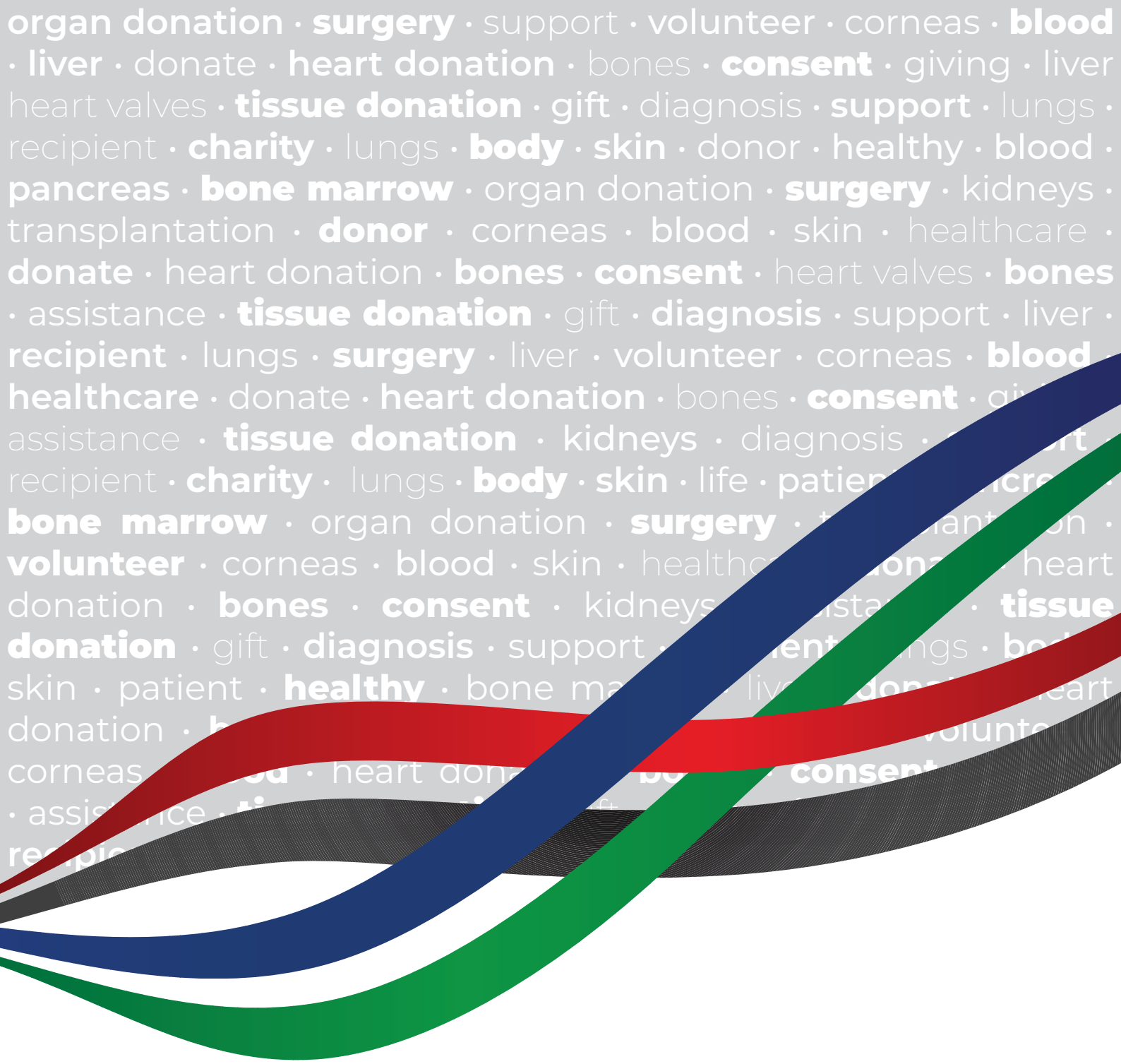


Transplant Coordinators Society

South Africa

THE SOUTH AFRICAN TRANSPLANT COORDINATORS SOCIETY

WHO WE ARE

The **South African Transplant Coordinators Society** (SATCS) is a body created to represent and unite all transplant coordinators in South Africa. Founded on 30 June 2017, SATCS is a special interest group functioning under the auspices of the **Southern African Transplantation Society** (SATS).

SATCS adheres to a **Code of Conduct** which embodies how members facilitate organ and tissue donation and transplantation in South Africa. Our aim is to educate, develop and support all transplant coordinators in South Africa, and at the same time contribute to the development and improvement of the transplant sector in the country.

Ultimately, we exist to serve South Africa's patients and we are committed to do so in an empathetic, transparent and ethical manner.

THE ORGAN AND TISSUE DONATION REFERENCE FILE (RED FILE)

SATCS created the red reference file as a guide for medical professionals in hospitals. It is meant to inform, educate and supply quick reference information to anyone who is faced with a potential donor scenario.

The files need to be placed in the Emergency Department(s) [EDs] and Intensive Care Unit(s) [ICUs] of all South African hospitals.

While care was taken to provide accurate, up-to-date information at the time of printing, we understand that contact details, protocols and approaches change over time. We undertake to provide updated information periodically.

YOU CAN HELP

If you become aware of inaccuracies, outdated information or contact details which may have changed, please email anjameyer85@yahoo.com

HOW TO USE THE ORGAN AND TISSUE DONATION REFERENCE FILE

1. Information in this file has been documented by subject. For quick look-up, use the **CONTENT** page or refer to the **RED TABS**
2. Important **CONTACT DETAILS** are at the front of the file
3. **CHECKLISTS** can be found under **RESOURCES**
4. A digital copy of the document and forms can be downloaded from www.sats.org.za

WHEN IN DOUBT, OR IF YOU HAVE ANY QUESTIONS,
PLEASE CALL YOUR LOCAL TRANSPLANT OR TISSUE DONATION COORDINATOR.

CONTENT

HOSPITAL NAME

The transplant coordinator for this hospital is:

Contact details:

The tissue donation coordinator for this hospital is:

Contact details:

1. CONTACT DETAILS

1.1 NATIONAL TRANSPLANT COORDINATORS CONTACT LIST

GAUTENG			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Johannesburg	Gauteng Province Solid Organ Transplant Division	011 488 3863	076 729 2801
Johannesburg	Netcare Milpark Hospital, Netcare Transplant Division	011 480 5916	082 820 5453
Johannesburg	Wits Donald Gordon Medical Centre Transplant Unit, Wits Transplant	011 356 6407	083 556 6773
Pretoria	Netcare Jakaranda Hospital, Netcare Transplant Division	012 421 6803	082 820 6229

KWAZULU-NATAL			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Cato Manor	Inkosi Albert Luthuli Central Hospital (IALCH)	031 240 2288	082 297 4293
Durban	Ethekwini Hospital and Heart Centre	031 581 2723	
Durban	Life Entabeni Hospital	031 204 7828	
Durban	Netcare St Augustine's Hospital, Netcare Transplant Division	031 268 5225	
Empangeni	Ngwelezana Hospital	035 901 7198	
Pietermaritzburg	Greys Hospital	033 897 3000	083 335 2623
Umhlanga	Gateway Private Hospital	031 492 1378	083 301 1743

WESTERN CAPE			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Cape Town	Groote Schuur Hospital	021 404 4300	082 458 2343
Cape Town	Netcare Christiaan Barnard Memorial Hospital, Netcare Transplant Division	021 441 0384	082 455 8024
Cape Town	Red Cross War Memorial Children's Hospital	021 658 5955	
Cape Town	Tygerberg Hospital	021 938 5082	083 640 0194
Cape Town	UCT Private Academic Hospital, Netcare Transplant Division	021 442 1870	082 301 9559

NORTHERN CAPE			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Whole region	All private hospitals		0716038057

1. CONTACT DETAILS

1.1 NATIONAL TRANSPLANT COORDINATORS CONTACT LIST

EASTERN CAPE			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
East London	Frere Hospital	043 709 2169 043 709 2109	
Gqeberha (Port Elizabeth)	Livingstone Hospital		083 378 0893 081 756 2254
Gqeberha (Port Elizabeth)	Netcare Greenacres Hospital, Netcare Transplant Division	041 363 4861	

FREE STATE			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Whole region	All private hospitals		071 603 8057

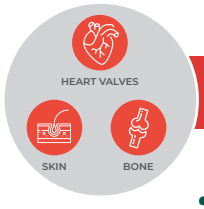
LIMPOPO			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Polokwane	Polokwane Provincial Hospital	015 528 5613	082 580 8394 072 143 3539

NORTH WEST			
CITY	**INSTITUTION**	**TELEPHONE NUMBER(S)**	**CELL NUMBER(S)**
Klerksdorp	Klerksdorp Hospital	018 406 4401	083 562 1094
Mahikeng	Mahikeng Provincial Hospital	018 383 6735	072 424 0375

1.2 NATIONAL TISSUE DONATION COORDINATORS CONTACT LIST

CORNEA DONATION

vitanova	CENTRE FOR TISSUE ENGINEERING	KZN Cornea & Eye Association
Western Cape, Eastern Cape & KwaZulu-Natal	Gauteng, Vaal Triangle, North West, Limpopo, Mpumalanga, Free State, Northern Cape	KwaZulu-Natal
087 068 8000 (24/7/365) 071 573 7317 donation@bonesouthafrica.co.za	082 379 8536 082 825 9176 info@tissuedonation.org.za	031 581 2723 082 307 1654 082 781 3828 kzneyebank@mweb.co.za



BONE, SKIN & HEART VALVE DONATION

vitanova	CENTRE FOR TISSUE ENGINEERING
Western Cape, Eastern Cape & KwaZulu-Natal	Gauteng, Vaal Triangle, North West, Limpopo, Mpumalanga, Free State, Northern Cape
087 068 8000 (24/7/365) 071 573 7317 donation@bonesouthafrica.co.za	082 379 8536 082 825 9176 info@tissuedonation.org.za

FEMORAL HEAD DONATION

vitanova	CENTRE FOR TISSUE ENGINEERING
Western Cape, Eastern Cape & KwaZulu-Natal	Gauteng, Vaal Triangle, North West, Limpopo, Mpumalanga, Free State, Northern Cape
087 068 8000 (24/7/365) 071 573 7317 donation@bonesouthafrica.co.za	078 845 0424 info@tissuedonation.org.za

1.3 NATIONAL HEART VALVE DONATION CENTRE

HEART VALVES

HEART VALVE DONATION

Bloemfontein Tissue Bank

ROBERT FRATER CARDIOVASCULAR RESEARCH CENTRE

at the

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA

UFS HEALTH SCIENCES
THE SCHOOL OF CLINICAL MEDICINE
CARDIOTHORACIC SURGERY

University of the Free State, Bloemfontein

Department of Cardiothoracic Surgery, Robert Frater Cardiovascular Research Centre, School of Clinical Medicine, Faculty of Health Sciences

Contact: Dr Hans van den Heever

051 405 3435
083 461 4052
vdheeverjj@ufs.ac.za

1.4 WHOLE BODY DONATION PROGRAMMES

Full body donation and **organ and tissue donation** is mutually exclusive. Full bodies can be donated to the anatomy department of a university, exclusively for educational purposes. If a donor, or donor's next of kin chooses full body donation, **no organ or tissue donation for transplantation can take place.** The donor's body is preserved for a period of 1 to 3 years, after which it is cremated (ashes are returned to the family if requested).

