Case study

Informing family members at risk

Ben is a 32 year-old man who has been referred to a consultant cardiologist because he has recently come to know about a history in his family of young people dying suddenly. This family history became apparent at a recent Christmas dinner where several generations of the family were gathered together.

Ben went to his GP and explained that several young people in his family had died suddenly of what was thought to be a 'heart attack'. He said that he knew that two siblings of his paternal grandfather, a boy and a girl had died in their teens and that the patient's uncle (his father's brother) had also died suddenly at the age of 20. His father also died of a heart attack but in his early fifties. Ben's aunt on his father's side seems well.

Because of the family history, clinical tests were carried out on Ben including exercise tests, an echocardiogram and the wearing of a heart monitor for 24 hours. As a result of these tests a diagnosis of Hypertrophic Cardiomyopathy (HCM) has been made. Ben was investigated 5 years previously for some dizzy spells for which no cause was found. Taking into account this information and results of the earlier investigations the cardiologist estimates that he has a 4% risk per year of sudden cardiac death.

During counselling following these tests Ben is asked about other family members. HCM is an autosomal dominantly inherited condition. He mentions that he only has one brother, Paul. Paul is 25 and is an airline pilot. Ben asks the cardiologist not to contact his brother. He says that firstly Paul would not want to know, and secondly, if anyone found out Paul would lose his job.

Should the cardiologist inform Ben's brother?