

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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## Care in the community

### Editorial

Community matters!

*Shaun Watson* ..... **1**

### Features

Complex care in the community

*Alison Thompson* ..... **2**

HIV and mental health: a lesson in communication

*Nicola Galbraith* ..... **6**

Country file: HIV community care for those who  
live outside cities

*Charlotte Broughton* ..... **9**

Ready, set, go! The time trials and challenges of hospital  
discharge planning in HIV care

*Sara Scarborough* ..... **12**

The reluctant carer

*Shaun Watson* ..... **15**

The role and future of the voluntary sector

*Phil Greenham* ..... **18**

The role and future of the voluntary sector: a HIV service  
provider's perspective

*Kathryn Dombrowicz* ..... **22**

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## Aims and Scope

*HIV Nursing* has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

*HIV Nursing* is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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# Community matters!

Shaun Watson

Clinical Nurse Specialist, Hammersmith and Fulham Primary Care Trust

I was beyond excited to be given the opportunity to shape and edit this issue of *HIV Nursing*. It gives me a chance to highlight an area of HIV care I have been involved in for most of my career, that of community services, the poor cousin to acute HIV care, but a valuable family member. Whether as a ward manager, clinic nurse, HIV clinical nurse specialist or voluntary sector worker, I have had first-hand experience of the power of seamless, well-communicated community care. It is a vital component to the wellbeing of our patients.

The challenges of community HIV care are many. For most general practitioners (GPs), their patients living with HIV may not have been seen on a regular basis and therefore HIV care will probably not figure highly on their list of priorities, and of course, for 20 years or so GPs have been used to the HIV clinics managing all aspects of care. Specialist social workers have joined the generic adult teams and there is a distinct lack of support and funding, making even the simplest request for help a minefield that requires a many-paged form. For community and district nurses, HIV can be an illness that they encounter rarely and, as most HIV mandatory training was stopped with the success of ART in the late 1990s, they may have no up-to-date knowledge or desire to learn. So, for those of us attempting to work in the community, this lack of priority, support, knowledge or desire can be extremely frustrating.

In this issue, Alison Thompson and Nicola Galbraith, both clinical nurse specialists, have taken realistic looks at the nature of the community HIV CNS role and they have vividly shown the all-too-common face of complex care and the need for clear interprofessional communication. Long gone are the days of HIV as a lone illness. We are now seeing patients with dual, triple, quadruple and infinitum diagnoses and a myriad of socioeconomic issues that we endeavour to manage and prioritise on a daily basis. Charlotte Broughton's article has skilfully highlighted her role in a rural setting. It is too easy to be city-centric (and particularly London-centric) when we discuss HIV, but it is heartening to see the excellent care that is provided, utilising all aspects of the multidisciplinary team. Sarah Scarborough's article on discharge planning has shown the complexities of the role and I remain shocked to see that the importance of skilled discharge planning is not an integral part of some nurse training (back in my day ... oh no, have I become one of those nurses?) For my part, I wanted to highlight the plight of reluctant carers caught in the trap of having to

provide care for a friend or family member. With an ageing HIV population and scarce support resources, this is an issue that I can only see increasing in importance in the future, as services are changed and support agencies closed down. This leads conveniently to the articles by Phil Greenham and Kathryn Dombrowicz who show the realities of the voluntary HIV sector. Once the envy of other long-term conditions and the benchmark which other care organisations have strived to attain, yet so easily destroyed, and viewed, perhaps, like many community services as a luxury service.

HIV has changed beyond all recognition from the terrible terminal illness days in the 1980s and early 1990s when community services were mobilised to provide palliative care and support, to the glorious introduction of antiretroviral drugs in the mid 1990s, and on to today, where self-management is king and community services are increasingly depleted yet frequently highlighted as the way forward in HIV care. Flexible, adaptable, responsive and dynamic: we have had to change to survive. We strive to provide an up-to-date service, yet retain those elements that make our service unique, providing time to talk, practical help when needed, sage advice and a friendly ear.

The face of HIV has changed. As our patients endeavour to live normal, undisrupted lives, HIV services have had to adapt to fit the individuals rather than them fitting in with us. HIV clinics now provide longer opening hours and weekend surgeries. Sexual health services are already moving out to general practice – how long before CD4 cell counts and viral loads are checked by the GP? The pressure is on to retain our patients.

As acute HIV services are pulled, stretched and changed by yet more governmental White Papers, as the safety of 'ring-fenced funding' is no longer there, as HIV organisations and volunteer groups are pulled apart by monetary cuts, community care and the many teams and organisations that support it will have increasing roles in the future of HIV care. The future for community management looks bright and I want to thank all those who have contributed to this issue.

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# Complex care in the community

Alison Thompson

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## Introduction

Many of the patients for whom we provide care can be described as having complex needs due to challenging clinical presentations, often entwined with equally challenging psychological and psychosocial needs. BHIVA has developed a model highlighting the 'four faces of HIV' [1] that identifies two areas of complexity that have a direct impact on how the client may be managed by clinicians and how the client might choose to access healthcare. This article presents the case of a client with very complex needs and examines some of the approaches towards managing care in challenging circumstances.

## The referral

Grace, a 30-year-old Ghanaian lady, was referred to the clinical nurse specialist (CNS) team following a discussion about her case during a multidisciplinary team (MDT) clinical meeting. The main reason for referral was to provide Grace with support to attend clinic appointments and support with adherence to antiretroviral therapy (ART).

Grace had been living with HIV for 5 years and was diagnosed following a period of acute illness and hospital admission, where she was treated for presumptive *Pneumocystis pneumonia* (PCP). Her viral load was high and her nadir CD4 cell count was 25 cells/mm<sup>3</sup> at time of diagnosis.

At the time of referral to the CNS team, Grace had been on three classes of ART and had taken the following combinations: nevirapine and Combivir; saquinavir, abacavir and tenofovir; and darunavir/ritonavir, efavirenz and tenofovir. She had a history of poor adherence with subsequent virological failure and resistance to efavirenz. Grace had been off medications for 5 months as a result of missing several clinic appointments. Her last recorded viral load was 20,913 copies/ml and CD4 cell count was 464 cells/mm<sup>3</sup>. Her physical health needs were complex as she was also living with a history of frequent headaches, obstructive sleep apnoea, mild renal impairment, hypertension, benign raised intracranial pressure and impaired vision. She had been prescribed antihypertensive medication but was not compliant. A previous MRI scan of her brain indicated that there were some diffuse white-matter changes.

Her psychosocial needs were also complex. She was a single mother with one child living in a

multi-occupied and overcrowded three-bedroom flat in a deprived area. Her immigration status was that of overstayer with a pending application for leave to remain. She had no recourse to public funds and was reliant on charitable support from friends and family. She had apparently disclosed her status to her UK-based sibling.

In spite of all her difficulties, clinic staff reported that when Grace attended clinic, she was always well presented, articulate, bright and engaging with an air of confidence bordering on nonchalance. She gave the impression that she was someone who was high functioning and capable of managing difficult situations.

## The initial assessment

On meeting Grace, I noted that she well dressed, overweight and breathless on slight exertion. Her living conditions were poor, with many possessions crammed into a small space. It was difficult to make an adequate assessment of her needs at this time, as she was very emotional, tearfully describing how she felt full of guilt and shame following an episode of unprotected sex with her then partner. Much of this first meeting revolved around trying to reassure Grace that she would not be judged and we were able to negotiate that she would return to the clinic. Appointments were made. Grace did not attend these clinic appointments and was also absent for two subsequent home visits.

The MDT members were not surprised that Grace was not attending appointments because this was a familiar pattern of behaviour. They encouraged me to persevere with attempts to make contact with her. I was appreciative of the support. It is well recognised that services should be designed to support the needs of staff dealing with complex clients [2]. After leaving several messages, I eventually managed to speak to Grace and arranged a new appointment.

Grace requested that our second meeting should take place in the clinic prior to her appointment with a clinician. She was late so we did not have an opportunity to complete her assessment. Following her consultation with the registrar, he called me to inform me that he was concerned that Grace had fallen asleep during the appointment and that her blood pressure had been recorded at 170/130. He also expressed concerns about how she might be managing to care for her child if she was not able to stay awake for long periods. She had also been re-commenced on antihypertensives.

Our third meeting took place in Grace's new home. She had moved into a less-crowded property and was sharing with one other family member. She was relaxed and appeared to have settled well in the more spacious environment. On this occasion I was able to make a more thorough assessment of her needs in accordance with NHVNA nursing competencies [3], and we were able to begin to negotiate an action plan that could address some of those needs. We discussed the following.

- *Adherence to medications*

Grace was not currently on ART and only taking antihypertensives. She was keen to re-start ART with support.

- *Hypertension*

She agreed to attend appointments with the hypertension specialist within the clinic and continue taking medications. As she was not registered with a GP, she was advised to start thinking about this.

- *Immigration issues*

She gave permission to be referred to a voluntary sector agency for advice and support

Grace also discussed how she had been in a state of fearfulness after being informed of some of the implications of having uncontrolled hypertension. Research has shown that 50% of patients may not adhere to antihypertensive medication but may become compliant because of 'positive experiences with a doctor' or 'pragmatic considerations' [4].

We discussed the welfare of her child and she disclosed that there had been a previous child-in-need referral, the outcomes of this being referral to tier-two support services. This support was apparently still ongoing.

## Planned admission

Urine tests and blood tests indicated that Grace had increasing proteinuria and worsening renal function. It was deemed necessary for Grace to be admitted to a clinical ward for investigations. She was distressed and anxious, and needed much support and encouragement to agree to admission. An important factor in making this happen was encouraging Grace to play a pivotal role in the planning of the admission, hence maintaining her sense of control and autonomy in the process. Effective case management acknowledges that the consent of the client is required in decision-making and supports their right to be self-determining [5].

During the inpatient stay, Grace appeared to relax and complied with all medications and investigations. She was referred to a renal team but unfortunately self-discharged before all investigations were complete as she was missing her child.

## Post-admission

Grace described how the admission to the ward had left her feeling as if she was losing control of her life. On return home she did not feel motivated to follow up any of our agreed action points. She was unkempt, and the one room in which she and her child were living was in a state of chaos. She appeared to be oblivious to the fact that her environment was not conducive to healthy living and she stated emphatically that 'laziness' and most definitely not depression or low mood was the cause of the chaos. I challenged Grace about her 'laziness', focusing my concerns on her child clearly not having enough space to rest, play or do homework. I think she may have thought that a child protection referral was imminent because at this point she offered contact details for the statutory and voluntary sector services involved in supporting the family. This proved to be very useful information.

There was a marked improvement in the environment during the next few home visits. The room had been tidied and organised. Grace looked quite well and reported good adherence to antihypertensives. She stated that she had made enquiries about registering with a local HIV-friendly GP. During this period she managed to attend the majority of her clinic appointments and permitted me to accompany her when she felt less motivated to attend. She was counselled and re-commenced on Truvada, raltegravir and ritonavir. I provided her with a variety of adherence support tools and methods to help her comply with her medications. She experienced some difficulty with adherence due to sleep apnoea but in spite of this she was able to achieve a viral load of 55 copies/ml.