University of the Witwatersrand, Johannesburg
School of Anatomical Sciences, Faculty of Health Sciences

Contact: Mrs Stella Modimoeng
011 717 2441
stella.modimoeng@wits.ac.za

University of Cape Town, Cape Town
Department of Human Biology, Faculty of Health Sciences

Contact: Abbigale van der Westhuizen
021 406 6235
abbigale.vanderwesthuizen@uct.ac.za

University of KwaZulu-Natal, Durban
Department of Clinical Anatomy, School of Laboratory Medicine and Medical Sciences, College of Health Sciences

Contact: Mr Celumusa Mbokazi
031 260 7388
061 859 6220
mbokazic@ukzn.ac.za

Stellenbosch University, Stellenbosch
Division of Clinical Anatomy, Department of Biomedical Sciences, Faculty of Medicine and Health Sciences

Contact: Mrs Jodie Lemphane
021 938 9416
jilayman@sun.ac.za or su_bodydonations@sun.ac.za

University of the Free State, Bloemfontein
Department of Basic Medical Sciences, Faculty of Health Sciences

Contact: Dr Henk Potgieter
051 401 7882
potgieterh@ufs.ac.za

Sefako Makgatho Health Sciences University, Pretoria
Department of Anatomy and Histology, School of Health Sciences

Contact: Johannes Manthata
012 521 4116
johannes.manthata@smu.ac.za

1.5 TRANSPLANT CENTRES IN SOUTH AFRICA

HOSPITAL	TYPE OF TRANSPLANT	CONTACT DETAILS
GAUTENG		
Charlotte Maxeke Johannesburg Academic Hospital	KIDNEYS, LIVER	Johannesburg Tel: 011 488 3863
Dr George Mukhari Academic Hospital	KIDNEYS	Ga-Rankuwa Tel: 012 529 3000
Netcare Jakaranda Hospital	KIDNEYS	Pretoria Tel: 012 421 6700
Netcare Milpark Hopital	HEART, LUNGS, KIDNEYS	Johannesburg Tel: 011 480 5916
Netcare Sunninghill Hospital	Paediatric: HEART	Sandton Tel: 011 806 1500
Nelson Mandela Children's Hospital (NMCH)	Paediatric: KIDNEYS	Johannesburg Tel: 010 133 0600
Steve Biko Academic Hospital	KIDNEYS	Pretoria Tel: 012 354 1140
Wits University Donald Gordon Medical Centre	LIVER, PANCREAS, KIDNEYS	Johannesburg Tel: 011 356 6000
KWAZULU-NATAL		
Gateway Private Hospital	HEART, LUNGS	Umhlanga Tel: 031 492 1130
Ethekwini Hospital and Heart Centre	HEART, LUNGS, KIDNEYS	Durban Tel: 031 581 2723
Inkosi Albert Luthuli Central Hospital	KIDNEYS	Cato Manor Tel: 031 240 1000
Life Entabeni Hospital	KIDNEYS	Durban Tel: 031 204 1300
Netcare St. Augustine's Hospital	KIDNEYS	Durban Tel: 031 268 5000

PLEASE NOTE: Most transplant centres do adult transplantation, but some also do paediatric transplantation. Please contact the transplant centre to enquire about paediatric transplantation.

1.5 TRANSPLANT CENTRES IN SOUTH AFRICA (cont.)

HOSPITAL	TYPE OF TRANSPLANT	CONTACT DETAILS
WESTERN CAPE		
Groote Schuur Hospital	HEART, LIVER, LUNGS, KIDNEYS	Cape Town Tel: 021 404 9111
Netcare Christiaan Barnard Memorial Hospital	HEART, KIDNEYS	Cape Town Tel: 021 441 0000
Netcare UCT Private Academic Hospital	HEART, LIVER, LUNGS, KIDNEYS	Cape Town Tel: 021 442 1800
Red Cross War Memorial Children's Hospital	Paediatric: HEART, LIVER, KIDNEYS	Cape Town Tel: 021 658 5111
Tygerberg Hospital	KIDNEYS	Cape Town Tel: 021 938 4911
FREE STATE		
Universitas Academic Hospital	KIDNEYS	Bloemfontein Tel: 051 405 3911
Universitas Private Hospital	KIDNEYS	Bloemfontein Tel: 051 506 3500

PLEASE NOTE: Most transplant centres do adult transplantation, but some also do paediatric transplantation. Please contact the transplant centre to enquire about paediatric transplantation.

1.6 ORGAN DONOR FOUNDATION OF SOUTH AFRICA

The Organ Donor Foundation of South Africa (ODF) is a non-profit, public benefit organisation, serving as the national umbrella body for the promotion of organ and tissue donation.

Established in 1988, our objectives are to:

- **address the critical shortage of organ and tissue donors in South Africa by promoting awareness of organ and tissue donation;**
- **motivate more members of the public to donate their organs and tissue;**
- **educate the public about informed consent for organ and tissue donation; and**
- **increase the number of members of the public registered as organ and tissue donors and to record these registered organ and tissue donors on a database.**

The ODF works alongside all the official organisations representing the different sectors of organ and tissue donation and transplantation.

PLEASE NOTE:

The ODF's focus is on public awareness and education. It is **not a medical organisation and is not responsible for the procurement or allocation of organs.**

THE ODF'S CONTACT DETAILS

Our office hours are 9am – 4pm, Monday to Friday.

Tel: **0800 22 66 11 (toll free)**
Email: **info@odf.org.za**
Website: **www.odf.org.za**

EMERGENCY AFTER HOURS NUMBER: 082 318 4376

Please use this number if you are calling in **connection with a potential organ or tissue donor after hours (between 4pm and 9am)**. We will put you in touch with a transplant or tissue donation coordinator in your area.

The ODF's work can be categorised as follows:

PUBLIC AWARENESS

The ODF uses consistent, distinctive, and easily identifiable branding for all **"Proud 2B"** awareness campaigns and events, which aim to get members of the public who know about organ and tissue donation, to register as donors. Public awareness is achieved through:

Toll-free Line (0800 22 66 11)

The public and stakeholders can use the ODF's free-call service to get information, ask questions and get assistance with referrals.

National Awareness Events & Campaigns

Awareness events and campaigns are carried out nationally.

- **educational talks** at schools, tertiary institutions and companies
- presence at **expos, awareness events** and **corporate wellness days**
- **stands** at **sporting events**
- **annual walks** in Cape Town and Johannesburg

www.odf.org.za

The public can register as organ and tissue donors on the ODF's website which also provides information on organ and tissue donation.

Information Distribution

The ODF distributes approximately 200 000 donor ID cards and information brochures on organ and tissue donation every year.

Social Media

The ODF is active on Facebook, Instagram and Twitter and uses these platforms to drive awareness and increase donor registrations. Social media provides an interactive platform for the public to engage with the ODF though comments and post sharing. Facebook Messenger allows the public to ask questions about organ and tissue donation.

Media Engagement

Organ and tissue donation awareness information reaches millions of South Africans through the media. The ODF has cultivated strong partnerships with the South African media and is the go-to organisation for any information relating to organ and tissue donation. This partnership results in substantial annual coverage in the form of television and radio interviews, as well as print campaigns.

EDUCATION

***Uluntu*, which means *Community*, is about **putting feet on the ground to reach the wider community** who often has a fear-based understanding due to never receiving factual information. This means that they may automatically say 'No' when approached for consent to donate after a loved one has passed away.**

The Uluntu Project takes into account that the current donor pool is not representative of the South African population. For this reason, cultural and traditional barriers, myths, and misunderstandings need to be addressed and resolved.

The Uluntu Project is carried out by **culturally similar and culturally sensitive messengers** in **under-resourced** and **vulnerable** communities such as townships, informal settlements, and when funding allows, in rural areas.

The Uluntu team regularly **visits state hospitals and healthcare clinics** where **thousands of patients are educated about organ and tissue donation** and made to feel more **comfortable about informed consent.**

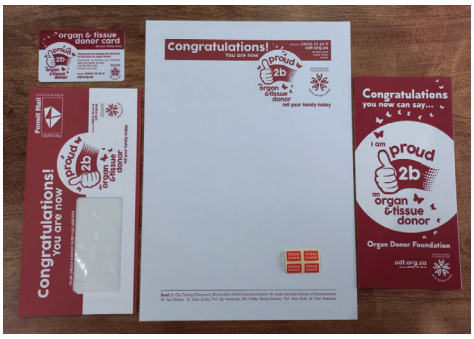
The team also **visits schools on an ongoing basis, educating learners during life orientation lessons** and equipping them to be **drivers of change in their communities and influence their elders.**

REGISTERING DONORS & MAINTAINING A DONOR DATABASE

The ODF **registers an average of 30,000 to 40,000** new donors a year. More than 90% of donor registrations originate from electronic platforms and in excess of 70% of registrants use mobile devices. For this reason, the ODF improved the online registration process to be simple, quick, and easy.

The streamlined process consists of:

- a short online registration form on www.odf.org.za;
- a follow-up call by one of our dedicated call centre agents to complete the registration; and
- a registration pack, containing a welcome letter, donor ID card, information brochure and stickers mailed to every new donor.



Registering as a donor does not mean that the donor's organs will automatically be donated at the time of death.

The ODF strongly urges newly registered donors to share their intention to be an organ and tissue donor with their loved ones.

Consent from the next of kin is always a requirement before a donation can take place.

HOW THE ODF IS ABLE TO REACH SO FAR AND WIDE...

Our Volunteers

The ODF has more than **a thousand able, committed, and active volunteers** who help to drive awareness nationally. All **new volunteers receive training** to ensure they are equipped and provide factual information about organ and tissue donation and can advise on the steps and procedures to follow for donation. Committed to ongoing development, the ODF is currently **creating an online course** to train new volunteers in outlying areas and to ensure continuous training, even through a pandemic.

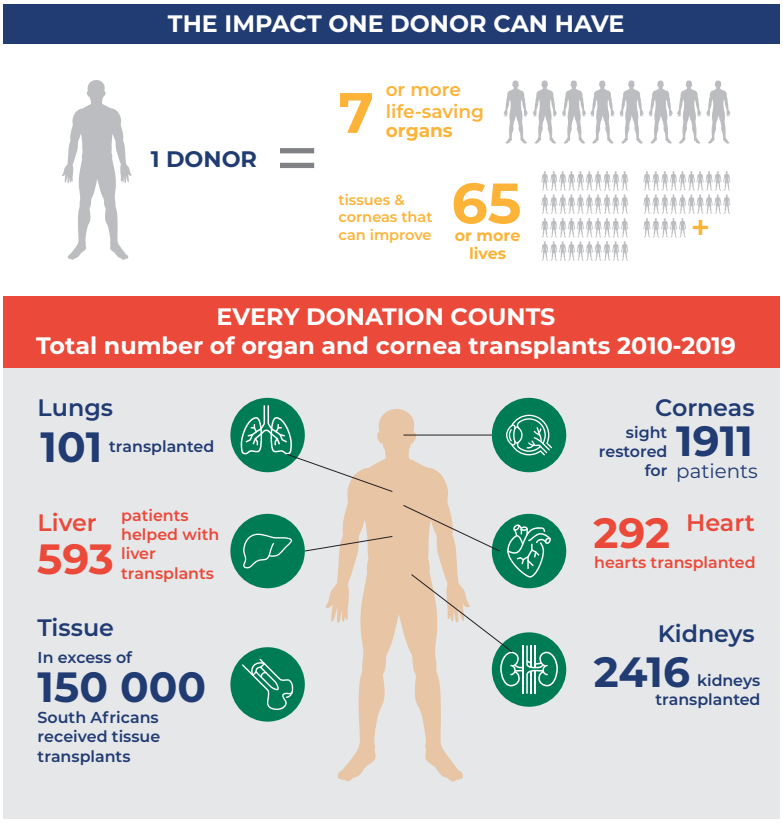
Partnerships and Collaborations

The ODF **extends its reach through partnerships and collaborations** with other organisations, which allows us to reach a vast number of South Africans, despite having limited resources and infrastructure. These include:

- Our successful partnership with a well-known South African insurer and estate administration company - and their passion to **Leave a Legacy** - has resulted in more than 40,000 new registered donors from their client base.
- The **'Valentine's at Leeuwenhof Estate'** event, which led to the Western Cape Premier's Office and 40 prominent companies pledging to display a donor registration portal on their electronic platforms, in support of the ODF.
- Other key partnerships include strong association with **stakeholders in transplantation, tissue banks, the medical community, the South African National Blood Services (SANBS) and other aligned non-profit organisations.**

2. WHAT IS ORGAN AND TISSUE DONATION?

2.1 INTRODUCTION TO ORGAN AND TISSUE DONATION



Organ and/or tissue donation is the act of giving an organ or tissue to save or improve the life of a patient who needs a transplant. Most organ and tissue donations are from deceased patients, but in certain circumstances, living persons can donate organs and tissue.

Organ transplantation increases the life expectancy and quality of life of patients with end-stage organ failure. Donated tissue can restore sight, increase mobility and reduce pain, save a patient's life after severe burn injury, and improve heart function.

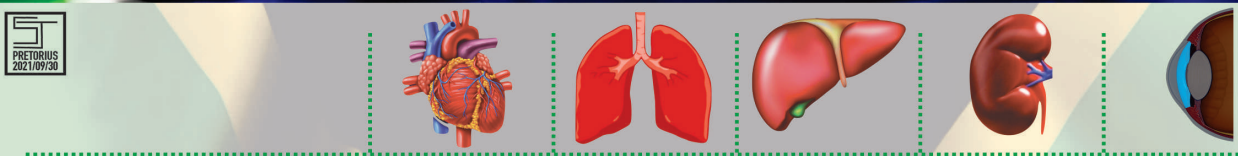
Thousands of patients are currently on waiting lists for lifesaving organ and/or tissue transplants.

The red reference file is designed to help you identify potential organ and tissue donors for discussion with your transplant and/or tissue donation coordinator. It is meant to equip you to have fully informed end-of-life discussions regarding all donation possibilities. It also provides information on living donation and the processes associated with it.

Organ and tissue donation and transplantation is a team effort, and you are a crucial part of the team.

