



HIV AND INFANT FEEDING

Guidance from the UK Chief Medical Officers'

Expert Advisory Group on AIDS

Updated: September 2004

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PREFACE

What is the Expert Advisory Group on AIDS?

- P.1 The Expert Advisory Group on AIDS (EAGA) was established in 1985 “To provide advice on such matters relating to AIDS as may be referred to it by the Chief Medical Officers of the Health Departments of the United Kingdom”. EAGA membership includes clinicians and scientists drawn from a range of specialties, together with voluntary sector representatives and experts in other relevant fields.
- P.2 EAGA produces evidence-based guidance for health care professionals on HIV-related topics and also provides advice to other government departments. EAGA is committed to keeping the evidence on which it bases its guidance under review, and issuing updates as necessary. (For further details, see www.advisorybodies.doh.gov.uk/eaga)

Why is EAGA revising this guidance?

- P.3 In 2004, EAGA reviewed the latest research findings from studies of breastfeeding transmission risk (published since EAGA issued revised HIV and Infant Feeding guidance in 2001) and considered them in the context of advances in management of HIV infection.
- P.4 EAGA’s review determined that little new evidence has emerged to inform the breastfeeding debate, despite completion of longer follow-up for a number of pivotal breastfeeding studies. These have, however, enabled better quantification of the contribution of breastfeeding to HIV transmission. In addition, many ongoing studies are exploring the

association between mode of infant feeding (exclusive feeding versus mixed feeding) and transmission risk.

- P.5 A key issue addressed by EAGA was the possibility that antiretroviral therapy could make breastfeeding 'safer'. A number of studies are investigating the effectiveness of antiretroviral therapy, given either to the mother or the uninfected infant over the breastfeeding period, for preventing breastfeeding transmission. These studies are being undertaken in resource-poor settings where feeding with infant formula milk is not a feasible option and the goal is to minimise the transmission risk associated with breastfeeding.
- P.6 In the UK and equivalent settings, the risk of HIV transmission through breastfeeding for women on highly active antiretroviral therapy (HAART) has not been quantified. While the risk is likely to be low if plasma viral load is undetectable, the potential for proviral DNA to transmit infection, resistance due to poor drug penetration into breast milk and prolonged exposure of the infant to antiretrovirals, all need to be considered in the balance of risks.
- P.7 EAGA's review concluded that there was no scientific basis for departure from its current advice. **In the UK, avoidance of all breastfeeding by HIV-infected women is recommended to prevent breastfeeding transmission of HIV.**
- P.8 This update includes references to recent research evidence and expands the information on access to assistance for women/families experiencing financial hardship.

1. INTRODUCTION

- 1.1 This guidance aims to help health care professionals provide the necessary information, advice and support to women who are infected with human immunodeficiency virus (HIV) to help them make personal, well-informed decisions about infant feeding. It is not intended to apply to the situation in less developed countries, where the risks associated with infant formula milk feeding are much higher [1].
- 1.2 Breastfeeding, in particular exclusive breastfeeding, is the ideal way to feed infants and should be protected, promoted and supported. Its benefits go beyond sound nutrition in that it protects against common childhood infections. However, as it is one of the routes for mother-to-child HIV transmission, HIV-infected women in this country need to consider carefully the information about relative risks and benefits to their babies of breastfeeding, compared with alternatives.
- 1.3 HIV-infected women will only be in a position to make informed decisions about the measures known to protect their babies from HIV infection, including avoidance of breastfeeding, if they are aware of their infection status. This highlights the importance of offering and recommending an HIV test to all pregnant women as a routine part of their antenatal care and providing adequate information about HIV during pregnancy, covering the possible implications for their babies and themselves [2,3].

2. MOTHER-TO-CHILD HIV TRANSMISSION AND THE RISK OF BREASTFEEDING

- 2.1 Most children with HIV are infected as a result of transmission of HIV infection from their mothers. Mother-to-child (vertical) transmission can occur before or during birth, or after birth through breastfeeding.
- 2.2 The rate of mother-to-child transmission of HIV in the absence of preventive interventions is about 15-25% among HIV-infected women who do not breastfeed [4] and 25-45% among HIV-infected women who do [5].
- 2.3 The risk of transmission can be greatly reduced by antiretroviral treatment (for the mother and the infant), delivery by caesarean section and the avoidance of breastfeeding. When used in combination, these interventions can reduce the risk of mother-to-child HIV transmission to below 2% [6].
- 2.4 The risk of transmission of HIV from an infected mother to her infant through breastfeeding is greater if she becomes infected during the breastfeeding period, compared with mothers who were already infected (see 3.1). Therefore, it is important that uninfected women who are considered at risk of exposure to HIV are offered appropriate advice and support to help reduce their risk of becoming HIV infected while breastfeeding.
- 2.5 Currently, most HIV-infected women in the UK diagnosed before or during pregnancy opt to consider antiretroviral therapy and caesarean delivery as well as to avoid breastfeeding. The decision to avoid breastfeeding may be a very

difficult one. In communities where breastfeeding is the cultural norm, this decision may be particularly difficult, because a woman's decision not to breastfeed may be viewed negatively. It is, therefore, important that the guidance in this booklet is applied with sensitivity and that women's concerns about this decision are recognised and discussed.

