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# Ethical Issues in Pre-Cancer Testing: The Parallel with Huntington's Disease

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Genetic testing and screening for susceptibility to various forms of cancer raise ethical issues about consent, confidentiality, the professional–patient relationship, and duties of care toward third parties, such as family members. The questions are both broad – because they cover so many core areas of medical ethics – and frustrating – because genetic knowledge for cancer remains imperfect. In this chapter I want to do two things that may alleviate some of the frustration. First, I want to look primarily at one set of ethical questions out of the many that arise: decisions about whether genetically susceptible individuals should have children. The ethical debate about pre-cancer testing and screening, at least in the West,[1] has so far largely centered on the affected individual's right to know, together with the confidentiality of that information. In practical terms this may be understandable, given the conflicting interests of those tested and their employers, health providers, and insurers. But an equally pressing issue is the decision whether or not to have children, if testing reveals a strong familial tendency towards breast, bowel, or any of the other cancers that are thought to have a genetic component. Is it morally wrong to transmit the risk to the next generation? I will be drawing on a case study from UK clinical practice, about "Peter" – a young man whose father tested positive for Huntington's disease shortly before his death. But Peter did not want to know his own genetic status, although he and his wife had young children and were considering having more.

I shall thus suggest that we can gain a better grip on the issues involved in pre-cancer testing by looking at genetic testing for quite a different condition. This is the second way of making the ethical issues in pre-cancer testing less frustrating. There, the imprecision that marks genetic testing at the pre-cancer level is replaced by something much more akin to black and white. What we have in the case of Huntington's disease is a small population of at-risk individuals – compared with an enormous population at risk for one form of cancer or another – whose probability of developing the disease is accurately predictable with a low error rate mutation test – compared to much fuzzier probabilities in the case of cancer. By using Huntington's disease as an extreme limit of questions about risk, benefit, and certainty of the testing procedure, we can suggest parallels that may help us to predict with greater clarity the ethical issues which will arise as pre-cancer testing and