

Hospital:

Blood and Transplant

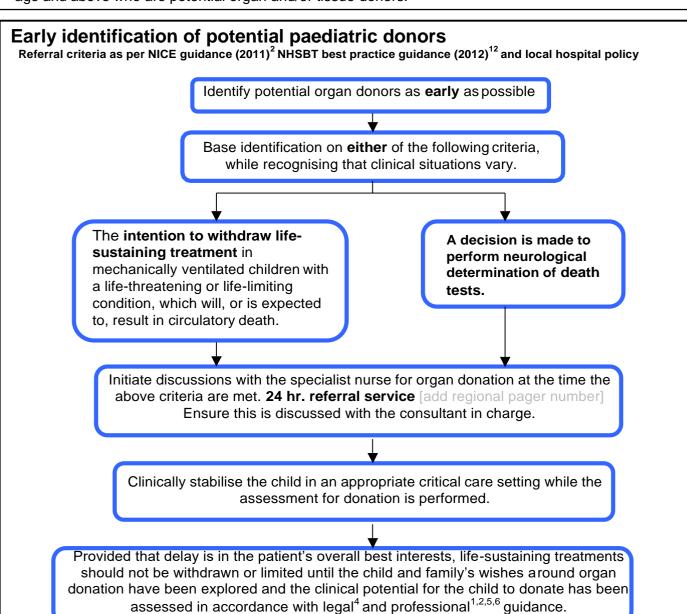
Integrated Care Plan for the Referral and Consideration of Paediatric / Neonatal Deceased Organ and Tissue Donation 24 hr. referral service

[add regional pager number]

HOSPITAL ADDRESSOGRAPH or Surname First Name Date of Birth NHS Number

Provenance: This Integrated Care Plan was adapted and produced by a working party of the Paediatric Subgroup of the National Organ Donation Committee, NHSBT and ratified on 22/09/17. Comments should be directed to reinout.mildner@nhs.net or angle.scales@nhsbt.nhs.uk **Objective of Care:**

- To ensure all families are given the opportunity to consider organ and/or tissue donation where appropriate, in line with GMC (2011) guidance.¹
- To provide clinical guidelines for the management of children and infants from 37 weeks' gestational age and above who are potential organ and/or tissue donors.



The above referral criteria are in accordance with NICE (2011)₃ and NHSBT best practice guidance (2012).⁸
The NICE criteria also recommend the use of clinical trigger factors to prompt Figure (deptification and Paferral, in potients who have been prompt for the prompt factors of the prompt factors and prompt factors are prompt factors.

The NICE criteria also recommend the use of clinical trigger factors, to prompt *Early Identification and Referral*, in patients who have had a catastrophic brain injury, defined as: the absence of one or more cranial nerve reflexes (e.g. one fixed pupil) *and* a Glasgow Coma Scale score of 4 or less that is not explained by sedation unless there is a clear reason why the above clinical triggers are not met. NICE recognises that a proportion of the patients who are identified by these clinical triggers will survive. Contact between the clinical team treating the potential donor and the SN-OD before the decision has been made to withdraw life-sustaining treatment is ethically acceptable.

Child's Name: NHS Number:

Guidance and Accountability Notes for Using this Care Plan:

- This Care Plan must be read in association with any local guidelines or policies. All drugs are the responsibility of the prescribing physician and must be checked against any local pharmacy guidance.
- This Care Plan forms part of the child's record of care and is completed in addition to all other nursing and medical documentation. This Care Plan should be stored within the patient's medical notes.
- Care Plans are heavily informed by clinical knowledge and expertise. They are designed to assist clinical judgment, not replace it.
- Children fulfilling the NICE (2011) 'Early identification of potential donors' referral criteria as given at the front of this document, should be placed on this Care Plan.
- If a care activity is not fully completed, please give rationale in the relevant notes/variance section of the document.
- This Care Plan may be audited by the Hospital Trust.

Supporting Documentation and Evidence Based Best Practice used within this Care Plan: check for updates

- 1. GMC (2010) "Treatment and care towards the end of life." www.gmc-uk.org/guidance/ethical guidance/end of life care.asp
- 2. NICE (2011) "Organ Donation for Transplantation" http://guidance.nice.org.uk/CG135
- UK DEC (2011) "An Ethical Framework for Controlled Donation after Circulatory Death"
 http://www.bts.org.uk/Documents/Publications/An%20Ethical%20framework%20for%20controlled%20dona tion
 %20after%20circulatory%20death%20-%20Full%20Report.pdf
- 4. Department of Health (2009) "Legal Issues Relevant to Non-heartbeating Organ Donation." www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108825
- 5. DCD consensus meeting report, available from https://www.bts.org.uk/Documents/Guidelines/Active/DCD%20for%20BTS%20and%20ICS%20FINAL.pdf
- 6. Report from the Organ Donation Taskforce (2008) "Organs for Transplant" http://www.nhsbt.nhs.uk/to2020/resources/OrgansfortransplantsTheOrganDonorTaskForce1streport.pdf
- Academy of Medical Royal Colleges (2008) "A Code of Practice for the Diagnosis and Confirmation of Death" http://www.bts.org.uk/Documents/A%20CODE%20OF%20PRACTICE%20FOR%20THE%20DIAGNOS IS%20 AND%20CONFIRMATION%20OF%20DEATH.pdf
- 8. HTA (2009) "Code of practice 2 Donation of solid organs for transplantation" http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice/code2donationoforgans.cf
- 9. NHSBT (2013) "Donor Optimisation Guideline for the Management of the Brain-stem Dead Donor (Adult)." http://www.odt.nhs.uk/pdf/donor_optimisation_guideline.pdf
- 10. Academy of Medical Royal Colleges (2015.) Ethical issues in paediatric organ donation a position paper by the UK Donation Ethics Committee (UKDEC).
- 11. NHS Blood and Transplant (2012) Timely Identification and Referral of Potential Organ Donors: A Strategy for Implementation of Best Practice.
- 13. NHS Blood and Transplant (2013) Approaching the Families of Potential Organ Donors: Best Practice Guidance.
- 14. College of Emergency Medicine and British Transplantation Society (2011) Report of a Workshop on The Role of Emergency Medicine in Organ.
- 15. PICS standards (2015) http://picsociety.uk/wp-content/uploads/2016/02/PICS_standards_2015_.pdf
- 16. RCPCH (2015). The diagnosis of death by neurological criteria (DNC) in infants less than two months old. http://www.rcpch.ac.uk/system/files/protected/page/DNC%20Guide%20FINAL.pdf
- 17. Larcher V. et al. on behalf of RCPCH (2015) Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a framework for practice. Arch Dis Child; 100: s1 s23.

