

8 August 2006

## **Right to life case - Leslie Burke appeal rejected by European Court of Human Rights**

Leslie Burke, who suffers from Friedreich's ataxia, a rare and progressive neurological condition, has failed in his appeal to the European Court of Human Rights in Strasbourg for the right to receive artificial nutrition and hydration ("ANH") once he is unable to voice his wishes.

Mr Burke (46) who is from Lancaster had previously challenged the General Medical Council's (GMC) guidelines on when life sustaining treatment should be withdrawn in both the High Court and in the Court of Appeal. An application for Permission to Appeal to the House of Lords was refused and Mr Burke therefore took his case to the European Court of Human Rights in Strasbourg.

The European Court of Human Rights (ECtHR) announced, in a written judgment released last week to Mr Burke and the UK Government, that they have declined his application to effectively overturn a ruling last year by the Court of Appeal which said it would be lawful for doctors to refuse him

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artificial nutrition and hydration once he loses competence to determine his own best interests.

His solicitor, healthcare public law specialist Muiris Lyons of Irwin Mitchell Solicitors said: "Leslie has been determined to take his case as far as the law allows and he is deeply disappointed that the European Court of Human Rights has ruled that there is no breach of his human rights."

"Leslie wanted to have his position in law clarified now, before he loses competency to determine his own best interests. The Court has effectively determined that his application is premature. However, once he loses the capacity to make his own decisions he will also lose the ability to make such an application in his own right. It is a "catch 22" situation for him. He has now done all he can legally but he remains very concerned that at some point he will lose control over determining what treatment he receives and that doctors, without necessarily being obliged to make an application to the High Court, could decide to withdraw ANH from him."

"Whilst he takes some comfort from the Court's view that the presumption of UK law is in favour of prolonging life wherever possible, he remains very

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concerned that the main reason behind not requiring doctors to make a formal application to the High Court in all such cases is that it would be “prescriptively burdensome”. In other words that it would be inconvenient. We are dealing with matters of life and death – what could be more important for our Courts to be deciding? He considers that the fact that it would be inconvenient for both the Courts and the doctors is simply not good enough.”

Mr Burke learned of the decision whilst in Ireland where he was attending the funeral of his brother who sadly passed away after suffering from the same genetic condition, Friedreich’s ataxia. From watching the progress of his brother’s illness Leslie Burke knows all too well the likely progress of his own illness. This was one of the reasons that motivated him to take his case so far.

The ECtHR considered that Mr Burke had failed to establish that UK law is such that he faces a real or imminent risk that ANH will be withdrawn in circumstances precipitating a painful death by thirst. The ECtHR stated that it was satisfied that the presumption of UK law was in favour of prolonging life wherever possible in accordance with the spirit of the Convention.

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The Strasbourg Court agreed with the Court of Appeal that the GMC Guidelines which Mr Burke sought to challenge simply set out good practice for doctors and did not alter the law. They approved the Court of Appeal's judgment and confirmed that if a doctor withdrew life-prolonging ANH from a competent patient who desired treatment to continue then it would be murder. Where a patient was incompetent, or had become incompetent, then as a general rule they considered ANH should continue for as long as it prolonged life. There were, however, circumstances where a doctor might find that ANH in fact hastened death and thus it was impossible to lay down any absolute rule as to what the best interests of a patient would require.

In the circumstances Mr Burke is concerned with, a doctor would be obliged to take into account his previously expressed wishes and those of persons close to him as well as the opinions of other medical personnel and if there was any conflict or doubt as to his best interests then an application to the High Court should be made.

In so far as having his views taken into account once he becomes incompetent the Court considered Mr Burke was able to make a living will or advance statement.

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Mr Burke's concern is that once he loses competence to determine his own best interests doctors may decide to withdraw ANH without being under an obligation to obtain the approval of the High Court first. The Strasbourg Court considered this and approved the view of the Court of Appeal that it is not for the High Court to authorise medical actions but merely to declare whether a proposed action is lawful. Doctors were fully subject to the sanctions of the criminal and civil law and would only be recommended to obtain legal advice, in addition to proper supporting medical opinion, where a step is controversial in some way. Any more stringent legal duty would be "prescriptively burdensome".

Further, the EctHR considered that it was not possible to pre-determine the administration of specific treatment in future unknown circumstances.

Mr Burke commented "I am to say the least extremely disappointed with the ruling from the ECtHR, I only hope that if I am lucky enough to be in hospital, that the doctors treating me will not believe at some stage that it will be in my best interests for ANH to be withdrawn even when death is imminent, effectively letting me die of starvation and thirst when I am no longer able to communicate my wishes."

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“I will be making a living will, even though it will give me no comfort, for as it stands living wills are not legally binding and can be disregarded if the wishes contained in it conflict with the doctor’s view.”

-ENDS-

## Notes

Friedreich's ataxia - a rare and progressive neurological condition. It is a form of spino-cerebellar ataxia.

Ataxia - the word ataxia means 'absence of order'. People with ataxia have problems with co-ordination. This is because parts of the nervous system that normally control co-ordination and balance are affected. Ataxia is the principal symptom of a group of rare neurological disorders called the cerebellar ataxias. Most cerebellar ataxias are progressive. Ataxia can also be a symptom of other conditions such as multiple sclerosis or cerebral palsy. There are many different types of cerebellar ataxia. Some are inherited. The most common of these is called Friedreich's ataxia.

## Timeline

July 2004 - Judicial review in the High Court. Leslie challenged GMC guidelines: 'Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision Making'.

July 2005 - the GMC successfully appealed the decision in the Court of Appeal.

December 2005 - House of Lords Appeal. The Lords decided not to hear the case.

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May 2006 - Leslie lodges appeal with the ECtHR

July 2006 – ECtHR decision

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Irwin Mitchell, incorporating Alexander Harris, was established over 90 years ago and is the 8th largest law firm, and the largest Personal Injury practice, in the UK. The practice employs more than 1800 staff - including over 800 fee-earners, with 94 partners and has offices in Birmingham, Leeds, London, Manchester, Newcastle, and Sheffield as well as the Spanish cities of Marbella and Madrid.

IM Personal Injury works at the cutting edge of the law winning many significant cases that have reshaped legislation. Recent cases include representing injured victims of the Northwick Park Clinical Trials, which put six people into intensive care following adverse reactions to the testing of a Leukaemia drug in 2006. Irwin Mitchell also acts for victims of the 7 July London Bombings and represents more than 150 victims of the arthritis drug Vioxx.

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