Organ Donation Statistics, South Africa

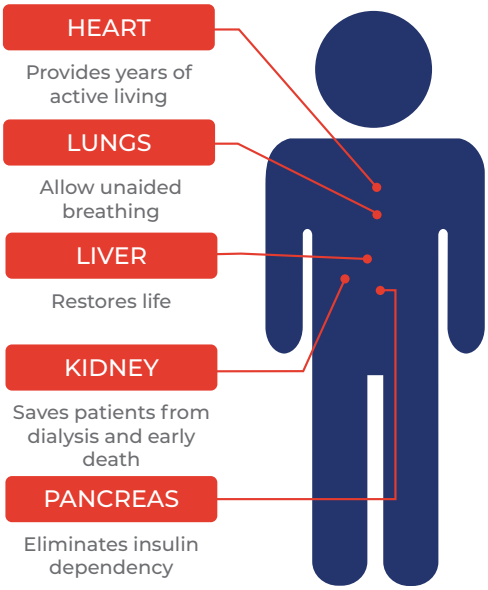
A Ten Year View



Total/Organ:	292	101	593	2416	1911
	Heart	Lungs	Liver	Kidney	Cornea
2019 451 Organ and Cornea Transplants 355 Solid Organ Transplants	29 adults 1 paediatric	13 adults	54 adults 34 paediatrics	216 adults 8 paediatrics	96 adults, adolescents & paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2018 508 Organ and Cornea Transplants 373 Solid Organ Transplants	38 adults 4 paediatrics	23 adults	49 adults 29 paediatrics	212 adults 18 paediatrics	135 adults, adolescents & paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2017 524 Organ and Cornea Transplants 368 Solid Organ Transplants	31 adults	9 adults	51 adults 24 paediatrics	230 adults 23 paediatrics	158 adults, adolescents & paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2016 504 Organ and Cornea Transplants 353 Solid Organ Transplants	23 adults 2 paediatrics	14 adults	40 adults 4 adolescents 21 paediatrics	234 adults 3 adolescents 12 paediatrics	151 adults, adolescents & paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2015 540 Organ and Cornea Transplants 361 Solid Organ Transplants	27 adults	12 adults	44 adults 5 adolescents 22 paediatrics	231 adults 4 adolescents 16 paediatrics	179 adults, adolescents & paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2014 507 Organ and Cornea Transplants 313 Solid Organ Transplants	32 adults 1 adolescent	7 adults	34 adults 3 adolescents 23 paediatrics	195 adults 1 adolescents 17 paediatrics	194 adults, adolescents & paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2013 577 Organ and Cornea Transplants 317 Solid Organ Transplants	25 adults 1 paediatric	7 adults	37 adults 2 adolescents 16 paediatrics	222 adults 4 adolescents 3 paediatrics	231 adults 14 adolescents 15 paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2012 562 Organ and Cornea Transplants 308 Solid Organ Transplants	24 adults 3 paediatrics	8 adults	28 adults 3 adolescents 4 paediatrics	213 adults 14 adolescents 11 paediatrics	254 adults adolescents paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2011 549 Organ and Cornea Transplants 323 Solid Organ Transplants	25 adults 1 adolescent	4 adults	26 adults 4 paediatrics	234 adults 11 adolescents 18 paediatrics	197 adults 14 adolescents 15 paediatrics
	Heart	Lungs	Liver	Kidney	Cornea
2010 591 Organ and Cornea Transplants 331 Solid Organ Transplants	24 adults 1 paediatric	4 adults	30 adults 2 adolescents 4 paediatrics	244 adults 8 adolescents 14 paediatrics	231 adults 14 adolescents 15 paediatrics

Source: www.odf.org.za

2.2 ORGAN DONATION



Organ donation can only take place in a clinical setting. Early donor identification and optimal management of any potential organ donor are crucial for successful organ procurement and transplantation.

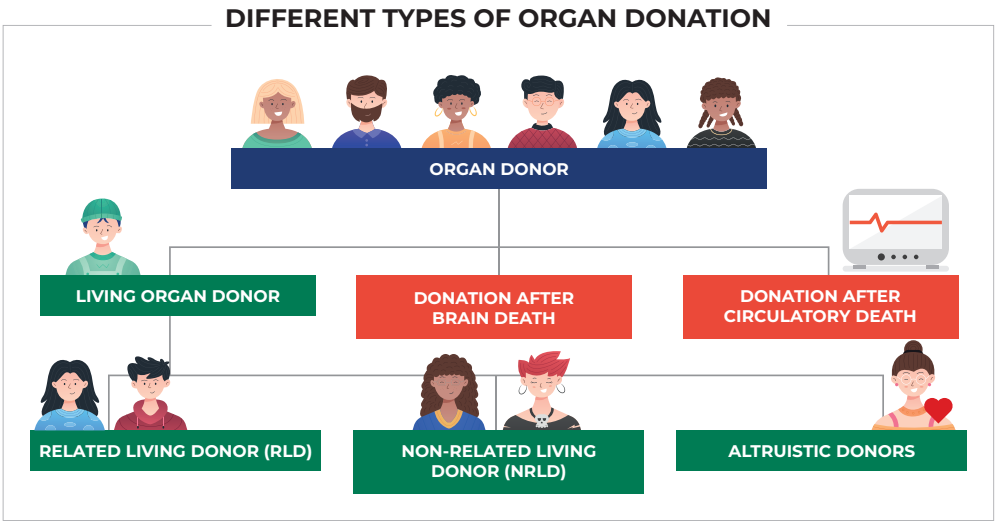
Heart, lung, kidney, liver and pancreas transplants are done at designated hospitals in South Africa. Donated organs are allocated to patients who are on transplant waiting lists at hospitals nationally.

Every donation starts with a referral.
MAKE THE CALL.

TYPES OF ORGAN DONATION

Three types of organ donation exist:

- Living donation
- Donation after brain death
- Donation after circulatory death



Living donation

A living organ donor is an individual who makes a conscious decision to donate a kidney or a liver segment to a patient in need of a kidney or liver transplant.

There are three types of living donors:

- a **related living donor** (RLD) is a person related to the recipient, such as a parent, sister, brother, or grandparent.

TYPES OF ORGAN DONATION (cont.)

- a **non-related living donor** (NRLD) is a person known, but not related to the recipient, such as a husband, wife, or family friend.
- an **altruistic donor** is a person who does not know the recipient and volunteers to donate an organ as a selfless act of kindness.

Donation after brain death (DBD)

Organ donation that takes place after a patient who is connected to a mechanical ventilator, is declared brain dead by two independent doctors, is known as donation after brain death. The donor's body is maintained on the ventilator with maximum organ support to facilitate optimal organ preservation and procurement, and ensure the best possible transplant outcome.

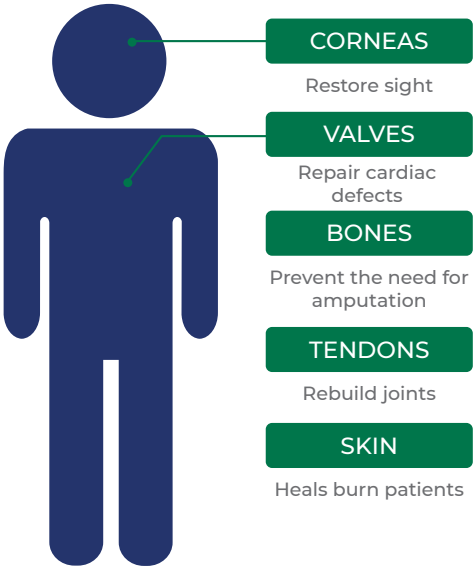
Donation after circulatory death (DCD)

Donation after circulatory death can occur in palliative care settings where there is planned withdrawal of non-beneficial treatments and imminent death is expected. Referral to the transplant coordinator needs to occur when the decision is made to palliate (not after extubation), so that organ procurement can be arranged should the patient arrest within a defined period from extubation; and consent for donation can be facilitated.

2.3 TISSUE DONATION

Tissue refers to bone, ligaments, tendons, skin, heart valves, corneas, and scleral tissue. Living and deceased donors can donate tissue.

Early identification and referral of potential tissue donors are crucial to allow the tissue donation coordinator enough time to obtain consent for donation from the next of kin.



Almost anyone can be a tissue donor.
PLEASE REFER ALL DEATHS.

FIVE important ways tissue donation differs from organ donation

- While exclusion criteria and safety protocols apply, many more people can donate tissue, than people able to donate organs.
- An organ donor can also donate tissue, but not all tissue donors can be / are organ donors.
- Tissue donation can take place irrespective of the manner of death.
- Tissue recovery can take place in hospital, at a funeral home, mortuary, or forensic pathology facility.
- Certain time limits apply to tissue viability, but generally there is more time to recover tissue than organs.

TYPES OF TISSUE DONATION

Two types of tissue donation exist:

- Deceased donation
- Living donation

Deceased Donation

Deceased donation takes place after death. On receiving a referral from a hospital, funeral home, mortuary or forensic pathology facility, the tissue donation coordinator will obtain consent from the next of kin and arrange tissue recovery.

The next of kin elects which tissue may be recovered, and donation may include:

- bone (femur, tibia, fibula, humerus, radius, ulna, bone from the iliac crest and cartilage)
- skin (from the thighs, calves, back and abdomen)
- corneas or the whole eye
- ligaments and tendons
- heart valves

Tissue recovery is done with great care and the body is restored to its original state with the aid of prostheses post-recovery. An open casket funeral is possible after tissue recovery.

Living Donation

It is possible to donate tissue as a living person. Living tissue donation normally occurs as a result of surgery.

Femoral head donation

A patient undergoing hip replacement / arthroplasty surgery, can elect to donate the femoral head, which is removed during the surgery to fit the prosthesis. The bone that is removed is normally discarded as medical waste. A **Femoral Head Donation Programme** exists in hospitals in major centres to collect donated femoral heads. The patient consents prior to the surgery. The donated bone is processed into bone tissue, which is used for transplantation and implantation in patients who require bone.

2.4 WHEN TO REFER

PLEASE REFER ALL POTENTIAL DONORS

For **organ donation**, best practice is to assess the potential for donation ***before death***, to allow all end-of-life discussions to be fully informed about the potential for donation.

Alert the transplant coordinator about a potential organ donor when one of these clinical triggers occurs:

- a decision is made to perform brain death testing; or
- a patient with a catastrophic brain injury has a Glasgow Coma Scale (GCS) measurement of four (4) or less, not explained by sedation; or
- a decision is made to withdraw organ support and death is expected.

Most patients who die are potential tissue donors. Please refer all deceased patients to a trained tissue donation coordinator to evaluate the potential for donation.

3. LEGAL REQUIREMENTS FOR ORGAN & TISSUE DONATION

3.1 LEGAL REQUIREMENTS

There is no legal requirement for the **referral** of a potential donor. However, **organ and tissue donation** is closely regulated and legal safeguards exist ensuring death is independently certified and consent is always obtained from the family and forensic pathologist (in cases where death occurred from unnatural causes, i.e. motor vehicle accidents).

The following legal criteria need to be met for organ donation:

1. **Certification of brain death** must be completed by two registered medical doctors who are not part of the transplant team. One of the doctors must be registered with the Health Professionals Council of South Africa (HPCSA) for at least five (5) years.
2. **Consent** must be obtained from the next of kin or legal guardian. 'Next of kin' refers to a spouse, parent, child, brother, or sister.
3. **Consent** from the state pathologist or district surgeon if the death is due to unnatural causes, and therefore part of a police investigation.
4. **Consent** from the medical superintendent or hospital manager at the hospital where organ recovery will be done.

The following legal criterion applies to tissue donation:

1. Consent for donation must be obtained from the next of kin or legal guardian. 'Next of kin' refers to a spouse, parent, child, brother, or sister. The comprehensive consent includes:
   - next of kin personal details
   - personal and medical information of the donor
   - permission to recover specified tissue from the donor
   - agreement that tissue that is not fit for transplantation and implantation may be used for ethical research purposes.

3.2 LEGAL CRITERIA

3.2.1 CERTIFICATION OF BRAIN DEATH

1. The certification of brain death is a clinical diagnosis.
2. An EEG is not required.
3. Two medical doctors must make the diagnosis of brain death.
4. The doctors must be registered with the Health Professionals Council of South Africa (HPCSA). One of the doctors must be registered for at least five years and the other may not be an intern.
5. Neither doctor may be a member of the transplant team.

6. Several tests are required to confirm brain death (refer to Determining Brain Death on page 23). The tests do not have to be done separately, or within a specified timeframe.
7. Ideally the brain death testing should be done together with a single apnoea test.

3.2.2 WHEN IS THE PATIENT BRAIN DEAD?

The legal time of death, which must be recorded in the patient's notes, is when both doctors have completed all the required tests and have confirmed that the patient is brain dead.