Child's Name:	Child's Name: NHS Number:			
All staff recording in throughout the Plan		nt must complete the si	gnature box be	elow so that initials or signature only are needed
Print First Name and Surname	Role	Signature	Initial	Pager / Bleep, Location/Extension
Persons Responsible Dr / Nurse Achieved Signature / Initial the Box	Potential Donor Identification Child meets NICE, 'Early identification of potential donors' referral criteria 2 Inform Consultant team(s) involved of planned referral to SN-OD Discuss with SN-OD via 24-hour pager [add regional pager no.] Name of SN-OD spoken to: Ensure you have the child's notes, including: NHS number/hospital number date of birth, postcode, blood results and latest observations. If appropriate the SN-OD will check the Organ Donation Register and advise on the child's status (or call 0117 – 975 7580) Member of SN-OD team will attend if agreed.			
NOTES / VARIA	ANCE			

Child's Name:	NHS Number:	

Date	Please follow the appropriate Potential Donor Care Plan below,			
Time	as identified by the NICE 'Early identification of potential donors' referral			
	criteria and as agreed by the SN-OD and Consultant			
		(or most senior docto	<u>`</u>	
Persons	_	A decision is made to perform	The intention to withdraw life-	
Responsible	2	neurological determination of	sustaining treatment in children	
Dr / Nurse		death testing.	with a life-threatening or life-	
			limiting condition which will, or is	
Achieved			expected to, result in circulatory death.	
		Baradan affan Na arlantari	Barada attacking later Bard	
Signature / Initial the Box		Donation after Neurological Determination of Death (DBD) may be possible.	Donation after Circulatory Death (DCD) may be possible.	
			Co to many 45	
		Go to page 5	Go to page 15	
		Co to page 3		
		Tissue Donation may be possible.	No Donation possible.	
			-	
		Go to page 23		
			Go to page 24	
		Early Notification of Potential	Other. (Please document below)	
		Donor, please re-refer when	Other. (Please document below)	
		Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
		Donor, please re-refer when	Other. (Please document below)	
		Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	
NOTES / VARI	ANCE	Donor, please re-refer when (Please detail plan for re-referral	Other. (Please document below)	

Child's Name: NHS Number:	Child's Name:	NHS Number:
---------------------------	---------------	-------------

Donation after Neurological Determination of Death (DBD)

Dete	A a41		
Date	Activity	Activity	
Time	Number	7.0	
Persons	DBD	Referral Check	
Responsible	1		
Dr / Nurse		A decision is made to perform neurological determination of death testing.	
Achieved		Check SN-OD has been notified (SN-OD may attend).	
		The SN-OD will begin assessing the patient's suitability for donation prior to discussion with the family.	
Signature / Initial the Box		Ensure the child's Consultant teams involved in care have been informed.	

Date	DBD	Normal homeostasis is maintained until neurological determination of
Time	2	death testing (NDT) is appropriate.
Persons		
Responsible Dr / Nurse		 Maintain mandatory and protective ventilation (Tidal Volume (VT) 6- 8mls/kg),
		 Maintain PaCO₂ 5.0-6.5 kPa, pH 7.35 –7.45 or [H+] 45-35 nmols/L and PaO2 8-14 kPa or SaO2 >95% on minimal FiO₂.
Achieved		
		Maintain Mean Arterial Pressure (MAP) appropriate for age. Consider insertion of central line and start inotropes. If central access is deemed inappropriate, start peripheral inotrope infusion.
Signature /		
Initial the Box		 Aim Na 130-155mmol/L and monitor for signs of Diabetes Insipidus (DI): If DI, administer DDAVP or vasopressin infusion (for doses see page 12). Consider IV fluids as per local fluid resuscitation guideline.
		If there are any plans to carry out ancillary investigations or drug levels, explore early.

NOTES / VARIANCE				

Child's Name	:	NHS Number:
Date	DBD	Discussion with family regarding plan for neurological determination of
Time	3	death testing. (See Appendix 1)
Dr / Nurse		Destan Norman and CNLOD plan the discousies with the family in advance
A alalassa al		Doctor, Nurse and SN-OD plan the discussion with the family in advance and prepare for pourse discussion of death testing.
Achieved		and prepare for neurological determination of death testing.
		 SN-OD (if present) is introduced to the family where appropriate and agreed with clinician. Example: "[SN-OD Name] is a specialist nurse who supports families in this situation."
		• Discussion of donation is not initiated at this time unless initiated by the family. See Appendix 1.
Signature / Initial the Box		 Neurological death testing is explained to the family by the Doctor and SN- OD. It is important the family understand that the neurological death tests may confirm that their child has died.
ZOA		Family offered the option to witness neurological determination of death testing.
NOTES / VAR	IANCE	

Date	DBD	Preparation for neurological determination of death testing
-		
Time	4	Refer to Diagnosis of Death using Neurological Criteria testing form
Dr / Nurse		(See Appendix 2a / b)
Achieved		Prepare Equipment
		- Pen torch
		- Gauze
		50ml bladder syringe, inco-pad / kidney bowl (to collect injected water)
		- Ice cold water
		Otoscope with ear pieces Vantage and a second control of the control of
Signature /		- Yankauer sucker
Initial the		 Suction catheter + oxygen tubing / appropriate anaesthetic hand ventilation
Box		circuit (if PEEP required)
Box		 Blood gas syringes (pre and post apnoea test x2)
		Prepare the Patient
		Prior to neurological testing the following ABG should be maintained at
		PaCO2 < 6.0 kPa, PaO2 >10 kPa and pH 7.35 - 7.45.
		Pre-oxygenation and ABG should be adjusted as per guidance prior to the
		apnoea testing element of the tests (see ref 7 &16).

Child's Name	:	NHS Number:	
D-4-	DD2	Ast and ond named add data and	
Date	DBD	1 st and 2 nd neurological determination of death testing undertake	n
Time	_	One of the eventing dectors should be a consultant additionally in	, abildran
Dr / Nurse	5	One of the examining doctors should be a consultant, additionally in	
A a la ! a a . l		one of the doctors should normally be a paediatrician or should have	
Achieved		experience with children and one of the doctors should not be prima involved in the child's care.	ırııy
		involved in the child's care.	
		A complete set of tests should be performed on each occasion, i.e.,	a total of
		two sets of tests will be performed. The tests, in particular the apno-	
		therefore performed only twice in total.	sa test, are
Signature /		therefore performed only twice in total.	
Initial the		Whilst NDT may be carried out 12-24 hours apart, there is no requir	ement for
Box		this and this should not be prolonged.	omone for
		and and and ordered never proteinge an	
		See Appendix 2a /b for an abbreviated testing forms, which has be	en
		endorsed for use by UK PICS and the Paediatric Subgroup of the N	ational
		Organ Donation Committee. This is designed for use by clinicians e	xperienced
		in confirming death using neurological determination of death criteri	a.
		Consider carrying out a recruitment manoeuver after each apno	oea test.
Date	DBD	1 st and 2 nd tests consistent with neurological death?	
Time	6	Yes	I
Dr / Nurse		Nurse, Doctor and SN-OD inform family the outcome of the	I
		neurological determination of death tests, as per plan.	
Achieved		Family given time to accept the result.	
		 Rarely, organ donation may be discussed at this stage if 	YES
		deemed appropriate. Usually, this requires another	I
		meeting if the family is not deemed ready (see DBD 7).	I
Signature/		No	I
Initial the		Nurse, Doctor and SN-OD inform family the outcome of the	I
Box		neurological death test, as per plan.	
		If the plan is to retest at a later time, it is advised to start a new	
		Deceased Donation Plan.	NO
		If retesting not planned, consider Donation after Circulatory	I
		Death (DCD) and start DCD Plan (page 15).	
NOTES / VAR	IANCE		

Child's Name:		NHS Number:			
		Contraindications to Deceased Organ Donation			
		Are best decided through consultation with the SN-OD			
Date Time Dr / Nurse Achieved Signature / Initial the Box	DBD 7	 Approach regarding organ donation (See Appendix 1) Planning The SN-OD will have checked the Organ Donation Register and is able to advise on the patient's status. A multi-disciplinary team should plan the approach. This may include local faith representative(s) and/or family support worker where relevant. Clarify any coronial / legal or safeguarding issues. If subject of a child safeguarding investigation, notify key professionals as per local policy at this stage. Document outcome in medical notes. Identify key family members. Identify a setting suitable for private and compassionate discussion. The approach Doctor, Nurse and SN-OD (and others as agreed) approach the family. Confirm understanding of the results of the neurological death tests and that death has occurred, before discussing donation. Once professionals involved agree that the family has understood and is felt to be ready, information is given on process of end of life care including organ donation and the family is given the opportunity to ask questions. If the family needs time on their own, the SN-OD remains available to provide support to the family and the staff. 			
1101207 17	111711102				

