HEALTH AND SPORT COMMITTEE

Transplantation (Authorisation of Removal of Organs Etc.) (Scotland) Bill

Note by the Clerk and SPICe, Informal Meeting – Organ donor families

11 November 2015

Members in attendance –, Duncan McNeil MSP, Malcolm Chisholm MSP, Rhoda Grant MSP, Nanette Milne MSP, Dennis Robertson MSP

Background

The group included organ donor families with a range of experiences these included:

- A mother and father whose 14 year old son donated after a sudden and tragic death in 2012.
- A mother whose son donated in October 2010
- A mother whose daughter donated in June 2008
- A husband whose wife donated in September 2014
- A father and son whose wife/ mother donated in May 2014
- A mother and son whose husband/ father donated in June 2015

Detailed below is a summary of the views expressed and discussed at the meeting:

Bill proposals

- Overall all would support the change to an “opt-out” system
- Concerns were raised about how much time the addition of an authorised investigating person (AIP) would add to the process. Would it just add another level of bureaucracy? It was also queried who would undertake this role and what qualifications and/or experience they would require
- Some had concerns around the role of a proxy and that they would have the power to make decisions on organ donation over the immediate family. They felt that proxies could complicate the system and could not understand how they would work in practice. They also felt that proxies could reduce donor numbers.
- Additional concerns were raised over the proxy and how much extra time this would add to the process before organs could be removed. One mother spoke of how in her son’s case the process took so long that his lungs were no longer viable for donation. She was worried that having to contact up to three proxies, essentially adding another layer to the process, could make such situations more common.
- One individual believed that with an “opt-in” system it gave the family a choice to donate all or some organs, their belief being that it was sometimes easier to agree to donation if you could chose only some organs. Their worry was that with an “opt-out” system then all organs would be taken without discussion which could lead to greater distress.
- One individual thought that the Bill should increase organ donation rates
- Needs to be a clear and simple process.
- The Bill should have something about the family in it.
• Process for the framing of the Bill should be done in a positive way rather than the negative connotation of having to ‘opt-out’.
• One individual felt that the Bill had to be ethical and there was a discussion about organ donation being seen as a ‘gift’.
• One individual felt that there should be a non-medical person to oversee things and a trained councillor to help with the process.

**Current Process**

• All attendees agreed that the hospital staff involved in the donation process were excellent. They really helped the families come to terms with what was happening and were very reassuring and supportive.
• Specialist donor nurses were highly praised for their role and for ensuring that family members were reassured that their loved one was being respected properly during the donation process.
• Everyone confirmed that they received a follow-up from the donor service, which they found very helpful; with most advising that they had on-going communications, generally annually. This included an invitation to a remembrance service for most.
• It was very reassuring to the families to hear that the organs had been used to help others.
• Agreed that the follow-ups helped confirm the sense that they had done a “good thing” by agreeing to donate loved ones organs and that they found it very useful when they received information on what had happened with their loved one’s organs.
• Comments were heard that the system of organ donation was good, in particular the approach about donation.
• One individual had concerns with the timing and links between the Crown Prosecution Services and the NHS i.e. organ donation was discussed before the Crown Prosecution Services had allowed for the body to be potentially used for organ donation (this has to be done in the case where a crime may have been committed).
• One individual had concerns about the lengthy, probing and very personal questions that were asked, to the family, about their family member who was going to be an organ donor.

**Education**

• Most agreed that education was the most important factor going forward.
• People need to be better educated and informed about organ donation generally and in particular about the current opt-in system.
• Organ donation must be talked about in all settings – between families, in schools at university and in the work place. It was believed that if discussions were more “mainstream” then the numbers on the donor register would increase.
• Educate younger people about organ donation – at least three of the participants at the meeting were already involved in awareness raising with young people about organ donation.
• Most advised that they had never discussed organ donation with their families and as such when the worst happened they had to work out themselves if that
is what their loved one would have wanted. It was felt that the situation would have been a bit easier if they had had these conversations as routine.

- It was agreed that medical staff must be trained to a very high standard to carry out the roles around organ donation. The actions of the staff discussing the issue can have a huge impact on the family so they must be very knowledgeable and have excellent communication skills.