HEALTH AND SPORT COMMITTEE
31st Meeting, 2015 (Session 5), Tuesday 17 November 2015
Transplantation (Authorisation of Removal of Organs Etc.) (Scotland) Bill
Note by the Clerk and SPICe, Informal Meeting - Transplant recipients
4 November 2015

Members in attendance –, Duncan McNeil MSP, Bob Doris MSP, Malcolm Chisholm MSP, Rhoda Grant MSP, Nanette Milne MSP

Background
The group included transplant recipients with a range of experiences these included:

- A mother whose two children were diagnosed on the same day as requiring a heart transplant. Her children were aged 7 and 11 when diagnosed. Both have had successful transplants. The woman’s husband died during a heart transplant
- An individual who had received a heart transplant
- An individual who had an emergency live transplant a number of years ago
- An individual who had received a kidney transplant 25 years ago
- An individual who in total had been on the waiting list 12.5 years and had currently been on the waiting list for 5.5 years waiting for a second kidney transplant
- An individual who received a transplant after being on dialysis for six years

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

The current system

- More people are currently willing to donate than the numbers captured on the organ donor register
- One individual felt that the supply of organs may become less because not as many organs would be suitable for donation and transplantation due to people’s lifestyles e.g. obesity, issues with alcohol etc.
- The current system misses those who have not articulated their views (and they are very likely to have been those who support organ donation)
- Some current confusion over the status of the current donor card – does this mean you are on the register? The use of the organ donor card to encourage people to register for organ donation has reduced – the cards and leaflets are no longer displayed in chemists, doctors’ surgeries.
- Any campaigns around organ donation are short, it should be on-going if it is going to increase organ donation rates
- At the time of loss can be a difficult time to have a conversation with a family about donation – understandably they can be too caught up in their own feelings of loss to think of others
- Should be more leaflets about organ donation in doctors surgeries and wishes on organ donation documented in wills
• There have been occasions later on when family members have regretted the decision not to agree to organ donation.
• The 2006 Human Tissue Act has increased the number of living donor transplants

Role of practitioner

• How visible/accessible is an organ donor coordinator in hospitals?
• Key is the ‘mindset’ of the Doctors – will they ask families about organ donation?

Transplants

• “Life is terrible while on dialysis”
• “We are the lucky ones because we survived” but several participants had seen others who were not so lucky and had died while waiting for a transplant
• Hearts and lungs are more difficult to donate as the donor must be deceased whereas liver and kidney transplants can be provided by live donors. Liver donations can also be a partial transplant (given the liver can regrow).
• One individual explained that the heart transplant for her daughter required six trips to Newcastle after receiving call to say there was a potential organ. On each occasion the heart was then found not to be suitable
• One individual explained that while he was awaiting an organ donation there was potentially a number of suitable organs, but on several occasions, sometimes when he was prepped and ready for the transplant operation, the organ was then found not to be suitable. He commented that this impacts significantly not only on the potential recipient, but also on the family of the potential recipient
• There are emergency transplants so not everyone is on waiting lists
• People can die before they even get onto transplant waiting lists
• Several individuals spoke about receiving an organ which had originally been intended for someone else but they had been too ill to receive it

Bill proposals

• “The Bill should be titled ‘The gift of life Bill’
• “This Bill will start a conversation about organ donation in every household”
• “I’ll be very disappointed if this Bill does not progress”
• The Bill isn’t a political issue. Members should be able to vote on their views on the Bill rather than along party lines (it should be a free vote)
• Needs to be a clear and simple process with as few layers as possible
• The Bill will increase the number of donations as it will increase donations from those who agree with organ donation but don’t want to think about their own mortality. An opt out system will also provide a system for those people who really don’t want to donate.
• One individual said should that Scotland should not wait to see what happens in Wales. They felt this will be too late because it will be three to four years before we know how successful it has been and a number of people will have died by then waiting for transplants
• If the new system, under the Bill, was introduced it would need to be well publicised
• There was some discussion in the group about the role of families – with some thinking there was a need to ask relatives and others thinking they do not need to be asked
• Should be an individual and personal point of view with regards to organ donation transplant recipients were keen to emphasise that they wouldn’t want to receive an organ that had been taken without consent. It isn’t about persuading somebody to donate organs if they don’t want too
• If the new system, under the Bill, was introduced it would need to be well publicised
• Some participants had also spoken with representatives of Asian communities who were supportive of Bill. Participants highlighted that it was four times more difficult to match organs to people from ethnic minorities

Proxy
In discussing the proposals in the Bill to appoint a proxy, participants highlighted the following:
• “A Proxy is unnecessary”
• “A Proxy is an unnecessary distraction”
• Concerns expressed regarding how long it will take to contact a proxy, and the impact of this on potential availability of the organ
• Concern that if individuals are asked to identify a proxy it may result in people deliberating the issue longer than is required – makes the process more cumbersome than needs to be

Alternatives to the Bill if it wasn’t passed
• Retain the organ donor card – but get it counter signed by the next of kin. This approach would engage the family in discussing organ donation and ensure they understood the family member’s wishes. This approach may ensure family members don’t veto organ donation as they would know their family member’s wishes before death and would respect them. Some participants indicated that NHS BT does not agree with this approach.
• Have a three part donor card:
  o Normal donor card
  o Form sent off to register
  o Card given to family – which would encourage discussion within family
• If the Bill doesn’t pass money must be spent on encouraging conversations in families.
• Role for social media – Facebook in raising profile of issue, capturing people’s views and experiences.