The period of stability did not last and a period of chaotic behaviour ensued, with missed follow up appointments with the HIV, renal, sleep studies and hypertension clinics, and with me. This pattern of behaviour continued for a few months. Grace did not appear even to respond positively to stark messages about her mortality or the fact that she looked unwell. Occasionally her child was at home during my visits and concerns about their welfare were routinely discussed during the MDT meetings. I had established good communication with the family support worker who had close working links with the school. The interdisciplinary working was effective in this case and helped to prevent an unnecessary child protection referral.

When challenged, Grace was unable to verbally rationalise the cause of her sporadic engagement with clinicians. She indicated that basic survival and not health needs were her priority at the time and, although she never appeared to be destitute, she expressed concern about finances. Her Home Office application was still pending and she had not followed up on the referral to the charity for help with this. It is well documented that clients with

uncertain immigration issues may worry more about whether they may be given leave to remain than the status of their health [6].

Grace was reluctant to discuss how she truly felt about things but occasionally, she would cryptically remark that she was 'angry' about HIV but would not elaborate on this point. I suspected that she had some deeply rooted HIV adjustment issues. She went to church occasionally and spoke of her faith but did not appear to be basing any of her decisions about her health on a choice of healing by prayer alone.

The following sequence of events then occurred:

- Grace received notice to leave her home and was fearful that she would become homeless. She was supported by a friend and moved into a new home.
- It became difficult to contact Grace on the phone. A series of unannounced visits were necessary at the new address.
- Blood pressure monitored during home visits averaged 140/100. She disengaged with the hypertension clinic.
- Grace expressed concern about weight gain but disengaged with the dietetic service.
- She eventually registered with a GP. She was supported by a children and families support worker from a statutory service.
- She consistently ran out of medications and would miss several doses. She would then present at the walk-in clinic for prescriptions of ART and not attend regular appointments.
- Following several discussions about motivation, Grace agreed to be referred to a psychologist. She attended an assessment and one follow-up appointment but stated that she did not want to revisit certain places that evoked sad feelings. She disengaged with psychology services before really engaging.
- Grace complained of swollen, oedematous and heavy legs. She was helped to make appointments with the GP practice nurse but did not attend.
- An attempt to introduce Grace to the concepts of self-management of chronic conditions to help improve her health literacy was made. She appeared interested but was not willing to participate in the process.
- With worsening renal function and increasing proteinuria, a decreased dose of Truvada was advised. Resistance tests showed an extensive history of mutations and ART was switched to a kidney-sparing regimen.
- She disengaged with all clinical services for months.
- The CNS team was informed by family support services that Grace was to be made homeless and would be moving out of the borough to stay with family. MDT was informed.

- Presented in crisis to CNS team after long absence. Encouraged to re-engage with clinicians.

## Observations

This case was incredibly difficult to manage due to the complexity of Grace's needs and her attitude towards her health and well-being. Frustratingly, she appeared to have full capacity to make better choices about her health but chose not to. At times I wondered how I could continue working with her and she became the topic of many formal and informal supervision sessions.

Her statements of good intention were incongruent with her actual behaviour and at times I wondered if her lack of insight was indicative of deteriorating mental health. She made great efforts to focus on engaging me in intellectual debates about all kinds of topics but never seemed to have the ability to apply the same logic and enthusiasm to her health needs. I was very disappointed when she did not engage with the psychology service but I recognised her fear of delving into the recesses of her mind. Maslow writes that after fulfilling our basic needs for food, warmth, shelter and safety we need recognition, status and self-esteem [7]. I often felt that Grace's primary need was to maintain her self-esteem as a firm foundation, without which she would probably crumble.

## Conclusion

This case demonstrates the importance of interdisciplinary working in the hope of achieving the best health outcomes for the client. Varied patterns of behaviour called for varied approaches to care provision including counselling, motivational interviewing, coaching and action planning.

A degree of flexibility is essential when working with this level of complexity and this should be evident at all stages of the care we provide. We should never underestimate the fact that some patients will prioritise other needs over their health needs. We may not fully understand their rationale but we have to respect their right to make choices.

We are in the business of caring and it is incredibly difficult to observe a client engaging in behaviour that is detrimental to their health. In response, our emotions may run awry, ranging from sadness to anger. It is essential that we monitor ourselves and seek supervision from colleagues if the situation is becoming too difficult to manage.

This case taught me a valuable lesson about recognising the point at which we must acknowledge that we have done all we can, before taking a step back. We can attempt to steer our clients in the right direction but must also be prepared to follow their course from a safe distance.

When clients with complex needs completely disengage from services, it can be a time of uncertainty and of trying to fill in the blanks. There may be a policy-driven need to discharge them from the service; but our hope is that they re-surface before it is too late. The BHIVA briefing paper on extending the role of primary and community care in HIV [8] was circulated in 2007. I look forward to the final publication of this document and welcome any initiatives that seek to promote collaborative efforts to improve the health-seeking behaviours of our clients.

## References

1. Independent Advisory Group on Sexual Health and HIV. Building on Progress, Enhancing the response to HIV in England. Department of Health, London, 2009; p.17. Available at: [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_108981.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_108981.pdf) (last accessed May 2011).
2. Doyal L, Anderson J. My heart is loaded. African women with HIV surviving in London. Report of a qualitative study. Terrence Higgins Trust, London, 2003; p.19. Available at: [www.mambo.org.uk/VirtualContent/133911/My\\_Heart\\_is\\_Loaded\\_\\_African\\_Women\\_with\\_HIV\\_Surviving\\_in\\_London.pdf](http://www.mambo.org.uk/VirtualContent/133911/My_Heart_is_Loaded__African_Women_with_HIV_Surviving_in_London.pdf) (last accessed May 2011).
3. NHVNA. Assessment of health and well-being. Level 4. In: National HIV Nursing Competencies. NHVNA, London, 2007; p. 5. Available at: [www.nhivna.org/competencies/supportdocs/pdf/Competencies07.pdf](http://www.nhivna.org/competencies/supportdocs/pdf/Competencies07.pdf) (last accessed May 2011).
4. Benson J, Britten N. Patients' decisions about whether or not to take antihypertensive drugs. Qualitative study. *British Medical Journal*, 2002, **325**, 873.
5. New York State Department of Health AIDS Institute. Standards for HIV/AIDS Case Management. 2006; p.7. Available at: [www.health.state.ny.us/diseases/aids/standards/casemanagement/docs/casemanagementstandards.pdf](http://www.health.state.ny.us/diseases/aids/standards/casemanagement/docs/casemanagementstandards.pdf) (last accessed May 2011).
6. Flowers P, Davis M, Hart G, Rosengarten M, Frankis J, Imrie J. Diagnosis and stigma and identity amongst HIV positive Black Africans living in the UK. *Psychology and Health*, 2006, **21**, 109–122.
7. Wright CC, Barrow JH, Turner AP, Barncroft GV. (2003) Self-management training for people with chronic disease. An exploratory study. *British Journal of Health Psychology*, 2003, **8**, 465–676.
8. Maslow AH. A theory of human motivation. *Psychological Review*, 1943, **50**, 370–396.
9. BHIVA. Briefing Paper. Extending the role of primary and community care in HIV. BHIVA, London, 2007; p. 3. Available at: [www.bhiva.org/documents/Guidelines/Standards/090320%20PCBriefingPaper.pdf](http://www.bhiva.org/documents/Guidelines/Standards/090320%20PCBriefingPaper.pdf) (last accessed May 2011).

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# HIV and mental health: a lesson in communication

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Within the HIV Clinical Nurse Specialist (CNS) team, we are familiar with managing a complex caseload, and mental health issues often arise in our client group. Most common are feelings of acute emotional distress, depression and anxiety. We are often the first to assess the risk of mental distress and observe for its signs and symptoms. We are best placed to do so, as we have often known the client for many years. We have had to develop and maintain the necessary skills to recognise and address mental health problems, in addition to the factors that can be triggers. However, we are HIV specialist nurses and not mental health nurses. We regularly find ourselves expected to be both, and we often are.

This case study highlights the complexities and challenges of managing a HIV-positive individual with mental health issues in the community setting, and the difficulties in creating a collaborative and effective professional relationship with mental health services.

## History

Anne is a 49-year-old Nigerian lady who was referred to the CNS Team. She was diagnosed HIV-positive after being admitted to hospital and subsequently treated for *Pneumocystis pneumonia* (PCP). Her CD4 cell count was 60 cells/mm<sup>3</sup> and viral load was 332,314 copies/ml. She was commenced on Atripla prior to discharge home.

Anne is a single mother living with her three teenage children in a three-bed second-floor flat. Prior to her diagnosis, Anne had been working but had accrued debts and was in severe financial difficulties with mortgage arrears. Anne disclosed her diagnosis to her eldest daughter and ex-husband only. Her ex-husband, who lives abroad, arranged testing and was negative as was her eldest daughter. It has recently come to light that Anne's other children were never tested as planned.

## Mental health

Anne had no previous mental health history but, 5 days after commencing treatment, she was taken to A&E after her daughter reported inappropriate, bizarre behaviour, wandering and hysteria.

Both psychiatry and HIV teams reviewed Anne, and all blood results were normal, as was an EEG and CT head.

She was diagnosed with acute psychosis secondary to efavirenz, and she remained an inpatient for 1

week, requiring one-to-one supervision, before being transferred to the mental health unit (MHU) under Section 2 of the Mental Health Act. She was switched to Truvada, darunavir and ritonavir.

Anne was followed up by the HIV medical team during her admission to the MHU and was found to have CMV retinitis resulting in significantly reduced sight in one eye.

## Transfer to community

Anne remained an inpatient at the MHU for 3 weeks, during which time the CNS team endeavoured to maintain close contact with the mental health service, reiterating the importance of our involvement in discharge planning. The care for those living with HIV and mental health disorders should be a collaborative effort involving patients, primary care and mental health teams [1]. Frustratingly, when we called for an update, we were informed that Anne was being discharged that day and care was being transferred to the Community Mental Health (CMHT) and HIV CNS teams.

Although the HIV CNS team visited Anne while an inpatient, and due to her being mentally unstable previously, we hoped to gain a better insight into Anne's life during the first assessment at her home. Anne's flat was very dark and cluttered; however, she looked well presented. She was quiet and could not maintain eye contact and did not initiate conversation. Her main concern was the number of tablets she was taking. It was agreed with Anne that a dosette box might ease the distress and confusion caused by her perceived high pill burden and that the CNS would refill boxes temporarily with a view to Anne becoming independent in managing this herself.

Anne soon appeared to build up a good rapport with the CNS team, which played a pivotal role in maintaining her adherence. A strong patient-provider relationship, including trust and engagement with the provider, has been associated with improved antiretroviral adherence [2].

Anne was keen to return to work as soon as possible, and in the interim, was allocated a mental health social worker to assist in applying for benefits and act as an advocate in relation to her mortgage arrears. These issues soon became Anne's primary concern as her home was under threat of repossession.

