

# **Sustaining Human Lives Through Family Efforts In Organ Donation**

**Farah Salwani bt. Muda@Ismail**

Faculty Syariah & Law, Universiti Sains Islam Malaysia,  
salwani@usim.edu.my

## **ABSTRACT**

Human lives are too precious to waste. Therefore, maximum effort is taken to guard and protect lives of each and every human being on earth. Organ donation, as a miracle in the modern medical world, clearly spells out this concept. Vital organs are supplied from other humans with the intention to allow lives of patients in need, suffering from end stage organ failures to be extended and saved.

Malaysia positively supports this kind deed, though unfortunately we still suffer from severe organ shortage problems. This paper will encapsulate a spectrum of knowledge by introducing steps that could possibly help overcome organ shortage in Malaysia, including by eliminating family refusal and introducing a family-witness support system. These suggestions will obviously contribute towards the sustainability of precious human lives.

**Key Words:** organ donation, family, law, shortage

## **INTRODUCTION**

Organ donation has always been seen as a miracle. Thousands of people's lives have been saved, not to mention the joy and happiness that it brings. As Malaysia continues to face the challenge of addressing organ shortage, it is believed that the root cause is not due to the lack of suitable donors, but is rather the consequence of failure to secure potential donors. It is horrifying to learn the fact that from approximately 28.5 million population in Malaysia, frustratingly we have less than one donor for every one million population (National Transplant Registry, 2007). What puzzles us more is, despite the increasing number of organ pledgers registering every year, statistics clearly show that until 31st July 2012, only 378 have finally become actual donors, though contrastingly, 200,756 people have already pledged as potential organ donors.

## **ELIMINATING FAMILY REFUSAL AND INFLUENCE**

The main factor causing the small number of actual donors in Malaysia is family rejection. Each year, many donation opportunities from potential candidates are missed because of lack of familial consent (Britton, 2008) which very much relates to their misunderstanding and acceptance of the brain death concept, fear of unequal access to transplantation and, of course, misconceptions of religious opinions (Kalicinski et al, 2003). Family rejection is something that can possibly be changed and avoided. Lee Lam Thye, chairman of the Health Ministry's Public Education Subcommittee on Organ Donation, Malaysia, concurred with the fact

that, although there is an overwhelming response from the public in Malaysia to become organ donors, in reality there are very few actual donors because, when the hospital authorities approach the family of the pledger, they refuse and accuse the doctors and nurses of being heartless at their time of mourning (Cruetz, 2009). Consequently, a lot of potential organ donation opportunities continue to be lost year after year and drastic changes must be taken to prevent this situation from continuing.

Family rejection can interfere in two separate situations. Firstly, it can take place as early as before the individual registers as an organ donor, consequently stopping the individual from pursuing his intention to register; the other is when it hinders an existing registered organ donor in becoming an actual organ donor. This takes place when the deceased dies with known intentions of becoming an organ donor but, out of respect for the grieving family, their consent is sought before the actual organ procurement procedures are carried out. Any denial or objections expressed by the deceased's family can consequently prevent organ donation procedures from proceeding as hoped for.

In Malaysia, The sole legislation in Malaysia which regulates organ transplantation is the Human Tissues Act 1974 which is very much consent-based. The Act recognizes family rejection as valid and authoritative. The Act clearly spells out that the person lawfully in possession of the body may, after death, authorize removal of the specified body parts according to the request made, after ensuring that the deceased had not expressed any retractions soon after the request. The person lawfully in possession of the deceased body, after making reasonable and practicable enquiry, may also permit donation where, after making reasonable and practicable enquiry, he believes:

- a) that the deceased had not expressed an objection to his body being dealt with after his death or
- b) that the surviving spouse or any surviving next of kin of the deceased has not objected to the body being used for the above-mentioned purposes.

Section 2(2) (b) of the 1974 Act above, clearly provides optional power to the surviving spouse or next of kin to authorize removal of any part of the deceased body, though it is still subject to any express objections by the deceased himself during his lifetime or any family objections brought forward. This is the exact situation where potential organ donors, who are suitable to become organ donors and have even pledged their willingness in doing so, have their wishes overridden by their families. Therefore, immediate action must be taken to stop families from using their conclusive authority to reject and oppose organ donation intended by their loved ones, as according to research, almost half of the families of potential donors do indeed refuse consent (Mark et al, 2001).

One of the most effective ways to achieve this is to legally amend the Human Tissues Act 1974, particularly by removing the section contained therein

which permits such occurrence to take place. So, section 2(2) (b) of the Act, which clearly acknowledges family objections particularly from the deceased's spouse and next of kin, must be removed. Hopefully, by implementing this change, we will be able to see more actual organ donations taking place as intended.

The same Act also does not provide for a specific definition of the phrase "next of kin" as found in the wording of section 2(2)(b). So, there is vagueness as to where should this list of next of kin stop at? It is suggested that a specific list should be added consisting of close relatives confined to the surviving spouse and deceased's children only. However, in cases where there is no spouse, or for those who are unmarried, it should be the parents, and in cases involving children it should be limited to their parents or legal guardian.