- 2.6 The guidance in this booklet is aimed at women living in the UK. If a woman will be moving to somewhere where safe infant formula milk feeding is unavailable, different considerations will apply and these should be discussed with her.

3. FURTHER INFORMATION ABOUT HIV TRANSMISSION THROUGH BREASTFEEDING

- 3.1 Transmission of HIV through breast milk can occur where there is established maternal infection. It can also occur in situations where a breastfeeding mother newly acquires HIV infection – in which case the risk of transmission is even higher. This is because a newly infected mother may be particularly infectious due to high viral load.
- 3.2 The risk of transmission of HIV through breastfeeding varies in relation to maternal clinical and immunological status, plasma and breast milk viral load and possibly breast health (subclinical or clinical mastitis, cracked nipples etc) [7].
- 3.3 With current laboratory techniques, it is difficult to distinguish between infection occurring at the time of delivery and infection through breastfeeding during the first 4 weeks of life.
- 3.4 There is no evidence that colostrum, the milk produced in the first few days after birth, poses a greater or lesser transmission risk than the later milk.
- 3.5 Mother-to-child transmission can occur late in breastfeeding. Studies of breastfeeding infants who were uninfected at 4 weeks of age indicate that, by 18-24 months of age, about one in ten will become infected [8]. (For more detailed information on the epidemiological evidence, see [9].)
- 3.6 An observational study from South Africa reported that mixed feeding (defined as breast milk plus water, other fluids and foods) in the first 3 months of

life was associated with increased risk of infant HIV infection when compared with exclusive breastfeeding¹ [10]. Further information from this study showed that, at 15 months of age, the lowest rates of infant infection were found in the never-breastfed group, followed by the exclusively breastfed group and that the rates in the mixed-fed group were the highest [11].

- 3.7 The evidence is still evolving and the international research community continues to give high priority to developing good quality research evidence. Further studies are planned or are in progress [12-14].

¹ Exclusive breastfeeding is defined by WHO as giving an infant no other food or drink apart from breast milk (by any method). Expressed breast milk, medicines, vitamins and mineral supplements can be given.

4. COLLABORATIVE STATEMENT FROM WHO, UNAIDS AND UNICEF

- 4.1 The World Health Organisation's statement on HIV and Infant Feeding in 1997 [15] includes the following:

“All women and men, irrespective of their HIV status, have the right to determine the course of their reproductive life and health, and to have access to information and services that allow them to protect their own and their family's health. Where the welfare of children is concerned, decisions should be made that are in keeping with children's best interests.

When children born to women living with HIV can be ensured uninterrupted access to nutritionally adequate breast milk substitutes that are safely prepared and fed to them, they are at less risk of illness and death if they are not breastfed. However, when these conditions are not fulfilled, in particular in an environment where infectious diseases and malnutrition are the primary causes of death during infancy, artificial feeding substantially increases children's risk of illness and death.”

- 4.2 In autumn 2000, the WHO/UNICEF/UNAIDS recommendations on the prevention of mother-to-child transmission of HIV infection and previous infant feeding guidelines were endorsed [16]. When feeding with infant formula milk is acceptable, feasible, affordable, sustainable and safe avoidance of all breastfeeding by HIV-infected women is recommended from birth. For HIV-infected women who choose to breastfeed, exclusive breastfeeding is

recommended during the first months of life, but for not more than 6 months. However, to minimise HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman's situation and the risks from infant milk formula feeding such as infections other than HIV and malnutrition. Weaning should be as rapid as possible to minimise the period of mixed feeding.

- 4.3 There are increased health risks, such as gastroenteritis, when giving infant milk formula. These can be reduced by ensuring women are given clear information about the importance of sterilizing all feeding equipment and have access to the resources to achieve this.
- 4.4 In the UK, where it is possible to ensure uninterrupted access to infant formula milk (see Annex, page 18) and where the risks of contamination associated with preparing the feeds can be minimised, the Departments' of Health policy is to advise HIV-infected women not to breastfeed, so as to reduce transmission of HIV to their children.

