

## **Social Housing and HIV in Cornwall (pre-ONE Cornwall) - 24 February 2009**

An overview by KPS of the impact housing has on the health and well-being of people living with HIV in Cornwall and the way people coping with HIV experience housing related services in the present local authority areas.

KPS works County wide with one client group, all of the people KPS works with are on a low income and have a housing related need. Therefore KPS is in a unique position to mystery shop for housing related support for its client group in most of the local authority areas in Cornwall. The timing for this report comes at the first anniversary of the KPS housing related support service and crucially immediately prior to the change from six governing authorities to ONE Cornwall. In most cases the clients have initiated the process of accessing housing related support from local authorities and run into difficulties, these difficulties range from making little or no headway on the housing register and access to homelessness support to being refused benefit. In almost all cases the medical need because of HIV has been secondary to being homeless or some other primary need. It appears that local authorities do not have a coherent policy or the flexibility to provide housing related support to people suffering from HIV/AIDS. What we do not know is the numbers of people who are not our client group but receive a similarly poor service. If the distinction is that the entire KPS client group have HIV/AIDS, and none AIDS sufferers receive a better service than our clients experience, serious questions need to be asked of the people who administer these services, but as I have said we do not know. ONE Cornwall has an opportunity to deal with all the issues raised in this report and it is our hope they will take onboard the changes which must be made.

### **Summary**

Effective treatment of HIV in Cornwall is transforming lives; it has effectively changed this illness from being terminal to a long term manageable illness where people are living active lives. Nevertheless HIV remains a complicated illness and particular aspects of it are adversely affected by poor housing, temporary housing and the stress and uncertainty of homelessness. Unfortunately the social aspects of this illness are also still very much with us and appear exacerbated by close nit Cornish communities. KPS works county wide with one client group, people with HIV, most of the people we work with are living on benefits and claiming housing allowance and many have applied for social housing, a few are also owed a statutory duty to be re-housed and are living in temporary accommodation. KPS is funded through Supporting People to provide floating housing related support county wide, it does this by working closely with the Social Services link social worker seconded to the RCHT at Treliske hospital Truro and through self referral.

### **Attitude to HIV**

HIV is a sexually transmitted disease; I would think everybody knows that, but changing the perception that it only affects one section of society is more difficult than educating people about what it is. Many people have psychological problems related to the perception society has about who has HIV and how they were infected, and these attitudes are very slow to change. This creates an underclass of people living with a terrible secret, and many do not disclose to family, friends, employers, government officials, insurance companies and the list goes on. The pressure of living without being able to confide in others for fear of discrimination and harassment has a serious impact on the person's ability to access services and people go to extreme lengths to get over this problem. KPS works with people who travel out of county to access HIV services, and others who visit Cornwall for the same reason. So they cannot be identified in the area where they live as having HIV/AIDS. I doubt if any other disability causes similar reactions from its sufferers.

### **Case Study**

A Cornish man returning to Cornwall after living for over thirty years on the African continent where every other person had HIV, and nobody gave it a second thought, finds he cannot mention his illness to anybody in the place where he now lives with an aging relative for fear of discrimination and the stigma it would bring to his family.

Poor housing, temporary housing and the stress of homelessness reduces the impact of better medication, and undermines a person's health by:

- Making it difficult for a person to adhere to the drug regime which reduces the effectiveness of the medication and has the potential to do lasting harm.
- Making the person more susceptible to certain illnesses like PCP and other infectious diseases which affect the lungs.
- Can have the potential to accelerate the decline in general health, and bring the need for HIV medication sooner than would otherwise be the case.
- Has the potential to cause mental health difficulties which impact on both physical and social activities, places families under pressure and as a consequence decrease the value of taking the medication and has long lasting health implications.
- Prevents people from having the privacy necessary to protect themselves from discrimination, abuse and harassment.
- Causes difficulties in managing the side effects of HIV medication.

Decisions about the priority of people with HIV for social housing appear to be made on an ad hoc basis in Cornwall, and are not made in the light of long term disability. These decisions

appear to be based on how the person's disability impacts on them at the time of application, and are not part of an informed assessment of the person's ability to function over time. This short-sighted approach which appears to have been universally adopted across Cornwall is dangerous to a HIV positive person's wellbeing and is probably costing support agencies and the NHS far more than is necessary, and ultimately these people are being re-housed at some stage but only after considerable hardship has been endured by the people and families involved.

