

Response to Organ Donation Consultation – Blaenau Gwent Health & Social Network

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The Health and Social Care Network in Blaenau Gwent discussed issues around organ donation starting from the premise that many Welsh, and British patients, die each year whilst waiting for suitable organs to replace their own failing ones. Further to this, there are many others who remain on transplant lists living lives which are disabled by chronic and acute conditions, illness restricting employment, dependent on benefits, restrictions on fulfilling their role in family life, frequent calls on primary, secondary and tertiary care and dependent on medication. It was the Network's overwhelming opinion that not enough organs are procured and it is agreed that this situation needs to be addressed. There was no dissent from the principal of using body organs or tissues to save, or enhance the lives of others following the donor's death. Every member agreed that ensuring the delivery of individual's choice about whether they wish their body to be used in this way was of paramount importance. Most members were disturbed that it is the case that families over-rule some individual's stated wishes, which has been confirmed by clinicians.

The issues around organ donation are sensitive and members were aware that a very substantial number of families refuse to let organs be used after death. There is clearly need to scrutinise the reasons behind the discrepancy between numbers in the general population supporting the principal, but then with-holding permission. It was noted that younger people display more active support for donor registers, even though anecdotally, they may appear to think they'll live forever. Members had themselves experienced barriers raised by older people in speaking of death or committing themselves, whilst alive, to giving directives to their next of kin about the disposal of their bodies. The meeting felt it should be seen to be a responsible and desirable act to have family whose members' are aware of your wishes for the use and disposal of your body. Taboos need to be lifted. Members recommended that public acceptance through discussions around giving organs freely, as a desirable social act needs to be made in the media and through publicly funded campaigns. Children should be able to learn about the subject and ask questions within appropriate school lessons and be encouraged to take those discussions home to their families.

Further to the issues related to family consent are those around the use of retrieved organs which are unusable. It is understood that delays in acquiring the organs and their transportation over wide areas may mean they are no longer functional and whereas many people want to save lives they may not want to donate an organ for research purposes. Research is important, many significant breakthroughs would not have occurred without human tissue use. However as time goes on, other options have been developed. After organ storing scandals have alienated public opinion, the issues have become confused. This meeting therefore recommends an additional options asking for consent for the use of organs for these other purposes.

It was suspected that the infrastructure to support the retrieval of organs and utilize them, has substantial capacity for improvement. It was felt that the situations in which appropriate staff approach recently bereaved families are not sufficiently wide. Members noted that the majority of organs are obtained from patients in intensive care facilities and previously on life support systems, where the immediacy of death and donation would be harder to appreciate emotionally. Members assume relatives may have experienced greater problems giving consent in these situations than, for example, in situations where death has occurred following heart failure, the lesser but still significant source of donations. It is suggested that all patients entering hospital be asked to express their wishes and this be recorded. If the hospital (IT) record system is sufficiently robust, this could

remain with the patient indefinitely but on admission they could be asked if they wished to amend any view they had previously expressed. This practice in the short-term maybe alarming, but society needs to change. Alternatively, GPs could perform this task, again subject to electronic systems and the incorporation of the work into the GMS. Wider use of staff apart from consultants and co-ordinators should be considered, perhaps extending to “named nurses” who have achieved closer relationships with patients and their families. Resources should be allocated for appropriate training.

Potential donors who register reported that they received no confirmation of being on the register. This lack of communication doesn't build confidence in the existing system.

It was felt that the law needs to be clarified immediately, particularly regarding advanced directives where some consultants are evidently reluctant to go against the family's wishes close to the time of death, although members appreciate the sensitivity of the situation. It is acknowledged that there are special issues where people lack mental capacity at any stage of life. However, ensuring consideration of Mental Capacity is a statutory obligation and guidance should be followed. Issues around race and religion were not raised but it is understood that no major religions have objections to the removal of organs where they save life or improve its quality for others. It has been identified that the current attitudes which identify and discriminate against homosexual individuals wishing to donate tissues and organs, perpetuate stigma and are clinically unfounded. This practise should be stopped.

It is recognised that within Wales, capacity is limited to only 2 types of organ transplant and that Welsh patients receiving organs, other than those for kidneys or pancreases, receive them in England. It is assumed that most patients have no knowledge of this. Blaenau Gwent Health & Social Care Network members regretted the lack of capacity for a wider range of transplant procedures due to the difficulties for patients and families in often travelling substantial distances for treatment. However, receiving the best provision and care is paramount and it is felt that Wales should continue this reciprocal arrangement with the rest of the UK. Members support measures to increase Welsh donations and feel that increased provision of intensive care facilities and fully trained staff would better facilitate this. Members do not recognise a need for unilateral legislation in Wales.

As previously said, ensuring the delivery of individual's choice is of paramount importance however this is not the same as ensuring the individual's right to choose, which of course embraces the right not to make a decision. Not deciding creates heartache and dissent in families and wastes the resource of organs and tissues which have the potential to save life and improve its quality for many years to come. The Network therefore supports an opt-in scheme.