5. ISSUES IN REACHING A DECISION ABOUT INFANT FEEDING

- 5.1 Both parents have a responsibility for the health and welfare of their children, and the infant feeding method has health and financial implications for the entire family. Health care professionals will need to bear in mind the confidentiality of the HIV-infected mother's status, which should be respected at all times within the family setting. Mothers, fathers and other members of the family, as appropriate, should be helped to understand the issues and risks, and encouraged to reach informed decisions together about infant feeding matters. Ultimately, the decision about feeding is the mother's.
- 5.2 Avoidance of breastfeeding may present particular difficulties for some women. Where breastfeeding is the cultural norm, women who do not breastfeed may be concerned that this may signal their HIV-infected status to others. Some women may find it difficult for social or cultural reasons – including fear of violence, stigma, ostracism or being abandoned because they are HIV infected – to avoid breastfeeding completely. In such cases, fears should be recognised and extra support provided to overcome these difficulties. There are reasons, other than HIV infection, why a woman may not be breastfeeding. It may therefore be possible to prevent deductive disclosure of a woman's HIV status. Individual circumstances will need careful assessment.
- 5.3 In the UK and other developed countries, feeding infant formula milk poses less risk overall to the health of the baby of an HIV-infected mother than exposure to infected breast milk. This is because the

risks associated with infant formula milk feeding can usually be minimised.

- 5.4 The issue of infant feeding should be raised by a well-briefed health professional with appropriate expertise – either a midwife, doctor or health visitor – at the earliest opportunity. This applies equally to women known to have HIV infection before becoming pregnant and those whose HIV infection is diagnosed during pregnancy. Information on infant feeding should be provided in the context of other ways to reduce the risk of mother-to-child HIV transmission. Those involved in providing advice need to keep up to date with the facts about HIV transmission and breastfeeding. As conflicting advice causes confusion and distress, it is important that those providing care agree how to advise each woman, taking account of her individual circumstances. Solutions should be sought that put the baby’s interests first.
- 5.5 Ideally, a named individual should take on the advisory role, as consistency and continuity are important. Midwives who are aware that a woman is HIV infected need to offer her every possible support in making infant feeding decisions and in keeping risk to a minimum on an ongoing basis. Careful instruction and support in the practical aspects of making up a feed and sterilizing equipment will be important for all mothers, but particularly for those from communities or cultures where use of infant formula milk is uncommon. Further expert advice should be sought if necessary.

6. IF AN HIV-INFECTED WOMAN CHOOSES TO BREASTFEED

- 6.1 For a variety of reasons, some of which may be complex, an HIV-infected mother may feel unable to avoid breastfeeding. Input from an expert professional, usually a midwife, may be helpful to explore the reasons for and implications of choosing to breastfeed. Local arrangements between health and social services can provide a positive way of resolving any practical difficulties and ensuring that all related matters are considered. For instance, if the cost of infant formula milk is the only reason why an HIV-infected woman feels unable to avoid breastfeeding, advice should be provided on how to access any financial assistance that may be available (see Annex on page 18). Some families may need help in achieving the hygienic conditions required for preparing infant formula milk feeds.
- 6.2 There have been several high-profile child protection cases involving mothers with HIV. These have questioned whether informed choice can be sustained under circumstances where not accepting interventions (e.g. avoiding breastfeeding) might constitute a child protection issue. There has been no judgement directly on this point to date and a further court decision is awaited for clarification. In the interim, it should be borne in mind that, under the Children Act 1989, courts have a statutory duty to treat the welfare of the child as paramount. Furthermore, the Act places a general duty on every local authority to safeguard and promote the welfare of children within their area who are in need.
- 6.3 The Royal College of Midwives (RCM)/Department of Health seminar on HIV and Infant Feeding [17] offered some pointers towards good practice which

maternity units and health professionals should consider adopting (see below).

HIV & Infant Feeding: Seminar Recommendations	
1	All maternity units should develop multidisciplinary protocols on all aspects of HIV testing and the care of women who are infected with HIV.
2	All midwives need to be aware of, and understand, the Children Act, the child protection policies of their local authority, and their own statutory responsibilities in relation to child protection.
3	Managers and Supervisors of Midwives should ensure that all midwives fully understand their role and responsibilities in relation to HIV issues, including antenatal testing and infant feeding.
4	Midwives should develop local strategies to facilitate informed choice on infant feeding.
5	Midwives should develop local strategies for positive support of infant formula milk feeding for women with HIV infection.
6	HIV-infected women who feel strongly committed to breastfeeding should be assisted to explore ways to reduce the risk of doing so.
7	Maternity services should monitor and audit the implementation of policies and protocols around HIV infection and infant feeding, to ensure their effectiveness and acceptability for both users and staff.
8	Midwives who are concerned that local policy or practice conflicts with their professional and ethical responsibilities, or with women's best interests, should consult their Supervisor of Midwives or the RCM.
9	Midwives should actively promote best practice in this area by sharing their experience and expertise with others.
10	Midwives should strive to offer services that are sensitive, culturally appropriate, accessible and trusted by women with HIV infection.
11	Care should be taken to ensure that supporting HIV-infected women to give infant formula milk does not undermine the promotion of breastfeeding, which remains the best way to feed the majority of infants in the UK.