## **THE FAMILY-WITNESS SUPPORT SYSTEM**

Malaysians are known with their strong family tie bonds. It is common for people to consult and involve their families in matters that affect the whole family. For example, in deciding a suitable date to solemnize a marriage, fixing marriage receptions, hosting familial functions. During religious celebrations for instance, it is almost essential for everybody to get together and celebrate it with their respective families. In such cases, everybody normally leaves for their hometown to be with their parents, siblings and relatives. Even in hard and depressing times, such as during illnesses and death, family members again unite to give support to one another. Therefore if family role and influence is totally set aside, especially in end-of-life issues like organ donation, this would presumably result in more unpopular consequences and perhaps provoke even more rejections from the general public, particularly the bereaved families towards organ donation. Therefore, any alternative suggestion must be able to balance between protecting one's right to human autonomy and at the same time respect the role and influence of the family as well.

Being in the organ shortage crisis that we face now, we should no longer hope that families of the deceased donor will honour and act in accord with the deceased's wishes to become an actual organ donor. So, to strike a balance, while continuing to be sensitive to both parties, we must find a solution that respects the registered organ donors wish while still including and treating family members equally important throughout the whole decision-making process. Therefore, the answer to this dilemma is by making some practical changes to the organ donation registration procedure itself.

By introducing a family-witness support system in the organ donation registration procedure, not only will the individual alone pledge his wishes to donate his organs, but there should also be two witnesses supporting the potential organ donor's intentions. These two witnesses should preferably be close family members, for instance, parents, spouse, children, siblings or any other family

members. Adding this requirement will indirectly allow the individual to ensure family involvement in such an important decision making process, allow him to discuss with them organ donation issues at an earlier stage and easily express his wish to become an organ donor sooner.

Many states in the United States have already required potential organ donors to indicate their commitment by signing an organ donor card in the presence of two witnesses (Etzioni, 2003). Luckily, Malaysians are already used to having the witness requirement as it is mandatory in other matters as well, such as in solemnizing marriages. Moreover, reports from the UK Organ Donation Taskforce also clearly emphasizes the importance of encouraging people to broach and discuss organ donation issues, especially with families, friends and those closest to them, in order to help the NHS carry out its work more effectively. So, the witness requirement does clearly promote this objective.

The Welsh Assembly Government once sponsored an organ donation awareness campaign called 'Donate Wales: Tell a Loved One' to encourage people to discuss organ donation intentions with loved ones first before registering as organ donors. Moreover, according to the European Union Committee, there is evidence that members of families who have discussed organ donation matters among themselves tend to be more likely to be willing to donate organs too.

Making family witnesses an additional requirement will also help lift the burden from family members in deciding about donation, following a very sudden, unexpected and untimely death, which is undeniably a situation of great distress and grief. As such, the emotional environment is significantly reduced when organ donation is already expected to take place and close family members are already aware of the deceased's wishes because the matter had already been brought up and discussed together with the deceased himself during his lifetime. Moreover, relatives might be reluctant to take a personal decision about the removal of organs, but they would find it easier to agree if they were simply confirming the intention of the deceased person (Kennedy et al, 1998). This suggestion will also prevent incidences of family members being totally ignorant of the deceased's intention to donate organs, which is similar to leaving the final say to the family.

This situation normally leads to refusal to allow donation as, in cases of uncertainty, added to the responsibility of making a big decision when they themselves are also feeling vulnerable and distressed, the family might feel that the safest course of action is to refuse permission for organ donation. The implication of the deceased not registering himself as an organ donor also invokes a belief within his family members that the deceased was against organ donation, and this is reinforced by the presumption that, if the deceased had wanted to donate his organs, he would have indicated such intentions during his lifetime (Tymstra, 1992). As a result, fewer organs are being donated. Conversely, if family members are already aware of the deceased's wishes, hopefully, when the actual time comes, it will be easier for them to accept and honour the deceased's wishes to become an organ donor.

The two family witnesses could also play an influential role by explaining and clarifying the wishes of the deceased to the other members of the family, as it is always easier, more comfortable and convincing to listen to people who are close to us compared to doctors and nurses, who are considered total strangers. In practice, these two witnesses need not be present during the registration process, and are only required to sign the registration form, including supplying their brief personal and contact details so that they can be easily reached by those in authority. These witnesses must be aged 18 and above, sane, and have family proximity to the registered organ donor. Nonetheless, in cases where the potential organ donor has no family members at all or in cases where none of the family members is available to willingly come forward, provide support and become a witness, exceptions could be made. This additional requirement should not become an obstacle hindering people in making their altruistic organ donations. So it is recommended that the preference for having family members as witnesses be made flexible in these cases and that they might be substituted by those who are in close relationships with the deceased as well. This could be a close friend, a colleague, a close neighbour or maybe an employer, for example, as long as they are able to certify and demonstrate awareness of the person's whereabouts and can at least provide some brief information about the deceased. After the potential registered donor has filled in his particulars on the registration form, has indicated which organs he would like to donate, and obtained the signatures from the two witnesses, the completed form will then need to be submitted as usual.