Child's Name) :	NHS Number:
Date	DBD	Outcome of family decision
Time	8	Outcome of family decision
Dr / Nurse	0	Document outcome of family decision
Achieved		SN-OD will take consent / authorisation, undertake child assessment with family and will answer any outstanding questions.
Signature/ Initial the Box		
NOTES / VAF	RIANCE	

PLE/	PLEASE CONTINUE BASED ON OUTCOME OF FAMILY DECISION						
Date	DBD	Proceeding with	Tissue Only	No Donation			
Time	9	DBD	Donation	Pathway			
Doctor			Pathway				
Achieved							
Signature/ Initial the Box		Continue	Go to page 23	Go to page 24			

Date	DBD	Consent / authorisation and formal clarification of any outstanding
Time	10	coronial / legal or safeguarding issues.
Dr / Nurse		Further discussion with family, Nurse and SN-OD.
Achieved		
		Consent / authorisation and child assessment paperwork completed. In case of neonate, maternal assessment as appropriate.
Signature/ Initial the Box		Consultant and/or SN-OD will seek approval from H.M. Coroner / Procurator Fiscal, if required and not previously clarified, and document any discussion in the medical notes.
NOTES / VAR	IANCE	

Child's Name: NHS Number:					
Date Time Nurse Achieved Signature/Initial the Box	DBD 11	Initial investigations Additional blood samples and investigations, including tissue typing and microbiology, will be required as advised by SN-OD. SN-OD will advise on quantity, will arrange requesting and arrange transport of samples as required.			
Date	DBD	To assess cardiac and/or respiratory function			

Date	DBD	To assess cardiac and/or respiratory function
Time	12	(SN-OD will advise if not required)
Dr / Nurse /		
SN-OD		Request CXR and document findings.
		ECG performed post neurological death confirmation and reported by a
Achieved		senior clinician.
		ECHO performed post neurological death confirmation and findings
		documented. Cardiologist or Echo technician to clarify with SN-OD which
		measurements are required.
Signature/		
Initial the		
Box		

	DBD	SN-OD Activities – For information only						
For	13	Detailed physical examination completed by SN-OD with the support of the bedside nurse.						
Information		Organ/tissue matching commenced (can be a prolonged process (>6 hours) and SN-OD will advise on progress).						
		External Organ Retrieval Teams organised plus Local Theatres and Anaesthetist where required.						
		SN-OD to keep family informed and supported.						

Proceed to Donor Optimisation

Donor Optimisation Care Bundle – Paediatric (37 wks CGA - 15 yrs)

Donor optimisation care bundle - paediatric Bibliography / References

- 1. European Paediatric Advanced Life Support 4th ed (2016). European Resuscitation Council. Lippincott Williams & Wilkins
- 2. SOP 5058 Neonatal and Infant Organ Donation
- 3. Rozenfeld V, Cheng JW. The role of vasopressin in the treatment of vasodilation in shock states. Ann Pharmacother. 2000; 34:250-4
- 4. Ralston.C & Butt. W Continuous vasopressin replacement in diabetes incipidus. Arch Dis. Child. 1990 65; 896-897 doi 10.1136/adc.65.8.896
- 5. Malleroy GB Jr, Schecter MG, Elidemir O, Management of the Paediatric Organ donor to optimise lung donation. Paediatric Pulmonol. 2009 Jun; 44(6):536-46
- 5. Paediatric Formulary Committee. *BNF for Children* (2015 -2016) London: BMJ Group, Pharmaceutical Press, and RCPCH Publications; (2015)
- 6. Optimisation care bundle http://www.odt.nhs.uk/pdf/dbd_care_bundle.pdf
- 7. Shemie. S Organ donation management in Canada; recommendations of the forum on medical management to optimise donor organ potential. 2006. Mar 14; 174(6):s13-s30

Systolic BP - Age specific ranges (mmHg) – EPALS guidance ¹				
0-1 month	50-60 mmHg			
1-12 months	70-80 mmHg			
1-10 years	70+(2 x age(yrs)) to 90+(2 x age(yrs))			
> 10 yrs	90-120 mmHg			

Drug	Standard infusion	Diluent	Rate of infusion	Dose
Dopamine	Dopamine 15mg/kg in 50mls (max 800mg in 50ml)		1ml /hr = 5 micrograms/kg/min	<10 micrograms/kg/min
Noradrenaline	0.3mg / kg in 50mls (max concentration 8mg in 5ml)	Glucose 5%/ Na Cl 0.9%	1ml/hr = 0.1 micrograms/kg/min (of standard infusion)	0-0.5 micrograms/kg/min (maximum rate = 5mls/hr of standard infusion)
Vasopressin/ Argipressin	20 units in 50ml diluent	NaCl 0.9% / Glucose 5%	0.0003 units/kg/min = 0.045ml/kg/hr	0.0003- 0.001units/kg/min (Max dose 6 u/hr) ³
Vasopressin – treatment for Diabetes Insipidus ⁴	2-5 units / litre diluent	NaCl 0.9% / Glucose 5%	ml for ml replacement of urine output	N/A
Adrenaline	0.3mg /kg in 50ml	Glucose 5%	1 ml /hr = 0.1micrograms/kg/min (of standard infusion)	0-0.5micrograms/kg/min
Dobutamine 30mg/kg in 50mls		Glucose 5%, 10% / Nacl 0.9%	1ml/hr = 10micrograms/kg/min	5-20 micrograms/kg/min

Esmolol	10mg/ml (pre-diluted)	50-300 micrograms/kg/min (max 500 micrograms/kg/min)	IV continuous infusion – titrated to response
Labetalol	5mg/ml (neat)	0.5 – 3 milligrams/kg/hr (max 5 milligrams/kg/hr)	IV continuous infusion – titrate to response

Drug	Dose	Administration
Methylprednisolone	15milligrams/kg (max 1g)	IV infusion over 1 hour
DDAVP (desmopressin)	1 month – 12 years 400 nanograms 12-18 years 1-4 micrograms	IV bolus
Insulin (50 units in 50ml)	0.1units/kg/hr	IV continuous infusion – titrated to response

Donor Optimisation Care Bundle – Paediatric (37 wks CGA - 15 yrs)

	Pat	tient Name_			D	ate of Birth_					
	Uni	it Number			D	ate					
nysiological Parameters / Goals Tick \checkmark = achieved, x = not achieved Contact SNOD / Recipient Centre for advice and / or support											
	O/A	+1hr	+2hrs	+4hrs	+6hrs	+8hrs	+10hrs	+12hrs	+14hrs	+16hrs	+18hrs
arget Systolic BP (primary goal)mmHg											
CVP 4 – 10 mmHg secondary goal)											
$PaO_2 \ge 10.0 \text{ kPa (>1month)}$											
37wk CGA - < 1month old PaO2 ·8 kPa and pH> 7.2)											
GO ₂ < 0.4 as able											
PaCO₂ 5 – 6.5 kPa or higher as long as pH > 7.25)											
lixed central venous oxygen aturation >60%											
Cardiac index > 2.5 - 6 l/min/m ²											
ScvO ₂ > 70%											
SVRI -00– 1200 dynes*sec/cm ⁵ /m²											
emperature 36 – 37°C											
Blood glucose 4.0 – 12 mmol/l											
/laintain Na < 150mmol/l											
Jrine output 1- 2 ml/kg/hour											
Signature / Print Name											
Date / Time											
			1	1			1	L	L		1

Date	DBD	Mementos
Time	14	
Nurse		Mementos (handprints, and locks of hair offered). If requested these are facilitated by the Nurse and SN-OD at an appropriate time.
Achieved		
		Offer spiritual or religious support – consider baptism or appropriate religious/cultural ceremony
Signature/ Initial the Box		
Child's Name:		NHS Number:

DBD	Organ Retrieval
15	
	Organ retrieval operation
	Last offices performed as per local policy.
	Family are given the option to return to see their child following the retrieval and participate in last offices.