3.2.3 CONSENT FOR ORGAN & TISSUE DONATION

Where possible, consent for organ and tissue donation should always be obtained by the transplant coordinator, and where organ donation is not relevant, by the tissue donation coordinator for tissue donation. As experienced and trained professionals, they are more likely to get consent from the family.

It is important to note that the primary treatment team remains responsible for communicating the diagnosis and prognosis to the next of kin.

1. Consent must be obtained in writing or telephonically from the next of kin or legal guardian. Two witnesses are required for organ and deceased tissue donation. For living tissue donation, one witness is required.
2. Where a person died from unnatural causes and consent for donation was obtained from the next of kin, the state pathologist or district surgeon must give permission for organs and tissue to be recovered.
3. For organ donation, permission for the recovery of organs must be obtained from the medical practitioner in charge of clinical services at the hospital, or another medical practitioner authorised by him or her. Where there is no medical practitioner in charge of clinical services at the hospital, a medical practitioner authorised by the person in charge of the hospital may grant authorisation for the recovery of the organs and/or tissue.
4. Tissue recovery usually takes place after the post-mortem examination. Recovery can be done in hospital, at a funeral home, a mortuary or a forensic pathology facility. The tissue donation coordinator will make the arrangements with the recovery location directly.

3.3 COSTS ARISING FROM ORGAN AND TISSUE DONATION

The donor's medical aid, the donor's estate and the next of kin are not responsible for any medical costs incurred after the donor has been declared brain dead and consent has been obtained for donation, in the case of organ donation. Likewise, the donor's medical aid, the donor's estate or the next of kin will not bear any costs for tissue donation.

IN ALL INSTANCES, TRANSPLANT COORDINATORS AND TISSUE DONATION COORDINATORS ARE RESPONSIBLE FOR ENSURING DONATION PROCEDURES ARE FOLLOWED.

4. IDENTIFYING POTENTIAL DONORS

4.1 WHO IS A POTENTIAL ORGAN DONOR?

Any patient who is declared brain dead can be assessed to be a potential organ donor.

Possible causes of brain death include:

- traumatic head injuries caused by motor vehicle accidents (MVA), motorbike accidents (MBA); pedestrian vehicle accidents (PVA), falls, assaults, gunshots;
- cerebral haemorrhage or stroke as a result of a ruptured aneurysm or hypertensive bleed;
- cerebral hypoxia due to drug overdose, drowning, failed resuscitation, fat or air emboli;
- primary brain tumour.

There is no age restriction for organ donation.

The transplant coordinator will perform an initial donor assessment once he/she receives a referral. **The transplant coordinator and transplant team** - who are aware of urgent listings (patients who may accept marginal organs) and are up to date on the latest medical advances in organ recovery - will discuss and document donor suitability.

It is best practice for the transplant coordinator to obtain consent from the family and to have discussions around donation, decoupled from the end-of-life discussions.

The transplant coordinator will oversee the donor management and coordinate the entire donation process.

If the potential donor's cause of death is classified as *unnatural* e.g., from trauma or as an anaesthetic death, the transplant coordinator will obtain consent for donation from the state pathologist or district surgeon.

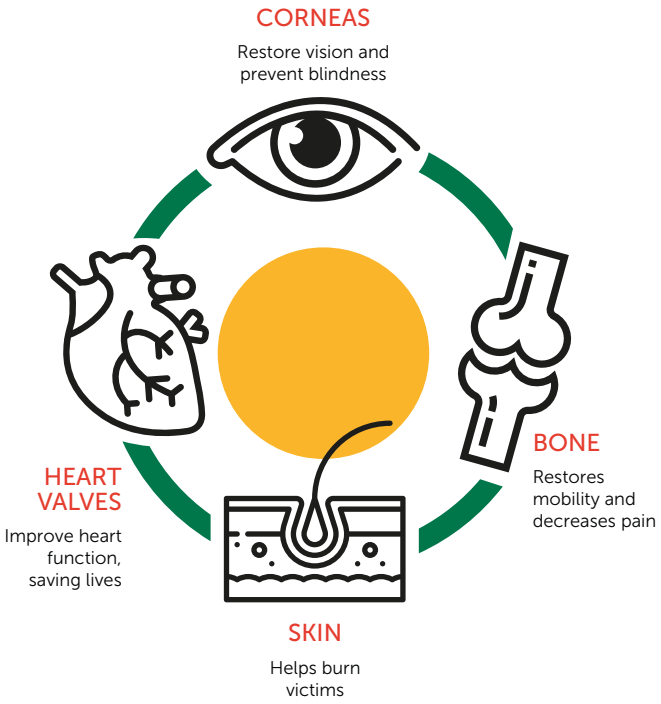
To address donor scarcity, **extended selection criteria** are sometimes applied and patients with certain comorbidities are considered as donors. Extended criteria donors have shown excellent outcomes and offer a significant survival benefit over no transplant. Individual organs are assessed for their transplantability in a potential donor with comorbidities such as hypertension, diabetes, and HIV. **PLEASE REFER ALL POTENTIAL DONORS.**

In the event of a patient declared **dead on arrival (DOA); dying unexpectedly** or **declared unfit for organ donation,** please contact the tissue donation coordinator and/or eye bank in your area for possible tissue and cornea donation.

EVERY DONATION STARTS WITH A REFERRAL.

When in doubt about donor suitability, please refer. We are here to assist.

4.2 WHO IS A POTENTIAL TISSUE DONOR?



While safety protocols and certain exclusion criteria apply, tissue donation is far less complex than organ donation. Most patients who pass away can be tissue donors. Tissue donation can – in most cases – take place irrespective of the cause of death.

Unlike organs, tissue does not have to be recovered immediately, but early referral is advised to allow the tissue donation coordinator enough time to organise the recovery.

As a rule of thumb, please refer all deceased patients. The tissue donation coordinator will assess the potential donor for suitability.

4.2.1 SELECTION CRITERIA

Cornea donation

Any person between the ages of 6 and 65 years (and even up to 70 years in certain cases), where death occurred as a result of either natural causes (such as heart disease, most cancers* or strokes) or unnatural circumstances (like motor vehicle accident injuries, and gunshot or stab wounds) is a potential cornea donor.

* *Corneas do not contain blood vessels, eliminating the risk of transmitting most types of cancer.*

Cataracts and poor eyesight do not prevent cornea donation.

If the patient's medical history includes amongst other factors, any of the following, the corneas cannot be donated:

- previous laser surgery to the eye(s)
- infections such as tuberculosis and/or HIV/AIDS
- lymphoma and leukaemia

For an extensive list of exclusion criteria, please refer to page 41.

Donation of skin, bone, ligaments and tendons

Any healthy individual between the ages of 16 and 80 years, who does not have cancer, an infectious disease such as hepatitis B and/or C, syphilis, HIV/AIDS or septicaemia, is a potential tissue donor.

Heart valve donation

Deceased individuals from the age of 6 months, up to and including 55 years can donate heart valves. If death was caused by septicaemia, cancer, poisoning, blood-borne infections, trauma to the heart, or if the cause of death is unknown, heart valves cannot be donated.

4.3 WHO IDENTIFIES AND REFERS A POTENTIAL ORGAN AND/OR TISSUE DONOR?

All medical and nursing personnel should be familiar with donor identification and donor referral protocols at their hospitals.

The responsibility for the referral of all potential organ and/or tissue donors lies with the entire medical team treating the patient and is an expected part of end-of-life care. It extends to and includes nursing staff and ancillary healthcare workers and is not exclusively the responsibility of the treating physician.

Any discussions regarding referral, and referral outcomes must be documented in the patient notes.

Organ and tissue donation is a team effort – you can play a vital role by referring **EVERY** potential donor.

BE A HERO, MAKE THE CALL!

5. DETERMINING BRAIN DEATH

5.1 DEFINITION OF BRAIN DEATH

Brain death, also known as brainstem death or death by neurological criteria, refers to a condition of irreversible structural brain damage with loss of brainstem function.

5.2 CRITERIA FOR BRAIN DEATH

It is important that brain death be confirmed promptly and accurately.

We distinguish between two types of brain conditions:

- **Persistent vegetative state**
  Patients in a persistent vegetative state have some brainstem function, even if it is abnormal. They can breathe spontaneously, open their eyes, and react to painful stimuli. The primitive grasp reflex may also be present. These patients can maintain biological functions without being aware of their environment. They are not ventilator-dependent, but are permanently bedridden and do not have the ability for meaningful communication. A persistent vegetative state may improve slowly over time, but typically only in tiny amounts.

  NB: These patients are NOT suitable as donation after brain death (DBD) organ donors. They are also not suitable as donation after circulatory death (DCD) organ donors, as they typically do not arrest within the time period that allows donation after circulatory death. They may potentially be suitable as tissue donors.

- **Brain death**
  Brain death implies that there is no remaining homeostatic function (please note: some hypothalamic function may remain). The patient cannot breathe spontaneously, and support of cardiovascular function is necessary. Some spinal activity may still be present but is compatible with a diagnosis of brain death.
  Remember: brain death is death.

  NB: These patients ARE suitable as potential organ and tissue donors.

Brain death certification is a standard of medical care. It must be performed thoroughly and remove all doubt of recovery. When brainstem reflexes are absent and there are no confounding factors the patient is dead. In a complex situation, where machines and medications support organ viability, and may appear to support life, brain death certification offers the family a final diagnosis and closure.

5.3 BEFORE COMMENCING BRAIN DEATH TESTING ENSURE THAT:

- the cause of brain death is known
- the effects of central nervous system (CNS) depressing drugs and muscle relaxants have been excluded by adhering to the following:
  - testing for brain death cannot be done within six (6) hours of administering a bolus
  - testing for brain death cannot be done within twelve (12) hours of ceasing an infusion (this is the accepted norm in patients with preserved renal and liver function)
- the rectal temperature is > 36°C and systolic blood pressure (BP) is >100 mmHg
- hypoglycaemia and hyponatremia in ranges* which mimic coma, have been excluded
- PH, pCO_2, PO_2 are within acceptable range* limits.

*** IF YOU ARE UNSURE OF ACCEPTABLE RANGES, PLEASE ASK YOUR TRANSPLANT COORDINATOR.**

5.4 TESTING FOR BRAIN DEATH

5.4.1 Legally the certification of brain death must be performed by two registered medical doctors who are not part of the transplant team. One of the doctors must be registered with the HPCSA for at least five (5) years and the other may not be an intern.

Ideally brain death testing should be done together with a single apnoea test. The time of death, which must be recorded in the patient's file, is defined as the time when the brain death testing was completed, and brain death was confirmed.

5.4.2 All brainstem reflexes must be absent

5.4.2.1 Pupillary reflex

Pupils should be fixed (unreactive to light) although not necessarily dilated.

5.4.2.2 Corneal reflex

There should be no response to light or touch (with cotton wool). Take care to not scratch or damage the cornea.

5.4.2.3 Gag reflex

The gag reflex should be absent when the back of the pharynx is stimulated.

5.4.2.4 Cough reflex

The patient should have no response to suctioning via the endotracheal tube.

5.4.2.5 Pain response in facial distribution

Supra-orbital compression must not elicit any response in a facial distribution.

NB: Spinal reflexes may be present.

5.4.3 OCULO-VESTIBULAR REFLEX / COLD CALORIC TEST

5.4.3.1 REQUIREMENTS:

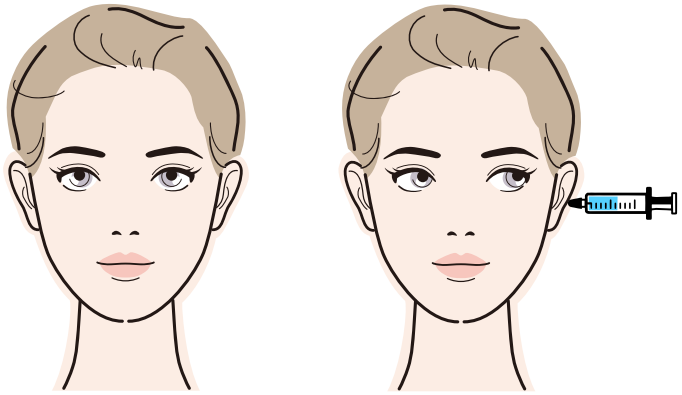
- otoscope, 50 ml syringe and 50 ml ice-cold water
- thin catheter, such as an infant gastric feeding tube

5.4.3.2 METHOD:

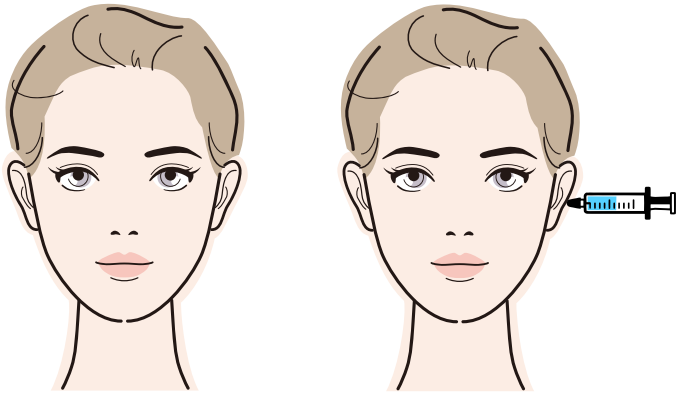
- inspect the external auditory canal with an otoscope to confirm that the eardrum is visible.
- if the eardrum is not visible, the canal must be cleared before testing can occur.
- elevate the head to 30° to align the semi-circular canal and generate a maximal response.
- flush 50 ml of ice-cold water into the ear canal using a syringe.
- hold eyelids open and observe for eye movement for a minimum of 60 seconds.

