

Western Health & Social Care Trust Annual Organ Donation Report 2017 - 2018

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1. Executive Summary

The whole issue of organ donation has been increasingly in the public eye in the last year. At a national level, the issue of legislating to introduce an "opt out" system for organ donation has been taken forward in England and in Wales.

Within Northern Ireland, legislation was introduced to the assembly in 2016 requiring the Department of Health to promote organ donation, and the Department undertook a formal consultation on how best to do this in the latter part of 2017/18. There were a number of public meetings and an opportunity to respond to their consultation document. We will see the outworkings of this during 18/19, and this will be important and supportive in the work of all Trust Organ Donation Committees.

The Western Trust Organ Donation Committee had a clear work plan for its year, and there were very notable areas which were new for us. In particular, we advanced the relationships we have with both Fermanagh & Omagh and Derry City and Strabane District Councils during the year, and Dr Grace and I formally presented to DCSDC on the work of the Organ Donation Committee. Linkages with our local councils will be important partnerships going forward and there is collective agreement with council officers and elected officials to build on the strong relationships we have with our community and local partners to promote organ donation through promotional activities with their staff and in local communities.

We also had an exceptional opportunity to participate in the installation of a "Gift of Life candle" installation during this year, which was aimed at celebrating the Gift which individuals and their families give through the decision to donate. This celebration event linked the Western Health and Social Care Trust's Organ Donation Committee with the 'Strange Boat' Organ Donation Charity, and Derry City and Strabane District Council.

The Charity arranged an international organ donor event in November 2017, which centred around the choreographed unveiling of commemorative stone sculptures in cities around the world. The event was attended by the mayors of Derry City and Strabane District council and Limerick council, and Dr Grace acted as a focal point for the Trust and the council in the event, which coincided with the 50th anniversary of the first heart transplant operation having been performed in Groote Schuur Hospital in Cape Town in 1967.

The commemorative sculpture was installed formally within St Columb's Park at the event, and is a fitting tribute to all who donate to give the gift of life to others.

Finally I want to acknowledge the diligent work of the all members of the Organ Donation Committee, and the commitment and dedication of the Clinical Lead for Organ Donation in the Trust, Dr Declan Grace, Consultant in Anaesthesia and Critical Care Medicine, as well at our Specialist Nurses for organ Donation, Maria Coyle and Martina Conlon.

There were some notable changes to the committee which occurred or were agreed this year. We are very sad to report that our great friend and colleague John Hunter died in February 2018. For the past four years John was the donor-family representative on Trust's Organ Donation Committee. John contributed greatly to the work for the committee and his wise counsel and always cheerful demeanour will be sorely missed.

We also agreed to wider participation on the committee during the year, and to this end invited Mr Joe McMonagle, the chair of the Altnagelvin renal support group. Joe has kindly agreed to join the Organ Donation Committee for the year ahead.

With all of its partners the Western Trust is well placed to build upon the excellent progress made thus far in promoting, securing and facilitating donation. We shall continue to enable the wishes of patients to become donors after death and we are honoured to do so.

2. Report from the Organ Donation Committee (O.D.C.)

The Organ Donation Committee's remit is to (i) promote an organ donation culture within Trust and (ii) to ensure that all patients who might potentially be organ donors are given the opportunity to do so. 2017 - 2018 year was another successful year for The Western Health and Social Care Trust in securing organ donors and in developing a donation culture both within Trust and in our community.

The Organ Donation Committee meets three times per annum and reviews progress and developments arising. The committee has a wide membership and includes representatives of Donor families, local Donation Charities, the Bereavement service, the Trust's Communication's service, the Trust's Critical Care and Operating Theatre departments, the Chaplains' service and the Mortuary service. The committee's composition and role is currently being reviewed and updated. The Trust's Board receives a formal report on the work of the Committee and this will be presented formally to Trust Board in early autumn 2018.

Policies and protocols pertaining to donation have been reviewed, updated and made available to relevant staff both electronically and in published form and are immediately accessible to I.C.U. staff via the electronic I.C.U. patient information systems that operate on the computer terminal at each patient's bedside. Similarly, staff are regularly updated on all developments as they arise.