Date	DBD	Final Activities
Time	16	
Nurse		Patient transferred to the mortuary.
Achieved		If tissues to be donated this will be facilitated in the mortuary as agreed.
		SN-OD will provide donation outcome information to staff and family as agreed.
Signature/ Initial the Box		

Child's Name: N	NHS Number:
-----------------	-------------

Donation after Circulatory Death (DCD) Activity Date **Activity** Time Number Dr / Nurse DCD **The Withdrawal Decision Achieved** The intention is to withdraw life-sustaining treatment in a child with a lifethreatening or life-limiting condition, which will, or is expected to, result in imminent circulatory death. Two senior doctors, who should both have been registered for at least Signature/ five years, and at least one of whom should be a consultant, should Initial the verify that further active life-sustaining treatment is no longer of **Box** overall benefit to the patient³. Ensure the child's Consultant team(s) is (are) informed of and in agreement with withdrawal of life sustaining treatment (WLST) decision and referral for potential DCD. Consultant has documented the above clearly in the patient's medical notes, including the planned method of withdrawal.

NOTES / VARIANCE

Child's name		NHS Number
Date	DCD	Referral Check
Time	2	
Dr / Nurse		Check SN-OD has been notified.
Achieved		SN-OD will assess and advise on medical suitability for DCD
		The SN-OD will check the Organ Donation Register and advises on the patient's status.
Signature/ Initial the Box		If suitable, SN-OD will attend.
		If medically unsuitable for DCD, tissue donation may still be possible. Tissue services can be contacted on 01514279813 or in Scotland the SNBTS should be contacted on 07659107029. Alternatively contact can be made via the SN-OD [add regional pager no]. See Tissue Only Donation Pathway (page 23).

Contraindications to Deceased Organ Donation – if yes proceed to DCD 6

(These are best decided through consultation with the SN-OD)

Date	DCD	Family discussion regarding withdrawal decision (See Appendix 1)
Time	3	These activities are best explored in conjunction with DCD 4.
Dr / Nurse		
Achieved		SN-OD (if present) introduced to family where appropriate and agreed with clinician.
Signature/		 Consultant undertakes full explanation to the family of why the multidisciplinary team believes that WLST is in the overall benefit of their child. If family is accepting and in agreement with the withdrawal of life sustaining treatment, Consultant undertakes explanation of the withdrawal process. Alternatively, this may require another meeting if the family is not deemed
Initial the Box		 Alternatively, this may require another meeting if the family is not deemed ready. This must be documented clearly in the patient's medical notes, including the planned method of withdrawal. Do not resuscitate order should be in place, according to local policy.
NOTES / VAR	RIANCE	

Child's Name		NHS Number:
Date	DCD	Approach regarding organ donation
Time	4	(See Appendix 1)
Dr / Nurse		
		Planning
Achieved		 The SN-OD will check the Organ Donation Register and advise on the patient's status, if not done so already.
		A multi-disciplinary team should plan the approach. This may include local faith representative(s) and/or family support worker where relevant.
Signature/ Initial the Box		 Clarify any coronial / legal or safeguarding issues. If subject of a child safeguarding investigation, notify key professional as per local policy at this stage. Document outcome in medical notes.
		Identify key family members.
		 Identify a setting suitable for private and compassionate discussion.
		 The approach Doctor, Nurse and SN-OD approach the family (rarely this may form part of the initial conversation as per DCD 3 but more usually is decoupled from that conversation according to family's acceptance and understanding). Confirm understanding and acceptance of the plan to withdraw lifesustaining treatment, before discussing donation. Once professionals involved agree that the family has understood and is felt to be ready, information is given on process of end of life care including organ donation and the family is given the opportunity to ask questions. If the family needs time on their own, the SN-OD remains available to
		provide support to the family and the staff.
NOTES / VAR	IANCE	•

Date	DCD	Outcome of family decision
Time	5	
Dr / Nurse		 Doctor, SN-OD and Nurse return to family (as agreed) to answer further questions and hear outcome of family decision.
Achieved		
		Document outcome.
		SN-OD will take consent / authorisation, undertake child assessment with family and will answer any outstanding questions.
Signature/ Initial the Box		family and will answer any outstanding questions.

Child's Name:			NHS Number:	
Р	LEASE (CONTINUE BASED ON (OUTCOME OF FAMILY	DECISION
Date	DCD			
Time	6	Proceeding with	Tissue Only	No Donation
Dr / nurse		DCD	Donation Pathway	Pathway
Achieved			i uliiway	
Signature/		Continue	Go to page 23	Go to page 24
Initial the		Continuo	oo to pago 20	oo to pago 2 :
Вох				
	1			
Date	DCD		n and formal clarification	of any outstanding
Time Dr / Nurse	7	coronial / legal or safe	guarding issues.	
Di / Nuise		Further discussion with	th family, Nurse and SN-O	
Achieved			•	
		 Consent / authorisation 	on and child assessment pa	aperwork completed.
		 Consultant and/or SN 	-OD will seek approval fror	n H.M. Coroner /
Signature/			equired and not previously	
Initial the		any discussion in the		,
Box				
NOTES / VARIA	ANCE			

Date	DCD	New care plan and treatment goals
Time	8	The child will continue to be cared for as per local end of life guidance and
Dr / Nurse		
		 Treatment decisions must continue to be in the child's best interests. In a child whose family wants him/her to be a donor, actions to facilitate donation will usually be in the child's best interests provided the actions do not cause harm or distress, or place them at significant risk of experiencing harm or distress.¹⁰ Decide on place of continued care / place of withdrawal of life-sustaining treatment as per local agreement. The end of life care plan for a child on the DCD care plan should include a plan for how to proceed if the time to death following WLST is incompatible with successful donation, and the family and all staff (donor and retrieval teams) should be fully informed. SN-OD and Consultant agree physiological goals and limits of premorbid interventions (e.g. inotropes & fluid for BP management, FiO2). Goals and Limits agreed:
		A useful guide to timelines and responsibilities of the team can be seen in
		Appendix 3.
		 Any request for further investigations on behalf of the retrieval team (e.g. ABG on 100% O2, CXR) requires consultant approval (or most senior medical doctor if delegated) and this may require further discussion with family.

NHS Number:

Child's Name:

Date	DCD	Initial investigations
Time	9	
Nurse		 Additional blood samples and investigations, including tissue typing and microbiology, will be required as advised by SN-OD.
Achieved		 SN-OD will advise on quantity and will arrange requesting, and arrange transport of samples as required.
Initial the Box		

Child's Name):	NHS Number:
Date Time For information only	DCD 10	SN-OD Activities – For information only Detailed physical examination completed by SN-OD with the support of the bedside nurse. Patient registered with ODT duty office as a donor. Organ/tissue matching commenced (can be a prolonged process (>6 hours) and SN-OD will advise on progress). Positive microbiology may limit or exclude donation, SN-OD to advise. External Organ Retrieval Teams organised plus Local Theatres and Anaesthetist. (No anaesthetist required unless lung donation). SN-OD to keep family informed of provisional timings to enable them to prepare for WLST.