It could be argued that this additional requirement of having to obtain two witnesses' signatures makes the registration process appear more rigid and complicated; the author believes, however, that if a person is seriously intending to donate his organs, this additional requirement will never prevent him from continuing to do so. It is actually not at all difficult to adhere to, especially in a Malaysian scenario where family members are normally close and reachable. This suggested requirement could also be seen as a test to measure ones' seriousness and willingness to proceed as an organ donor and should be considered a blessing in disguise as it respects the wishes of the individual and at the same time acknowledges the importance of family support.

It is believed that this will be no hindrance to any person continuing with their altruistic intentions to officially become a registered organ donor; it will actually make things more certain and run more smoothly. As for the registered donor himself, he could rest assured that his wishes to donate his organs will be honoured and carried out upon his death, without fear of his decision being overruled by the family later. However, the implementation of this additional witness requirement must not in any way prohibit the potential organ donor from retracting his decision to donate. To do this, he could simply inform the National Transplant Registry (NTR) of his intention to de-register and subsequently his name would be removed from the list of registered potential donors. He might inform the witnesses of this change of heart but it will, nevertheless, always be the responsibility of the NTR to inform the witnesses of any changes.

This witness requirement is also possible for online organ donor registrations. Here, the organ donor will enter his particulars online as usual and additionally state the name and brief details of the two family witnesses supporting his registration. Later, the NTR will contact these two witnesses to record their agreement and support. In cases where family support is clearly obtained, in the event of the death of the registered organ donor, the hospital can in fact implement the organ procurement procedures immediately, even without first informing the family members. This will reduce delays in procuring the donated organs while ensuring the possibility of a better outcome from the transplantation by facilitating earlier tissue-matching and other related procedures. However, in cases where the registered organ donor only managed to enlist a non-familial witness, the hospital will still need to try and contact the family of the deceased. This is not to obtain their consent, but is more a matter of courtesy and respect for them.

In relation to approaching families, change should be made to the purposes for so doing. The current practice now is that families are approached for their consent to organ donation; however, once families no longer have the power to overrule the deceased's wishes to donate organs, approaching them shortly before organ procurement procedures take place should be no more than a sign of respect and to keep them abreast of what is happening to the deceased's body. Hopefully, families would be more comfortable when approached on the issue and might accept it as a routine part of end-of-life care. It is absolutely crucial for the families to know and understand their new, limited role, and that they are being approached only to further affirm organ procurement proceedings, and are no longer sought for their consent for the procedure. This does not in any way imply that they are disregarded; rather, it indirectly entails the attempt to fully honour and respect both the deceased and his family.

In a study conducted by Ashley et al. to increase donation consent rates in patients with prior Department of Motor Vehicle (DMV) donor designations, it was shown that modifying the approach to families, from seeking their consent to organ donation to asking them to honour the patient's wishes instead, had actually increased the organ procurement rate to an outstanding 100% result (Britton et al, 2008). Before this approach was introduced, only 20 of a total of 24 families of patients having prior DMV designations proceeded with organ donation. This means that the remaining four families had dismissed the opportunity to proceed with the organ donations hoped for. However, after this modified approach was introduced, the families of all 19 DMV designated donors had consented to organ donation.

This approach also signifies how a balance can be struck between providing respect and honour to the grieving family while at the same time ensuring that the deceased's wishes can still be carried out. However, in cases where family rejection is too strong and they cannot be persuaded to compromise, or they have perhaps even commenced legal proceedings to block such procurement from taking place, it is better to adhere to the family's wishes, as any compulsion used to proceed with organ donation despite the families' strong opposition will

impact not only the patient, but also their families, who must cope with the sudden loss of the deceased. So, in such exceptional cases, it is important to maintain respect for the families as well. Consulting family members at the time of death could at least positively facilitate the process of obtaining details and information about the potential donor's current medical and behavioural history, which plays an important role in ensuring the success of a transplant.

## CONCLUSION

Organ shortage is indeed a worrying problem that we face. Nevertheless, if proper action is taken in tackling the potential donor and their family members, a lot of positive impact could surely be seen. By eliminating family refusal through amendments in the Human Tissues Act 1974, wishes of these organ pledgers can be secured. The family-witness support system is also seen as very promising, as approval of the family members are essential, though they may no longer carry as much authority as before. Nevertheless, the main aim is to add up to the donors pool and ensure that more precious lives can be saved and sustained.

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## **BIODATA**

DR.FARAH SALWANI MUDA@ISMAIL is a senior lecturer at the Faculty of Syariah and Law, Universiti Sains Islam Malaysia. She obtained both her degrees in Law (LLB) and Master of Comparative Laws (MCL) from the International Islamic University Malaysia. She was awarded her Doctor of Philosophy in Law from the University of Southampton, United Kingdom. Her area of expertise is medical law and ethics.