用語解説

1）多剤併用療法
1996年に米国でプロテアーゼ阻害薬が登場し、それまで行われていた、核酸系逆転写酵素阻害薬だけの治療法に比べ、プロテアーゼ阻害薬を加えた3剤で強力な治療を行ったことから、このような呼び方が使われた。3種類以上の抗HIV薬を組み合わせた強力な治療のこと。抗HIV薬による多剤併用療法、カクテル療法とも言う。

2）末梢神経障害
原文ではニューロパシー（neuropathy）。末梢ニューロパシーともいわれる。ニューロは神経、パシーは障害を意味し、あわせて神経障害。脳や脊髄（中枢神経）の外側の末梢神経のレベルに障害が起こり、足先や指のジンジン感、しびれ感などの知覚障害、筋力低下や麻痺までの運動障害などの症状が起こる。HIV感染症では中枢神経から末梢神経のどのレベルでも障害が起こることがある。

3）痩せ
HIV/AIDSにみる特徴的なHIV消耗性症候群（スリム病、やせ病）では、数ヵ月のうちに発熱もしくは下痢を伴う10%以上の著明な痩せをきたす場合がある。

4）リボジストロフィー
抗HIV薬の服薬と関係があるとされる副作用のひとつ。「リボ」は脂肪とか脂肪組織、「ジス」は異常や病気、「トロフィー」は栄養とか成長という意味を持つ。症状としては、乳房や腹部、首の後ろに脂肪がついたり、逆に顔や手足が細くなるといった脂肪分布異常と、血糖値や中性脂肪、コレステロールの上昇といった代謝異常をきたす。

5）スティグマ
他者や社会集団によって個人に押し付けられた負の表象、烙印、不名誉や屈辱、汚名の徴。ネガティブな意味のレッテル。もともとは、奴隷や犯罪者であることを示す刺青などの肉体的刻印のことを指す言葉。

注釈（Notes）

1. See the HIV Commissioning Toolkit（DoH 2003）

2. Complementary therapy use is a good illustration of how one intervention may be ‘needed’ for very different personal needs. Pawluch（2000）describes the wide range of meanings that individuals with HIV ascribe to complementary therapies and the many different benefits they expect such therapies to deliver.
3. Since the health and social care reforms of the 1990s, need has usually been defined as an individual’s ‘capacity to benefit’ from services (see Price Waterhouse 1993, Wright et al. 1998). This leaves need defined entirely in relation to what services can offer. Although this is a useful way for service providers to think about what they can actually deliver, it risks marginalizing the experience of need. For a more detailed discussion, see Anderson et al. (2000), Weatherburn et al. (2002).

4. We can capture this understanding by defining need as: the difference, for any aspect of someone’s life, between their current state and the state they wish to be in. Someone who falls ill will probably want to return to the state of health they enjoyed - that will be their goal. Their need for health is the difference between their current state of (ill) health and their expectations of what their health should be. So their need will be reduced either if their health improves or if they lower their expectations (a common response to chronic illness). This model of need draws on the subjective model of need of Per-Erik Liss (1993).

5. See Anderson & Weatherburn (1998) for a detailed account of the early social impact of combination therapy.

6. In the introduction to their description of the challenges faced by families with HIV, Boulton et al. (1999) stress the positive view of families’ experience: ‘A fundamental theme. . . is the active and positive efforts that families make to address their problems and the immense resilience and resourcefulness they show in dealing with the stresses they encounter. . . While it is important to recognise the devastating impact of HIV infection on families, it is also important to recognise the positive ways in which they try to deal with it.’

7. Weatherburn et al. (2002). A survey of the needs of 1,821 people living with HIV in the UK.

8. Catalan (1999) provides a detailed description of the factors that contribute to the psychological problems of people with HIV.


10. This is a particular problem for children and young people living with or affected by HIV, for whom friendships may be the only source of support outside the immediate family (Lewis 2001).

11. However, the infectivity of HIV does not prevent the sexuality of people with HIV from being positive, healthy and life-affirming. This is a key point made by Schiltz and Sandfort (2000) in their review of the sexual behaviour of people with HIV.

12. The concept of sexual well-being is taken from Keeping it to ourselves (Summerside and Davis 2002).


14. ‘Family life’ is used here to mean the relationships between adults and children that sustain the latter through their childhood. The definition of ‘family’ is of course open-ended. The HIV epidemic has clearly
demonstrated the diversity of ways in which people create families beyond their biological relationships. Gay relationships, care-giving relationships and close friendship networks may all be valued as family. Heaphy et al. (1999) describe the creation of families by lesbians and gay men affected by HIV. The wider need for family, beyond raising children, is not addressed directly here (though see Relationships and friendships).