Date	DCD	Family Care
Time	11	
Dr / Nurse		 Mementos (handprints, and locks of hair offered). If requested these are facilitated by the Nurse and SN-OD at an appropriate time.
Achieved		Offer spiritual or religious support – consider baptism or appropriate religious/cultural ceremony
Signature/ Initial the Box		

Date	DCD	Withdrawal
Time Dr / Nurse	12	When retrieval team have set up in theatre, the nominated medical personnel will prepare the family for WLST.
D171141100		The process of organ donation must not compromise the child's
Achieved		comfort and dignity at the end of life.
		Comfort measures should be administered or continued as per usual practice, local end of life guidelines and in accordance with GMC guidance and RCPCH guidance 7.
Signature/		WLST as per agreed plan. Any concerns from the team should be escalated to the Consultant in charge.
Initial the		The bed and bed area prepared for transfer to theatre.
Box		Family who wish to be present are in attendance.
		Clinician is available to diagnose and confirm death.
		Time of Withdrawal of Life-Sustaining Treatment:
		DateTime
		SN-OD will notify retrieval team of exact time of WLST.
		Family kept updated and supported throughout by the bedside nurse and SN-OD.
		 SN-OD will make discrete observations of child's monitors. Family will be informed when asystole occurs.

Child's Name);	NHS Number:				
Date	DCD 13	Confirmation of Death				
Time Dr / Nurse		Death will be diagnosed following 5 minutes of monitored asystole and in accordance to the AoMRC Code of Practice ⁷				
Aabtanad		Time of Death:				
Achieved		DateTime Prolonged time from WLST to asystole may preclude solid organ donation.				
Signature/ Initial the		SN-OD will advise on this.				
Вох		Following confirmation of death, the child will immediately be transferred to theatre, as agreed with the family.				
Data	DCD	Organ Retrieval For information only				
Date Time	DCD 14	Organ Retrieval – For information only				
For Information only		 The organ retrieval operation will be carried out by the National Organ Retrieval Team (NORS) and an anesthetist may be requested to support tracheal intubation where DCD lung donation is occurring. 				

Date	DCD	Organ Retrieval – For information only
Time For Information only	14	 The organ retrieval operation will be carried out by the National Organ Retrieval Team (NORS) and an anesthetist may be requested to support tracheal intubation where DCD lung donation is occurring. Additional guidance regarding this will be made available from the SNOD. This is supported by SN-OD and where appropriate other NHSBT staff

Date	DCD	If the time to death following treatment withdrawal is
Time	15	incompatible with successful transplantation
Dr / Nurse		
		As per DCD 8, the end of life care guide should include how to proceed if the time to death following WLST is incompatible
Achieved		with successful transplantation.
		Tissue donation may still be possible. See Tissue Only Donation (see page 23).
Signature/ Initial the Box		
20%		

Date Time 16 Dr / Nurse Achieved Achieved Signature/ Initial the Box DCD 16 Final Activities Final Activities Last offices performed as per local policy. Family are given the option to return to see their child following the retrieval and participate in last offices. Child transferred to the mortuary or other place of care as agreed in advance such as hospice. If tissues to be donated this will be facilitated in the mortuary as agreed. See Page 23. SN-OD will provide donation outcome information to staff and family as agreed.	Child's Name	:	NHS Number:
	Time Dr / Nurse Achieved Signature/	_	 Last offices performed as per local policy. Family are given the option to return to see their child following the retrieval and participate in last offices. Child transferred to the mortuary or other place of care as agreed in advance such as hospice. If tissues to be donated this will be facilitated in the mortuary as agreed. See Page 23.

Tissue Only Donation Pathway Activity Date Activity Number **Time** Date TD All deceased children can be referred / considered for Time 1 Tissue Donation. Dr / Nurse **Achieved** National Referral Centre (NRC) for Tissue Donation is available on pager (24 hours) 01514279813. In Scotland SNBTS can be contacted on 07659107029. A comprehensive assessment will need to be made to ensure Tissue Signature/ Donation is possible, so please have the notes, and child's charts with you Initial the including: Box **GP** information Past medical history **Next of Kin Contact Details** Medication & Fluids administered in the last few days on ICU • The NRC will advise if the child can be considered for potential tissue donation and advise on the subsequent sequence of events • NRC will not contact the family without their knowledge, so a discussion regarding the option for tissue donation will need to **occur.** This discussion can be held with the family by a member of the nursing or medical team as deemed appropriate. • Document the outcome of discussion with the family & inform NRC of the outcome as agreed In the case of non-proceeding DCD if the SN-OD has taken consent / authorisation for tissue donation from family then copies of consent / authorisation, and Patient Assessment document to stay with the patient if transferred to the ward, and ward staff at handover to be made aware that the National Referral Centre (NRC) must be contacted when the child dies. Paperwork to accompany the patient to the mortuary. Time of Death: Date.....Time.... Last offices performed • Mementos (handprints, and locks of hair offered). If requested these are facilitated by the Nurse and/or SN-OD at an appropriate time. If tissue donation is to proceed, the child must be transferred to the mortuary within 6 hours of death.

Time of Transfer to Mortuary:

Date.....Time....

Child's Name: NHS Number:

Child's Name) :	NHS Number:
		No Donation Pathway
Date	Activity	Activity
Time	Number	, , , , , , , , , , , , , , , , , , ,
Date	ND	Family Care
Time	1	Decree of the form of the Property of the Conflict
Dr / Nurse		Document outcome of any discussion with family. Family the global for considering depoting if any reprints.
Achieved		 Family thanked for considering donation, if appropriate. Mementos (handprints, and locks of hair offered). If requested these are
Acilieved		 Mementos (handprints, and locks of hair offered). If requested these are facilitated by the Nurse and/or SN-OD at an appropriate time.
		 Offer spiritual or religious support.
		If appropriate, inform local Eye Retrieval Nurse of family decision not to
Signature/		donate to prevent second contact.
Initial the		
Box		
Date	ND	
Time	2	Life-sustaining treatment withdrawn.
Dr / Nurse		SN OD may remain present to support family and staff
Achieved		SN-OD may remain present to support family and staff.
Achieved		
Signature/		
Initial the		
Box		
		<u> </u>
Date	ND	
Time	3	Last Offices performed as per local policy.
Dr / Nurse /		
SN-OD		Child transferred to the mortuary or other agreed lace of care such as
Achieved		hospice.
Achieved		
Signature/		
Julia Lui e/		

Initial the Box

Date and Time	Activity Number	MDT Notes	Signature / Initial

NHS Number:

Child's Name:

GLOSSARY

ABG Arterial Blood Gas

AoMRC Academy of Medical Royal Colleges

AST Aspartate aminotransferase

BSD Brain Stem Death Blood Pressure

Ca Calcium

CJD Creutzfeldt–Jakob Disease
CVC Central Venous Catheter
CVP Central Venous Pressure
CPP Cerebral Perfusion Pressure

CXR Chest X-Ray DDAVP Desmopressin

DCD Donation after Circulatory Death

DI Diabetes Insipidus
DVT Deep Vein Thrombosis
ECG Electrocardiogram
ECHO Echocardiography
FBC Full Blood Count

FiO₂ Fraction of Inspired Oxygen
GMC General Medicine Council

GTN Glyceryl Trinitrate

HTA Human Tissue Authority
HTA (2004) Human Tissue Act (2004)
HIV Human Immunodeficiency Virus

K Potassium kPa Kilopascal

PaO₂ Partial Pressure of Oxygen

PaCO2Partial Pressure of Carbon DioxidePEEPPositive End Expiratory Pressure

RIJ Right Internal Jugular
MAP Mean Arterial Pressure

MC&S Microscopy, Culture and Sensitivity

MDT Multi-disciplinary Team

Mg Magnesium

mmHg Millimetres of Mercury

Na Sodium

NHSBT NHS Blood and Transplant

NICE National Institute for Health and Clinical Excellence

O₂ Oxygen

ODT Organ Donation & Transplantation
SN-OD Specialist Nurse-Organ Donation
SpO₂ Pulse Oximeter Oxygen Saturation

T3 Triiodothyronine VT Tidal Volume

WLST Withdrawal of life sustaining treatment

Approaching the families of potential donors

Planning

Who: Consultant, SN-OD and nurse

Why:

- Clarify clinical situation
- Seek evidence of prior consent (eg ODR or other)
- Identify key family members by name
- Define key family issues
- Agree a process of approach and who will be involved
- Agree timing and setting, ensuring these are appropriate to family needs
- Involve others as required, eg faith leaders

When and where: in private and before meeting the family to confirm understanding and acceptance of loss.



