Response to the consultation document of Professor S. McLean*

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To whom correspondence should be addressed

Letter to Mr. Evans

Dear Mr Evans,

Thank you for the opportunity to comment on the Consultation Document by Professor Sheila McLean.

Firstly I would like to say that I am very concerned by the impression given by the portrayal of the Court of Appeal’s decision in Chapter 8. I have enclosed a separate schedule on this to correct some of the items discussed.

As for more general matters, of course my own views on the subject of written consent and posthumous conception are very well known. Broadly speaking, I welcome the benefits afforded by the continuing advances in medical technology and feel strongly that the law ought not to provide a legal straight jacket, but a degree of flexibility. I find it hard to conceive how any rigid law, framed at a particular point in time, could take into account the differences in potential patients, future developments or, for that matter, social and ethical points of view. It would be difficult to review the law regularly, but not impractical to allow an appointed authority like the Human Fertilisation and Embryology Authority (HFEA), family law courts or clinics’ ethics committees to look at each case on its merits.

I feel that the state should only interfere in the lives of individuals and couples where absolutely necessary. I am not against the autonomy of the individual. Far from it. But I do not accept that strangers with no knowledge of the deceased or their family situation are a better judge of their wishes than their partner or next of kin. Where there is a stable relationship and the relevant wishes are known and not in dispute, I find it hard to justify any case at all for outside interference on the grounds of protecting the rights of the individual. To me it can only serve to do the exact opposite.

There is then, I believe, only two possible remaining reasons for seeking to block a case like mine – the welfare of the child or if it would offend against contemporary moral values. On these two points my situation was and is no different in substance to any other case of posthumous conception, where the wishes of the deceased are recorded in writing. This was fully debated before the 1990 Act and it was decided to discourage the procedure, but more importantly, not to make it illegal. The Warnock report which put forward this view was written in 1984, twelve years before my case became public knowledge. Society today may hold a more liberal view than at that date. Despite a number of children being conceived after their father’s death (the eldest British child, I understand now to be 20 years old), there is no evidence to show it has any adverse affect on the child and no-one would dispute the almost universal support which I received from the British public in favour of my action.

In her report Professor Sheila McLean sets out a number of questions. I can see that my response would be seen as being somewhat partisan and to that extent I have not answered all of the questions set out by Professor McLean. However I can see certain areas particularly on the question of ‘best interests’ (question 4) where my own experience may be helpful. I also think that my case raises other issues which are important and have not been fully addressed. Professor McLean begins to touch on one such issue when she raises the point that the interest and knowledge of posthumous conception caused by the media coverage of my case may well raise requests for this procedure. I believe this knowledge has further implications. Following my case I fail to see how there can be a status quo. I will expand later.

Firstly I will attempt to answer question 4 on ‘best interests’. The question asks: ‘Does the removal of gametes from a comatose individual who is unlikely to recover satisfy this exception to the general rule?’

I find the phrase ‘unlikely to recover’ too ambiguous for such an important question. Doctors do not know who will recover and who will not. At the time I requested the removal of my husband’s sperm he still stood a good chance of recovery. His subsequent death was by no means a foregone conclusion.

Instead I believe question 4 should comprise two questions, both of which I would answer in the affirmative. I also think the question needs to include storage. Taking sperm could hardly be in someone’s best interests if the prevention of storage meant it was of no practical use. Also the question needs to commence with ‘Can’ rather than ‘Does’. Clearly it won’t always be is someone’s best interests to remove gametes. It depends on the circumstances.

My questions then would be: 4a) Can the removal and storage of gametes from a comatose or mentally incapacitated individual, who is not clinically dead, satisfy this exception to the rule?

It would seem to me that this question has already been answered by doctors who without challenge or repercussion

*Copy of letter to: Mr Michael Evans, Secretary to the Consent Review, Department of Health, Room 423 Wellington House, 133–155 Waterloo Road, London SE1 8UG, UK, who has granted permission for publication here.