Over the next 3 months, Anne's adherence was good despite her deteriorating eyesight, mental health and financial issues. Anne was also diagnosed as a type 2 diabetic and commenced on metformin. She always attended clinic appointments and her viral load was undetectable with an increasing CD4 cell count of 288 cells/mm<sup>3</sup>.

However, Anne soon required ophthalmic surgery, which was followed by a gruelling regimen of different eye drops several times a day and managing her uncontrolled pain. This, coupled with increasing financial pressure, caused Anne to become very low in mood. The CNS team raised our concerns with the CMHT and agreed to continue monitoring her.

Anne's physical health improved over the coming months and her mental health seemed to follow suit, she was discharged from the CMHT and was no longer requiring psychiatric medication. She also attended a course in the hope of returning to work.

As she continued to improve, her mood was much brighter, as was her flat. Her financial issues were under control and she had a new job. It was suggested to Anne that we would start encouraging her to take control of managing her HIV and medication as she had done so well in other aspects of her life. Anne was enthusiastic about this and proud of how far she had come. The ability to take antiretroviral therapy well and consistently is a key part of self-management [3].

Anne had booked a holiday to Nigeria, and requested we meet on her return in order to teach and assess her in managing her medication.

Once home, I met with Anne and she was very happy and reported having had a wonderful holiday. She reported no problems with her medication and/or adherence while abroad and felt well throughout the 3 weeks away.

## Readmission to mental health unit

On her next clinic appointment, it was noted that Anne's viral load had become detectable and she had admitted that she had missed a few doses while on holiday. I decided to discuss this with Anne and arranged to visit.

However, the following day I received a call from Anne who sounded distressed. She was crying, screaming and pleading with me to come to her flat immediately as 'they think I'm mad and they're coming to take me away.' When I asked who she was referring to she said the police and ambulance. Unfortunately, I was unable to get to Anne's so requested she asked them to call me. Within 10 minutes, I received a call from a paramedic. I gave him background information with Anne's consent. I was informed that it was Anne who had called the ambulance and the police and they agreed to take her to the hospital where she had her HIV care. She was subsequently readmitted to the MHU

voluntarily. It had been 2 years since her previous admission.

I made contact with the ward and provided a list of Anne's current medications and reiterated the importance of adherence to her antiretroviral therapy. I also requested that I be kept informed of Anne's progress, in particular the discharge planning.

When I visited Anne in the MHU, the deterioration in her mental health was extraordinary. Her mood was manic but she was happy to be there for a 'rest.' She was wearing a very extravagant headpiece labelled 'high prophetess' and she informed me this was the new title she had obtained while in Nigeria. Anne then became distressed, and informed me that the pastor at her church had disclosed her HIV status to the entire congregation and that he and his wife had tried to kill her and had used her urine to make black medicine.

Anne's children were being cared for at home by her daughter. While I was there, Anne continually called her, demanding that she brought her money to send to Africa. It became apparent that Anne had been spending excessively on credit cards and making large purchases, such as plasma TVs. Her financial and debt issues had returned.

## Discharge: communication is vital!

The MHU were reminded regularly of my role and the importance of keeping me informed of discharge plans. I also attended ward rounds. However, despite me speaking to the ward one morning and being told there were no discharge plans, Anne was discharged that day, without my knowledge, and without her antiretroviral therapy dosetted. I feel it's fair to say I was completely exasperated by this turn of events and had to change all my appointments and go immediately to Anne's to ensure she had her medication.

The catalogue of poor communication continued. I called Anne's community psychiatric nurse (CPN) to arrange a joint visit and left a message requesting they call me back, but they never did. I continued to try and make contact with the CMHT and, while I was at Anne's flat, I called again and was informed that there was nobody available to speak to me. I mentioned I had left several messages over the previous 2 weeks with no response and was told it would be marked as urgent. There was still no response.

Anne also informed me they were visiting her every other day, rather than the daily visits I was told about. Given Anne's complex physical and psychiatric needs, I found this complete lack of communication surprising and frustrating.

As my visits continued it was clear Anne was becoming increasingly manic. She had set up a 'church' in her living room complete with altar. She looked very well, having had her hair done, and was

wearing new clothes. She told me she was making an effort, by wearing false eyelashes, so people did not think she was sick. Anne appeared to have some insight that she had not been well. She told me she had found herself approaching people in the street telling them she was setting up a church and asking them if they wanted 'joy', and when she got home she realised this was not normal behaviour and wondered what was wrong with her.

I made Anne an appointment to see an advocate who could assist her to reapply for benefits as she had recently returned to work. I continued to try and make contact with the CMHT but to no avail.

When I eventually spoke to the CMHT, we arranged to have a joint visit; however, they did not turn up or call to cancel. Anne was crying and appeared very unstable. I spent a long time with her and had concerns about her low mood. Doctors from the CMHT arrived to review Anne. Her behaviour was very unpredictable. She again admitted she never took her antiretroviral therapy while in Nigeria, but took other Nigerian medicines. She also informed me that she had a new husband who would be coming to live with her. Anne said the new husband had cured her HIV and she requested another HIV test to confirm this.

Yet again, her behaviour was increasingly chaotic. A new tenant moved in and her eldest daughter moved out. These changes concerned me, particularly as Anne had no idea what her new tenant was even called. Anne started crying loudly and was talking in 'tongues,' saying she had a vision from God. All of this was now witnessed by the doctors from the CMHT, and they commenced her on additional antipsychotics.

This chance meeting with CMHT doctors allowed me to voice my concerns and discuss my frustrations with their lack of communication, and I was reassured this would not happen in future.

On my next visit to Anne, she refused me entry to her front room and I had to fill her dosette boxes in the hallway. She was manic and having conversations and arguments with 'visions' and kept going into the front room and shouting loudly. She became increasingly agitated with me and at times aggressive towards me, which she had never been before. Anne was shouting about money and how I should get her some. She said the Devil was in her living room and someone in Africa stole £1.5 million from her and she was going to 'punish him through the Devil.'

Anne then said if the CMHT did not bring money when they came to see her that day, she would 'pour boiling water on their faces.' I was extremely frightened and concerned, unsure of what Anne was capable, and I left promptly.

I immediately attempted to call the CMHT to inform them of Anne's threats but they were in a meeting and refused to acknowledge my concerns. This

shocked me as I felt that Anne or someone else could be at risk of harm, so I persevered. I contacted the emergency psychiatric service for advice and was put through to an assessment team. I explained my serious concerns and that I was not able to express them to the appropriate team. I was again advised that they were in a meeting at that time and did not like to be disturbed. However, they advised me that I had taken the correct action, and took all the information from me.

Reporting valid concerns took a significant amount of effort and time, and left me feeling as if I were a nuisance, rather than a professional doing my job. I felt it necessary after so many incidents to look in to making a formal complaint.

Later that day I received a message from the MHU advising that Anne had been readmitted. I reiterated the importance of her having her antiretroviral therapy administered daily and on time, and again requested that I be informed of any discharge plans. Yet again, Anne was discharged home without me being informed and without her medications dosetted.

Anne currently remains under the care of both the CMHT and CNS teams, and is at present stable on medication and trying to resolve her debt problems.

## Conclusion

Ideally, I would refer to this case study as an isolated and extreme example but unfortunately it is not, there are several. We continue to strive to achieve a professional and effective multi-disciplinary approach to managing our many patients living with HIV and mental health issues. We are realistic and understand that resources are limited, but effective communication costs nothing, and can have a significant impact in reaching positive health outcomes and maintaining a patient-centred approach to the care we provide.

## References

1. Office of the Medical Director, New York State Department of Health AIDS Institute. *Adherence to antiretroviral therapy among HIV-infected patients with mental health disorders*. Available at: [www.hivguidelines.org/clinical-guidelines/hiv-and-mental-health/adherence-to-antiretroviral-therapy-among-hiv-infected-patients-with-mental-health-disorders](http://www.hivguidelines.org/clinical-guidelines/hiv-and-mental-health/adherence-to-antiretroviral-therapy-among-hiv-infected-patients-with-mental-health-disorders) (last accessed May 2011).
2. Bakken S, Holzemer WL, Brown MA *et al*. Relationships between perception of engagement with health care provider and demographic characteristics, health status, and adherence to therapeutic regimen in persons with HIV/AIDS. *AIDS Patient Care STDS*, 2000, **14**, 189-1397.
3. Gifford AL, Groessl EJ. Chronic disease self-management and adherence to HIV medications. *Journal of Acquired Immune Deficiency Syndromes*, 2002, **31** (Suppl 3), S163-S166.

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# Country file: HIV community care for those who live outside cities

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## HIV care in leafy Surrey

This is an interesting article to be writing because I have been working as an HIV/AIDS and Sexual Health Clinical Nurse Specialist (CNS) for Surrey Community Health for the last 4 years. This has been a very different position to be in after having spent from the mid-1990s to the early 2000s in the East End of London working at Mildmay Hospital. I write from my current perspective as a CNS in rural, leafy Surrey, thus highlighting the contrast in services and care delivered in this setting, in comparison to that of an inner-city primary care trust (PCT).

Initially, I held the opinion that if one had an HIV diagnosis, the best treatment and care was to be found at a big teaching hospital in a large city. However, as I have now worked in Surrey for several years, my opinion has changed. I believe the care in Surrey and many other counties outside large cities is second to none.

I am one of four HIV clinical nurse specialists employed by Surrey. I work with a colleague to deliver care to those patients with HIV mainly in the northern part of Surrey. Two other colleagues cover the southern part of Surrey. My colleague and I currently have 80 patients on our records, 50 of whom I currently see regularly.

My role is funded by the PCT and I take referrals from various sources. Most referrals come via the sexual health clinic at the local district general hospital where I have an honorary contract and also have regular virtual clinics with the HIV consultants and health advisors. These meetings serve to share information and give me the opportunity to update the clinicians on the picture I gain from a community perspective, and which often reveals many different issues that may remain hidden when a patient puts on their nice clothes and attends a clinic appointment with their doctor or nurse. My remit is very broad and varied mainly because this long-term chronic health condition affects patients very differently. Some patients may need greater support than others to cope with and explore their diagnosis initially, and then to adhere to their antiretroviral therapy (ART). This consistent input, in the form of telephone calls and visits to the patient, helps them to engage more fully with their HIV care and treatment. I also have the ability to prescribe a wider range of antiretroviral drugs too, which is important in some complicated cases where resistance is a big issue.

I deal with many more complicated issues, such as help with housing advice, debt management, psychological issues linked to HIV status and the current changes in benefits for this group of patients. I also give a lot of practical support to enable capable patients to engage and return to the work place, whether that be re-training or creating a curriculum vitae. Each situation is very different and each patient copes with an HIV diagnosis in different ways. One area in which I spend quite a lot of time is in helping a patient engage more fully with their GP and challenging the patient to consider the GP first, before the sexual health clinic, when, for example, they have a simple chest infection and require antibiotics. This is a constant issue, particularly with patients who have been diagnosed for many years and consider the HIV physician to be the only safe place to discuss their health. Often, I liaise with the GP on issues where I need their support and input, and I hope that with continually delivering this message, and helping GPs and patients understand, we will make this symbiotic relationship healthier!