Potential DBD donor: ensure the family understand that death has occurred. Spend time with the concept, using diagrams or scans if necessary.

Potential DCD donor: ensure the family understand and accept the reasons for treatment withdrawal and the inevitability of death thereafter. Donation should only be raised at this point if it is clear that a family has understood and accepted their loss. If this is not the case, suggest a break.

Discussing donation

Only consider the transition to organ donation when it is clear that a family have accepted their loss and are ready to consider the next steps.

- · Provide specific information on process before expecting a response
- · Avoid negative, apologetic, manipulative or coercive language
- Emphasise the benefits of transplantation the ability to save lives
- Sensitively explore an initial 'No', some of which are a result of misconceptions.
- For patients on the ODR, or who have given their legal consent in other ways, eg donor
 card: sensitively explain that consent for donation has already been given; do not mislead the
 family into believing that their consent is also required
- For patients whose wishes are not known in advance: use open questions to ascertain
 patient's and family's wishes; avoid styles that focus exclusively upon the wishes of the patient
 (because the law passes responsibility for decision making to the family when the patient's
 wishes are not known).

Appendix 2a: Form for Neurological Determination of Death 2 months - 18 years old

This form is consistent with and should be used in conjunction with, the AoMRC (2008) A Code of Practice for the Diagnosis and Confirmation of Death and has been endorsed for use by the following institutions: Faculty of Intensive Care Medicine, Intensive Care Society, Paediatric Intensive Care Society and National Organ Donation Committee: Paediatric Subgroup.

HOSPITAL ADDRESSOGRAPH or

Surname First Name Date of Birth NHS

Primary Diagnosis:

Evidence for Irreversible Brain Damage of Known Aetiology:

Diagnostic caution is advised in certain 'Red Flag' patient groups. See Page 3 for details

Exclusion of Reversible Causes of Coma and Apnoea							
	1st Test	1st Test	2nd Test	2nd Test			
	Dr One	Dr Two	Dr One	Dr Two			
Is the coma due to depressant drugs? Drug Levels (if taken):	Yes / No	Yes / No	Yes / No	Yes / No			
Is the patient's body temperature ≤34°C?	Yes / No	Yes / No	Yes / No	Yes / No			
Is the coma due to a circulatory, metabolic or endocrine disorder?	Yes / No	Yes / No	Yes / No	Yes / No			
Is the apnoea due to neuromuscular blocking agents, other drugs or a non brain-stem cause (e.g. cervical injury, any neuromuscular weakness)?	Yes / No	Yes / No	Yes / No	Yes / No			

Tests for Absence of Brain-Stem Reflexes								
	1 st Test Dr One	1 st Test Dr Two	2 nd Test Dr One	2 nd Test Dr Two				
Do the pupils react to light?	Yes / No	Yes / No	Yes / No	Yes / No				
Is there any eyelid movement when each cornea is touched in turn?	Yes / No	Yes / No	Yes / No	Yes / No				
Is there any motor response when supraorbital pressure is applied?	Yes / No	Yes / No	Yes / No	Yes / No				
Is the gag reflex present?	Yes / No	Yes / No	Yes / No	Yes / No				

Is the cough reflex present?	Yes / No	Yes / No	Yes / No	Yes / No
Is there any eye movement during or following caloric testing in each ear?	Yes / No	Yes / No	Yes / No	Yes / No

Patient Name: NHS Number:

Apnoea Test				
	1st Test	1st Test	2 nd Test	2nd Test
	Dr One	Dr Two	Dr One	Dr Two
Arterial Blood Gas pre apnoea test	1st Test		2 nd Test	
check: (Starting PaCO ₂ ≥ 6.0 kPa and starting pH < 7.4)	Starting PaCO ₂ :		Starting PaCO ₂ :	
	Starting pH:		Starting pH:	
Is there any spontaneous respiration within 5 (five) minutes	Yes / No	Yes / No	Yes / No	Yes / No
following disconnection from the ventilator?	,	,	,	,
Arterial Blood Gas Result post	1st Test		2 nd Test	
apnoea test: PaCO ₂ should rise > 0.5 kPa .	Final PaCO ₂ :		Final PaCO ₂ :	
	Perform lung recruitment		, ,	

Document any Ancillary Investigations Used to Confirm the Diagnosis or any required Clinical Variance from AoMRC (2008) Guidance

Completion of Diagnosis			
Are you satisfied that death has been confirmed following the irreversible cessation of brain-stem function?	YES / NO	YES / NO	
Legal time of death is when the 1st Test indicates death due to the absence of brain-stem reflexes.	Date: Time: Dr One	Date: Time: Dr One	
Death is confirmed following the 2 nd Test.	Name Grade GMC Number Signature	Name Grade GMC Number Signature	
	Dr Two Name Grade GMC Number Signature	Dr Two Name Grade GMC Number Signature	

It remains the duty of the two doctors carrying out the testing to be satisfied with the aetiology, the exclusion of all potentially reversible causes, the clinical tests of brain-stem function and of any ancillary investigations so that each doctor may independently confirm death following irreversible cessation of brain-stem function.

Guidance Summary of the AoMRC and RCPCH Guidance

The diagnosis of death by neurological criteria should be made by at least two medical practitioners who have been registered for more than five years and are competent in the conduct and interpretation of brain-stem testing. Both doctors should be competent in the diagnosis of death by neurological criteria it is recommended that one of the doctors should be a paediatrician and at least one should be a consultant.

Testing should be performed completely and successfully on two occasions with both doctors present. Doctor One may perform the tests while Doctor Two observes; this would constitute the first set. Roles may be reversed for the second set.

Diagnostic caution is advised in the following 'Red Flag' patient groups. (Based on the literature and unpublished case reports.)

- 1. Testing **<6 hours** of the loss of the last brain-stem reflex
- 2. Testing **<24 hours** where aetiology primarily anoxic damage
- 4. Patients with **any neuro-** 6. Prolonged **fentanyl** infusions muscular disorders
- 5. **Steroids** given in space occupying lesions such as abscesses
- 7. Aetiology **primarily** located to the **brain-stem or posterior** fossa
- 3. **Hypothermia** (24-hour observation period following re-warming to normothermia recommended)

Evidence for Irreversible Brain Damage of Known Aetiology

There should be no doubt that the child's condition is due to **irreversible brain damage of known** aetiology. Occasionally it may take a period of continued clinical observation and investigation to be confident of the irreversible nature of the prognosis. The timing of the first test and the timing between the two tests should be adequate for the reassurance of all those directly concerned. If in doubt wait and seek advice.

Drugs

- The child should not have received any drugs that might be contributing to the unconsciousness, apnoea and loss of brainstem reflexes (narcotics, hypnotics, sedatives or tranquillisers). Where there is any doubt specific drug levels should be carried out (midazolam less than < 10mcg/L, thiopentone <5mg/L). Alternatively consider ancillary investigations.
- There should be no residual effect from any neuromuscular blocking agents (atracurium, vecuronium or suxamethonium), consider the use of peripheral nerve stimulation.
- Renal or hepatic impairment and immaturity may prolong metabolism / excretion of these drugs.