5.4.3.3 INTERPRETATION:

If there is no eye movement in response to the cold water and the eyes remain in the midline within the socket, it is an abnormal response which indicates brain death.



Normal



Abnormal

IN A BRAIN DEAD PATIENT THERE WILL BE NO EYE MOVEMENT.

5.4.4 APNOEA TEST

5.4.4.1 REQUIREMENTS:

- humidified oxygen supply
- suction catheter or T-piece for delivery of oxygen via endotracheal tube
- heparinised syringe for blood gases

5.4.4.2 METHOD:

- pre-oxygenate the patient for 10 minutes with 100% oxygen.
- ensure the PCO_2 is within normal range (4,0 – 5,3 kPa or 35-45 mmHg) before disconnecting patient from ventilator.
- then disconnect the ventilator and place patient on a T-piece with O_2 flow rate of 15 litres per minute.

OR

- Administer oxygen with the catheter via the endotracheal tube at 4 - 6 litres per minute, by ensuring that the catheter tip is at the end point of the endotracheal tube.

5.4.4.3 INTERPRETATION:

One of three responses may occur:

1. The patient may show some respiratory effort. The patient is not brain dead, although he may become brain dead later. Resume ventilator support for the patient and consider for donation after circulatory death if the decision is made to withdraw support and death is expected.

2. If after ten (10) minutes, there are no signs of spontaneous respiration, a blood gas test must be done to confirm whether the patient has a raised PCO_2 of >8 kPa (60 mmHg). Based on this result, the patient may be certified brain dead.

3. If the patient desaturates or becomes haemodynamically unstable, before ten (10) minutes have passed, reconnect the ventilator and do a blood gas test to see if the PCO_2 is elevated. If it is, and there is no spontaneous respiration, then the patient may be certified brain dead.

   In conclusion, if no spontaneous respiration occurs within ten (10) minutes and a PCO_2 of > 8 kPa (60 mmHg) or higher remains, there is no brainstem function.

   AT THE END OF THE TEST, IT IS ESSENTIAL TO RECONNECT THE PATIENT TO THE VENTILATOR.

5.4.5 ATROPINE TEST

NB: This test is not a required test for brain death certification but can be done as a coordinator specific test. It should be conducted once all other tests are completed to not confuse any subsequent pupillary assessment.

5.4.5.1 REQUIREMENTS:

- atropine 0.04 mg/kg
- independent line with no concurrently running chronotropic agents

5.4.5.2 METHOD:

- document pulse rate prior to the administration of atropine 0.04 mg/kg.
- atropine to be injected in an independent line with no concurrently running chronotropic agents.

5.4.5.3 INTERPRETATION:

A brain dead patient should have no response to the atropine test and the pulse rate should not increase to more than 10% of the baseline pulse rate.

6. OPTIMAL DONOR MANAGEMENT

The best place to preserve organs prior to transplant, is within a well-functioning body, which is why optimal donor management is critical for **organ donation**.

The focus of management moves away from a patient-focused approach to an organ management approach.

Brain death causes adverse cardiovascular, respiratory, endocrine, and metabolic changes.

Optimisation of the organ donor physiology increases the number of transplantable organs.

Prior to consent, the obligation lies with the referring units to ensure haemodynamic stability and organ viability. Once consent is obtained for donation, management of the donor becomes the responsibility of the transplant team. The transplant coordinator, with support from local critical care experts will facilitate optimal donor management in consultation with the various transplant teams.

NB: No sedation or analgesia is administered during donor management.

Tissue donation does not require specialised donor management, but eye care is important to preserve corneas for transplant. At the time of death, the potential donor's eyes need to be moisturised with saline-based eye drops and closed. The body may then be released to the relevant funeral home, mortuary, or forensic pathology facility. Early referral to the tissue donation coordinator will assist with the recovery of viable tissue.

6.1 BEST PRACTICE GUIDELINES FOR THE CLINICAL MANAGEMENT OF AN ORGAN DONOR

DONOR MANAGEMENT GOALS

- **Maintain adequate oxygenation and perfusion**
- **Ensure organ viability**

PULMONOLOGY

Objectives:

- Maintain adequate ventilation
- Keep oxygen saturation > 90%
- Maintain PO_2 > 60 mmHg or > 12 kPa if possible
- Maintain CO_2 levels within normal limits

During ventilation with brain death, a **catecholamine storm** and **cytokine response** may start and spread to the lungs and other organs.

Management:

- do daily CXR
- ensure routine suctioning is performed
- maintain tidal volumes (6-8 ml/kg)
- keep O_2 saturation > 90% with FiO_2 at 0.4 or higher if needed
- PEEP 8-10 cm H_2O
- perform ABGs 2-4 hourly, and manage all abnormalities to optimise oxygenation and ventilation
- prevent fluid overload

NB: High PEEP creates high intra-thoracic pressure which can cause hypotension and barotrauma.

Recruitment manoeuvres are particularly important after tracheal suction or after apnoea testing. When bag-valve-apparatus is used, have a PEEP valve in place to prevent loss of intrinsic PEEP.

CARDIOVASCULAR

Objectives:

- To ensure good organ perfusion:
  - Maintain systolic blood pressure ≥ 100 mmHg **OR**
  - MAP > 60 mmHg
  - Treat diabetes insipidus (DI) immediately

Intravenous lines:

- two **reliable IV lines** are required (one line preferably needs to be a central line) as fluid resuscitation is often ongoing.
- insert a **CVP line** (for fluid management and inotropes) and an **A-line** (for monitoring and to do ABGs).

The potential donor may need large volumes of fluids (crystalloid and colloid) to restore blood pressure (BP).

IV fluid:

- administer IV fluid of choice to manage diabetes insipidus, hypernatremia and acid/base balance on ABG e.g., % saline alternated with % dextrose, Ringer's lactate and/or Balsol (Plas B).

NB: If you are unsure, consult your transplant coordinator.

If blood pressure fails to respond:

- if HB is less than 8 mmol, transfuse with leuko-depleted red cells.
- check that the patient is adequately hydrated.
- if the patient is adequately hydrated, commence inotropic infusion and titrate according to blood pressure.

NB: Rehydrate the patient first BEFORE using inotropes, otherwise the inotropes may cause tachycardia.

CARDIOVASCULAR

Inotrope protocol:

- avoid haemodynamic instability as organs can be damaged by poor perfusion.
- first rehydrate the patient, then administer adrenalin or nor-adrenaline according to unit protocol.
- titrate to maintain MAP > 60 mmHg.
- use Dobutamine only when patient is vasoconstricted (patient will have a raised SVR; and present with cold, cyanosed extremities).

NB: Please use phenylephrine and dopamine cautiously.

- Phenylephrine must be used sparingly due to the extreme vasoconstriction it causes in the splanchnic bed.

- Dopamine can cause unstable arrythmias.

- wean inotropes AS SOON AS POSSIBLE.

Development of diabetes insipidus (DI):

- monitor donor for additional signs:
  - hypernatremia
  - urine SG < 1005
  - raised serum osmolality

Management of diabetes insipidus (DI):

- administer DDAVP (or Desmopressin x 2 nasal sprays) in event of polyuria lasting for 2 hours.
- administer half an ampoule (2 mcg) IV DDAVP (4 mcg/ml per ampoule) in 50 ml saline.
- repeat DDAVP IV after 2 hours if polyuria does not improve.
- To correct **hypernatremia:**
  - administer dextrose 5% as maintenance fluid.
  - give 50 - 100 ml tap water hourly via nasogastric tube (NG tube).

NB: Uncorrected hypernatremia could result in non-viable organs.

- **Administer hydrocortisone –** please use your regional protocol, obtainable from your transplant coordinator:
  - SOLU-CORTEF
  - SOLU-MEDROL
  - T3 (Triidothyronine)

Pulmonary oedema:

- systemic fluid overload results in oedematous organs.
- in the event of pulmonary oedema, administer IV 10 mg Furosemide (Lasix).

NB: The transplant team may give special orders regarding treatment of pulmonary oedema.

RENAL

Objectives:

- Maintain urinary output 0.5 to 1 ml urine per kg per hour as a guideline
- Manage diabetes insipidus (DI) – (see protocol on previous page)

Catheter:

- insert a urinary catheter - **a catheter is essential to monitor urine output.**
- donors may become polyuric *(secondary to the brain injury and ADH secretion)* and require large volumes of fluid to maintain adequate urine output *(can even be more than one litre per hour - in this setting consider a repeat dose of DDAVP).*
- replace the previous hour's output with current fluid maintenance regime.
- as soon as polyuria presents (urine output greater than 300 ml/hr for 2 hours), administer DI protocol.

THE ACID / BASE BALANCE

Objectives:

- Maintain an optimal acid / base balance

Management:

- correct respiratory acidosis with increase of breath rate, OR
- correct metabolic acidosis with Soda Bic (sodium bicarbonate) 8.5% IV *(please use conservatively as sodium bicarbonate may cause hypernatremia).*
- perform ABGs 2-4 hourly and manage all abnormalities to optimise donor.
- keep pH above 7.3.
- normal venous lactate (0.5 to 2.2 mmol/L) is an indicator of good organ perfusion.

MONITOR CRITICAL INDICATORS

Objectives:

- Ongoing monitoring and correction of critical indicators

Management:

- monitor the following regularly:
  - arterial blood gases
  - serum electrolytes
  - urea
  - creatinine
  - loss of glucose control – use unit insulin protocol
- correct or treat when necessary.

BODY TEMPERATURE

Objectives:

- Maintain body temperature > 36°C

Management:

- measure body temperature rectally.
- maintain body temperature > 36°C.
- facilitate adequate warming through the use of a bear hugger, warm fluids and blankets.

EYE CARE

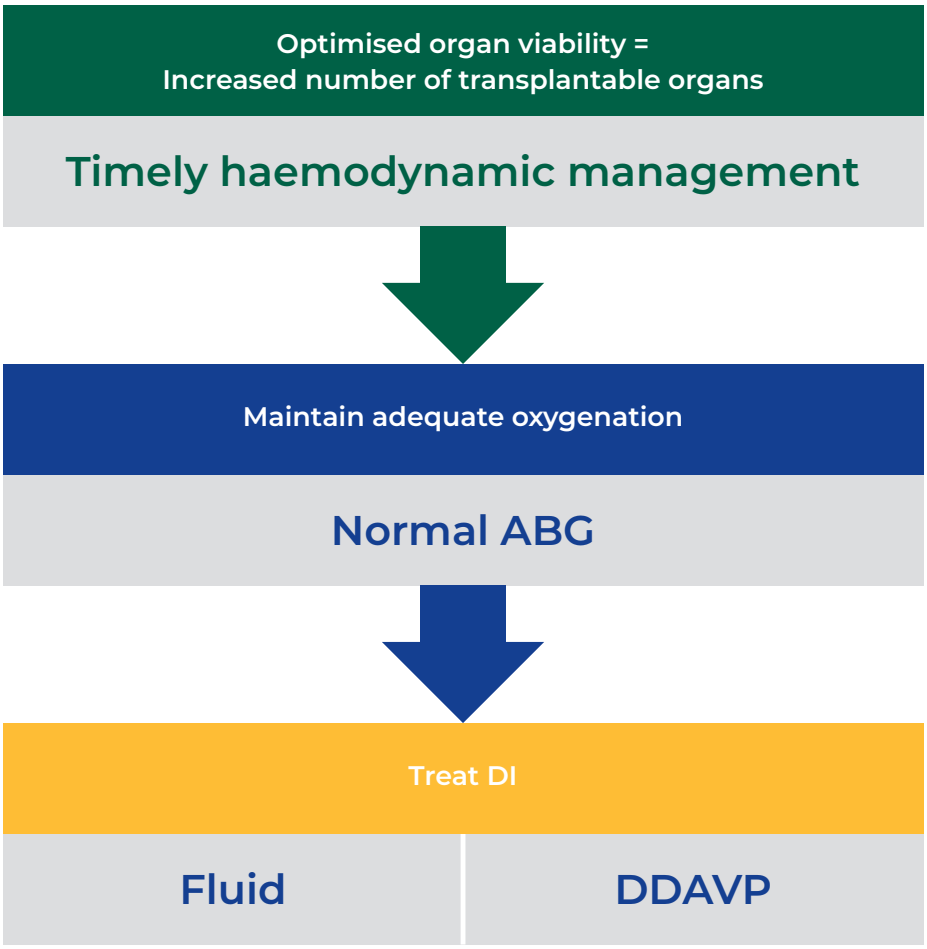
Objectives:

- Preserve the donor's corneas for transplant

Management:

- keep the eyes closed.
- moisturise when needed with saline-based eye drops.

