

NHSBT BOARD MEETING

28th September 2017

A Donor Story: Deemed Consent for Organ Donation

Since 1st December 2015 in Wales, the Human Transplantation (Wales) Act allows for consent to be deemed in the absence of an express decision (recorded or verbal), provided the patient is not considered an 'excepted individual'. Excepted individuals are:

- Under 18 years old
- Are not ordinarily resident in Wales (or have lived in Wales less than 12 months)
- Those who lack Mental Capacity
- Those who have expressed / recorded a donation decision
- Those who have appointed a representative.

As part of the public promotion of organ donation leading up to the legislation change, the key messages directed individuals to make a choice about their donation decision. They can decide to opt-in by registering on the Organ Donor Register, decide to opt-out on the Organ Donor Register or decide to take no action and understand that their consent can be deemed.

Mr Smith is in his 40sⁱ, a husband and a father of two young children, who was admitted to hospital after he collapsed at home while complaining of a severe headache. He was rushed to hospital by ambulance, received a head scan while in the Emergency Department which showed a bleed on his brain and was admitted to the Intensive Care Unit for ongoing treatment and observation.

After a few days, it became obvious that the bleed which occurred was catastrophic and would go on to end his life. As part of routine end of life care the Specialist Nurse for Organ Donation (SNOD) was contacted to make an assessment for the potential for organ donation. On assessment, there were no contra-indications to donation so the SNOD and Consultant in charge of Mr Smith's treatment planned to approach his family. The Organ Donor Register was checked by the SNOD to ascertain if Mr Smith had registered an organ donation decision but there was none found.

In Mr Smith's case, the SNOD was confident to determine mental capacity, residence and age before speaking with the family, although these would need to be confirmed during the conversation. It was not known if Mr Smith had ever discussed Organ Donation with his wife / family and made clear an intention to donate or not. This would need to be explored at the appropriate time with Mrs Smith who would be the highest-ranking family member (if no representative had been appointed).

When the SNOD (Tina), introduced organ donation, Mrs Smith confirmed that she and her husband had never discussed it. Tina provided information about the benefits of donation and how it can help save many lives. She also clarified that because Mr Smith had not recorded or expressed any donation decision, his consent could be deemed and Mrs Smith would be expected to support that decision. Her immediate response to that was to say no, that donation wasn't something she wanted to consider and would prefer to leave things as they were. Mrs Smith and Tina discussed the merits

of donation and the comfort it may bring to her and her family. However Mrs Smith remained uncomfortable, as it was her decision, she could not move forward with it. “If he really wanted to be a donor, he would have opted-in”, she said.

It was at this point that Tina recognised that Mrs Smith still believed the decision to donate rested with her. Tina decided to talk Mrs Smith through what the Welsh Organ Donation legislation meant and that by deciding not to register a donation decision, Mr Smith had made a decision that consent can be deemed and therefore was not a decision for Mrs Smith to make. The point that if he wanted to be a donor he would have opted-in was reflected conversely in that if he felt strongly enough not to be a donor he would have opted-out.

Mrs Smith agreed that this might well be the case but the uncertainty of not having had a conversation about organ donation with her husband made her very reluctant to support donation and started to shut the conversation down, reduced eye contact and became mono-syllabic. At this point, Tina decided to slow the conversation down and they took a break. Tina went to make them a cup of tea but as she was leaving she said that when she returned they were going to talk about the potential for regret at not donating Mr Smith’s organs. Tina recognised the surprise on Mrs Smith’s face as regret was something that hadn’t occurred to her.

Tina returned with tea for them both and noticed the tension in the room had dissipated. For a while, they made small-talk and spoke about Mr Smith as a person and a father and how his children meant the world to him. The children were still very young and she was upset that they would only ever have vague memories of their dad. She then asked if many people regret not donating. Tina responded by saying that some people do regret it, especially if it goes against an original decision to donate or if it goes against the character of the individual who may have been the giving or generous type. By donating, it may also leave a legacy for his children to remember that their dad saved lives when his was over.

Mrs Smith sat quietly contemplating while Tina let the silence hang, until finally, Mrs Smith said “Okay”. Mrs Smith agreed to support the deemed consent and her husband went on to donate kidney’s, liver, pancreas and corneas, all with successful outcomes.

Phil Walton
Regional Manager, South Wales, South West and South Central

ⁱ The donor’s personal details have been anonymised.