I have also spent some time working with the district nurses in my locality helping them to understand that they may start to see more HIV patients who require their support and that they are not patients who should be feared. I have found that with some simple teaching they felt better equipped to deal with people with HIV. I have also had to run teaching sessions on various wards at the local hospital following unsatisfactory care being delivered to some of my patients with HIV who I care for too. These examples highlight the need for a raised awareness of HIV, not just by the general public, but also by the medical and nursing professions as well, and is something that we in NHVNA have been discussing for many years.

## Robert's story

I believe that the care I can deliver in Surrey may not always be possible to reproduce in an inner city owing to the larger numbers of people requiring HIV services. For example, today I visited a single mother of Spanish origin and her young adult son, Robert. This was a very complicated visit that involved talking at length with the mother who has psychological issues related to her past heavy use of illicit substances. I was able to spend time with this woman and help her explore her anxiety related to her chaotic past. I also offered to call the community

mental health team and request a follow-up appointment that I would attend too, to discuss a very distressing letter she had received and the impact it appeared to have had on this patient.

During this visit, accompanied by the specialist social worker for HIV in Surrey, we were able to highlight some pressing issues that were having a very negative effect on Robert. It became apparent that Robert (who also has an HIV diagnosis) was practically housebound due to the effects of gossip and taunting from local teenagers. It also became clear that, although he had made the first steps to secure council housing for himself away from the maternal home, Robert was unable to complete the application form. Within my role, I can give practical support of this kind. In this case, to be able to assist him to secure a new home away from small-town gossip would help this young man's psychological well-being profoundly.

I work a 3-day week and have the opportunity to see on average 12 patients each week. I tailor each visit to a patient's individualised care plan, which takes into consideration the specific needs of that patient. I plan my return visits to the needs of each person. Those who have very complex needs tend to be seen fortnightly, while those with less complex needs are seen monthly.

### Paul's story

Paul is an older gay man who has been living with HIV since the early 1990s, is very isolated and has no family or close friends. He lives in a small village in Surrey where he has told only a few people about his diagnosis. On first appearance, it could be thought that this white man in his late fifties had very few needs, but I have learned over the years that this man really benefits from regular visits. In particular, he adheres much better to his ART. This social contact and opportunity to discuss his feelings and the issues with which he is struggling, such as debt and coping with his daily loneliness, helps this patient to thrive, and in turn, he takes his medication as prescribed.

It is very important to support patients like Paul. The role I play is particularly beneficial as the time that Paul may receive from his GP or clinic consultant will most likely not be enough to explore some of the emotions that challenge him. This is of utmost importance to this particular patient, who is slowly running out of ART options owing to the many combinations he has already taken.

I completely understand the argument that HIV is now considered a long-term chronic health condition, and that as health professionals we need to be equipping our patients to go out into the community and to be less scared of disclosing to others. However, in more isolated communities, our patients still face bigotry, and HIV stigma is still very much present in many of our patients' lives.

This is highlighted by both of the voluntary organisations I work with in Surrey and the Hampshire borders. Both centres are very anonymous in appearance and one centre still even operates with a PO Box number. I believe that this is due to the smaller number of people with HIV in Surrey, and the understanding that people with HIV in these counties want an anonymous service where they can attend without the possibility of having their diagnosis revealed. It is still quite different in other ways at some of the services outside London. One voluntary organisation still offers lunch on two days a week for its clients who attend the centre in order to see a professional, for example from the Citizens Advice Bureau, counsellor, massage therapist or to attend the Women's Group. However, times are changing with dwindling financing for social services and local councils.

### Betty's story

Another patient who I have been visiting regularly for the past 4 years is Betty. This white, half British lady grew up in South Africa and enjoyed a happy and healthy lifestyle there until she met the father of her daughter, a black African man, and later discovered she had HIV. Betty returned to England in the early 1990s to support her aged parents, leaving behind her now-married daughter. She also returned to England for her own health after having observed many dying of HIV in Africa. Betty was a very complicated patient when I first met her. She was not taking ART for her HIV when we first met, and has continued over the past 4 years to remain very low in mood, struggling to cope with her mother's death some 5 years previously. During my regular visits, we have continued to discuss the benefits of taking medication and I have monitored her virus with regular CD4 cell counts and viral load tests. It seemed that Betty was never going to change her mind, but eventually she turned a huge corner in her life and wanted to actively manage her HIV, visit her daughter and grandchildren in South Africa and clear out and sort her reclusive flat.

It was a very surprising day, the day I visited her after Christmas, and found a totally changed patient with ambition and drive, who had cleared out her flat, was off to visit her daughter and was champing at the bit to commence ART again. It can be very difficult to measure the outcomes in my job, but this is one remarkable outcome that no one had suspected. Betty had not visited a doctor or clinic in four years but had suddenly woken from her slumber, ready to confront her HIV and live with it positively!

### Maria's story

Maria is a patient with very complex problems. She came to England on a student visa, which has now

expired, and met her Portuguese husband, James. Maria has no recourse to public funds and, due to their extreme lack of money, she is applying for a change to her visa so that she may continue her stay in the UK. I have been supporting this family since Maria's daughter was born. I visit monthly to observe both the mother's health and the well-being of the baby. James works as and when he can, but has recently lost his driving licence due to driving while on a ban. As this family's money is very limited, they have had to move out of their privately rented flat in Surrey because they were unable to pay the rent. The council has re-housed them in a bedsit as an emergency measure, mainly because of their vulnerable situation.

Since I have been seeing this family, I have been encouraging James to engage with the sexual health clinic and go for an HIV test, as he has not yet had one. Maria discovered her diagnosis during pregnancy, and their baby is now an 11-month-old little girl. I continue to discuss safer sex practices with this family and the importance of James having a test so that we can look after his health fully, but like many, he is reluctant to know his diagnosis and is very reluctant to actively take care of his health.

I have very little training in giving advice to my patients with immigration issues and so my first recommendation is that we seek advice from a specialist solicitor through the Terrence Higgins Trust or an appointment at the Refugee Council in South

London. Maria is an educated woman who has confidently filled out the Border Agency forms in order to continue her application for leave to remain in the UK. Due to Maria's immigration status we have not been able to support her financially with the AIDS support grant.

This woman has a very limited social network and her husband is unstable, so a monthly visit enables her to discuss issues that are worrying her and I can keep a close eye on her health and the health and well-being of her daughter. Lack of money means that, at times, this patient is unable to keep her appointments and I am a very real link to the clinic.

## Conclusion

In summary, I hope this gives a clearer perspective of how we are working in the counties outside the larger cities in the UK. I have portrayed a range of problems that my patients deal with, and shown how my role as an HIV CNS in Surrey is very valuable in continuing the support, often started at the sexual health clinic, for these diverse patients with often complex needs.

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# Ready, set, go! The time trials and challenges of hospital discharge planning in HIV care

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## Introduction

**W**hen starting work in an HIV inpatient unit, I would never have imagined that my career path would lead me to the role of ward and day care community liaison nurse. The skills of discharge planning are not taught to nursing students [1] and when I began the role, much of the discharge process was learned through experience.

Discharge planning may be perceived by some as the more functional, less rewarding aspect of delivering patient-centred care, but I would challenge this perspective. Ensuring that every patient receives the optimum level of care and support on discharge from hospital is incredibly satisfying.

Hospital discharge planning can be a complex process that may involve many health- and social-care professionals and the voluntary sector. It is dependent on interprofessional collaboration to support each patient's complex needs and expectations. Nurses play a central role in the discharge process, being able to assess the physical and psychosocial needs of patients.

## Why is planning patient discharges important?

Discharge planning is a routine feature of health systems in many countries. Shepperd *et al.* [2] suggest that a patient's length of hospital stay and emergency readmission can be reduced when discharge planning is incorporated into multidisciplinary team care. The importance of discharge planning has increased since the publication of the NHS Plan [3], which made a clear distinction between acute and intermediate care. However, for this to be effective the patient's social diagnosis needs to run parallel with the patient's medical diagnosis, as this allows for holistic discharge plans to be formulated.

## Ready! Admission to hospital

When an individual is admitted to hospital, the stresses and strains of daily life are not left at the hospital entrance. This may involve the patient having housing difficulties, worries about immigration status or perhaps fears of disclosure regarding their HIV status.

I know it is a well-worn phrase that we hear when newly qualified as nurses and starting out on the

ward, but discharge planning really does begin on admission. Taking a patient's social history ensures that appropriate referrals can be made with realistic goals being set. Involvement of different members of the primary healthcare team allows for continuity of care to become a reality [4]. For example, GPs, clinical nurse specialists, community mental health teams and district nurses may all work together, with the patient, to promote quality of life. This may include use of the multidisciplinary team's knowledge of local resources and support networks.

Involvement of outside agencies and voluntary sector organisations may be especially relevant to patients with issues of drug or alcohol dependency alongside management of their HIV. Furthermore, due to the changing nature of HIV care from inpatient to outpatient/community-based, along with an ageing cohort on effective therapies, there is an ever-greater emphasis on continuity of healthcare for this specialist patient group.

## Get Set! Coordinating community care services

Forces in the acute care environment often impede the discharge planning process. This can include time constraints on ward staff and pressure to create hospital beds, through increasing the speed of patient discharges [5].

Some days, my role involves an element of improvisation to coordinate community care services within financial restrictions. For example, it may be a patient's wish and medical recommendation when leaving hospital to have a period of respite/rehabilitation following a long inpatient stay. Funding for this is obtained from the clinical nurse specialist (CNS) based in the patient's housing borough. However, it may be the case that although this transitional service is appropriate, the budget is restricted and consequently the funding unavailable. Therefore, alternatives may need to be found to provide support for the patient on discharge, such as the setting up a package of care with meals-on-wheels through social services, and making appropriate referrals to the voluntary sector. However, this can present further challenges, as social workers (also known as care managers) also work within financial limitations, which may restrict the home-care packages that patients can receive.

Financial stress may be experienced by the patient, particularly if an HIV-related illness prevents the

individual from paid employment. This is particularly relevant with the forthcoming reassessment of all those in receipt of disability living allowance. Patients on the ward regularly benefit from a referral to the Citizens Advice Bureau (CAB). CAB advisors visit the ward once a week to discuss patients' financial concerns and potential entitlements.

Housing is often problematic for patients for whom renting is commonplace, often with poor amenities. This can impact on discharge planning for those who cannot return to their property on discharge, without a deep clean or repairs being required beforehand. Patients have described insect and rodent infestations, which make their accommodation unsanitary and inadequate, especially for individuals living with HIV who may be more susceptible to opportunistic infections.

It is also important to highlight the complex needs of patients with late-stage HIV who require end-of-life care at home. For the individual's needs to be met, many members of the multidisciplinary team will need to be involved in discharge planning along with the patient's family, carers or support network [6]. This emphasises the need for effective communication and coordination of services, which may include the GP, district nurses, community palliative care nurses, home carers and possibly home oxygen.