Questions raised by looking through our files identify issues which should not exist but do, and the change to ONE CORNWALL has an opportunity resolve these inequalities.

KPS would like to see:

- One Cornwall to recognise people with HIV as a priority category for Social Housing.
- Homeless people or those threatened with homelessness, who have HIV to be seen as a priority for emergency support regardless of current health.
- People with HIV in Cornwall should not be housed in shared accommodation.

All the following examples are taken from our files; they have been anonymised to protect the client group.

Much evidence exists of the harm that poor housing can do to the health and wellbeing of people living with HIV, the NAT/Crusaid 2006 report(1) Poverty and HIV, highlighted housing as a major concern for people living with HIV. Housing concerns also feature large in the Waverley Care/Crusaid 2007 report (2) Poverty and HIV in addition HIV is an identified group singled out for support by the Government and therefore a priority target group for Supporting People funding. If this is not enough HIV is recognised as a disability from the moment of diagnosis not from the onset of symptoms and the 2005 amendment to the Disability Discrimination Act 1995 makes it illegal to discriminate against HIV positive people in the provision of accommodation.

Structure of this report

This report looks at several case studies from five of the present six local authorities; all of the case studies identify anomalies and deficiencies in social housing provision offered to HIV positive people over the past year. The reason for presenting the case studies prior to ONE Cornwall in April 2009 is that comparisons can be drawn at a later date with the differences ONE Cornwall brings to HIV positive people seeking social housing in the year 2009/10. It is not my intention to de-skill the reader by dwelling on housing law but I have touched on it where it is relevant to a particular case study, I also mention homelessness as it relates to many of our clients and the time they spend in temporary accommodation. Other areas covered in this report are HIV and Housing Entitlement, the Health Implications for people with HIV, HIV and Discrimination, HIV and Mental Health and the Implications of Living in Shared Accommodation.

**Patchy response.**

Living in Cornwall and having the HIV virus means the response to a social housing application will vary according to the area where you made the application, of course it will also vary according to the symptoms you are presenting at the time. From our records we have been able to identify that people presenting similar symptoms and disclosing HIV status can routinely be banded from Bronze to Gold with no universal application of qualifying criteria.

**Case Study**

An HIV-positive person approached PDC for housing support because the housing situation was damaging to this persons health, an application form was completed including the disclosure of HIV. This person also requested a Medical Assessment form which was comprehensively completed and returned with a letter of support from a HIV hospital consultant and a four page accompanying letter describing the difficulties being experienced. The response from PDC was low priority need, Bronze Award, no further support was offered and no referral to another agency was made. Section 167 of the Housing Act 1996, as modified by the Homelessness Act 2002 and the Housing Act 2004 requires specific attention to be paid to People who need to move on medical or welfare grounds relating to disability.

It is not difficult to understand the pressures faced by housing department but much is said about IAG (information, advice and guidance) departments of local authorities and partnership working, but it has to happen. The local authority interpret the weight given to the conditions laid down in the Housing Act and this is a breeding ground for inconsistencies and definitely an area which ONE Cornwall must address, HIV positive people must have a uniform housing experience county wide with a minimum standard of expertise. HIV is a complicated illness which affects many aspects of a person's life and has to be considered in that light, of the fourteen potentially vulnerable client groups identified in the ONE Cornwall draft housing document KPS is working with people in ten of the groups, these people have HIV in addition to the identified vulnerable group.

**Vulnerable from HIV also Homeless**

People with HIV are vulnerable and have housing needs, being homeless and dealing with that aspect of a person's housing need is not good enough, a HIV positive person housed in a homeless shelter is being placed at risk and the agency involved is failing its duty of care.

**Case Study**

An HIV-positive person approached New Connection in Kerrier for housing support, the support provided was a room in a shared house and an application was made to

Coastline for inclusion on the housing list. After several weeks this person was moved to another room in another shared house, he was asked to sign the licence before being shown the room and told he had to move. He was allocated a first floor room which had two outside walls without insulation and was wet with condensation; the shared facilities were on the ground floor including the toilet. This person had mobility and care needs and was in receipt of DLA. For the time he lived in that house he did not shower because it was too cold and the step into the shower was too high. This person was treated as a homeless person only, and none of his HIV physical or psychological needs were considered or met. After a KPS intervention this person was provided with a HA flat.