6.2 OPTIMAL DONOR MANAGEMENT FLOWCHART



THE TRANSPLANT COORDINATOR WILL ADVISE ON BEST PRACTICE REGARDING DONOR MANAGEMENT; DON'T HESITATE TO CALL.

6.3 ORGAN DONOR MANAGEMENT SUMMARY

Objective: Maintain adequate oxygenation and perfusion

Ensure organ viability for excellent transplant outcomes

Maintain adequate oxygenation

Intubated and ventilated

Sat > 90%

PO_2 > 60 mmHg

Normal CO_2 values

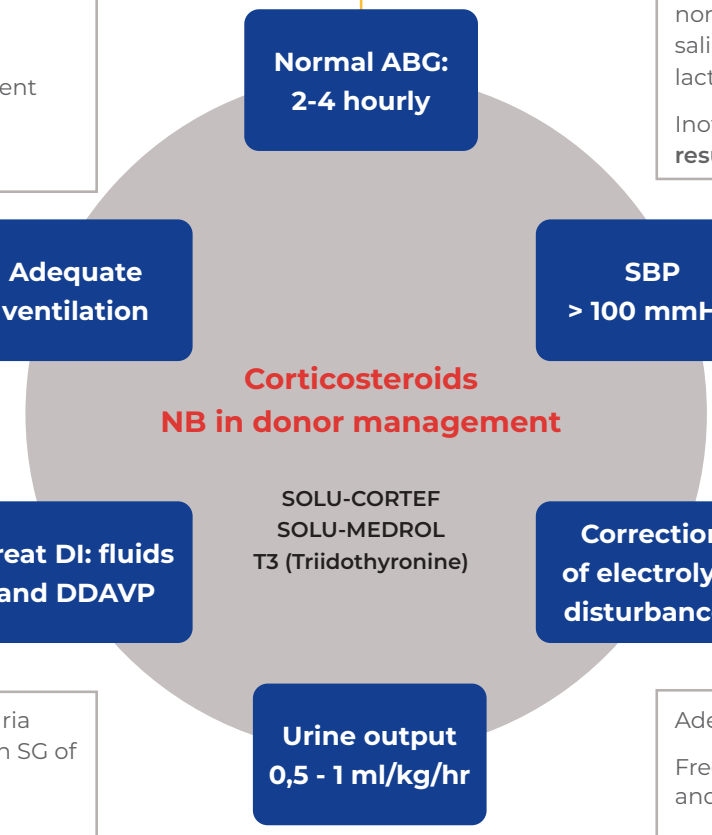
For organ donor management no sedation or analgesia is administered

Maintain normal pH

Correct all abnormalities

Give fluids for example 0,9% normal saline, 0,45% normal saline, 5% dextrose, Ringer's lactate or Balsol

Inotropic use with **adequate fluid resuscitation**



Appears as hypotonic polyuria > 4 ml/kg/hr of urine with an SG of less than 1005

Treat STAT

- Replace urine vol / vol hourly
- Replace electrolytes as required
- DDAVP is essential but is given with caution!

Adequate fluid resuscitation is NB

Frequent imbalances of K+, Na+ and CMP can occur

Potassium lost in excessive diuresis, replace K+

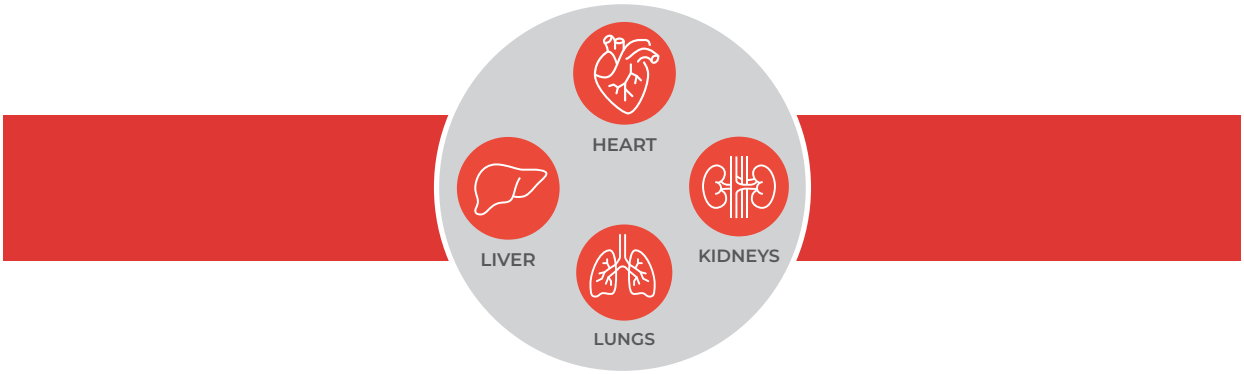
Sodium increases with brain injuries, treat hypernatremia with tap water via NG tube

If you have any questions, please don't hesitate.
CALL YOUR TRANSPLANT COORDINATOR FOR ASSISTANCE.

7. LONG DISTANCE REFERRALS

A ***long-distance referral*** is defined as the referral of a potential organ and tissue donor to a transplant centre, or a tissue bank, outside of the immediate area where the donor is located.

We encourage early referral so that we can assist you and your team with potential donor management, step-by-step guidance, and any support you may need. Teamwork is key. Optimal donor management contributes to the recovery of viable organs and tissue, which increases good transplantation outcomes.



To assist you with referrals, please see INFORMATION CHECKLIST FOR POTENTIAL ORGAN DONOR REFERRAL on page 46.

For **organ donation**, the information required by the transplant team about the potential organ donor, is essential to make informed decisions and to support and guide you and the team. It is crucial to maintain the viability of organs so that the grateful recipients who will receive the gift of life, have the best possible outcomes. You and your team play a vital role in saving lives and we are a phone call away. Please call your nearest transplant centre for assistance.

Once you have identified a potential organ donor, the transplant coordinator will need the following details:

- your name (the referrer), designation and telephone numbers
- the name, location, and telephone number of the hospital where the potential donor is
- the unit's name and telephone number
- the name of the potential donor's medical doctor and his/her contact number(s)
- the name, surname, age, and gender of the potential organ donor.

To facilitate the organ donation process, the transplant coordinator will ideally need the following information (please supply whatever information you can. Refer even if all the information is not immediately available.):

- the time and date of admission
- the cause of brain death
- time of brain death certification
- estimated height and weight of the donor
- blood group
- test results for HIV; hepatitis B and hepatitis C; and RPR if available
- a description of the condition of the donor (especially blood pressure, urine output, inotropes, etc.)
- any other relevant information such as other injuries, additional blood test results, etc.

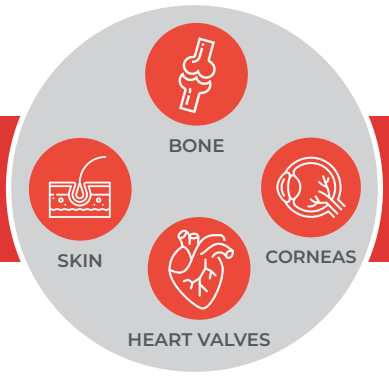
What happens next?

After a comprehensive discussion, the transplant team will be able to determine the suitability of the potential organ donor for donation. Once the transplant coordinator has confirmed that the potential donor is suitable, consent for donation must be obtained from the next of kin. Please refer to Family Approach and Consent on page 38 for guidance.

Should the patient not be suitable as an organ donor, the transplant coordinator will inform you. He/she will normally also refer the patient as a potential tissue donor to the tissue coordinator. Please ask if the tissue donation referral was done and if not, please contact your tissue donation coordinator. He/she will engage with the family to discuss and obtain consent for tissue donation and make all the necessary arrangements for tissue recovery.

You should continue to support and assist the family as you would for any other end-stage patient.

THE TRANSPLANT COORDINATOR WILL STAY IN CONTACT WITH THE REFERRER THROUGHOUT THE PROCESS TO SUPPORT, ASSIST AND ADVISE.



There is a constant shortage of tissue donors in South Africa and every referred death can make a difference.

Potential tissue donors are referred at the time of death and can even be referred post-mortem. Unlike organ donation, there is a little more time for tissue recovery.

The process is simple and easy. To refer a potential tissue donor, call the tissue donation coordinator for your area. Have the following information on hand:

- your name (the referrer), designation and telephone numbers
- the name, location, and telephone number of the hospital where the potential donor died and the unit the person was admitted to
- the name, surname, and ID number of the deceased, or if the ID number is not available, the age and gender of the deceased
- the date of admission to hospital
- the reason for admission
- the date and time of death
- the cause of death
- the name and contact details of the next of kin (**Please Note:** this is the person who was informed when the patient died and is not always indicated on the patient's file)
- the relationship between the next of kin and the potential donor (father, mother, wife, husband, etc.)
- if the body has already been moved to a funeral home - the name and telephone number of the funeral home

If more medical information is required to assess donor suitability, the tissue donation coordinator will request it.

The tissue donation coordinator will contact the next of kin to explain tissue donation and ask for consent to recover tissue. If the family consents, he/she will arrange tissue recovery at the most suitable location and keep the family informed.

CHANGE THE ENDING TO SOMEONE'S STORY. PLEASE REFER.

8. FAMILY APPROACH AND CONSENT

8.1 CONSENT FOR ORGAN DONATION

Organ donation cannot take place without consent from the family. Having a productive and compassionate conversation about organ donation requires preparation, careful orchestration, warmth, and empathy.

Wits Transplant has developed the **Wits Transplant Procurement Handbook**, which is a practical guide to organ donor procurement.

The handbook contains the ***'Family approach to consent for transplant strategy (FACTS)'*** which details how to plan for the family discussion; break bad news; assess understanding; have the consent conversation; as well as provide continued support and feedback to the donor family.

It is an invaluable resource, and we include the ***FACTS*** excerpt for your reference in this section (pages 10 to 24).

A digital copy of the complete **Wits Transplant Procurement Handbook** is available for download free of charge, at
http://www.dgmc.co.za/docs/Wits-Transplant-Procurement-Handbook.pdf

For ease of reference, please use the mini-index of the excerpt below.

Wits Transplant "Family approach to consent for transplant strategy" (FACTS)

Wits Transplant FACTS is a programme of structured communication for approaching families and seeking consent for deceased organ donation. FACTS is an adaptation of The National Health Service Blood and Transplant Group (NHSBT) strategy for "Approaching the Families of Potential Organ Donors" [1]. It's been modified to suit our South African healthcare setting.

This section is intended as a practical guide for any procurement coordinator wanting to implement Wits Transplant FACTS in their practice. As with all communication, your individual personality, the hospitals in which you work and the dynamics of the family from whom you are asking consent may require that this strategy is adjusted to suit your needs. Furthermore, your clinical considerations will differ depending on the situation of each patient.

That said, there are some aspects of FACTS which, based on our experience, are essential to ensure the best chance of converting that referral into a consent from the family.

These are marked with an ⚠ SIGN.

FACTS is an 8-step process, and each step is described in enough detail for you to replicate. There is also a **quick access guide** to FACTS on the last page of this Handbook.

Wits Transplant FACTS Overview

Planning the approach

Formulate a strategy for approaching the family, involve staff who may be able to assist. Discuss introduction of the TPC with the management team. **If an interpreter is being used, involve them at this point.**

Breaking bad news

Dr informs family that patient is brain stem dead, then hands over to the coordinator who is introduced as a "nurse who helps us in these situations". NB for doctor to use words that leave no doubt that BSD is death. Preferably done in a private space away from the bedside.

Give family privacy and time to reflect. Encourage spending time with loved one at the bedside. Do not mention anything about organ donation at this stage.

Assessing understanding

Regroup with family in a private space. Assess their understanding of the patient's situation. The family must understand and accept the BSD diagnosis before moving to a discussion about organ donation.

Consent conversation

The coordinator introduces the concept of organ donation, listens to family's concerns and answers their questions in a supportive and empathetic manner.

Give the family some privacy to discuss their decision amongst themselves. Excuse yourself from the room and tell them you will be waiting for them to get back to you at the nurses' station.