## Go! Promoting a safe discharge

A multidisciplinary team meeting takes place once a week on the ward to discuss in greater depth the individualised care plans for all patients on the ward. This is when predicted discharge dates can be set. If this discharge date is finalised, then effective communication and coordination needs to take place between hospital- and community-based professionals [6]. For example, if a referral has been made to the HIV specialist team to offer adherence support for a patient on discharge, then this referral needs to be confirmed with the CNS prior to the patient leaving hospital.

If a patient's discharge has been more complex, perhaps involving a social-care agency to provide a package of care and input from district nurses, then I will always try to follow up with the patient after discharge. This may help to prevent patient readmission, promote patient satisfaction and offer continuity of care for when he or she perhaps visits the hospital for a future outpatient appointment.

To highlight some of the challenges related to hospital discharge planning and discharge outcomes, which can be influenced by a patient's complex care needs, I have outlined a patient-based case study below (name has been changed to protect confidentiality).

## Thomas

Thomas is a 57-year-old gentleman originally from Grenada. He transferred his care from St Mary's Hospital to Chelsea and Westminster Hospital in 2006, when newly diagnosed with HIV and cytomegalovirus (CMV) retinitis. He required treatment with cidofovir, which, at that time, was not available at St Mary's.

When he was transferred, Thomas was experiencing diarrhoea, weight loss and multiple skin lesions, which were diagnosed as Kaposi's sarcoma (KS). His past medical and social history included alcohol and possible opiate dependence, depression, recurrent chest infections and non-compliance to his antiretroviral therapy (ART).

His KS initially responded well to ART but he later had a relapse of disseminated KS that required eight cycles of chemotherapy. During this time, Thomas had frequent hospital admissions with symptoms such as dysphagia, oesophageal candida, severe leg pain and weakness. Discharge planning during these early admissions was perceived as relatively simple because Thomas declined any support services on discharge, as he lived with his long-term partner, Mark.

However, his social diagnosis took on greater significance. After collapsing in his local pub, Thomas was admitted to hospital and required enteral feeding for malnutrition, which required him to have a nasogastric feeding tube on discharge, and therefore district nursing input at home. He was also continuing to receive doxorubicin for treatment of KS. In addition, in joint discussion and agreement with Thomas, a referral was made to the hospital-based drug and alcohol treatment centre.

Thomas was receiving benefits prior to his hospital admission but he was able to apply for higher rate Disability Living Allowance due to the complexities of his medical diagnoses and impaired mobility. This was facilitated by the CAB advisor who met Thomas during his inpatient stay.

During the following 6 months, Thomas was readmitted and received treatment at different times for lobar pneumonia, anaemia, profuse diarrhoea and active CMV, which has left him blind in his right eye. His adherence to ART continued to be poor, but with support from the advanced adherence nurse practitioner, along with a referral to the HIV CNS in his borough, and regular input from the specialist symptom control doctor and medical team, his adherence has now greatly improved.

The ward and day-care nurses along with the dietician, therapies team, doctors and HIV/oncology hospital clinical nurse specialist have all been involved in Thomas' care with the aim of reducing his regular readmissions to hospital and promoting his well-being. Thomas has said to

me that he now feels better informed regarding his HIV care and understands the importance of taking his ART. Initially, I organised district nurses to re-fill his dosette box at home, but Thomas and his partner now manage his medication independently.

It was also possible for me to confirm funding via his CNS for a 2-week admission to Mildmay, which gave Thomas the opportunity for rehabilitation and psychological support related to his depression and alcohol dependency.

Thomas could be described as a 'frequent flyer' to the hospital but now in an outpatient capacity rather than for regular inpatient stays. He tells the ward team about how pleased he is with the care and support he always receives at hospital and in the community. This highlights the value of effective and efficient interprofessional working to promote a more positive outcome for the individual and to provide ongoing continuity of health and social care.

## Conclusion

NHS reforms are imminent, which will impact on the provision of HIV services, both from an inpatient and outpatient perspective. Regardless of the NHS changes ahead, I believe that every nurse working in HIV care aims to provide the highest level of holistic care and support to their patients.

I really do love my ward-based role and, although it may not provide much opportunity for clinical nursing input, my aim is to make an impact on the quality of patient-centred care that is being delivered. Having the time to talk with patients and

establish their wishes during a hospital admission and then being able to coordinate multidisciplinary care in the community is immensely rewarding. Therefore, I would encourage all nurses to become involved as much as possible in hospital discharge planning and if it appears like the less exciting side of nursing, I invite anyone to spend a day with me on the ward and I promise to show you how wonderful it is to be a patient's link between hospital and community care at home.

## References

1. Nobusch JM, Weiss, ME, Bobay KE. An integrated review of the literature on the challenges confronting the acute care staff nurse in discharge planning. *Journal of Clinical Nursing*, 2001, **6**, 754-774.
2. Shepperd S, McClaran J, Phillips C *et al*. Discharge planning from hospital to home. *Cochrane Database of Systematic Reviews* 2010, 1, CD000313.
3. Health Protection Agency. HIV in the United Kingdom: 2010 Report. November 2010. Available at: [www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb\\_C/1287145264558](http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1287145264558) (last accessed April 2011).
4. Pethybridge J. How team working influences discharge planning from hospital: a study of four multi-disciplinary teams in an acute hospital in England. *Journal of Interprofessional Care*, 2004, **1**, 29-41.
5. Wagstaff N, Butler J, Katanovic S, Shepley M. High impact actions: discharge planning. *Nursing Management*, 2010, **3**, 12-16.
6. Pratt RJ. *HIV & AIDS: A Foundation for Nursing and Healthcare Practice*. 5th edn. Hodder, London, 2003.

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# The reluctant carer

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I have always admired carers. Caring and supporting someone takes a lot of strength, patience and devotion. Partners, siblings, friends or family members have willingly given their time and support to care for their loved one, whether as formal (paid) or informal (unpaid) carers. Statistics from the last 2001 census show that 1 in 8 adults (around 6 million people) are carers and it is believed that by 2037, the number of carers will increase to 9 million. The role that carers provide is invaluable, saving the NHS and social care millions of pounds a year and providing free care that should be paid for.

As a clinical nurse specialist for HIV, I provide care, support, patience and time for a patient, but only once a week, for an hour or so. I arrange to see patients again and off I go: it is easy and there is not too much stress or pressure. It is not for 24 hours a day, 365 days a year. However, I have become increasingly aware of people forced into the caring role, what I call 'reluctant carers'. Siblings or friends thrust unwillingly into the role of carer, who may feel they have a moral responsibility to provide care because it is not, and will not be, provided by statutory services, or the patient will not accept care from someone they do not know. It may start off with the odd bit of cleaning, shopping or running the odd errand. It could lead on to administering medications and laundry, to organising appointments and providing transport, and in some cases, providing personal care and advocacy. Rallying the professional services can be a tricky, complicated web. To be told that the only criteria social services will accept to provide cleaning is if someone is on oxygen therapy or has a de-scaling skin problem can be frustrating and disheartening. There is little research about 'reluctant carers'. I suppose it takes a lot of strength to admit it, but they do exist and we have probably all met them.

Take one of my patients, James; he is an 83-year-old man who was diagnosed with HIV in 1996. He jointly owns a house with his sister, Jenny, who is 80. They occupy a three-storey house where he 'runs' the first two floors and Jenny lives in a self-contained flat on the third. Since his diagnosis all has been relatively well; however, over the past 2 years, Jenny has noticed that James has been exhibiting some concerning behaviour. It started with a bit of absent-mindedness whilst cooking, the odd exploding hard-boiled egg, burnt baked beans or charcoaled fish. James was engrossed in some TV news story and totally forgot until he heard the smoke alarm or smelled the burning pan. It was all so understandable. James also forgot the odd tablet

or two, little piles of pills were found in drawers, in his bedroom, on the coffee table or in his drinks cabinet. So, he forgot one or two pills, so what? His CD4 cell count was amazing, his viral load was undetectable, whatever he was doing he was doing OK. Jenny believes he thought he was 'indestructible'. His absent-mindedness continued, however, and this is where I came in to observe his adherence and his behaviour. James was charm personified. Dapper, well-turned out, witty, he was full of stories about his young gay life during the war, his love of books and his not so conventional lifestyle. He enjoyed being different. His adherence continued to get worse. I would mark off in his notes how many doses he had missed, although he was convinced he had taken them every day. Some shrewd detective work was undertaken each visit to find the pills he had hidden and, after Jenny's dog swallowed a Truvada, I attempted to up the interventions. I tried it all. I swapped the large blue dosette box for something more recognisable and rainbow-coloured, but he still forgot. We set up an alarm system: he didn't hear it. I laminated 'Have You Taken Your Pills?' signs and stuck them on his door: he took them down. We had long discussions about his medications, the 'whys and wherefores', we even discussed the price and how much NHS money he was wasting. He was mortified, and vowed (as he had on each intervention) to take his pills. He did not. Jenny reminded him; even their lodger became involved and reminded him; but most of their interventions were greeted with 'I'll take them later' or 'I'll do it in my own time, stop fussing'. He presented at clinic very well: he was articulate, jovial and compliant. The perfect patient! He was seen by the Over-50s team and I requested that he was assessed by the psychologists who recognised his poor short-term memory and diagnosed vascular dementia. Medically there was little that could be done. I continued to monitor and maintain his safety.

After a spell in hospital for constipation (his poor memory, lack of exercise and fluids, cake-rich and fibre-light diet meant it was inevitable), James had his antiretroviral medications changed from pills to Kaletra liquid (as we believed he had a swallowing problem). Social-service carers were arranged to call in every evening to provide a meal and to encourage him to take his medication. Jenny diligently measured out his liquid Kaletra and I ensured his dosette boxes were kept up to date. This worked well for a good few months, but after another spell in hospital (for constipation again: he refused to take his senna, lactulose and Laxido) and

a belief that he required more care, the social-service carers were removed and he entered a period of re-assessment when he was provided with different carers every day. They arrived at 08.30 and were usually sent away as James, as predicted, had just gone to bed. Meals on Wheels were organised but, as James tended to be in bed when they arrived, it meant that Jenny had to be in every day to receive them, and if she was out, the police would be informed and they would 'kick the door in' if there was no response. Jenny cancelled them after a week.

As the months went by, James became worse. He left the gas cooker running so the house filled with flammable, noxious fumes. (The cooker was changed from gas to electric within weeks of this incident.) He fell down the stairs, without harm. James became more reclusive. He stopped going out and Jenny felt compelled to do more for him, cooking meals that he did not eat or buying shopping that frequently was thrown out. However, the overriding thoughts that Jenny had were 'how long will this last?' and 'the unfairness of it all'. Jenny felt she had to offer to do the shopping for him and was obviously concerned for her, and James', safety. His faecal incontinence (a consequence of his constipation, again) was the last straw. Jenny and I discussed looking for some private care. District nurses were called in to assess and treat his constipation but unfortunately, after the initial assessment, they did not arrange future visits as requested, but dropped in 'on the hoof' and James was either asleep or completely bemused by their need to 'check his bowels'. A private carer was sought, a young gay man to whom James could relate. He would provide some company, do the shopping, provide an evening meal and encourage James to take his medication. It worked and the carer came for an hour or so each day.

