as possible.

22. Domestic violence:

the facts

Many women – and, indeed, men – find that an HIV diagnosis can lead to domestic violence and family breakdown. In a recent study, HIV positive women were found to be almost three times more likely than HIV negative women to have experienced a violent episode by a current partner. Young HIV positive women (those under thirty) were ten times more likely to report partner violence than young HIV negative women. *(Maman S et al., HIV and Partner Violence: Implications for HIV Voluntary Counselling and Testing Programs in Dar Es Salaam, Tanzania, The Population Council, 2001)*

For many women with HIV, domestic violence and family breakdown may follow on the heels of other experiences with violence and associated trauma. This may be as a result of upheavals which have caused them to flee their home country, some of which may have contributed to their contracting HIV in the first place. In a recent study of African women living with HIV in London, a majority of the women had already experienced at least one profoundly traumatic life event. These included rape, murder of partners and family members and various other forms of persecution. About a third of the women reported direct experience of HIV related stigmatisation such as rejection by husband or partner, eviction from their family home and refusal to allow them contact with their children. *(Anderson J and Doyal L, African women with HIV surviving in London, Terrence Higgins Trust, in press)*

the experience

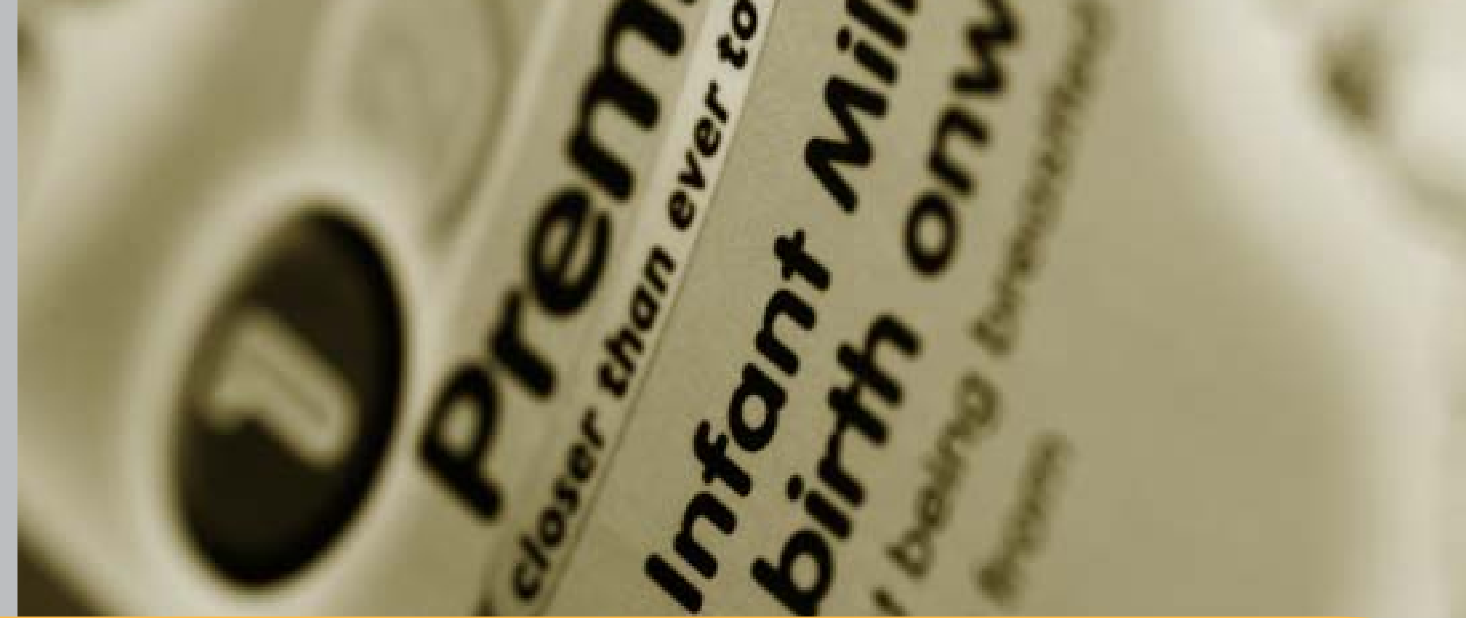
Serinda, 29, lived in the West Midlands with her husband of three years and worked as a secretary. When her husband became very ill and was diagnosed with HIV, their GP suggested that she should also take a HIV test, but her husband did not want her to. He also told her not to tell anyone else in the family the reason for his illness.

However, a friend persuaded Serinda that she should get tested for HIV for her own sake. When she told her husband that she, too, had HIV, he became very angry and beat her viciously, breaking her arm twice, fracturing her pelvis and burning her with a cigarette. While she was hospitalised with these injuries, he told both their families and her workplace that she had infected him with HIV and tried to kill him. Both families disowned her immediately, and her brother-in-law was overheard by a nurse on her hospital ward threatening that he would kill her after she was discharged from there.

Understanding the urgency of the situation, the local authority found Serinda a place of safety away from her home district. However, the new home they offered her had no furnishings at all except vinyl floors, curtains and a bed. She was unable for fear of assault or death to return to her former home or take anything of her belongings from there.