Final family discussion

Regroup in private and ask family for their final decision. Address common concerns and respect all family requests. Continue giving support irrespective of the final decision. **If family consents, explain the "donor pause" and ask family if they would like to be present.**

Follow-up and feedback and support

Continue to update the family and referral team after the organ retrieval and transplant has taken place. Advise them on next steps and notify them about the organs used.

This figure is a basic depiction of Wits Transplant FACTS. Much more detail is provided in this section. The primary steps of the NHSBT process are in green. The main changes that we have made are highlighted in orange.

Wits Transplant FACTS Step 1 - Planning

Planning starts the moment that a potential organ donor is referred. Planning is key as it allows you to assess eligibility of the potential donor and formulate your strategy for how to approach the family. We recommend involving as many members of the multidisciplinary treatment team in the planning process as possible. This will ensure the family receives optimal support.

Effective planning – Involve the treating team

When accepting a referral telephonically, give the referring party an idea of the kind of information you will need to carry the referral forward.
⚠ **Tell the referring party that neither they, nor anyone else, should mention the phrase "organ donation" to the family.** When you arrive at the hospital, the first thing you should do is to gather the essential clinical information you will need to proceed with the organ donation approach, which is detailed on **page 25**. The doctors, nursing sisters and supporting staff who have been treating the potential donor will be able to assist you. The more information gathered during the planning phase, the more accurate your approach will be, and optimal family support can be given.

Enable effective planning by ensuring that staff in the treating team feel like valued participants in the family approach process. Take time to explain your strategy to the staff and to answer any questions they might have. This will give members of the treating team the opportunity to align their views towards the shared goal: Presenting the possibility of organ donation to key family members.

Explain exactly how, where and when you would like to approach the family. This will help the treating team understand and agree on who is going to do what, and when. It will also help to provide insight into why this is done in such a way.

⚠ **It is important that families are approached at the appropriate time, in the appropriate manner and by someone with the appropriate skills – that is – YOU! The procurement coordinator.**

⚠ **The planning stage is a great time to make sure that everyone in the treating team is on board with the idea of organ donation. If anyone seems to be against organ donation, it would be best if their interaction with the family were limited as much as possible.**

Effective planning – Will you need a translator?

If you can't speak the first language of the family you are planning to approach – something that happens often in South Africa – you might need to engage a translator to assist you in communicating with the family. If you are using a translator, it is essential that the right person is chosen for this important role. You need someone who is compassionate and caring, ideally with a medical background. It is also helpful to have a translator with whom you have built a relationship, and who is supportive of organ donation. You should include the translator from the beginning of the planning phase, and the role of the translator must be made very clear. A doctor or nursing sister who is part of the treating team, and who volunteers to translate as well, would also be a good choice provided the family trusts them, you trust them and they are in favour of organ donation. Another person who would make an excellent translator is a Transplant Ambassador (see **page 9**).

Effective planning – Ask these key questions!

1. Who are the key family members and what are the "family dynamics" between these members?

2. What language is the family most comfortable speaking? What language will they best understand Can your translator speak this language?

3. Are there any socio-cultural or religious practices that are important to the family? If so, you might need to involve additional resources like a faith representative.
   ⚠ **Even if it seems that there are socio-cultural or religious issues, don't let this put you off! We have been in many situations where sensitively exploring these issues has changed a family's decision about organ donation.**

4. When is the best time to meet with the family? At what times of day are all (or most) key family members usually present?

Effective planning – The next steps

Once you've gathered all the necessary information in a proactive and inclusive manner, it's time to organize a meeting with the family. Try to secure a private venue – away from the patient's bedside – at a time that will be most convenient for the family. Ask a member of the treating team to invite key family members.

⚠ **It's essential that this meeting does not happen at the bedside. As we know all too well, it can be difficult to get a private venue at some hospitals. However do your utmost to make this happen. If you can avoid "corridor consultation" try to do so.**

Checklist for the first family meeting

✓	Stable hemodynamics
✓	Cause of brain-stem death confirmed
✓	No analgesic or sedative infusions given in the last 24 hours. (No analgesic or sedative boluses given in the last 12 hours)
✓	No clinical concerns pending
✓	Brain-stem death tests done and confirmed irreversible
✓	Patient`s potential for donation confirmed with transplant team
✓	Approaching team include: • Doctor • Nursing sister • Transplant coordinator • Trauma counselor – if available • Translator – if applicable • Faith representative – if applicable
✓	Each member of the approaching team understands exactly who is going to do what and when
✓	Distraction free appointment secured in a private space away from bedside. Corridor consultation should be avoided if possible
✓	Key family members identified and invited to family meeting

Wits Transplant FACTS Step 2 - Breaking Bad News: "Brain death is death"

Even though families may have been updated about their loved one's condition on a number of occasions, it's our experience that they often don't really understand just how serious this condition is. The most important part of the "Breaking Bad News" phase of FACTS it to make sure all family members have been told about how serious the condition of their loved one is. This conversation gives you the opportunity to ensure that family members have a common understanding of what has happened to their loved one, and the reality of the situation. This conversation can be really difficult, because it has to be frank and to the point, but it is also very important to make sure that you are professional, compassionate and caring.

⚠ **The treating doctor must lead the conversation in which key family members are informed that their loved one has died. Make sure the doctor realizes that it is important to emphasise this. "Brain death is death. The patient is already dead". It is vital to be direct and unambiguous, and leave no room for false hope or 'miracles'.** Once the doctor has broken the bad news to the family, they should hand over to the transplant coordinator.

⚠ **This handover is a very important part of the FACTS process, and it is discussed in more detail on Page 15.** Throughout the breaking bad news conversation, and afterwards, make sure there is someone on hand to support the family emotionally. This should be done by you, but can also be done by the nursing sister, trauma counselor, faith representative or any other key person where applicable.

Breaking bad news – Some key points for a productive and compassionate conversation

- The doctor, nursing sister, transplant coordinator, trauma counselor, translator, faith representative and any other essential person (as applicable) should be present at the meeting with the key family members at the set time.

- Try and ensure there is enough seating for everyone.
  ⚠ **This sounds strange, but it is important. If some people are sitting and others are standing, it may seem that you are "looking down" at the family. If you can't get enough seating, then all stand. You can also use props as seats, storage boxes etc.**

- Bring a good supply of tissues, and your most supportive, compassionate self. This should be standard of care.

- ⚠ **The most important part of the meeting is when the doctor breaks the bad news, and leaves no doubt that "brain death is death"** (See example on **Page 16**)

- ⚠ **Do not mention anything about organ donation in this conversation. The family is not ready to deal with the option of organ donation now. Organ donation should not be discussed until the family has accepted the reality of the clinical situation. See the Section entitled "Examples of individuals who are accepting of their loss" on page 18 for a guide.**

- After the doctor has broken the bad news, they should hand the meeting over to the transplant coordinator.
  ⚠ **The doctor should never introduce the coordinator by their title (transplant coordinator). Rather, just use the name of the coordinator at this stage**. In introducing the coordinator, the doctor should make it clear that they are part of the medical team. (See examples on **Page 15**).

Breaking bad news – Helping doctors achieve the best result from this conversation

As health professionals – whether doctors, nurses or in the allied disciplines – we all understand that telling a family that their loved one has died under our care is a very difficult thing to do. Sometimes, it makes us feel that we have "failed" in our main calling, which is to cure patients. Because this conversation can be so emotional and uncomfortable for so many of us, here are some pointers that can help the doctor get the best result.

Helpful Hints for Doctors

- Start off by asking the key family members what they already know about the condition of their loved-one, and what they understand this to mean.
- Use visual aids like the patient`s scans or diagrams to explain and demonstrate the extent of the injury.
- Avoid medical words. Unless the family who has some medical background, try to use simple language that everyone will understand. (For the coordinator - if you feel a doctor is getting too technical, join the conversation – and make things simpler).
- Give a warning shot before breaking the bad news (see example on Page 16).
- Speak frankly but compassionately.
- Allow moments of silence as this gives the family time to process the message that has ust been given to them
- Encourage the family to ask questions
- ⚠ **Avoid words like "life-support" or phrases like "machines are keeping him / her alive".**

Breaking bad news – Immediately correcting misunderstandings

⚠ **If family members use words like "life-support" or say that machines are keeping the patient "alive" this is a clear sign that they have not understood the finality of brain stem death.** This should act as a trigger that you need to spend some more time explaining the concept of brain stem death to the family. Gently correct the family in their understanding and explain that the machine is merely supporting the loved one's organs by delivering oxygen to his/her body. Confirm again that their loved one is already dead.

Offering to demonstrate the brain stem death tests at the bedside can be helpful. Some family members will appreciate the opportunity to witness the testing and it will be a confirmation of what was just explained to them. Others might decline the offer because they feel it will be traumatic to witness, and that's fine.

Breaking bad news – The family has already accepted what's happened

Sometimes families might have already accepted and fully understood that their loved one has died before this meeting takes place. These families may be ready to move naturally to Step 5 of FACTS – the consent conversation. However, this is the exception to the rule and not recommended.
⚠ **A good rule of thumb is that the possibility of donation should only be discussed in the "Breaking Bad News" meeting if the family initiates the conversation.**

Breaking bad news – How to Introduce the transplant coordinator

⚠ **Organ donation should not be discussed until the family has accepted the reality of the clinical situation of their loved one. Therefore it is best if the transplant coordinator is introduced by his/her name and as part of the medical team at this stage. The term "transplant coordinator" or "organ donor coordinator" should not be used. At this stage the family is not ready to deal with organ donation or transplantation and avoiding these words is a form of respect for the family.**

Example on how to introduce the transplant coordinator, adapted from the NHSBT:

Dr: "Mr and Ms Mtembu, let me introduce you. This is Rebecca Makoti, she is a nursing sister that we often call in to help us support families in situations like these. Joseph is our trauma counselor and Victoria you know, our ICU nurse. She will also translate if there is something that you don`t understand"

Breaking Bad News – Some examples adapted from the NHSBT

Dr: "We have talked yesterday about Mandla`s injuries – can you perhaps tell me what you can remember about that conversation?

What do you see when you look at Mandla?"

——————

Dr: "We have done the brain-stem death tests on Mandla this morning. As I explained to you yesterday, the reason we do these tests is to see if there is any brain activity, if the brain is still working or not". **(PAUSE)**

Unfortunately I have got some devastating news. **(WARNING SHOT)**

The tests we have done this morning confirmed what we suspected. **(PAUSE)**

There is no brain activity in Mandla`s brain. Mandla`s brain is dead, he is brain dead. **(PAUSE)**

This doesn`t mean he is going to die, or that he might die, it means that he is already dead, I am so sorry". **(PAUSE)**

Wits Transplant FACTS Step 3 – Time-Out Break

After receiving bad news, it's important that you support families by just being there for them. They may need time to calm down, and that's fine, just be there in whatever way you can. After the family has calmed down, encourage them to spend some time with their loved one, give them some privacy and as much space as they need.

This "time-out break" (also known as decoupling), allows the family to reflect on the clinical reality of the situation and gives them an opportunity to come to terms with it. Don`t underestimate how much time families need to reach a state of acceptance that a loved one has died. This is their moment and it is important to respect that.

Showing support – Small gestures and careful words are key

✓	Encourage the family to spend as much time as they need with their loved one.
✓	Give the family some privacy.
✓	Comfort them as much as you can.

Time-out break – An example of what to say, adapted from the NHSBT

"I can see that you are finding this really difficult. I am sure you need some time on your own. I will come back a bit later or you can find me in ICU if you need me."

Medical management during the time-out break

During the time out break, families will likely be at the bedside of their loved one, and members of the treatment team will be entering and leaving the bedside.

⚠ **If you have a family who has not accepted the finality of brain death, it is very important that the treating team do not confuse them by using language that suggests there is still hope.** Sometimes this is done knowingly, by staff who do not support organ donation – and in those cases there isn't much you can do. But we have found that in these situations, the best thing to do is address this issue with the treatment team in the planning stage, so everyone is on the same page.

Wits Transplant FACTS Step 4 – Assessing Understanding and Acceptance of Loss

Once the family has had time with their loved one, and to process the bad news, you need to assess whether they have accepted that their loved one has died. At this point, you should secure a second family meeting where you can discuss these issues,

and what will happen next. The format of this meeting should be the same as the breaking bad news meeting (**Page 14**). As with all these interactions, be professional, compassionate and caring. The conversation to assess understanding and acceptance should include the key family members and the transplant coordinator, nursing sister, trauma counselor and translator (if applicable). The transplant coordinator or trauma counselor can lead the conversation.