I found myself spending less time with James as he was increasingly bemused by my visits. 'Why do you come so often?' 'Surely there are people who need your attention more than me?' 'I feel fine, I don't know what all the fuss is about.' I spent more time with Jenny and we chatted over a cuppa. Monitoring from a distance and listening to Jenny's concerns was my main aim now.

Jenny describes their relationship as 'not close'. They tolerate each other. Jenny believes that her brother thinks women are the weaker sex and he revels in causing Jenny to cry as it proves him right. At first, she believed that he would be deliberately 'rude, ungrateful and forgetful'. She said '... he just expects it' when she did shopping or made him a meal. The diagnosis of dementia was good for her as it meant she could hang James' behaviour on to this and it helped her to be a little more understanding when talking to her friends. They have Christmas and celebratory meals together (sometimes) but that is about it. James lives his life

and Jenny lives hers. In all respects, they are housemates. Jenny is rooted to her routine: she wakes early, walks her dog until lunchtime and then she will either go out to see her many friends for dinner, theatre, cultural visits or horse racing. On the other hand, James does nothing and he has no routine. He'll sometimes be awake until the early hours and he'll get up at 10.00, 13.00 or 19.00. He rarely goes out, has no close friends, will sometimes watch TV and occasionally buy a newspaper, which he rarely reads. His sitting room is filled with hundreds of books on shelves and thousands of newspapers in piles on the floor, he has boxes of cakes and biscuits hidden in drawers or sitting on the sofa. Rentokil have been called to deal with the mouse infestation on many occasions. James' carer was instructed to clear the newspaper barricades. Jenny's flat is a model for *Homes & Gardens*.

However, Jenny also had regrets that if they'd had a better relationship she 'wouldn't mind doing things' for her brother. She feels he has a sad life now because he has no friends, and the ones he has, he has lost contact with, or 'can't be bothered'. We have discussed the possibility that he is envious that she has a social life and is active, and there may be some truth here. The once-dapper man has turned into one who looks gaunt, wears dirty, moth-eaten clothes and is unwashed and unshaven. I have had long talks on the phone where she has vented her frustration about the situation. This helps for a while. Her underlying thoughts, though, are: 'Why is he like this?' 'I'm stuck with him!' and 'Why me?' Jenny has even discussed selling her half of the house to move away from the situation she has found herself in but would have to have James' agreement to do so and '... then what would happen to him?'

Jenny feels anxious in her flat when James is in and has had many sleepless nights. We have had numerous conversations about her fears that James would set the house on fire, 'It's OK for him he'll get out, I'm on the top floor'. She's frustrated as he does not believe or will accept that anything is wrong with him so it had been difficult to get him to accept help. The formal social service care that was provided was unwanted by him 'but I can take will take my tablets if that's all these people are here for' was one of the frequent battles I have had with him. Thankfully he will accept care from his private carer.

Jenny and I are well aware of the detrimental effect all this is having on both her and her brother's physical and mental health. She wonders constantly, 'What would happen if something happens to me?' and the realistic answers are that either he would be placed in a nursing home or he would have a huge care package with carers having access keys. Jenny knows that if the private carer is away her brother 'will not do anything', so it all weighs heavy on her to provide meals and

drinks, etc. On more than one occasion Jenny has made this statement to me: 'Why should I bother ... if it was me who was ill, he wouldn't do anything for me'. She is right, I very much doubt he would.

## Conclusion

A recent survey [1] found that, amongst other things:

- Carers were more likely to be women than men; 60% of carers in England are women;
- Carers were most likely to be aged 45–64 (42%); a quarter (25%) were aged 65 or over;
- Carers performed a wide variety of tasks for the person they mainly cared for. They were most likely to provide practical help, such as preparing meals, shopping and doing the laundry (82%), keeping an eye on the person they cared for (76%), keeping them company (68%) or taking them out (62%).
- Around half (52%) of carers said their health had been affected because of the care they provide. A wide range of effects were mentioned a third: of carers reported feeling tired (34%), 29% felt stressed, 25% had disturbed sleep and 22% reported being short-tempered or irritable.

Jenny is not alone. She is an 80-year-old woman forced to care for her brother as they share the same house and, if they lived apart, I doubt she would have felt this pressure. In my CNS role, I have many patients who have informal care carried out by

partners, children, friends and family, and the stress and anxiety this has caused has been voiced many times. There is sometimes little that can be done when someone's disability living allowance is used to pay bills instead of providing extra care, or patients are reluctant to have strangers coming into their home. What may start off as a bit of shopping can snowball into hours of care provision. With an ageing HIV population this is a huge issue. Who will provide care for them in the future? Friends and family will become the backbone of care and for some this may be imposed and they too will become the 'reluctant carer'. This is an area rich for study; there is research into young carers and partners providing care, but very little looking at those who are older and may have the carer's role thrust upon them.

## References and further reading

- 1 Information Centre for Health and Social Care. Survey of Carers in Households 2009/10. Available at: [www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/survey-of-carers-in-households--2009-10-england](http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/survey-of-carers-in-households--2009-10-england) (last accessed May 2011).

Reference 1 gives information on the needs of carers but for information about support please see [www.carers.org/](http://www.carers.org/) and for practical help see [www.direct.gov.uk/en/CaringForSomeone/index.htm](http://www.direct.gov.uk/en/CaringForSomeone/index.htm) (last accessed May 2011).

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# The role and future of the voluntary sector

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**T**his paper focuses on the HIV voluntary sector so far, its role in community care and support, and what its future may be in light of current financial cutbacks.

## What is the voluntary sector and what has it contributed so far?

Volunteering predates the state, has its own diverse characteristics and is distinct from other market providers. Independent voluntary organisations come in different formats: charities, not-for-profit, cooperatives; all with a range of legal configurations. To discuss the role of the HIV voluntary sector, it is first important to widen thinking to the whole of the independent voluntary sector's work. It is predominantly contributed by civil society for mutual benefit, and the last 2 years have seen this emerging as the 'Big Society' politic.

In 2009, the Independent Commission on the Future of the Voluntary Sector in England [1] stated that there were about 200,000–240,000 voluntary bodies, with social care representing 37% of their total activities, and a total operating expenditure estimated at £13.5 billion in 1995. Of these monies, sales and earned income account for 40%, grants and donations for 43%, and investments 17%. The monies are attributed as coming from: individuals (41%); government (24%); and other charities, businesses and investments (35%). The Charity Commission figures suggest that there may be as many as 620,000 paid workers in this sector alone. Local government is the main source of statutory funding for many voluntary and community organisations, historically through grants, although increasingly resources are distributed through contracts.

## What does the voluntary sector do that is different from the market?

The voluntary sector is traditionally closer to the community of interest and operates with a strong degree of autonomy and control; however, it still has a wide range of governance, quality and legal regulations. Although the voluntary sector may be supported financially by the state, it is not just another means of delivering public services. Voluntary action is a means of providing support to users, and is often user-led, centering on the most marginalised individuals and communities.

## Why do people volunteer?

The National Council for Voluntary Organisations (NCVO) reported on why people formally volunteer today [2].

- People get involved because they want to make a difference.
- People feel strongly towards the cause they choose to support.

Additionally, a need within the community was part of one of the top six reasons [3].

Today, however, there is an emerging language describing a plethora of voluntary sector organisations that now sit under the broad umbrella of the 'third sector'. The 'Big Society' is part of that new language. The Big Society formed a key element of the Conservatives' 2010 election campaign and was the subject of the first major policy announcement of the new coalition government in May 2010 [4].

The main Big Society themes are:

- Supporting the voluntary and community sector.
- Devolving power to communities and local government.
- A greater role in public services for voluntary and community organisations (VCOs) and civil society organisations.

## The evolution and complex environment of the voluntary sector

The voluntary sector has contributed significantly to today's models of HIV service delivery and evolved as a result of competitive market demands. It lives symbiotically alongside other agencies, statutory and private, and is a major stage in the 'patient journey'. The same pressures that are exerted on other providers challenge and influence the voluntary sector. The HIV voluntary sector emerged out of a complex past, as strong individuals from marginalised communities began working together for a single goal.

In the 1980s, the HIV voluntary sector in the UK developed to meet an overwhelming demand. Three decades ago, there was very little, or no, community care, therapeutic or peer support for people diagnosed with HIV. The sector emerged out of a need for it, and community-based work such as 'buddying' programmes and palliative care support started to develop. Initially gaps were filled though 'peer-' or 'user-led-' support. LGBT-led community

activism was critical to the development of the sector, and served to strengthen and enhance user voices. This model then became an exemplar, and was used in wider areas by clinicians and within emerging social care provision [5]. It is encapsulated in the ethos of the disability movement maxim: 'Nothing about us without us' [6].

In the last three decades, the partnership between someone living with HIV and clinical and social care, research, activism, and voluntary and community engagement, has not only driven HIV services, but also pioneered new models of delivering for other health conditions. The social model of disability has gained ground and established a strong foundation. When clinicians had no immediate medical answers, the user-led movement blossomed to meet its own needs. The national HIV voluntary sector grew out of peer-led charities such as the Body Positives.

### Patient advocates

Action and reflection were vital tools in helping to expand understanding, particularly for those silenced voices that needed to be heard. Within the social-science context, HIV has always demanded insider participatory and human inquiry, as HIV is a lived and complex experience. Ledwith [7] suggests there are no absolutes or truths; only the authority of knowing that is located in the reality of people's lives. The voluntary sector supported the emerging role of the HIV patient advocate, a role that is still common within clinical treatment centres. The Treatment Action Groups were the forerunners of patient and public involvement forums. For the last two-and-a-half decades most HIV clinics have had a patient advocate working alongside the research and medical teams.

### New models of working and management

To manage a growing epidemic, people, from activists to clinicians, began reflecting on internal and external environments, both as individuals and in collectives globally, to find solutions and to make sense of the epidemic's complexity. Existing hierarchical management models diversified to accommodate the new partnerships. In the 1990s, a number of NHS public-health practitioners seeking evidence-based practice [8] adopted action-learning sets in order to disseminate and strengthen public-health learning across communities. The voluntary sector had, however, already introduced reflective action learning models [9] as a tool earlier in the previous decade as a natural model of governance. It has also been used widely in HIV resource-poor areas, such as parts of Africa, to gain consensus and consolidate actions. BPNW still uses reflective practice as an established part of its management, influencing the

development of the operational team's activities and BPNW's strategic business plans. The voluntary sector was instrumental in shifting patient and clinician power balances and supporting new models of engagement.

### Peer-led self management

Stanford University developed the specialist Positive Self-Management Program [10]. This programme has since been brought to the UK and the Expert Patient CIC now supports large numbers of volunteers to cascade the peer-learning. The HIV-specific programme is also embedded in the HIV voluntary sector.