The Hardship Fund worked with the local social services and a charity furniture store to provide enough basics for Serinda to be able to move in – bedding, a table and chairs, crockery, a microwave and so on. These cost £400 altogether. Through these links, Serinda was also able to link up with a project that supports women in her situation. She has begun to make friends and to come to terms with her diagnosis. Although she still lives in fear of her husband, she can begin to rebuild her life.

24. Asylum system problems:



the facts

The Hardship Fund is frequently approached by individual people seeking asylum who have problems managing on the reduced rate of benefits they receive. However, alongside this lowered rate of general funds, asylum seekers also have no other recourse to public funds; in other words, they cannot access any of the small, ordinary benefits that citizens of the UK often take for granted.

Far from coming to the UK seeking treatment, women with HIV who are asylum seekers are often only diagnosed through routine antenatal screening (which now covers HIV as well as a number of other conditions). They are able to obtain healthcare during the pregnancy in order to prevent transmission of their HIV to the baby in the womb, and advanced care techniques are used to prevent transmission during childbirth. However, once the child is born, financial support to enable the mother to avoid transmission through breast feeding, by paying for milk formula and the associated equipment, is a matter for social services – and asylum seekers are specifically disbarred from receiving any form of social benefits above and beyond their basic allowance.

Many people are unaware of the extent of extreme poverty and deprivation amongst people waiting to hear if their claims for asylum have been successful. In 2002, Oxfam and the Refugee Council published a research report on poverty and asylum seekers in the UK. They consulted with 40 organisations which work with asylum seekers in England and Scotland. Of these:

- 85% of organisations reported that their clients experience hunger
- 95% of organisations reported that their clients cannot afford to buy clothes or shoes
- 80% of organisations reported that their clients are not able to maintain good health.

(Poverty and Asylum in the UK, OXFAM/Refugee Council, 2002)

the experience

The Hardship Fund was approached by the social work department of a large London hospital about a problem they were experiencing in supporting women seeking asylum who had given birth there.

Women with HIV are strongly discouraged from breast feeding their babies, because this is a primary route of transmission of HIV from mother to child. However, formula feed for those who cannot or should not breast feed is an expensive proposition and while most women on benefits can get free baby formula and equipment, women seeking asylum are explicitly debarred from this benefit.

Social workers were finding that, although women wanted to protect their babies by not breast feeding, they could not afford to do anything else if they wanted to be able to feed the rest of their families on the money they received. The hospital was able to secure formula milk donations from a milk products company, but not the equipment to use them.

The Fund was approached and agreed to purchase sets of sterilisers and bottles, which enabled the hospital to set up a loan scheme for nursing mothers. This enabled them to keep their babies free of HIV infection. Eventually a court case brought by the Child Poverty Action Group, alongside concerted lobbying by organisations such as the Terrence Higgins Trust and others, forced the government to provide funds for baby formula to all asylum-seeking mothers who needed it.

Policy recommendations:

1 The Government should establish a cross-departmental task force to tackle the rising epidemic of HIV and sexual ill-health in the UK, including measures to tackle discrimination against people with HIV and those communities most at risk.

2 The recommendations on reform of the asylum system contained in the report *Migration & HIV: Improving Lives In Britain (All Party Parliamentary Group on AIDS, 2003)* should be enacted in order to promote both individual and public health. In particular, asylum seekers with HIV should only be dispersed to areas with appropriate medical and social support systems, and with enough notice to be able to transfer their care.

3 A review should be undertaken by the Department for Work & Pensions of the benefits system in order to improve its ability to support people with intermittent or relapsing medical conditions and enable them to attempt to return to work without endangering their entitlement to benefits. In particular there should be an increase in the amount of time a person can spend in work before they lose the security of the Welfare to Work scheme.

4 Local authorities and housing trusts should treat HIV-related and homophobic abuse and violence with the same seriousness as racist abuse and violence and act accordingly in rehousing people. They should also ensure that HIV-related ill-health is appropriately evaluated during assessment of housing need.

5 The Department for Education & Skills should include the treatment of children affected by HIV and other blood-borne conditions in the National Healthy Schools Standard accreditation scheme.

6 The Department of Health should issue guidance for primary care staff to ensure that appropriate offers of HIV testing are made in order to support early diagnosis and management of HIV before a patient's health is irreversibly damaged.

7 The Department for Work and Pensions should work with groups with relevant expertise to produce good practice guidance in relation to employment and HIV, to reduce inappropriate behaviour by uninformed employers upon news of someone's diagnosis.

8 Research funding bodies should support further research into the links between HIV-related ill-health, discrimination and poverty in the UK and ways of breaking the cycle between them.

Contact information

For information on how to access the Hardship Fund, call the Hardship Fund Direct Line at Crusaid on 020 7539 3881. The Hardship Fund Officer is Keith Atkinson.

For information on THT services plus advice on HIV and sexual health, call THT Direct Helpline on 0845 12 21 200. The service is open every day, and calls are charged at local rates. Information is also available at www.tht.org.uk, or by email from info@tht.org.uk.

To donate to the Hardship Fund or for more information on how Crusaid is funding education initiatives and care for those living with HIV and AIDS, please visit our website at www.crusaid.org.uk or contact the Head of Grants & Projects, Steven Inman, at 1-5 Curtain Road, London, EC2A 3JX or call 020 7539 3880

For further copies of this publication, contact Policy, Campaigns & Research at Terrence Higgins Trust on 020 7816 8625 or via campaigns@tht.org.uk or Steven Inman at Crusaid (as above).

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