Temperature, Circulatory, Metabolic or Endocrine Disorders

- Prior to testing aim for: temperature > 34°C, mean arterial pressure should be consistently maintained at age appropriate levels, maintenance of normocarbia and avoidance of hypoxia, acidaemia or alkalaemia (PaCO2 < 6.0 kPa, PaO2 > 10 kPa and pH 7.35-7.45).
- Serum Na⁺ should be between 115-160 mmol/L; Serum K⁺ should be > 2 mmol/L; Serum PO₄³⁻ and Mg²⁺ should not be profoundly elevated (>3.0 mmol/L) or lowered (<0.5 mmol/L) from normal.
- Blood glucose should be between 3.0-20 mmol/L before each brain-stem test.
- If there is any clinical reason to expect endocrine disturbances, then it is obligatory to ensure appropriate hormonal assays are undertaken.

Brain Stem Reflexes

- Pupils should be fixed in diameter and unresponsive to light.
- There should be no corneal (blink) reflex (care should be taken to avoid damage to cornea).
- Eye movement should not occur when each ear is instilled, over one minute, with 20 -50 mls of ice cold water, head 30°. Each ear drum should be clearly visualised before the test.
- There should be no motor response within the cranial nerve or somatic distribution in response to supraorbital pressure. Reflex limb and trunk movements (spinal reflexes) may still be present.
- There should be no gag reflex following stimulation to the posterior pharynx or cough reflex following suction catheter placed down the trachea to the carina.

Apnoea Test

- End tidal carbon dioxide can be used to guide the starting of each apnoea test but should not replace the pre and post arterial paCO₂.
- Oxygenation and cardiovascular stability should be maintained through each apnoea test.
- **Confirm PaCO₂ ≥6.0 kPa and pH < 7.4.** In patients with chronic CO₂ retention, or those who have received intravenous bicarbonate, confirm PaCO₂ >6.5 kPa and the pH < 7.4.
- Either use a CPAP circuit (eg Mapleson C or Ayres T piece) or disconnect the patient from the ventilator and administer oxygen via a catheter in the trachea at a rate of 2-6L/minute.
- There should be no spontaneous respiration within a minimum of 5 (five) minutes following disconnection from the ventilator.
- Confirm that the PaCO₂ has increased from the starting level by more than 0.5 kPa.
- At the conclusion of the apnoea test, manual recruitment manoeuvres should be carried out before resuming mechanical ventilation and ventilation parameters normalised.

Ancillary Investigations

Ancillary investigations are NOT required for the diagnosis and confirmation of death using neurological
criteria. Any ancillary or confirmatory investigation should be considered ADDITIONAL to the fullest
clinical testing and examination carried out to the best of the two doctors capabilities in the given
circumstances.

Organ Donation

- National professional guidance advocates the confirmation of death by neurological criteria wherever this seems a likely diagnosis and regardless of the likelihood of organ donation.
- NICE guidance and PICS Standards recommends that the specialist nurse for organ donation (SN-OD) should be notified at the point when the clinical team declare the intention to perform brain-stem death tests and this is supported by GMC guidance.

Further Reading

Academy of Medical Royal Colleges (2008) "A Code of Practice for the Diagnosis and Confirmation of Death" www.aomrc.org.uk

GMC (2010) "Treatment and care towards the end of life." www.gmc-uk.org

Heran et al (2008) "A review of ancillary tests in evaluating brain death." Can J Neurol Sci; 35:409–19

NICE (2011) "Organ Donation for Transplantation" www.nice.org.uk

Report from the Organ Donation Taskforce (2008) "Organs for Transplant"

www.webarchive.nationalarchives.gov.uk

Paediatric Intensive Care Society (2014) "PICS Organ Donation Standards" http://picsociety.uk/resources/ Wijdicks E (2001) "The Diagnosis of Brain Death" NEJM 344:1215-21

Form authorship and feedback

This form was written by Dr Dale Gardiner, Nottingham, Dr Alex Manara, Bristol and Dr Kay Hawkins, Manchester, Dr James Fraser, Bristol, Dr Margrid Shindler, Bristol and Andrea Macarthur, Manchester, Angie Scales, NHS Blood and Transplant. Comments should be directed to kay.hawkins@cmft.nhs.uk

Appendix 2b: Form for Neurological Determination of Death in infants < 2 months old

This form is consistent with and should be used in conjunction with, the AoMRC¹ (2008) *A Code of Practice for the Diagnosis and Confirmation of Death* and RCPCH (2015) *The diagnosis of death by neurological criteria in infants less than two months old²* and has been endorsed for use by the following institutions: Paediatric Intensive Care Society and National Organ Donation Committee: Paediatric Subgroup.

HOSPITAL ADDRESSOGRAPH or

Surname First Name Date of Birth NHS

Examining Doctors

The diagnosis of death by neurological criteria should be made by at least two medical practitioners. Both medical practitioners should have been registered with the General Medical Council (or equivalent Professional Body) for more than five years and be competent in the assessment of a patient who may be deceased following the irreversible cessation of brain-stem function and competent in the conduct and interpretation of the brain-stem examination. Both doctors should be competent in the diagnosis of death by neurological criteria, both should be paediatricians or paediatric intensivists and one should be a consultant.

Clinicians unfamiliar with the test should seek advice from Neonatal or Paediatric Intensivists in Regional Units.

Testing should be undertaken by the nominated doctors acting together and must always be performed on two occasions. A complete set of tests should be performed on each occasion, i.e., a total of two sets of tests will be performed. Doctor One may perform the tests while Doctor Two observes; this would constitute the first set. Roles may be reversed for the second set. The tests, in particular the apnoea test, are therefore performed only twice in total.

Preconditions

The following preconditions should be met prior to testing:

- The infant is comatose and mechanically ventilated for apnoea.¹
- The diagnosis of structural brain damage has been established or the immediate cause of coma is known and in particular:
- > Drugs are not the cause of coma
- Neuromuscular blockade has been demonstrably reversed
- > Hypothermia does not exist (temp > 34°C)
- ➤ There is no endocrine or metabolic disturbance that could be the primary cause of the state of unresponsiveness.¹
 - An additional precondition to be taken in this patient population:
- In post-asphyxiated infants, or those receiving intensive care after resuscitation, whether or not they have undergone hypothermia, there should be a period of at least 24 hours of observation during which the preconditions necessary for the assessment for DNC should be present before clinical testing for DNC. If there are concerns about residual drug-induced sedation, then this period may need to be extended.²

Diagnostic caution is advised in the following 'Red Flag' patient groups. (Based on the literature and unpublished case reports.) For advice in difficult circumstances contact the local or regional Clinical Lead for Organ Donation, or regional paediatric / neonatal intensive care unit.

1. Testing <6 hours of the loss	4.	Patients with any neuro-	6. Prolonged fentanyl	
of the last brain-stem reflex		muscular disorders	infusions	
2. Testing <24 hours where	5.	Steroids given in space	7. Aetiology primarily located	
aetiology primarily anoxic		occupying lesions such as	to the brain-stem or	
damage		abscesses	posterior fossa	
3. Hypothermia 24-hour observation period following re-warming to normothermia				

Evidence for Irreversible Brain Damage of Known Aetiology

• There should be no doubt that the infant's condition is due to **irreversible brain damage of known aetiology**. Occasionally it may take a period of continued clinical observation and investigation to be confident of the irreversible nature of the prognosis. The timing of the first test and the timing between the two tests should be adequate for the reassurance of all those directly concerned. **If in doubt wait and seek advice**.

Drugs

- The infant should not have received any drugs that might still be contributing to the unconsciousness, apnoea and loss of brainstem reflexes (narcotics, hypnotics, sedatives or tranquillisers). Where there is any doubt specific drug levels should be carried out (midazolam less than <10 mcg/L, thiopentone <5 mg/L).
- There should be no residual effect from any neuromuscular blocking agents (atracurium, vecuronium or suxamethonium), consider the use of peripheral nerve stimulation.
- Renal or hepatic impairment and immaturity may prolong metabolism / excretion of these drugs.

