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Centre for Narrative Research, UEL

**Living with HIV and ARVs:
Precarity and para-liberalism**

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(Narratives of Everyday Lives and Linked Approaches)

- A 2011 HIV support study: What kinds of support people living long-term with HIV and ARVs used and need, in the UK
- Cuts talk: about medical and psychosocial service constraints and socioeconomic precarity
- Austerity discourse: individual responsibility, lack of citizenly entitlement, cost-benefit analyses
- Market-framed, 'neoliberal' resistance: citing false economies, social 'value'.
- Framings of care, justice, and meaning outside of value
- Para-liberal movements between these narratives

Jana, UK (female, 40s, heterosexual, non-British origin, diagnosed 2000s) : I don't tell because I just feel like, I don't have much time. I'm not going to start 'oh by the way do you know I'm doing', you know, I feel let's get to the point you know and I leave quickly/Yeah/It's taken a lot of time realising that how I feel about it I because I'm used to it, I know it, where in the past I have (ignored it), but now I'm thinking, as I'm listening to myself, I'm thinking this is not right, you know...I know that it's a big queue, I know everybody's running late, everybody's stressed, my doctor is stressed, 'let's not make things any worse' you know. I shouldn't be feeling like that obviously.

Gerry, UK (male, 50s, gay, North American origin, diagnosed 1990s): I don't want to appear to be complaining... but I would maybe actually trade the medical side for a little bit more support.

Gerry, UK: I think that the people that get left behind are really the people who are medically well enough to not really need that much support but emotionally may be not quite so secure, um and again it comes down to the fact that they have to design our programmes around this target , um, you know fair enough reason to limit the supply of money and you I mean, you can maybe have a drop-in centre , I don't think that there are drop-in centres any more (laughs), years ago kind of thing that's kind of, I know if I would if I got a leaflet in the post tomorrow I would see that a new drop-in centre , I would be there on day one , I would be there making cup cakes (laugh)/(laugh)/ a day centre kind of thing.

Penelope, UK (female, 40s, heterosexual, African origin, diagnosed 2000s, asylum seeker): I don't want anything I just want to live a normal life and er, I'm not after benefits, where I come from, nobody gives you anything you have to work for everything /yeah/... if I could I would really want to pay back you know, just do something just help somebody/ of course of course sure/yeah like a/like a support worker or a/Yeah help somebody, an elderly lady, somebody, I want to pay back and do something but it's not easy because there a lot of um, I dunno if I should say it nasty, nasty criminals you know who are after something who are not really willing to help... I don't know what else to do, you know who to turn to, can't do anything can't plan can't do nothing just doing the same thing every day, go out come back sit watch TV go to bed wake up same thing.

Gerry, UK: And as well, I had lately, been medically reassessed through benefits and, and quite, left a number of stresses um and again I don't know if I am about to be reassessed...um it's almost that I feel like, I feel I am being told that I am out of life , because if you have a life then you don't need benefit and support, you can get up and work.

Olive, UK (female, 50s, heterosexual, African origin, diagnosed 2000s): But with me now, I feel like I'm empowered now. I always do counselling on my own yes, especially with other newly diagnosed, yeah, helping them.

Interviewer: Oh really, so how do you do that, with a group or -

Olive: No, it's individually yeah, because sometimes we have got a lot of friends, so sometimes you hear so and so is really down, she can't cope, she's got problems, yeah. So, we try to contact her, if she wants to come in and talk to us, then we will go and have a friendly talk with her, then he or she can ask questions, so. 'Are you really', because some of them they ask 'are you really positive?' I tell them 'yeah, we've been there before', and we tell, we share our own experiences, yeah. That is how it helps, it helps because it's a long journey from that moment when you used to cry, and now accepted it as normal life, yeah ... some have got relatives who are dying, children who are dying, they can't go home, they are still grieving here. They are dealing with people's issues, it is difficult, it is difficult. I can put myself in that position. I've got a friend who is dealing with that same issue. She went through , she is going through a lot, she is now depressed, yeah. Sometimes I will go their house, sleep over, two days or three days, yeah. I will sleep over then I will invite her, I have told her 'you are welcome to my house, come anytime, if I am not there then my children are there.' Because, sometimes I got my grandchildren, 'feel free, don't be on your own' yeah 'come I will cook for you – if you want to cook anything, sleep on my bed' (laughs) yeah, because I know what she is going through, unfortunately, it's difficult.