People with HIV are vulnerable from the HIV infection, they may also be homeless. It is obvious that in Cornwall having the HIV virus is not seen to be enough to be in priority need, and this has to change. The cost of declining health of a HIV positive person to the NHS, Social Services, the Benefit Agency and other support agencies has to be considered, and this decline can be rapid when a person is homeless or living in sub standard housing or shared accommodation. HIV positive people have a duty to look after themselves and many take this seriously, unfortunately many of the properties in the private sector suitable for people with HIV are outside housing allowance limits.

#### **Housing allowance financial limits are not enough.**

HIV-positive people are required to adhere to a strict drug regime, look after themselves including diet, and protect themselves from damp and cold. Renting from the private sector is problematic and costs are more than double social housing costs. In many areas of Cornwall renting a reasonable flat from the private sector requires subsidising the rent, local authorities fail to recognise the needs of a HIV positive person in this situation and fail to respond, or make an application for discretionary housing payment so difficult that many people give up and use a disability benefit (if they have one) to pay the difference.

#### ***Case Study***

An older person who was HIV-positive and who had been seriously ill with PCP needed accommodation which was of a reasonable standard. After approaching Kerrier DC and making an application for LA housing and being told there was little chance of a property contacted a letting agency and agreed to rent a home in excess of housing allowance limits. This person was determined to have a safe, clean, easy to run home where adherence to the HIV medication and strict diet could be followed to prevent a return to hospital with HIV related pneumonia. Initially this person funded the rent shortfall by using DLA which is not what DLA is intended for and made an application for Discretionary Housing Payment which was refused more than once. With support

this person made a further application and was finally awarded discretionary housing payment but for twelve weeks, being told by Kerrier DC that during that time this person must find more affordable accommodation and would be contacted by the support and housing advice department who would work with this person to that end. After twelve weeks the discretionary housing payment stopped automatically without any contact by the housing office, furthermore the support and housing advice department had not made contact or worked with this person. After KPS intervention this person was again awarded discretionary housing payment but told they (Kerrier DC) did not know what would happen after April when ONE Cornwall comes into existence.

As can be seen with the case studies so far, after an intervention by an outside agency (KPS) support was provided to the HIV positive person by the respective housing department. Not before the person had been caused much stress and worry which in most cases has resulted in a worsening of the person's condition. If a full cost recovery culture within the public sector were in place, and the relevant cost of extra support and healthcare passed on to the housing departments I think we would see a rapid change in the way these people are being treated. Housing is not a separate issue it is part of the overall picture and this is especially true of HIV positive people. HIV for most people is now a long term manageable condition but stability is an important issue, treatment must be strictly adhered to, this stops the virus becoming resistant to the medication. The drugs are highly toxic and must be stored properly, some medication needs to be kept cool in a refrigerator and the times medication can be taken in respect of certain foods is also important. People who are homeless or in stressful situations or in shared accommodation are particularly vulnerable in this respect. Regular monitoring of the persons CD4 blood count and the amount of HIV virus in the persons system (Viral Load) is also very important, both to establish when treatment needs to start, and the effectiveness of the treatment when it has started.

### **Access to Treatment**

As we know transport links in Cornwall are not brilliant because of the rural nature of the area, and Truro is the natural choice for providing HIV related treatment. For many people accessing treatment in Truro is difficult and fraught with difficulties, especially when considering the needs of other members of the family. The lack of understanding of some housing departments of local authorities about the difficulties people face when trying to access essential treatment is astounding.

### **Case Study**

An HIV-positive person approached Restormel DC after moving to Cornwall to escape violence, and the local authority recognised they had a statutory duty to house this person in temporary accommodation. The accommodation was in a small village without

a bank, only one shop, and with poor transport links to St Austell and Truro. This person remained in temporary accommodation in this location for over two years making access to the only centre for HIV in Cornwall at Treリスケ Hospital in Truro particularly difficult. The accommodation was in a poor state of repair without insulation or effective heating causing further hardship and a series of illnesses requiring treatment. Despite many attempts to work with Restormel DC in the interests of this person no partnership working was possible, in addition Restormel DC were secretive about what additional support could be provided.

The draft homelessness document for ONE Cornwall refers to the time limit on temporary housing to be six weeks, and I am not sure that the transformation to ONE Cornwall will automatically release additional housing stock to meet the needs of homeless families. The previous case study refers to a family in temporary accommodation for over two years, but to focus on that misses the point, despite Restormel knowing the HIV status of this family treated them as homeless not homeless with HIV. Temporary accommodation which was very inaccessible to the only HIV centre for medical treatment in Cornwall, in addition, the property was in poor condition with no consideration to the needs of a HIV positive person being considered.