Temperature, Circulatory, Metabolic or Endocrine Disorders

- Prior to testing aim for: temperature >34°C, mean arterial pressure should be consistently >37mmHg, maintenance of normocarbia and avoidance of hypoxia, acidaemia or alkalaemia ($PaCO_2 < 6.0 \text{ kPa}$, $PaO_2 > 10 \text{ kPa}$ and pH 7.35–7.45).
- Serum Na $^+$ should be between 115-160 mmol/L; Serum K $^+$ should be >2 mmol/L; Serum PO $_4$ ³⁻ and Mg $_2$ ⁺ should not be profoundly elevated (>3.0 mmol/L) or lowered (<0.5 mmol/L) from normal.
- Blood glucose should be between 3.0-20mmol/L before each brain-stem test.
- If there is any clinical reason to expect endocrine disturbances, then it is obligatory to ensure appropriate hormonal assays are undertaken.

Brain Stem Reflexes

- Pupils should be fixed in diameter and unresponsive to light.
- There should be no corneal (blink) reflex (care should be taken to avoid damage to cornea).
- Eye movement should not occur when each ear is instilled, over one minute, with 20-50 mls of ice cold water, head 30°. Each ear drum should be clearly visualised before the test.
- There should be no motor response within the cranial nerve or somatic distribution in response to supraorbital pressure. Reflex limb and trunk movements (spinal reflexes) may still be present.
- There should be no gag reflex following stimulation to the posterior pharynx or cough reflex following suction catheter placed down the trachea to the carina.

Apnoea Testing

- End tidal carbon dioxide can be used to guide the start of each apnoea test but should not replace the pre and post arterial paCO₂.
- Oxygenation and cardiovascular stability should be maintained through each apnoea test.
- Confirm PaCO₂ ≥5.3 kPa
- Either use a CPAP circuit (e.g. Neopuff or Ayres T piece) or disconnect the patient from the ventilator and administer oxygen via a catheter in the ETT at a rate of 2-6 L/minute.
- There should be no spontaneous respiration over the time period required for the child's pCO2 to rise. It is recommended that the period of observation should be at least 5 minutes providing haemodynamic stability can be maintained.
- Confirm that the PaCO₂ has increased from the starting level by more than 2.7 kPa to greater than 8.0 kPa. The lack of spontaneous respiratory effort in response to this hypercarbic stimulus is the most important clinical observation during the apnoea test in this population of patients.
- At the conclusion of the apnoea test, manual recruitment manoeuvres should be carried out before resuming mechanical ventilation and ventilation parameters normalised.

Organ Donation

National professional guidance advocates the confirmation of death by neurological criteria wherever this seems a likely diagnosis and regardless of the likelihood of organ donation.^{34,6}

• NICE guidance and PICS Standards recommends that the specialist nurse for organ donation (SN-OD) should be notified at the point when the clinical team declare the intention to perform brain-stem death tests and this is supported by GMC guidance.^{3,4,5}

References

- 1. Academy of Medical Royal Colleges (2008) "A Code of Practice for the Diagnosis and Confirmation of Death" www.aomrc.org.uk
- 2. Royal College of Paediatrics and Child Health (2015) "The diagnosis of death by neurological criteria in infants less than two months old" www.rcpch.ac.uk
- 3. GMC (2010) "Treatment and care towards the end of life." www.gmc-uk.org
- 4. NICE (2011) "Organ Donation for Transplantation" www.nice.org.uk
- 5. Report from the Organ Donation Taskforce (2008) "Organs for Transplant" www.webarchive.nationalarchives.gov.uk
- 6. Paediatric Intensive Care Society (2014) "PICS Organ Donation Standards" http://picsociety.uk/resources/

Form authorship and feedback

This form was written by Dr Dale Gardiner, Nottingham, Dr Alex Manara, Bristol and Dr Kay Hawkins, Manchester, Dr James Fraser, Bristol, Dr Margrid Shindler, Bristol, Dr Ajit Mahaveer, Andrea Macarthur, Manchester and Angie Scales, NHS Blood and Transplant. Comments should be directed to kay.hawkins@cmft.nhs.uk

Primary Diagnosis:

Evidence for Irreversible Brain Damage of Known Aetiology:

Diagnostic caution is advised in certain 'Red Flag' patient groups. See Page 1 for details.

Exclusion of Rev	versible Cause	es of Coma and	l Apnoea	
Michael of Rev	1st Test	1st Test	2 nd Test	2nd Test
	Dr One	Dr Two	Dr One	Dr Two
Is the coma due to depressant drugs? Drug Levels (if taken):	Yes / No	Yes / No	Yes / No	Yes / No
Is the infant's body temperature ≤34°C?	Yes / No	Yes / No	Yes / No	Yes / No
Is the coma due to a circulatory, metabolic or endocrine disorder?	Yes / No	Yes / No	Yes / No	Yes / No
Is the apnoea due to neuromuscular blocking agents, other drugs or a non brain-stem cause (e.g. cervical injury, any neuromuscular weakness)?	Yes / No	Yes / No	Yes / No	Yes / No
Tests for A	bsence of Bra	in-Stem Refle	xes	
	1st Test Dr One	1 st Test Dr Two	2 nd Test Dr One	2 nd Test Dr Two
Do the pupils react to light?	Yes / No	Yes / No	Yes / No	Yes / No
Is there any eyelid movement when each cornea is touched in turn?	Yes / No	Yes / No	Yes / No	Yes / No
Is there any motor response when supraorbital pressure is applied?	Yes / No	Yes / No	Yes / No	Yes / No
Is the gag reflex present?	Yes / No	Yes / No	Yes / No	Yes / No
Is the cough reflex present?	Yes / No	Yes / No	Yes / No	Yes / No
Is there any eye movement during or following caloric testing in each ear?	Yes / No	Yes / No	Yes / No	Yes / No

Apnoea Test						
	1st Test 1st Test		2nd Test	2nd Test		
	Dr One	Dr Two	Dr One	Dr Two		
Arterial Blood Gas pre apnoea test	1st Test		2 nd Test			
check: (Starting PaCO ₂ ≥ 5.3 kPa)	Starting Pacc	O_2 :	Starting PaCO ₂ :			
Arterial Blood Gas Result post	1 st Test Final PaCO₂:		2 nd Test			
apnoea test: PaCO ₂ shows a clear raise of >2.7 kPa (>20 mmHg)			Final PaCO ₂ :			
above the baseline to >8.0 kPa (60	Perform lung recruitment		Perform lui	ng recruitment		
mmHg).				ig reer arement		
Was there spontaneous						
respiration during the apnoea	Yes / No	Yes / No	Yes / No	Yes / No		
test?						
(To diagnose death using neuro-						
logical criteria, ALL answers should be NO)						
Should be NOJ						
C	ompletion of I	Diagnosis				
Are you satisfied that death		and and an arrangement of the second				
has been confirmed following	YES / NO		YES / NO			
the irreversible cessation of						
brain-stem function?						
Legal time of death is when the 1st	Date: Time:		Date: Time:			
Test indicates death due to the						
absence of brain-stem reflexes.	Day Out		D 0			
Dooth is confirmed following the	Dr One		Dr One			
Death is confirmed following the 2 nd Test.	Name		Name			
Z Test.	Name		Name			
	Grade		Grade			
	GMC Number		GMC Number			
	Signature		Signature			
	Dr Two		Dr Two			
	Name		Name			
	Grade		Grade			
	GMC Number		GMC Number			
	Signature		Signature			

Appendix 3: Timelines and Responsibilities in Donation after Circulatory Death as per the UK Donation Ethics Committee⁴

