Parent refuses consent

Case study: What should Dr Jegede do when an HIV positive mother refuses to allow her daughter to be tested for HIV?

Fara is 38 years old and was born and brought up in a sub-Saharan African country where until recently she lived with her husband and nine-year-old daughter, Amina. Fara’s husband died a year ago and Fara and Amina have spent the last six months living in the UK with Fara’s parents.

Fara was infected with HIV over ten years ago but received HIV treatment only sporadically during this period. Since arriving in the UK, she has started regular treatment and has been seeing an HIV specialist, Dr Jegede, at her local hospital.

Fara has had problems accepting her diagnosis and she has confided in Dr Jegede that she is very uncomfortable about letting people know she has HIV. Fara tells Dr Jegede that she is also anxious that her family would react badly and would blame her if they knew.

Fara has gone to the hospital for her third appointment with Dr Jegede where he takes her CD4 cell count and reviews her overall progress, which is good. Dr Jegede has asked Fara at a previous appointment whether Amina, who was conceived after Fara contracted HIV, has been tested for HIV, as the infection might have been vertically transmitted from Fara to Amina. Fara has told Dr Jegede that she never allowed HIV tests to be run on Amina and he has been trying to persuade Fara that testing Amina would be a good idea.

At this appointment Fara remains very reluctant to let Amina be tested and becomes upset when Dr Jegede brings up the subject. She tells Dr Jegede that Amina has always been healthy and that she would have become ill by now if anything was wrong. When Dr Jegede presses Fara, she adds that she is conscious of the stigma attached to HIV infection and wouldn’t want Amina to have to cope with the upheaval a diagnosis would bring to her life.

How should Dr Jegede respond to Fara’s concerns?

- Should he accept Fara’s decision as being within her rights as a parent?
- Should he insist that Amina be tested?
- Should he continue to discuss Fara’s concerns with her and emphasise the importance of testing Amina?
In paragraph 2 of Protecting children and young people: the responsibilities of all doctors, we say that all doctors must consider the safety and welfare of children and young people, whether or not they routinely see them as patients. Doctors who care for adult patients must consider whether their patient’s condition or behaviour poses a risk to a child or young person.

In paragraph 8, we also say that doctors should work with parents and families, where possible, to make sure that children and young people are receiving the care and support they need. Good communication with parents is essential.

In paragraphs 20–22, we say that doctors should normally discuss any concerns they have about the safety and welfare of a child or young person with their parents. Being open and honest with families, and avoiding judgemental comments or allocating blame, can encourage families to cooperate and help children and young people stay with their families in safety. Dr Jegede listens to Fara, explaining that he can see her distress and takes her concerns seriously. He asks her to think carefully about the benefits of agreeing to testing Amina, stressing that the earlier doctors make an HIV diagnosis, the more options they have for treatment and the better the prognosis is. He reminds her that treatment for HIV infection can be extremely effective.

Dr Jegede also describes the risks of not testing Amina, stressing that it is possible that she is infected with HIV even though she is healthy now. He tells Fara that if Amina is infected and is not treated, she is likely to become very ill at some point in the future and could eventually die as a result.

Fara remains reluctant to consent to tests, pointing out that it would be difficult to explain them to Amina without frightening her. Dr Jegede describes to Fara how this could be done sensitively and honestly without alarming Amina. He also stresses that he and the healthcare team have a duty of confidentiality to both Fara and Amina, and emphasises that any test results would remain completely confidential and private. He tries to make sure that Fara understands he has a duty of care to Amina, as well as to her, and that he has to consider Amina’s welfare.

Although Dr Jegede spends some time trying to persuade Fara that it is in Amina’s best interests for her to have the tests, he can’t change her mind. Dr Jegede is concerned about Amina’s welfare, but is also conscious of the risk of Fara disengaging from her own treatment if he applies further pressure. He is worried that this could result in a worse situation for both Fara and Amina and is unsure about how best to act on his concerns.

What should Dr Jegede do?

- Should he share information with child protection agencies about Amina straight away?
- Should he seek advice from a named or designated doctor for child protection, or an experienced colleague?

In paragraph 1(h) of Protecting children and young people: the responsibilities of all doctors, we say that if doctors are not sure about whether a child or young person is at risk or how best to act on their concerns, they should ask a named or designated professional or a lead clinician.
or, if they are not available, an experienced colleague for advice. We say in paragraph 43 that, if possible, they should do this without revealing the identity of the child or young person.