The organ donation training programme continues seamlessly and is delivered to relevant staff (medical and nursing) intimately involved with donation in the critical care units, anaesthesia and operating theatres. It is also delivered to other relevant and interested parties such as non-I.C.U. / non-Anaesthetic medical staff and Emergency Department staff. Generally medical staff are trained and updated by the Lead Clinician for Organ Donation and nursing staff by the Specialist Nurses. However, overlapping contributions are made to the training of all clinical staff both formally and informally. The training programme enhances the clinical knowledge of staff. Critically, it contributes greatly to the development of a "donation culture" within Trust.

The Donation Committee is very active in promoting organ donation to the wider community. Notable initiatives have included multiple further articles on organ donation in the local newspapers throughout the Western Trust's catchment area, plus further radio interviews and very successful promotional initiatives on Facebook, Twitter and the Trust's intranet. During 2017 we posted electronically video presentations promoting donation and these garnered quite a remarkable amount of interest. The committee facilitated 'Strange Boat' a Galway-based Organ Donation Charity in installing Life Candle sculptures in Derry and Melbourne as part of its multi-city multinational initiative to celebrate and promote donation globally. This global event was very successful and generated considerable positive publicity.

The Specialist Nurses continue to be very active in raising awareness of organ donation and promoting organ donor registration at schools, sporting clubs and businesses

The Trust's Bereavement Booklet incorporates useful information pertaining to organ and tissue donation.

3. Hospital Organ Donation Team Structure

TRUST NHS Blood &Transplant TRUST BOARD **ASSISTANT DIRECTOR CORPORATE MANAGEMENT TEAM REGIONAL MANAGER** ITU & Anaesthetics Mrs Monica Hackett **REGIONAL CLINICAL LEAD** Dr N Hemmings, Lead Clinician -ICU Dr Paul Glover **TEAM MANAGERS** Dr S Symington, Lead Clinician -Anaesthetics Ms Nikki Murray / Dawn McKimm **DONATION COMMITTEE CHAIR CLINICAL LEAD (CLOD) SPECIALIST NURSES (SNOD)** Mrs Teresa Molloy Dr Declan Grace Martina Conlon & Maria Coyle

WESTERN HEALTH AND SOCIAL CARE TRUST DONATION COMMITTEE

L					
CRITICAL CARE	L	EMERGENCY DEPARTMENT	THEATRES	END OF LIFE Facilitators	DONOR FAMILY REPRESENTATIVE
Sr H McDona	ald	Dr J Steele	Mrs C Reid	Ms Carol McKeeman	Mr John Hunter MORTUARY REPRESENTATIVE Ms Bridget Boyce COMMUNICATIONS REPRESENTATIVE Ms Clare Cunningham
				McKeeman	MORT REPRESE Ms Bridget COMMUNI REPRESE

4. Organ Donation Rates

Donation after Brain Death (D.B.D.)

Patients meeting referral criteria	15		
Referred to SNOD	14	93% *	
Neurological death testing	10	67% *	+
Eligible donors	9		
Next of kin approached	9	100%	
SNOD involvement in assent	8	89%	
Assent	7	78%	UK average 67%
Actual donors	6	86%	
Number of patients transplanted	17		
Number of organs transplanted	17		
Organs donated per donor	3.2		

^{*} due to personal circumstances pertaining to one patient and their family in one case it was deemed inappropriate to raise organ donation and thus refer the patient for consideration of donation

Donation after Circulatory Death (D.C.D.)

Patients meeting referral criteria ***	24		
Referred to SNOD	16	67%	
Eligible donors ****	15		
Next of kin approached *****	6		
SNOD involvement in assent	6	100%	UK average 86%
Assent	4	67%	UK average 60%
Actual proceeding donors	1	25%	
Number of patients transplanted	3		
Number or organs transplanted	4		

N.B. There were no patients with actual potential to donate 'missed'.

Definitions:

^{**} for physiologically reasons it was impossible to perform B.S.T. on two patients. In an additional case next of kin declined assent for donation and in the final case there was a contraindication to donation. In these two cases B.S.T. was not conducted.

^{***} a patient receiving mechanical ventilation in whom imminent death is anticipated within 4 hours

^{****} a patient who had life-sustaining treatment withdrawn and in whom death was anticipated within four hours and in whom there were no *absolute* contraindications to solid organ donation

^{*****} percentage of families of eligible D.C.D. donors approached for assent for donation – this number represents the actual number of patients who might realistically become D.C.D. donors per annum.