### Influences on the voluntary sector and the changing position of the welfare state

The last three decades have seen modern welfare states face significant challenges, such as ageing populations and greater competition for smaller monetary pots. This is against a background of growing distrust in public office and ever-decreasing democratic engagement.

It has long been apparent that rates of health spending have not been economically viable. Increasing longevity and improvements in pharmaceuticals and clinical medicine have been outstripping the ability of health services to meet demands. Gone are the days of the kindly consultant sitting at a patient's bedside in the cottage hospital making the 'rationing' decisions. These decisions are now made through management models, commissioning frameworks and NICE guidelines. Additionally, government legislation has increasingly controlled local NHS and local authority decision-making.

The current deficit crisis has clearly been 'the writing on the wall'. For the last 30 years, successive governments have struggled to introduce a pluralistic approach to strengthen the health economy and facilitate a new model fit for 21st-century delivery. However, the introduction of wider private medical services and the development of public private partnerships, have in many cases, increased fiscal pressures, with long mortgages for decades of repayments to public private finance initiatives (PPFI).

### What do we mean now by the voluntary sector?

The voluntary sector has evolved from groups of unqualified community helpers to sophisticated providers. As voluntary groups grew, they commanded a share in the delivery of care and, in particular, an equal share in the HIV commissioning budgets. Today, only some of the voluntary sector groups continue to be identified as

'user-driven'. There have been financial shifts from commissioners to individual community care budgeting and, although the AIDS Support Grant continues from central government for now, the ring-fencing has been removed. The personalisation agenda in HIV is anticipated to gain further ground between 2011 and 2013 as the welfare benefits and employment changes gather momentum.

The last decade has seen a dominant market culture developing within the voluntary sector. There has been more legislation to regulate and order individuals and communities, and even more complex contractual arrangements have been created. In order to meet these contractual demands, voluntary-sector providers have had to shift the focus of their work from communities to paperwork. They have had to provide outcome data, IT intelligence, objectives, mission statements and slick logos to compete in the market. The simple approach of meeting the needs of a particular community has instead become dominated by a business culture. In the last 10 years, a large proportion of the Body Positive charities across the country have closed. These smaller, local-community organisations were unable to meet the market demands and larger HIV charities now predominate over wider geographical footprints.

Third Way policies and the economic crash of 2008–2009 exposed the UK's mountains of public debt [11]. Legislative control has reduced community and neighbourhood participation at a local level. Central government seemed to seek to control and manage basic moral and ethical decisions. The new Big Society ideology is seen by some as a cynical attempt to harness the community and voluntary sector for free. However, while it has been poorly articulated, it could also be a reaction to being over-audited and may be a way of returning decision-making to communities.

### What voluntary organisations may look like after the impact of the financial cuts

HIV has perhaps seen as many new models of voluntary-sector organisations as there have been different antiretroviral drug regimens. So what is the voluntary sector experiencing? My belief is that the voluntary sector recognises that this is a complex and challenging situation for both those who set budgets and also managers who have to reduce costs. Globalisation has brought greater awareness of world markets and competition. However, the local conversations that we have had are about the critical impact on health outcomes and the wellbeing of local people, and how to minimise the devastating effect that this will have on the most vulnerable over the next few years.

Over the last months, behind the scenes, the increased emphasis on neighbourhood delivery

and the localism agenda has impacted on the work focus of the specialist HIV voluntary sector. If conversations are had early enough, then the HIV specialist services could develop strategies, for example, adopting a consortium approach, possibly with a hub-and-spoke model of delivery. This would ensure local delivery without a loss of expertise and economies of scale. However, providers have to agree on the needs that are being addressed [12] and a culture of trust must also exist. However, as we have just lived through a period of a competitive market culture, can agreement and trust realistically emerge when set against the backdrop of the current reductions in local authority budgets and services, and an increasingly unstable market?

Manchester City Council has proposed 22% cuts to the voluntary sector. The NHS faces less immediate pressures, but its need to reduce expenditure will impact in 2011–2012. Already national HIV voluntary sector agencies have made approximately 25% cuts in staff and delivery. In theory, the national Transitional Fund and Big Society bank loans could be available to cover short-term gaps while organisations develop funding streams. However, it is quite unclear what the future opportunities for funding are, and the voluntary sector is understandably reluctant to risk undertaking loans.

The current government's Health Secretary, Andrew Lansley, has embarked on a policy of NHS reform [13] that involves the abolition of primary care trusts and a transfer of commissioning power to GPs, and has the ambition to vastly increase participation of the private and the voluntary sector. As with other sectors, such as education, this indicates that the NHS will still be funded from taxation but that the government will take a step back from running the service.

### The possible future role of the voluntary sector

All sectors, including the HIV voluntary sector, are in a state of flux. What are the opportunities and possible directions of the HIV voluntary sector? Maximising limited resources to address needs effectively has never been more crucial. With the central localism agenda and local authority concentrating on activity at neighbourhood level, the role of users is even more crucial. The WHO defined three stages to the HIV epidemic [14], the third stage being that addressing HIV stigma is critical to people's health and wellbeing. Working across a socially inclusive integrated neighbourhood, with HIV found within the disability agenda, is a strategy for addressing that stigma.

The emerging Big Society could be an opportunity for the recognition and engagement of civil society, with greater emphasis on 'expert patient' models

being explored. Nurses working outside the NHS, or models of delivery involving volunteers, strengthen this agenda. Specialist HIV voluntary consortiums using a hub-and-spoke model could deliver a more cost-effective service. However, we must first overcome the barriers and mistrust resulting from competition for limited resources that providers are facing. South London HIV Partnership has piloted a working model with a single point of entry that has developed effective partnerships and improved outcomes for HIV clients [15].

Voluntary action is a major force in its own right, and voluntary bodies must always be free to act as advocates. It is not just an adjunct to the statutory sector, but rather it is a reflection of what emerges from communities. If the voluntary sector is to maintain its impact, diversity of funding sources is one of the best guarantees of independence. Some statutory and voluntary organisations have experienced significant loss of the resources that they have relied on.

A primary question for organisations to ask is: 'Have we got a passion to continue and a clear direction?' This is not a case of people simply securing jobs in the HIV voluntary sector. It is because the voluntary sector is user-led, understands needs and can respond rapidly and effectively. To survive, a strong strategic direction and business case is vital. For the next couple of years, trading commercially within the current climate will depend on a variety of sources including income from gifts, donations, grants, contracts, sales or trading. There will also be a substantial contribution, not to be underestimated, from volunteers, people learning a new skill, student placements or people living with HIV directing the work of the sector. A wider role for the voluntary sector in HIV prevention, sexual health and the whole blood-borne virus agenda also makes economic sense.

A healthy independent voluntary sector is the backbone of civil society and a vital indicator of democratic health. We can measure that democratic engagement against how much user-led HIV voluntary networks feature in the next decade.

## References

1. Robb C (ed.) Meeting the Challenge of Change: Voluntary Action into the 21st Century. National Council for Voluntary Organisations, London, 1996. Available at: [www.ncvo-vol.org.uk/uploadedFiles/NCVO/Policy/voluntaryaction2005.pdf](http://www.ncvo-vol.org.uk/uploadedFiles/NCVO/Policy/voluntaryaction2005.pdf) (last accessed May 2011).
2. National Council for Voluntary Organisations. Participation: Trends Facts and Figures. National Council for Voluntary Organisations, London, 2011. Available at: [www.ncvo-vol.org.uk/sites/default/files/UploadedFiles/participation\\_trends\\_facts\\_figures.pdf](http://www.ncvo-vol.org.uk/sites/default/files/UploadedFiles/participation_trends_facts_figures.pdf) (last accessed May 2011).
3. Department for Communities and Local Government. 2008–09 Citizenship Survey: Volunteering and Charitable Giving Topic Report. Available at: [www.communities.gov.uk/documents/statistics/pdf/1547056.pdf](http://www.communities.gov.uk/documents/statistics/pdf/1547056.pdf) (last accessed May 2011).
4. BBC News. Cameron and Clegg set out 'big society' policy ideas. Tuesday, 18 May 2010. Available at: [www.news.bbc.co.uk/1/hi/uk\\_politics/8688860.stm](http://www.news.bbc.co.uk/1/hi/uk_politics/8688860.stm) (last accessed May 2011).
5. Sang B, Selbie D. Integrating health and social care for mental health: frameworks for action and learning. *Managing Care*, 1998, June.
6. Charlton JI. *Nothing About Us Without Us. Disability Oppression and Empowerment*. University of California Press, Berkeley, CA, 1998.
7. Ledwith M. *Participating in Transformation: Towards a Working Model of Community Empowerment*. Venture Press, Birmingham, 1997.
8. Learmonth A. Action learning as a tool for developing networks and building evidence-based practice in public health. *Action Learning: Research and Practice*, 2005, **2**(1), 97–104.
9. Revans R. *The Origins and Growth of Action Learning*. Chartwell-Bratt, Bromley, 1966.
10. Stanford Patient Education Research Center. Positive Self-Management Program for HIV (PSMP). Available at: [www.patienteducation.stanford.edu/programs/psmp.html](http://www.patienteducation.stanford.edu/programs/psmp.html) (last accessed May 2011).
11. Jordan B. *Why the Third Way Failed*. The Policy Press, University of Bristol, 2010.
12. Carr B. Total Place Pilot Project in Birmingham. NCVO Needs Conference 2010. Available at: [www.youtube.com/watch?v=QZlpUdXi1ew](http://www.youtube.com/watch?v=QZlpUdXi1ew) (last accessed May 2011).
13. McCabe C, Kirkpatrick I. The NHS braces itself for privatisation. *The Guardian*, 12 April 2011.
14. Mann JM, Gruskin S, Grodin MA, Annas GJ (eds). *Health and Human Rights: A Reader*. Routledge, New York, 1999; p.7.
15. Markham C (ed.) *The Bigger Picture: The first Report of the South London Partnership*. 2011. Available at: [www.slhp.org.uk/The%20Bigger%20Picture.pdf](http://www.slhp.org.uk/The%20Bigger%20Picture.pdf) (last accessed May 2011).

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# The role and future of the voluntary sector: a HIV service provider's perspective

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In their submission to Parliament's Public Administration Select Committee Inquiry into Voluntary Sector Funding, the National Association for Voluntary and Community Action (NAVCA) reported that the government's budget deficit reduction plan has resulted in significant cuts to the sector's funding, leading to severe reductions and even closure of valued community services [1]. NAVCA estimates that approximately 26,000 jobs in the local voluntary sector will be lost this year, representing approximately 25% of the sector's salaried workforce.

The effect of budget cuts and the concomitant reduction in staffing and service provision will inevitably have far-reaching effects on the sector. Moreover, the recent and ongoing welfare reforms, plus a significantly reduced legal aid provision, seem set to add an increased burden to a diminished voluntary sector and, more importantly, it appears clear that the accumulation of such radical change will impact negatively on those who rely on the sector for a range of supportive and practical services.

This article will explore the combined effects of, and reaction to, the budget deficit reduction plan on the voluntary sector as experienced by River House Trust, a HIV service provider in west London.