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have taken and stored testicular and ovarian tissue from minors, who are unable to consent, but who are about to undergo therapy which may damage their reproductive future. This seems to me a logical and right conclusion, which should (and currently legally does, in the case of tissue) extend to adults as well as children. The problem arises because, in most cases, with a male adult you would not need to take tissue because it is easier and less invasive to take sperm. And it is not legal to store sperm (or eggs) where the person is unable because of their medical condition to give consent in writing. This can serve to discriminate between patients who have a slowly progressing disease, like cancer, and a rapid one.

Take my own case as an example. My husband died from meningitis. Like the treatment for cancer, the treatment for meningitis can cause sterility. Surely sterility is a ‘deterioration in health’, even if guarding against its consequences by preserving sperm is not (as I would argue) a necessity to preserve life. Even if you do not take life in its broader context to mean ‘quality of life’, the Collins’ English Dictionary states one of the primary definitions of ‘life’ as ‘the ability to reproduce’. It is also recognised in law and it is my belief that ‘best interests’ can be extended to include wider social interests (in Re:F).

My second question is: 4b) Can the removal and storage of gametes from a clinically dead individual satisfy this exception to the rule? Again I would answer, ‘Yes’. Firstly on the grounds that it is a final act of life as per the aforementioned definition of life and secondly that it is still within their wider social interests, which should not cease with their death. I would argue that in assessing an individual’s best interests, one ought to take into account the assessment of those with whom they were engaged on what might be called a ‘joint venture’ at the time of their death. This ‘joint venture’ test I believe is a good test to identifying the intentions of the donor (question 8).

I would also like to comment on question 12 which asks about the preservation of status and therefore inheritance rights, but to me does not address a most important aspect relating to this – the information given on the child’s birth certificate.

To fill in father ‘unknown’ as the law currently demands is, I find, a relatively unimportant, however, blatant lie. Why not put the father’s name, followed by deceased and the date he died? This does not necessarily give the child the same status and rights as a child conceived in the normal manner, but gives truthful and relevant information.

The second part of my answer deals with the heightened awareness and subsequent clarification of the legal requirements of posthumous conception following my case.

The Court of Appeal stated that my case could not set a precedent because the situation could never reoccur. This is true. However, without legislative change, other tragic situations may occur because of it.

When I told the doctors of the article my husband and I had read and discussed, I had no reason to believe it was of anything other than educational value to the doctors themselves who did not immediately know of the procedure. I could not have lied about my husband’s wishes even if I’d have wanted to. I did not know that what I said was relevant at the time I said it. Of course it is now not only the doctors who know we need written consent, but thousands of potential patients as well. Evidence of verbal consent could never again be as ‘compelling’ as in my case, but I have hundreds and hundreds of letters from people stating their own views, obviously in writing. Some sympathisers to my case have even informed me that their husbands have now written down their wishes for their own safekeeping and these have been placed somewhere safe. My husband and I never had the chance to do this because we didn’t know we needed anything other than a knowledge and respect of each other’s wishes, but these people do know and a few of them have acted accordingly.

I accept that whilst most would wish to allow their surviving partner the opportunity, very few people would want the treatment for themselves anyway. But what if the unlikely happened and one of these men was to become ill and die as rapidly as my husband? The wife asks for removal and storage of the sperm, stating she has written consent stored at the bank. Is someone going to disbelieve her? Is someone going to argue that they didn’t have all the necessary information to make that decision? Following the media coverage of my case, for such an unlikely procedure, it must be one of the most widely, publicly debated, medical topics possible.

It is no secret that I believe that man and wife are ‘as one flesh’ and that there is therefore no need for written consent between married couples. However, if the law is not to be changed then I believe ordinary people, who feel very strongly, must be given the chance to take whatever steps are necessary to record their wishes in accordance with the law. Why not add the question to organ donor cards? They currently have separate boxes to tick for different organs why not also have one for gametes with two options, either for general use or for the use of their partner only? Alternatively forms could be given out at Family Planning Clinics. Infertile couples seeking help to conceive are asked to contemplate the question. Should fertile couples not be asked the same question? It is not as though the distribution network for this kind of information and data recording does not already exist.

Having said all that it is my sincere hope that the law is changed, not to enable the wishes and rights of individuals to be ignored, but that they may be honoured. Not that the family unit may be weakened, but that it be strengthened.