6.4 Under exceptional circumstances, and after seeking expert professional advice on reducing the risk of transmission of HIV through breastfeeding, a highly informed and motivated mother might be assisted to breastfeed. It must be understood, however, that any breastfeeding carries some risk. This risk can probably be reduced by certain measures (see below) but not eliminated. These should be considered as part of the risk assessment.

- If a woman chooses antiretroviral drug therapy for herself and her child to reduce mother-to-child transmission of HIV, the risk of transmission from breastfeeding may be reduced. However, this reduction may not be as great as if she avoided breastfeeding.
- Women who choose to breastfeed should be advised to breastfeed exclusively, i.e. not to supplement with infant formula milk or other drinks. This recommendation is based on general health benefits rather than on any reduction in HIV transmission that might ensue [see 3.5 above]). Women may need support to breastfeed exclusively where this type of feeding is not standard practice.
- The longer the duration of breastfeeding, the greater the additional risk of HIV transmission through breast milk. Early discontinuation of breastfeeding should therefore be considered, substituting infant formula milk for breast milk before 6 months or solid foods after 6 months.
- The risk of HIV transmission through breastfeeding may be reduced if mothers are given early skilled help with positioning and attachment

of the baby at the breast. Poor breastfeeding techniques, especially poor attachment, may result in cracked nipples, inflammatory conditions and/or bacterial infections such as mastitis, all of which may increase the risk of mother-to-child transmission of HIV [18].

- Inflammation of the mucous membrane of the baby's mouth (e.g. oral thrush) may also increase the risk of transmission and should be treated promptly. It should also be noted that recurrent severe thrush can be a sign of HIV infection in a child born to an HIV-infected mother.

7. CONCLUSIONS

- 7.1 Breastfeeding is an important route of HIV transmission to the infant of an HIV-infected mother. In the UK and other developed countries, feeding infant formula milk poses less risk overall to the health of the baby of an HIV-infected mother than exposure to infected breast milk. This is because the risks associated with infant formula milk feeding can usually be minimised. Avoidance of all breastfeeding by HIV-infected women is therefore recommended.
- 7.2 The efficacy and safety of alternative strategies to reduce the risk of breastfeeding transmission, such as HAART for the mother or prophylactic antiretroviral therapy for the infant for the duration of the breastfeeding period, have yet to be demonstrated.
- 7.3 The risks of breastfeeding should be discussed with HIV-infected women at an early stage. Ideally, a named individual should take on the advisory role, as consistency and continuity of care are important. Women should be supported to reach a fully informed decision that takes account of their own family circumstances. Local arrangements between health and social services can provide a positive way of resolving any practical difficulties and ensuring that all related matters are considered.
- 7.4 Children born to HIV-infected women should be under the care of a paediatrician, ideally working within a Shared Care network for paediatric HIV services. The paediatrician should promote infant formula feeding and should be aware of the support

- available locally to help mothers overcome any obstacles.
- 7.5 When an HIV-infected woman chooses to breastfeed, exclusive breastfeeding should be encouraged and the woman supported to make it achievable.
 - 7.6 Health professionals should work with social services colleagues to develop clear protocols to guide practice in the very few cases where there are child protection concerns.
 - 7.7 An enabling environment should be promoted for women living with HIV, by strengthening community support and by reducing stigma and discrimination. Voluntary organisations are experienced in providing support and advice for HIV-infected women outside the clinical setting (see list on page 25).
 - 7.8 Health education programmes should continue to emphasise the benefits of breastfeeding, and breastfeeding should be promoted as the norm for infants of women who are not HIV infected.
 - 7.9 Infant feeding should be considered part of a continuum of care and support services for HIV-infected women. Access for these women and their families to health care, social and financial support should be ensured.

8. ANNEX: ACCESS TO ASSISTANCE

- 8.1 Where financial reasons are identified as a barrier to avoiding breastfeeding, advice should be provided on how to access any financial assistance that may be available to women/families.