The case studies throughout this report constantly identify local authorities who have paid little or no attention to a person's HIV status, and therefore little or no attention to the negative impact on the person's health and wellbeing. People suffering with HIV also suffer discrimination and stigma which adds significantly to the pressure households' face, and increases the incidence of mental health problems. Local authorities need to look at the needs of the person they intend to re-house from a holistic view point, and not the component parts which tick the boxes on the housing application form.

### **Lack of understanding**

When somebody has suffered discrimination and abuse and has mental health difficulties, and these difficulties have been disclosed on the housing application form and medical assessment form the local authority should have enough understanding not to put the normal pressure on people when they have a void to fill.

### **Case Study**

Ocean Housing recently offered a HIV positive person a flat in North Cornwall, the person was interested in the flat but was put in the almost impossible situation of having to make a decision on the spot. The person had mental health difficulties associated with paranoia as a result of discrimination and abuse in a former tenancy, the housing officer was insistent that the property would soon be taken if the HIV positive person didn't make an immediate decision.

In the case study above the person involved did not take the property as a result of the way the situation was handled, what was of prime importance to this person was the area the flat was located and many other factors affecting its security none of which was addressed by the housing officer. Many people with HIV suffer mental health difficulties because of the pressure of living with HIV, these range from depression to paranoia with clients reporting that they cannot confide in friends and neighbours for fear of harassment and discrimination.

We are well acquainted with the process people go through to try and access social housing, for the HIV positive person this is an ordeal by fire because of the numbers of people they have to disclose their HIV status too. There are HIV positive people who will not even attempt to get on the social housing register because of the fear of too many people knowing they are HIV.

### ***Case Study***

An HIV-positive person applied to Carrick Housing for inclusion on Carrick's Choice Based Letting Scheme and was awarded Silver Care Banding in 2005. In 2006 this person was invited to bid for a property and was unsuccessful, in December 2008 this person contacted Carrick by letter to ask why no further invitations to bid had been received, Carrick have not responded to that letter. KPS has also written to Carrick asking for information on this persons behalf, Carrick have not responded to this letter either.

### **Conclusion**

People suffering from HIV come from all walks of life and can be any age, they have housing need and have HIV. The response from local authorities across Cornwall to people with HIV is patchy at best and discriminatory at worst. People are routinely banded from Bronze to Gold with no consistency or regard. The level of service is generally poor with little support or information provided and few if any referrals to other organizations that might be better able to support them. Many housing associations and local authority housing offices completely overlook the HIV component of a person's application and as a result people are housed in totally unsuitable housing. HIV is not seen in its entirety but as a small snapshot that allows a limited response from the housing office. Housing offices do not recognise the need for a HIV positive person to have self contained accommodation with private facilities, and Housing Allowance payments are not high enough for HIV positive people to be able to rent suitable accommodation. Discretionary housing payment is hard to get and then only as a temporary measure. HIV positive people have to disclose to too many local authority and housing association staff and not enough care is taken about the confidentiality within these organisations. The change to ONE Cornwall is a rare opportunity to deal with some of these issues but the draft report which KPS has received does not address much of the above, we

have serious concerns about the ONE Cornwall approach to the numbers of people who will have access to confidential information and the way it will be used to identify housing need.

### **The Future**

The report is not about naming and shaming the present local authorities, it is about how the needs of the HIV community in Cornwall are being treated when they access social housing or benefit support. We appreciate that local authorities housing departments have been under pressure because of the lack of suitable housing in Cornwall. We also understand that we see housing related issues as one thing, when clearly it is several departments delivering services independently of each other with little or no mechanisms for linking them. ONE Cornwall is therefore a really good opportunity for change and we hope by identifying the issues in this report it will promote change. KPS was recently invited to PDC to put our client group's case to housing and benefit professionals, this meeting was instigated by the benefits division team leader Leigh Noall and was also attended by PDC customer care officer Michael Hopkins. We felt this was a positive response, and a chance for some real partnership working and we are grateful to Leigh Noall for this opportunity. Unfortunately neither the PDC allocations officer, nor the housing advice co-ordinator could attend or arrange alternative personnel to cover.

### **Report compiled by**

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*for and on behalf of Kernow Positive Support (KPS)*