17. Boulton et al. (1999). DeMatteo et al. (2002) note that the preservation of childhood ‘normality’ may be balanced by a desire to promote the self-sufficiency and independence of young people, although parental communication with children about future possibilities is rare.

18. Lewis (2001). Many adults living with HIV choose not to tell their children about their diagnosis, or to conceal the precise nature of their illness. The latter strategy had been successful for several participants in the consultation for this report, who had strong, mutually supportive relationships with their children.


20. McNaught and Spicer (2000) discuss the role of unfulfilled needs of gay men with HIV in creating the unendurable psychological pain that can lead to suicide. Respect and dignity are identified as key needs. They also cite needs for self-esteem, control, health, support, companionship and a relationship.

21. See the personal account of living with HIV in the era of HAART in the AIDS Reference Manual (Fieldhouse 2002).

22. Feedback from consultation with people living with HIV for this report.


25. Following the introduction of combination therapy, the incidence of opportunistic illnesses declined from 24 events per 100 person-years in 1994 to 14 events per 100 person-years in 1998. Mortality declined from 20 deaths per 100 person-years in 1984 to 8 deaths per 100 person-years in 1998 (Moore and Chaissen 1999). According to the EuroSIDA study, mortality further declined from 16 to 3 deaths per 100 person-years in 2001, with a greater proportion of these deaths due to causes other than AIDS (Mocroft et al. 2002).


27. Although mental health depends on a wide variety of factors, the onset of any symptomatic HIV-related illness typically has a profound impact on mental health because it is an indicator of disease progression (Catalan 1999). Many of the participants in the consultation for this report described the effects on their mental health of treatment side effects, particularly chronic or disfiguring side effects.

28. Wight (2000) describes the impact of caregiving on relationships, stressing the changes that a burden of dependency brings to a relationship, with sacrifices required on both sides.
32. In a review of studies comparing incidence of depression before and after the advent of HAART, Siegel and Lekas (2002) describe a trend towards improvement but conclude that the evidence that life with HAART is less distressing than life before HAART remains inconclusive. Catalan et al. (2000) suggest that the pattern of psychological distress has shifted from acute crisis events to the difficulties of adjusting to long-term life with HIV.
33. Depression demands a lot of support from partners, but care-giving is itself strongly associated with depression (Wight 2000).
34. One participant in the consultation for this report said that he often found that he wanted to go much further mentally than his body would allow and had to readjust his employment plans and expectations accordingly.
37. In the consultation for this report, participants described increasing unwillingness to go out as a consequence of generalised poor self-image and of the specific effects of lipodystrophy.
38. Tate and George (2001) describe how weight loss drastically reduced the willingness of a small sample of gay men to engage in social activities. This was reiterated by two of the African women who participated in the consultation for this report, for whom lipodystrophy had profoundly reduced their willingness to meet people and socialise.
42. Sherr et al. (1992) and Wright & Coyle (1996).
43. Sikkema et al. (2000).
44. Matovu et al. (1999).
46. Catalan (1999), Sikkema et al. (2000).
48. Parker & Aggleton (2003) argue that it is a mistake to understand discrimination solely in terms of inter-personal attitudes and actions, as it is broader social and institutional inequalities that sustain patterns of discrimination.
49. However, fear of the consequences of disclosure of HIV status may be greater than actual impacts. In an American study of gay and bisexual men, only a minority disclosed their HIV status to their employers but among those who did, outcomes were generally better than expected: out of 138 men, four were fired and eight were told to do different work (Simoni et al, 1997).
50. Warwick et al. (1999).

52. Feedback from asylum seekers during the consultation for this report.

53. Comparisons are made in the Nasah study (Weatherburn et al. 2003) between the Nasah results and the results of the What do you need? survey (Weatherburn et al. 2002).

54. Two of the participants in the consultation for this report whose immigration status was unresolved described the efforts of every public service they encountered to avoid communication and responsibility. Letters from the Home Office insisted that they should not ring, write or visit. However, the local social services department was threatening to withdraw the meagre support provided unless they actively chased the Home Office about their applications. They were told that social services were not for people who were well and their welfare problems (i.e. loss of the right to benefits) was essentially a matter for the Social Security office to address. Yet it was the denial of right to welfare by the Social Security office that had brought them to social services in the first place.

55. The Nasah study (Weatherburn et al. 2003).

56. This analysis of the impact of immigration problems on need is largely drawn from the consultation for this report.

57. In a review of the literature on the sexual behaviour of people living with HIV, Schiltz & Sandfort (2000) report that: ‘For people living with HIV, the risks of sexual behaviour are partly about protecting other people but also concern self-protection. The extent of the ‘problem’ of risk will therefore depend on how strong a responsibility the individual feels for the other person in any sexual encounter and their own desire to avoid other infections or reinfection with HIV. However, even the possibility of infecting other people can create feelings of guilt or fear.’