Asylum seekers

- 8.2 Pregnant women and children under 3: Pregnant asylum seekers who are in receipt of support from the National Asylum Support Service (NASS) are eligible to receive additional cash payments for themselves and dependant children under the age of 3 [19]. The payment is intended to provide a benefit similar to that of milk tokens under the Welfare Food Scheme (see below). It is meant for the purchase of healthy foods, but as the payment is in cash, recipients may choose what to buy. Currently, pregnant women and children aged between 1 and 3 each receive an additional £3 per week. Babies under 1 receive an additional £5 per week. Families who are applying for support do not need to request the payment for dependant children, as this will be issued automatically. Women who are pregnant need to apply in writing to NASS, enclosing confirmation of the pregnancy.
- 8.3 Maternity payment: Pregnant women may be eligible to apply for financial support (a single payment of £300) to assist with the costs associated with the birth of a new baby [20]. Once NASS has been notified of the birth, the family's support will be increased to include the appropriate rate for a child under the age of 16 and the additional payment of £5. The additional payment of £3 to the mother will cease.

8.4 Asylum seekers who are recognised as refugees:
Asylum seekers granted refugee status immediately qualify for Department for Work and Pensions' benefits. Those with refugee status are entitled to a back payment of the difference between NASS support and Income Support. This does not extend to milk tokens.

8.5 Useful contacts:

NASS Telephone Enquiry Bureau: 0845 602 1739

THT Direct (for information on local HIV support services): 0845 1221 200.

Recipients of Income Support, income-based Jobseeker's Allowance or Child Tax Credit, but NOT Working Tax Credit, with a family income below a certain limit²

8.6 Welfare Food Regulations 1996 (milk tokens):
Children aged under 5 in families receiving one of the above-named benefits qualify for milk tokens. The tokens can be exchanged for liquid milk (4 litres/7 pints). For non-breastfed children under 1 year, the token may be used for 900g of infant formula milk per week instead. (For further details, see reference [21].) No application is necessary; as long as the Inland Revenue has up-to-date details about the family, any award under this scheme is automatic.

8.7 Help is also available for pregnant women, but the qualifying conditions differ slightly (see [21] for more

² The family income limit to qualify for Child Tax Credit is £13,480 or below in 2004-05.

information). From October 2004, there will be a specific application process; full details will be available in GPs' surgeries. The scheme provides qualifying women with 7 pints of free milk a week during their pregnancy.

- 8.8 Healthy Start: Under 'Healthy Start', which is intended to replace the Welfare Food Scheme in England, Scotland and Wales, recipients will be able to exchange vouchers of fixed monetary value for milk (liquid or infant formula) or fresh fruit and vegetables. This will be phased in and details will be available in GPs' surgeries as the scheme is launched.

Other routes to accessing free or reduced-cost infant formula

- 8.9 Sale of Goods for Mothers and Children (Designation and Charging) Regulations 1976³: Under these regulations, Trusts and Health Boards may sell infant formula through clinics to the general public for the purposes of promoting the health of nursing and expectant mothers and young children. Clinics are permitted to sell infant formula milk at cost plus 10%, which may be a considerable cost saving compared with the retail price.
- 8.10 Welfare Food Regulations: Under these regulations, there is a provision allowing families with a baby aged under 1, who are in receipt of Child Tax Credit and working tax credit on an income below the prescribed income limit⁴, to buy infant formula milk

³ In Scotland, the National Health Service (Supply of Goods at Clinics etc.) (Scotland) Regulations 1976 apply.

⁴ The income limit to qualify for reduced rate infant formula milk is £14,600 or below in 2004-05.

at a reduced rate. (This provision will cease once Healthy Start is introduced.) Qualifying families are automatically identified and sent an NHS Tax Exemption Certificate. This Certificate provides access to various NHS schemes. Full details are sent with the Certificate, which should be presented whenever families wish to make use of the provisions.

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10. VOLUNTARY ORGANISATIONS AND HELPLINES

The following voluntary organisations and helplines provide information and support for HIV-infected women.

African AIDS Helpline: 0800 0967 500

African HIV Policy Network: <http://www.ahpn.org/>

Kenya Women's Association: e-mail
kewa@btconnect.com

Positively Women
<http://www.positivelywomen.org.uk/> (helpline: 020 7713 0222)

Terrence Higgins Trust
<http://www.tht.org.uk/> (helpline: 0845 1221 200)

Ugandan AIDS Action Fund (helpline: 020 7928 9583)

If you require further copies of this publication, quote 40596/*HIV and Infant Feeding* and contact:

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www.advisorybodies.doh.gov.uk/eaga/pdfs/hivininfantSep04.pdf