

Health and Social Care Committee
Human Transplantation (Wales) Bill
HT(Ind)110 - Diane Jones

Mr Mark Drakeford AM
Chairman
Health & Social Care Committee
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

Dear Mr Drakeford

I strongly oppose the taking of human organs at a person's death under what it pleases the Welsh Assembly Government to call "presumed consent/deemed consent". Wales has achieved a voluntary deceased organ donation rate of 27.7 per million people (pmp) which compares well with other European countries and the UK average rate of 16.3 pmp. The way forward is to build on the 27.7 pmp in a way that does not rob a person of autonomy over their own body, living or dead.

Masses of NHS money will be spent on this when there is so much progress that needs to be made in other areas of medicine, for example, cancer, dementia, macula degeneration, illnesses and diseases that blight the lives of millions of sufferers and their families. It is grossly unfair also that life-extending cancer drugs approved by NICE are being denied to patients by many hospitals and new treatments are not being prescribed for heart attacks, multiple sclerosis etc according to a recent report published by the Health and Social Care Information Centre. Where will the money come from to support what could be termed organ snatching?

Furthermore, I do not trust an 'opt-out' system in such an important matter. Will we be expected to carry an 'opt-out' card at all times? Really there has not been enough explanation and even when I attended a public meeting in City Hall (although missed the very beginning) I was no wiser at the end of the meeting about the 'opt-out' procedure.

I feel that with this proposed legislation the Welsh Assembly Government has taken to itself the power of unnecessary intrusion into people's lives and frankly based on this experience I worry about this government coming out with ideas in the future regarding issues of an ethical nature.

If you are serious about people's reactions at the very least would you please consider and take on board the following 2 suggestions:-

1. Put in hand arrangements for a proper inquiry to state and publish the principles of the Bill, before expecting the public to comment on them.

2. Ask the Business Committee to extend the deadline for written responses to March 31st; and for oral evidence to start at 1st April. This is only reasonable in view of the consultation from December 7th to January 18th. This period included busy Christmas preparations, 3 public holidays, a period when many organisations and businesses closed down and when norovirus and viral infections were rife, these problems have accentuated the shortage of time for many people to respond. I shouldn't think there could have been a more difficult time in the whole of the calendar for people to have their say. Without an extension there can be little doubt that the Stage 1 examination is cut short and inadequate. There seems little need for a hasty rush through this very important stage of the examination of the proposed Bill. The consequences of inadequate drafting will be with us for many years to come.

Yours sincerely

Diane Jones
Penarth
Vale of Glamorgan