## Overview of River House Trust

River House evolved from a pilot project called 'The Meeting Place', which was established in Hammersmith in the mid-1980s, opening in its present form in February 1988. River House aimed to harness the resources needed to offer an integrated range of services for people living with HIV (PLHIV) and it continues to fulfil this vision. Today, River House functions as a community-based resource centre that provides nutritional, practical, therapeutic and medical services, managed by the equivalent of six full-time staff members. A snapshot of our services is provided below:

- General health and sexual health clinic (clinical nurse specialist-led); condom supply
- Welfare benefit (CAB) and social services advice
- Nutritious daily lunch service
- Complementary therapies – massage, shiatsu, acupuncture, hypnotherapy
- A range of courses such as IT skills, back-to-work training, cookery classes

- Educational workshops from HIV/sexual health/dietetic specialists
- Advocacy, emotional and practical support
- Individual and group counselling
- Internet, photocopying, HIV informational resources, laundry service

We have strong relationships with our fellow service providers and local sexual health clinics, which we feel is important to the individual and collective care we provide to our clients.

## Client base and considerations

We process approximately 1500 visits to the centre per quarter, representing up to 500 people, including service users, carers and guests. Our membership reflects the diversity of PLHIV in terms of age, gender, sexual orientation and cultural background and we aim to support people of all backgrounds through the provision of general services, as well as through niche activities such as a women's group and a Muslim group. It seems of particular relevance to the services we develop in the future, however, that middle-aged and older white homosexual men represent our highest membership group. Approximately 67% of our user base consists of people aged between 50 and 84 years.

The majority of this group are individuals who have been living with HIV as a long-term condition. Together with the documented increased incidence of social isolation, anxiety and mood disorders in this group [2], we have also seen an increase in diagnoses of comorbid conditions such as osteoporosis, cancers and cardiovascular disease [3]. Correlation of a range of psychological and medical conditions with age/length of diagnosis clearly has implications with respect to the individual care and support we offer to our clients but it would also indicate that an increased level of social care will be required for this group in the future. Strategic considerations for River House, therefore, must include the development of services that support a client group with emerging clinical and psychosocial needs. However, we must also adapt our services to enable clients to cope with the potential consequences of voluntary-sector cuts, welfare-benefit reform and reduced social-care funding.

We began adapting our service during the past year to meet the challenges of a changing sector climate, while simultaneously looking at ways we

could add services to support clients during a time of welfare reform. Like many organisations in the voluntary sector, we have had a strong historical dependency on state funding, which puts us in a potentially vulnerable position for the future. To attempt to counteract this position, we have worked to develop ways of sourcing other funding streams through the recruitment of a volunteer funding specialist, development of our donation strategy and maximisation of room hire income. We have also analysed our financial outgoings and reduced costs through tendering exercises and/or moving to more cost-effective suppliers, while simultaneously developing a voluntary service to reduce service-provision costs.

The majority of our service users have been dependent on welfare support in the form of incapacity benefits and disability living allowance (DLA) on a long-term basis. As it is possible that a number of people may experience a reduced benefit income and/or be required to enter the workforce, we have developed a number of services that aim to provide practical support, education, development of life and work skills and opportunities for practical application of these skills. We have found that there is much confusion for many clients about how precisely the welfare system is changing, which we have attempted to address through group workshops, individual sessions and information sheets. We have appreciated the clarity provided by provider colleagues such as NAT, THT and T-Cell, which has assisted this process greatly.

## Service adaptations

### *The River House Law Clinic*

The River House Law Clinic was developed late last year and became operational in March 2011. The Law Clinic is a collaborative venture between River House Trust, the solicitors HCL Hanne & Co, and the School of Law at Birkbeck College, University of London. The Clinic was developed in response to the perceived need for PLHIV to have access to quality legal advice, given that many people still experience unlawful discrimination in work [4], housing and with issues such as hate crime [5], together with an emerging focus on HIV transmission and criminalisation [6]. Furthermore, we anticipated that public sector reforms would be associated with increased numbers of PLHIV attempting to access legal advice services in a climate of reduced legal aid provision.

At a procedural level, volunteer Birkbeck Law students undertake initial telephone assessments, which are supervised by the Assistant Dean of Law; their case notes are passed to volunteer solicitors at HCL Hanne & Co, who see clients at River House on a fortnightly basis, or at their office on a needs basis, for example when cases are time sensitive. In our first month of operation, the Law Clinic worked with 18

clients. We have limited the initial 3 months of operation to River House service users to enable us to tighten our procedures before rolling out the service to non-members, at which time we anticipate a rapid growth in the number of people accessing the service – perhaps particularly by those who wish to appeal benefit, social care and housing decisions.

### *Psychological services*

As mentioned earlier, we are seeing an increased incidence of poor mental health in our client group. Since the welfare reforms were announced, a large number of clients have reported that they feel increasingly anxious about how the reviews might impact on their particular life situations. Many have concerns that the employment and support allowance, which has replaced incapacity benefit assessments, will not take account of the fluctuating nature of HIV symptoms and medication side effects. There is also concern regarding the current lack of clarity surrounding the move from DLA to Personal Independence Payment in the next few years. In addition, as many clients are long-term unemployed, there is anxiety about feeling pressured to begin, or return to, work and clients fear the effects this might have on their physical and psychological health, possibly exacerbated by decisions regarding HIV status disclosure to potential employers. These signs of distress are of concern given the documented association between mood and anxiety disorders and compromised adherence to medication and increased risk of onward transmission of HIV infection [7]. Furthermore, the complex interaction of a challenging life situation, and introduction of a potentially stressful benefit assessment process, may have some impact on medical stability. For example, it has been found that low mood and stressful events may negatively affect HIV disease progression in terms of decreased CD4 cell count and increased viral load, potentially leading to greater risk for clinical decline [8].

River House has provided weekly individual counselling, via a Living Well therapist, for some years. However, given the growing demand for access to therapeutic services, we have recently increased our counselling provision through the introduction of a psychotherapeutic group, classes to help clients develop coping skills, and individual motivational interviewing sessions, all of which are facilitated by River House staff. We anticipate that this demand for therapeutic services will continue into the future and we aim to monitor this aspect of our service on an ongoing basis.

### *Development of volunteer services*

The development of a volunteer service at River House over the past 6 months has had a number of benefits. It has enabled us to provide a range of services at low cost, which combine to provide resources to help clients with pain management, stress reduction, behavioural change, such as

smoking cessation, and improved self-esteem (as reported in evaluative feedback). Current voluntary services include weekly yoga sessions, hypnotherapy, acupuncture and shiatsu. We are now planning to expand the services to provide opportunities for service users to volunteer at River House to enable them to gain work experience in a familiar, safe environment. Foreign language classes will soon be facilitated by service users and we also plan to provide opportunities for clients to train and work in supervised administrative functions at River House, for example reception duties, course bookings and dealing with telephone queries. We believe that the development of this service will be important in the coming years as it will enable us to reduce our service costs without reducing our service provision, while also providing opportunities for training and work experience for our clients.

### *Skill development*

We introduced skill development courses during the past year with a view to empowering clients to develop independence, self-confidence and also to develop skills they may need should they be required to enter or re-enter the workplace. Courses have included the development of personal financial management skills, cookery classes, a back-to-work course and a range of IT skills courses. The latter were enhanced by the donation of over 20 PCs from a local school, which we passed to service users who were unable to fund home computers. We have also worked with service users individually to help them to enter the voluntary workplace; some of whom have since taken on placements in charity shops, in voluntary-sector organisations and as St Stephen's volunteers at the Kobler Clinic, Chelsea and Westminster Hospital. We have now developed further courses, to be rolled out during the next few months, which will specifically focus on job search strategies, CV and application form completion and presentation and interview skills, which we believe will have particular relevance in the months ahead.

### **The future of voluntary-sector HIV service provision**

Many providers have been proactive in meeting the challenges we are seeing in our sector. At one level, this has had positive effects, such as increased partnership working and increased sharing of knowledge and expertise; and it has led to discussions regarding cost reduction through the merging of certain administrative functions. However, we have already seen the effects of actual and projected funding cuts in recent large-scale redundancies and service reduction across the HIV provider network. It is anticipated that current and future sector restructuring will lead to the loss of a number of smaller, niche organisations

that provide valuable services to our client group. This would inevitably lead to increased demand on a reduced service provision, which will prove challenging but, more crucially, future provision may not be able to sustain the rich variety of services that are currently on offer. These projected impacts have, of course, serious implications for those who have lost, or will lose, their jobs but must also impact on the people who depend on our services. As is usual across the voluntary sector, we work with many people who are vulnerable and often isolated. Our service users regularly tell us that the tailored services, plus the opportunity for peer support and social interaction, provided by River House and by our fellow providers are invaluable to them and to their well-being.

Given the rise in HIV transmission, together with an ageing client base with particular social care needs, it seems evident that the demand for HIV services will grow rather than decline in coming years. At River House, we believe that we must adopt a proactive approach to continue to cut costs and nurture alternative funding streams. We must also work closely with fellow providers, clinics and other specialist agencies to develop innovative and robust services to maintain the most effective support system possible for our clients in the challenging years ahead.

### References

1. National Association for Voluntary and Community Action (NAVCA). Public Administration Select Committee Inquiry into Voluntary Sector Funding. Submission for the National Association for Voluntary and Community Action HC716. NAVCA, London, 2011; point 1.1. Available at: [www.publications.parliament.uk/pa/cm201011/cmselect/cmpubadm/writev/716/fvs01.htm](http://www.publications.parliament.uk/pa/cm201011/cmselect/cmpubadm/writev/716/fvs01.htm) (last accessed May 2011).
2. Power L, Bell M, Freemantle I. *A National Study of HIV and Ageing (50 plus)*. Joseph Rowntree Foundation, London, 2010; pp 26–27.
3. Lewden C, May T, Rosenthal E *et al*. Causes of death among HIV-infected adults in France in 2005 and evolution since 2000. *14th Conference on Retroviruses and Opportunistic Infections*. Los Angeles, February 2007. Abstr. 976.
4. National AIDS Trust. *Working with HIV*. National AIDS Trust, London, 2009; pp 18–21.
5. National AIDS Trust. *Discrimination Law Review. Proposals for a single equality bill for Great Britain. Submission for the National AIDS Trust*. National AIDS Trust, London, 2009; p. 1.
6. United Nations (UNAIDS). Policy brief: Criminalization of HIV transmission. UNAIDS, 2008; p. 1. Available at: [www.data.unaids.org/pub/basedocument/2008/20080731\\_jc1513\\_policy\\_criminalization\\_en.pdf](http://www.data.unaids.org/pub/basedocument/2008/20080731_jc1513_policy_criminalization_en.pdf) (last accessed May 2011).
7. Scher L, Lampe F, Norwood S *et al*. Successive switching of antiretroviral therapy is associated with high psychological and physical burden. *International Journal of STD and AIDS*, 2007, **10**, 700–704.
8. Leserman J. Role of depression, stress and trauma in HIV disease progression. *Psychosomatic Medicine*, 2008, **70**, 539–545.

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