58. Rhodes and Cusick (2000) describe the balance in sero-discordant relationships between ‘relationship safety’ and ‘viral danger’. Protecting the intimacy of the relationship can be a higher priority than avoiding HIV transmission.

59. The risk of vertical transmission can now be reduced to about 2% (Newell & Rogers 2000). See The challenges for women.

60. Colson et al. (2002).


62. This finding in Weatherburn et al. (2002) was stressed by many of the participants in the consultation for this report.

63. Weatherburn et al (2002). One of the participants in the consultation for this report identified this as the most persistent and difficult problem she faced. She felt that her opinion was not always respected, her personal research through treatments newsletters had been ignored, and long-term side effects had been dismissed as being ‘just you’. These problems were exacerbated by the turnover of doctors and the inexperience of many of the new doctors she had dealt with.

64. For a review of the problems of adherence and current efforts to simplify treatment regimens, see Currier (2002).

65. Meyestre-Agustoni et al. (2000).

66. Sustaining a treatment regimen can be difficult both when it is going badly, i.e. because of side effects, and when it is
going well - one of the participants in the consultation for this report stressed the difficulty of maintaining her treatment regimen when she was feeling well.

67. Siegel and Lekas (2002) suggest that treatments are a constant reminder of ‘patient identity’ and as such conflict with attempts by people with HIV to normalise their lives.


69. There is considerable literature on the process of adapting to a positive HIV diagnosis. For an overview, see ‘Living with HIV: coping with a new status’ in Green & Sobo (2000).

70. This was a recurrent theme of the qualitative study by Anderson et al. (2000): ‘What mattered to most participants was not that a service provided exactly what they needed they recognised that any service could only do so much. What was important was that providers respected them as individuals, did not make assumptions about who they were, took the time to listen and understand, and were patient and flexible.’

71. The most prevalent social problem in the Nasah study of Africans living with HIV (Weatherburn et al. 2003) was ‘getting enough money to live on’. See also the Padare Project (Chinouya and Davidson 2003).

72. See the Nasah study (Weatherburn et al. 2003), the Padare Project (Chinouya and Davidson 2003) and Erwin and Peters (1999). The Padare Project reported that ‘[D]espite their high educational levels, the Padare respondents had limited access to economic resources and poverty characterised their lives. Due to poverty and other pressing needs, the presence of HIV may be less prioritised.’

73. Erwin and Peters (1999) draw attention to the fears of some Africans that medicines developed for Whites may not be appropriate for them and to the deeper mistrust of the medical profession that is rooted in harsh experience of seeing family members suffer and die.

74. Anderson & Weatherburn (1998) report that Africans were particularly likely to experience problems communicating with medical professionals in the early stages of treatment.

75. Chinouya and Davidson (2003).


77. Matovu et al. (1999).


80. The Nasah study (Weatherburn et al. 2003). In response to the question Who knows you have HIV? respondents indicated: partner 85%, GP 77%, mother 41%, father 30%, any friends 84%, any brothers or sisters 65%, any children 36%, any work colleagues 36% and any other people living with HIV 54%.

81. Malanda et al. (2001). Africans who do get referred to specialist mental health service are more likely than others to be suffering from AIDS and more likely to be suffering from major depression or organic brain disease.

82. 87% Christian (including 37% Catholic), 8% Muslim (Weatherburn et al. 2003).


84. Of the respondents to the Padare Project (Chinouya and Davidson 2003), 20% of
men and 7% of women reported same-sex partners.


86. Niebuhr et al. (1998) report that parents overwhelmingly fail to perceive that their children need emotional support to deal with HIV issues, nor do they perceive themselves as in need of assistance in interacting with their children about these issues.

87. Bond et al. (2000).


93. Donohoe MC & Wodak A (1998) provide a detailed description of both the health and social needs of drug injectors.


96. Keogh & Beardsell (1998) describe the experience of gay men in seeking support from communities, families and partners (and the potential for conflict between these).


99. Reid et al. (2002).

100. Sherr (1996) argues that gender differences should not be characterised merely in terms of power: such differences also concern commitment, honesty, concern for others, discrimination, self-sacrifice, selflessness and personal responsibility.

101. Lawless et al. (1996) describe the effects of multiple stigmatisation on women living with HIV.


106. Several of the participants in the consultation for this report drew attention to the characteristic problems faced by heterosexual men living with HIV. There is little research in this area.


109. See Church et al. (2001) and the two letters in the BMJ 2001 vol 323 (28 July) in response to the paper.