5. **Commentary**

The number of potential and proceeding donors in the Trust's Critical Care Units in 2017-2018 was similar to that seen in the 2016-2017 period. Quality indicators for good practice e.g. rates of identification, referral, brain-stem death testing, seeking assent for donation from next of kin collaboratively, obtaining assent successfully, the number of actual donors and the number of organs retrieved per donation remain robust within the Trust and are in line with national figures. Most critically the rate of obtaining assent for donation successfully from next of kin remains excellent as are the rates of approaching next of kin collaboratively. The total number of deceased donors (seven) secured by the Critical Care Units of the W.H.S.C.T. in 2017-2018 represents 17.5% of all deceased donors in N. Ireland in 2017-2018. Furthermore, for clinical reasons an additional three D.C.D. donations did not proceed. Thus, overall donation activity remains similar to that achieved over the past number of years. Thus, donation processes remain robust.

For many years W.H.S.C.T. has repeatedly provided between 17.5% and 22.5% of all the deceased donors in N. Ireland. The number of critical care beds in the W.H.S.C.T is approximately one tenth of the total N. Ireland Critical Care bed complement. Thus, repeatedly securing such a large percentage of the total number of deceased donors in N. Ireland is an outstanding achievement.

The next of kin of two potential D.B.D. donors and two potential D.C.D. donors did not give assent for donation to proceed. When next of kin decline assent for donation the process conducted is reviewed meticulously. The next of kin of these patients were all approached in an appropriate, empathetic way at an appropriate time. These families made an informed decision that donation would not proceed as is their right.

Donation after brain death (D.B.D.)

In patients suspected of having died of neurological causes death is confirmed by determining the absence of brain stem function (performing brain stem testing - B.S.T.). In 2017-2018 brain stem tests were performed on 10 patients. For physiological reasons it was not possible to perform formal testing in two patients. Thus the quoted rate of brain stem testing is spuriously low. Rates of identifying potential donors, referring donors for consideration for donation and collaboratively approaching next of kin for assent rates remain excellent.

The rate of obtaining assent for donation for D.B.D. was 78% which compares favourably with the national rate of 67%

Donor optimisation:

The Trust's donor organ optimisation outcomes remain robust and reflect the excellent standard of clinical management of patients in both the ante- and post-mortem periods. Organ optimization protocols are reviewed serially, updated and staff are updated serially in relation to best practice. The protocol has been incorporated into the bedside electronic patient management system. Thus, it is immediately available to clinical staff. The protocol mirrors closely standard clinical management protocols as have long-pertained within the Trust's Critical Care Units.

Donation after circulatory death (D.C.D.)

The collaborative approach rate and assent rate for donation after circulatory death are very robust at 100% and 67% respectively. Nationally the assent rate for D.C.D. was 60% The rate for referral of patients for donation after circulatory death has increased significantly in the past three years to 67%. This is praiseworthy. Additional measures were introduced to enhance referral and these are reviewed and any additional measures trialled as deemed necessary. However, whether this will increase the number of actual donors remains a matter of conjecture. The clinical team is confident that at present likely donors are not "missed". Indeed this was the case. Non-referred patients are those who very experienced clinical staff (the Consultant Intensivists) have correctly identified as not having any likelihood of donating (due to non-viability of organs). Nonetheless, we remain keen to optimise referral practices and we are continuing to enhance D.C.D. referral practices.

As alluded to in previous annual reports "raw" P.D.A. data pertaining to D.C.D. on casual inspection has been somewhat misleading. The data collection tended to discriminate poorly between patients

- (i) in whom active resuscitation was unsuccessful (e.g. discontinuation of C.P.R.),
- (ii) patients in whom on-going attempted curative treatment was deemed to be no longer in the patient's best interests in whom life-supporting treatment was therefore to be withdrawn but who clearly were not suitable to be donors and
- (iii) patients in whom on-going attempted curative treatment was deemed as being no longer in their best interests but who *might* possibly be potential donors.

Improvements in data recording have reduced this anomaly somewhat. However to the casual observer it is not immediately obvious that patients in categories (i) and (ii) above will never donate.

Collaborative approach to assent:

The Trust's Organ Donation Committee and all the clinicians directly involved in caring for potential donors strongly support the concept of "joint approach" by clinician and S.N.O.D. in seeking assent for donation from next of kin. This is reflected in both the remarkably good collaborative approach rates and assent rates. This is a splendid achievement given the relative geographical isolation of Altnagelvin Hospital and the South West Acute Hospital and thus the not inconsiderable time required for Specialist Nurses to travel from the greater Belfast area. On occasions it has not been possible to seek assent collaboratively because (i) families have initiated donation conversations, (ii) patients' physiological instability has precluded delaying relevant conversations or (iii) families may require decision-making in a time frame that precludes the arrival of the S.N.O.D.