Dr Jegede decides that he should seek advice on Fara and Amina’s care from senior colleagues who have had experience of similar issues. Dr Jegede discusses Fara and Amina’s situation, without revealing their identities, with a senior paediatrician and an HIV consultant. They advise Dr Jegede to keep talking the issues over with Fara and say that he should allow Fara some more time to get used to the idea of having Amina tested. However, they advise Dr Jegede to establish a timeframe with Fara for testing Amina. They tell Dr Jegede that if Fara continues to refuse consent for Amina to be tested, he should consider involving a multidisciplinary team, made up of other HIV specialists, paediatric specialists and an HIV social worker, who could monitor the child protection issues.

Dr Jegede, having taken into account the relevant factors, decides to establish a timeframe of eight months with Fara. At the next appointment, he explains to Fara that he is sure that it is best for Amina to be tested and that although it is not urgent now, he will need to involve other healthcare professionals in Amina’s care if Fara does not agree. If Amina starts to experience symptoms earlier than that and Fara continues to refuse to allow Amina to be tested, he explains he may need to take further steps, such as involving child protection agencies.

Dr Jegede sees Fara twice over the following months and continues to encourage her to have Amina tested. He also offers Fara access to voluntary and peer groups which provide advice and support.

Twelve months after her first appointment with Dr Jegede, Fara returns to the hospital for a routine consultation. After checking her progress, he again raises the issue of testing Amina. Fara remains adamant that Amina should not be tested and tells Dr Jegede that she is not going to change her mind. Dr Jegede thinks it unlikely that Fara’s attitude will change and comes to the view that he will not be able to arrange for Amina to be tested without involving a multidisciplinary team in Fara’s care, which would require sharing information with professionals outside his care team.

What should Dr Jegede do next?

- Should he share information about Fara and Amina with professionals outside his immediate healthcare team straight away?
- Should he ask for Fara’s consent to share information about her and Amina with professionals outside his immediate healthcare team?

In paragraph 34 of Protecting children and young people: the responsibilities of all doctors, we say that doctors should ask for consent from patients to share confidential information about them, unless there is a compelling reason for not doing so.

Dr Jegede seeks Fara’s consent to share information about her and Aaina with members of an HIV multidisciplinary team. He explains that the multidisciplinary team will be able to monitor the child protection issues raised by the situation and will consider how best to ensure Amina’s safety.
Fara is very resistant to the idea of involving other people in Amina’s care and refuses to give consent to Dr Jegede to share information with the multidisciplinary team. What should Dr Jegede do next?

- Should he share information about Fara with the multidisciplinary team without her consent?
- Should he continue to attempt to persuade Fara to give consent?

In paragraph 36 of Protecting children and young people: the responsibilities of all doctors, we say that doctors are able to share confidential information without consent if it is required by law, or directed by a court, or if the benefits to a child or young person that will arise from sharing the information outweigh both the public and the individual’s interest in keeping the information confidential. We say that doctors must weigh the harm that is likely to arise from not sharing the information against the possible harm, both to the person and to the overall trust between doctors and patients of all ages, arising from releasing that information.

In paragraph 38, we say that if doctors share information without consent, they should explain why they have done so to the people the information relates to. We also say in paragraphs 35 and 38 that doctors should explain what information they have shared, who it has been shared with, how the information will be used and provide information about where they can go for advice and support.

Dr Jegede thinks that the benefits to Amina of sharing information outweigh the benefits of keeping information confidential, and decides it is in the public interest to proceed without consent. He explains his reasons for doing so to Fara.

The multi-disciplinary team begins to monitor Amina’s care and shortly afterwards Fara starts to access peer support services. Over a period of time, with the ongoing help and support of Dr Jegede and his team, and her peer support group, Fara begins to accept her diagnosis and agrees to have Amina tested for HIV three months later.

See Protecting children and young people: the responsibilities of all doctors for further guidance on identifying children and young people at risk of abuse and neglect (paragraphs 2–12), on communication and support (paragraphs 13–22) and on confidentiality and sharing information (paragraphs 28–51).

For further guidance on what to do if you think a child is at risk of serious harm because their parents refuse to allow them to be tested for a serious communicable disease, see paragraphs 12–16 of Confidentiality: Disclosing information about serious communicable diseases.

For further information on testing children of parents with HIV infection see Don’t Forget the Children: Guidance for the HIV testing of children with HIV-positive parents (pdf).