The McLean report states at 6.27 that: 6.27 ‘...It is not unreasonable that a wife should state her husband’s wishes were the same as hers’.

Psychological research shows that we are most likely to marry those who share our views and wishes, so it is not unreasonable that they are likely to be the same as hers. However it seems to me, entirely unreasonable and offensive to suggest that she should be anything other than honest if they held different opinions. This comment seems to assume that people who married for love, to honour and obey, would deliberately go against a deceased partners’ wishes. Is it not better to live in a society where we assume that people have love and respect for those they know intimately, rather than to assume the worst of everyone?

Yours sincerely,

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Schedule on Chapter 8

I wish to correct a few matters with regard to the portrayal of the Court of Appeal’s decision in Chapter 8, especially points made in paragraphs 8.19, 8.20 and 8.21 on pages 54 & 55 and quoted below:

8.19 ‘...If a Member State determines, for sound reasons of public policy, that the export of sperm is to be regulated in any particular way, including imposing a ban on its export, then the European Court is likely to accept this as a legitimate exercise of the Member State’s discretion...’.

8.20 ‘... The Court of Appeal chose to stress the right of community nationals to receive medical services and to downplay the discretion of the Member State, and the HFEA, to impose a ban for reasons of public policy. The Court of Appeal required the HFEA to reconsider its decision in the light of European Law. In fact European Law would not require a different decision, since the HFEA was upholding legislation adopted by Parliament after lengthy debate precisely concerned with matters of public policy’.

8.21 ‘Had the HFEA directly considered these matters in the first place, the Court of Appeal could not have reached the decision it did. It was the failure to consider and not the imposition of the ban which ultimately led the Court of Appeal to its decision...’.

The HFEA did give reasons for their ban to the Court of Appeal. Moreover, if they had maintained their stance (after a further consideration), the refusal might very well have been held unlawful by the Court of Appeal, by virtue of EC law. The Court of Appeal did not in the end, have to decide this question. However the judges; (i) gave liberty to apply specifically so that the question could be revisited if necessary; and, moreover, (ii) indicated that it probably would be unlawful to continue to make a direction. The judgement made clear that the refusal of a direction infringed my legal right, and stated that it was ‘unlikely’ that any of the concerns identified by the Authority could be a lawful justification for that infringement.

This is at odds with the author’s conclusion that public policy reasons would have left me with no legal remedy. This is not only contrary to my own lawyers’ advice and the Court of Appeal’s comments, but also contrary to the HFEA’s own legal advice. On 13 February 1997, a document drafted for the HFEA, but copied also to my own solicitors, outlined the joint legal opinion of David Pannick QC and Dinah Rose, Counsel to the HFEA: 8.14 ‘...It is unlikely that the reasons previously given by the Authority could, in the exceptional circumstances of this case, satisfy the test of necessity and proportionality’.

This was stated somewhat more bluntly in an interview given by Ruth Deech to Mary Riddell, which was published in The New Statesman on 11 April 1997. Ruth Deech was attributed with the following quote regarding the HFEA’s final decision based on public policy reasons,

‘But we were advised we would lose if we said no again. We were told by our lawyers that we had to stop’.

In particular the author of Chapter 8 suggests in 8.14 that the HFEA could have justified its decisions, by for example stating:

8.14 ‘...the need to respect the rights of the male person from whom the sperm was procured without consent or on the basis of the welfare and interests of any child who might be born as a result of treatment’.

Without disputing my evidence that my husband had in fact stated his wishes as to my posthumous use of his sperm, the former was in fact given to the Court of Appeal as one of four reasons for refusal by the HFEA.

‘In the context of the use of genetic material the Authority considers that any consent should be given in clear and formal terms by the person himself or herself and that the Authority is reluctant to seek to identify a person’s wishes from the evidence of another person’.

This was plainly not regarded as a determinative justification by the Court of Appeal.

As to the welfare of a child, the 1990 Act states that this is for a potential treating clinic to decide.

I hope that these corrections will be noted and the necessary amendments made to the record.