The committee and the Trust's Intensivists continue to reiterate their collective commitment to the national standard that clinicians seek actively the involvement of the S.N.O.D. in any potential donation (D.C.D. or D.B.D.) as early as possible and work collaboratively with specialist nurses when seeking assent for donation.

Review:

Missed opportunities (to offer the opportunity to donate) such as failure to confirm neurological death, failure to refer possible donors to Specialist Nurses (S.N.O.D.'s), failure to approach next of kin collaboratively, failure to consider possible D.C.D. prior to withdrawing life-sustaining therapies are reviewed by the Lead Clinician and S.N.O.D.'s and feedback and additional training offered to relevant staff. Opportunities to identify 'true' potential donors are rarely missed.

Various initiatives have been introduced to facilitate referral of potential D.C.D. donors including (i) the embedded S.N.O.D.'s accompanying routinely the Critical Care morning ward round and (ii) daily telephone consultation by the on-call S.N.O.D. with our I.C.U.'s to determine the presence of potential donors within the ICU's, (iii) the positioning of reminders and aide-memoires for staff in prominent locations within the critical care units, (iv) empowering bedside nurses to identify potential donors and developing nurse-led referral of potential donors, (v) face to face updating of staff both collectively and individually. These

measures have undoubtedly contributed to improved D.C.D. referral rates and we shall continue to review progress and develop new approaches as required.

End of life care:

The staff of our I.C.U.'s possess great expertise in end of life care and symptom palliation and the quality of care given to patients (and their next of kin) during patients' terminal illnesses is outstanding. Furthermore, staff receive regularly excellent update and refresher training in end of life care.

Critical Care staff can remain proud of their achievements in facilitating (a) the wish of donors and donor families to donate and (b) enabling multiple recipients to benefit from optimised organs and tissues. An excellent donation culture exists within the Trust's Critical Care Units.

6. Promotion

The number of deceased donors in Northern Ireland and Britain has doubled in the past ten years. However, the number of patients requiring transplants continues to exceed the number of donors. Thus, the committee believes that it is essential that we continue to garner the support and enthusiasm of the population in promoting donation. To that end the committee promotes very actively awareness of the importance of organ donation in our community and indeed within the organization itself. Promotional activities are conducted throughout the year. We continue to seek imaginative and innovative ways to do so. We conduct serial and multiple promotional initiatives with the local print media, on radio, television and the internet. Specific opportunities to conduct promotion are embraced with much emphasis been placed on Organ Donation Week at the start of September each year. Furthermore, we have started promoting donation awareness on the Trust's intranet and via social media. This has proved very effective and has generated much interest and many 'hits'.

In the summer of 2017 local actress Eva Birththistle kindly unveiled artwork celebrating donation and commemorating donors at the entrance to the Critical Care Unit in Altnagelvin Hospital. Again this initiative garnered considerable good publicity.

As outlined in the opening section the committee facilitated Derry and Strabane District Council's involvement in the 'Strange Boat'-inspired multinational inter-city gifting of Life Candle sculptures to commemorate donors and to promote donation. Limerick City donated to Derry & Strabane and Derry and Strabane donated to Melbourne. This initiative achieved considerable attention in local, regional, national and international media.

The committee has been engaging with both Derry City and Strabane District Council and Fermanagh and Omagh District Council. We hope that in time these contacts will help facilitate us in promoting donation both in the community and within the workforces of both Councils.

7. Future Work

The Trust had been in position to commence an ocular tissue retrieval service at the start of 2018. However, a national review of tissue services encompassing ocular retrieval has been implemented. Thus, our initiative has been suspended for the moment pending the outcome of the national review. We have been liaising with and have forwarded our comments to N.H.S.B.T. Tissue Services to facilitate them in their deliberations.

8. Glossary

C.L.O.D.

D.C.D. Donation after circulatory death
D.B.D. Donation after brain death
P.D.A. Potential donor audit
C.P.R. Cardiopulmonary Resuscitation
S.N.O.D. Specialist Nurse Organ Donation

Clinical Lead for Organ Donation