⚠ **A great way of assessing acceptance is to encourage family members to tell the story of what happened to their loved one, what the doctor told them and what that conversation meant to them. Also encourage the family to tell you a bit more about the patient, who s/he was and what special role s/he played in each of their lives. Observe the body language of the family, listen carefully to words they use and what questions they ask. This will give a clear indication whether all of the members involved are on the same level of understanding and acceptance.**

If you feel that some family members have not accepted their loss, continue to support them. It`s possible that the conversation of breaking bad news (Step 2) and the time-out break (Step 3) must be repeated.

Assessing acceptance – Uniting the family

Often family members will accept the reality of their situation at different times, and it may take some longer than others. Sometimes, those family members who have accepted their situation will naturally move over to discuss the option of switching off the machines without any member of the medical team mentioning it.

⚠ **If it is clear to you that not all key family members have come to terms with their loss, rather confirm that the conversation about the machines will be discussed at a later stage and not right now.**

Checklist – Some key points for assessing acceptance

✓	Ask family members to tell the story of what happened to their loved one
✓	Find out what they can remember from the conversation with the doctor
✓	Make use of open-ended questions (see examples below)
✓	Observe the family's body language during this conversation
✓	Encourage all key family members to actively participate in the conversation
✓	Listen carefully to what they say and what questions they might have
✓	⚠ **Do not mention anything about organ donation at this stage. It should not be discussed until all key family members have accepted the reality of the clinical situation.**
✓	Continue to support individuals who have not come to terms with their loss, and repeat steps 2 and 3 of FACTS if necessary.

Assessing acceptance – Some open-ended questions from the NHSBT

"I know you have been through a great deal in the last few days, but can you briefly tell me what happened to Mandla?"

"What can you remember from your conversation with the doctor earlier today, that we had at the meeting?"

"You say the doctor said that Mandla is brain dead. What does it mean to you?"

Assessing acceptance – Some trigger words and phrases

The words and sentences a family uses during this meeting will give you a sense of whether they are coming to accept the finality of their loved one's situation. In the section below, we give some examples from conversations with donor families that we hope will help you. Names have been changed.

Examples of individuals who are accepting of their loss

"I know Mandla is not with us anymore, I can see it in his eyes"

" I will miss my husband so dearly ... when will you switch off the machines?"

"It's just her body that is lying in that bed, her soul is already gone"

"Who will give us the death certificate?"

"My husband died two years ago ..... This is not the first time I stand next to a death bed"

"What is going to happen now? When must we start with the funeral arrangements?"

"She is dead, I know the doctor did explain it to us. As soon as this drip is finished her heart will also stop"

Examples of individuals who haven`t come to terms that their loved one has died

"I heard what the doctor said but I refuse to believe it, my son will get better, he will wake up and he will walk out of this hospital!"

"Don`t speak like that! She can hear you! I demand that only positive words and positive energy enter her cubicle! Do you understand me sister?"

"I believe in miracles! He believed in miracles! My dad will wake up, I believe it!"

"I will not give anyone permission to switch off the machines! This will not be on me."

Wits Transplant FACTS Step 5 – The Consent Conversation

⚠ **The transplant coordinator is the best person to lead the consent conversation and to discuss the possibility of organ donation with the family. It is crucial that the consent conversation only occurs when it is clear the family has come to terms with the loss of their loved one.**

Approach the consent conversation as though none of the family knows about organ donation. Some of them might have heard of it, but this might not be true for everyone. This means you should provide specific information before expecting a response. A clear explanation of the process of organ donation and retrieval, possible interventions between consent and organ retrieval and when and where organ retrieval will take place is essential [1].

⚠ **Listen carefully to the common concerns and questions that families express at this time, these concerns often emerge later on as reasons for refusal [1].**

The consent conversation – Some key points

We strongly recommend that you follow this checklist when asking for consent.

✓	Be compassionate and always use positive language to describe donation
✓	Do not use any form of negative or apologetic language
✓	Do not use manipulative or coercive language
✓	Give a warning shot
✓	Explain to the family that their loved one can save and transform several lives
✓	Focus on the patient's donation potential and the specific benefits that this will bring to the recipients, their families and society in general

✓	Assure the family that the primary focus is always on the care and dignity of their loved one, whether donation occurs or not.
✓	Reassure the family that you or one of your team members will be with their loved one until the retrieval process has been completed
✓	Assure the family that when it comes to a donation decision, there is no wrong answer
✓	Explain the legislation and logistics regarding unnatural death, if it is applicable to the patient (More on page 25).
✓	Address family questions and concerns in a knowledgeable and sensitive

The consent conversation – Some examples from the NHSBT of what to say

- "I would like to talk to you about something you might not be expecting and that is organ donation. Mandla has the opportunity to be a hero to many people today. He can save and transform the lives of so many people."
- "Just like you have been sitting next to Mandla`s bed the past few days, there are also families sitting next to their mothers, fathers, brothers and children`s beds. The difference is that these patients have end-stage organ failure and their only hope is a heart transplant, lung transplant, liver transplant or a kidney transplant."
- "How do you think Mandla would feel about organ donation, about saving lives?"
- "Imagine Mandla was sitting here now and we could ask him if he would like to save lives, if he was willing to give hope to a mother who`s child is busy dying. What do you think Mandla would say?"
- "Donation is often a decision the family makes on behalf of their loved one."

The consent conversation - What NOT to say

Avoid any form of negative, apologetic or coercive language such as:

- "According to the hospital policy I must ask you about organ donation. Believe me, I don`t want to do it, but I must"
- "I am so sorry to do this to you but I must ask you if you want to give his organs away .... those people just come and take the organs and go"
- "It`s your fault that she died, it`s better if you agree to donation then at least you did one thing right"
- "You know that organ donation is the right thing to do"

Wits Transplant FACTS Step 6 – Time-Out Break

After you've raised the possibility of organ donation in the consent conversation, give the family your contact details and then give them another "time-out" break. This helps to ensure that family decision-making is done in an unhurried fashion and in a supportive atmosphere. As with the previous "Time-Out Break (FACTS Step 3) you should excuse yourself from the room and wait for the family at the nurses station. This will allow the family to discuss the possibility of organ donation in private and come to a decision that they are all in agreement and comfortable with.

Wits Transplant FACTS Step 7 – Final Family Discussion

This is the point where the family will inform you about their decision on organ donation. When the family consents to organ donation, verbal consent needs to be followed up with written consent. Answer questions in a knowledgeable, caring

way and respect family requests and limitations, if any, on how organ retrieval takes place and what organs and tissue they agree to donate.

⚠ **In the case where a family has given consent, explain the "donor pause" (explained on Page 24). Invite the family to be part of the donor pause at the bedside at a time that suits them best. It's also important to explain possible reasons why organ donation may not take place, even if consent is granted.**

Family decision – Support throughout the process

If you've followed Wits Transplant FACTS to this stage, you will probably be getting tired and feeling worn-out. The family may be in a state of inconsolable grief. At this point, it's easy to think to yourself, "I'll just leave the hospital and speak to the family over the phone".

⚠ **By leaving at this stage, you aren't supporting the family throughout the process, and it's very important that you are there for the family until they have made their decision. If the family needs time to think about their decision overnight, set-up another meeting at a specific time the next day, in a pre-arranged venue and make sure all the key family members can attend.**

If you have a family who seems to be stalling on deciding, first give them another time-out break. Then, approach them again. Tell them that the machines will be switched off, and that before they leave the hospital it's very important that they come to a decision about organ donation.

Family decision - Exploring an initial refusal

⚠ **When the family does not consent to organ donation, it is reasonable to explore the reasons for their decision, as it may be based on misunderstanding, insufficient information or on remarks taken out of context. [1]**

Even if a family has told you that their loved one was "against" organ donation, you can spend some time exploring whether this was a firm and lasting belief. Some examples of how to explore a "no" to organ donation are outlined below, and these are based on our experience.

Exploring an initial refusal – Family does not want surgery on the body

Some families say "no" to organ donation because they are wary of what the retrieval surgery will do to the body of their loved one. This should be acknowledged as a very understandable and instinctive objection. Address it by gently explaining that their loved one is dead and cannot possible feel anything, that the greatest of respect and care for them will be shown until the retrieval process has been completed. For some patients for whom a postmortem will be required it may be pointed out that a procedure will be performed in any event. You should also tell the family that in this case, the body of their loved-one will not be disfigured.

Exploring an initial refusal – Family states that the patient did not want to be a donor

Sometimes, families have had serious conversations with their loved ones about whether they would like to be organ donors [1]. If this is the case, then it's important to respect this decision. However, it might be that the person made a statement against organ donation without really considering the implications, or having all necessary information. It is unlikely that an individual would want a decision of this magnitude to rest on this type of remark. If you are in this situation, it's a good idea to explore the "no" in more detail. Here are some examples of questions to ask:

"You mentioned that Mandla had said he was not happy to donate his organs. Can you remember why not? Can you remember the conversation you were having when he told you this?"

"You mention that you saw an article in YOU magazine that made you feel very worried about organ donation. Can you tell me what worried you? What was the article about?"

Wits Transplant FACTS Step 8 – Family follow-up, feedback and support

It's important to carry on providing support to a family even when they don't consent to organ donation. Also, remember to inform the referring team, doctor, nursing staff, trauma counselor and any other personnel who have been involved about the family's decision. This is an opportunity to follow-through, and thank the staff for all their hard work.

For families who consent to organ donation, regular telephonic updates should be given to the family's appointed spokesperson when the retrieval process has been completed. Once transplants have taken place, let families know what organs were used for transplant, and which were not used

⚠ **Sharing this information is very important to facilitate the grieving process for families, it gives them closure and allays any uncertainty about the donation process they may have.**

For families, it is reassuring to know that "his lungs are in the body of a 25 year old, and his liver was split between two patients, but they couldn't use his kidneys because of a medical condition".

Throughout the post-consent process, special attention must be given to any requests that the family made. These requests might be anything from taking a rose with you to theatre, that the retrieval process be completed before 08:00 am the next morning or to have the body back at a certain time in order to have the funeral at the weekend.

After the consent - Following up and saying thank-you

A follow-up thank you letter should be sent the donor family. This is a great opportunity to tie up any loose ends about which organs were used and to answer any additional questions the family had.

⚠ **Families often want detail about whom the recipients of the organs. You need to balance the information you share – not enough that the recipient can be easily identified, but enough to satisfy the needs of the family.**

This is especially important in today's social media age, where it is very easy to find the identity of a recipient by posting on Facebook or Insta! There will be someone who knows someone.... Feedback about tissue donation will be a more general approach in the letter.

⚠ **Recipients should be encouraged to write anonymous thank you letters to donor families. There is nothing more special and sincere than a recipient saying thank you to a donor family.**

Follow-up should not only be for the family, but also the team from the referring hospital. Hand-delivered thank you letters for the primary attending doctor, the referring hospital, unit and theatre where the retrieval took place have big impact, but require very little effort on your part, considering you will be visiting the hospital in the near future to do some training.

Phone calls to check in with the donor family are recommended at intervals, and it's up to you to decide when these should take place. It's also good to recommend a family trauma counselor to assist with the grieving process if the family are struggling.

WITS TRANSPLANT FACTS – KEY DO'S AND DON'TS

Step 1: Planning	
Do identify and refer potential donors to the transplant coordinator as early as possible.	Don't withdraw mechanical ventilation or stop treatment to maintain optimal organ perfusion until the patients' donation potential has been assessed.
Do involve the transplant coordinator from the start of the planning phase.	Don't give misleading information to the family regarding the clinical situation of the patient.
Step 2: Breaking bad news – brain death is death	
Do introduce the transplant coordinator by name only, and as part of the treating team.	Don't mention the words "organ donation" or "organ transplant". Donation should not be discussed until the family has accepted the reality of the clinical situation.
Do let the Dr lead the conversation of breaking bad news, that brain dead is death and then hands over to the coordinator. Use words that leave no room for any doubt that brain death is death.	Don't use words like "life-support" or "it`s just the machines that is keeping him alive now". There must be no doubt that brain death is death, the patient is already dead.
Do make use of visuals like scans or diagrams to explain and illustrate the extent of injury and explain the brain-stem death tests.	Don't use medical terminology.
Step 3 - Time-out break	
Do a "time-out break" after breaking the bad news.	Don't discuss brain-stem death diagnosis and the possibility of organ donation in the same family meeting.
Step 4 - Assessing understanding and acceptance	
Do assess that all key-family members understand and accept their loss before having the consent conversation.	Don't mention anything about organ donation till you are sure family members understand that their loved one has died.
Step 5 - Consent conversation	
Do display compassion and always use positive ways to describe organ donation	Don't use negative, apologetic, manipulative or coercive language with a potential donor family.
Do address questions and concerns in a knowledgeable and sensitive way.	
Step 6 - Time-out break	
Do allow the family time to discuss the possibility of organ donation in private and come to a decision that they are all in agreement and comfortable with.	Don`t expect a response immediately after specific information was given on organ donation
Step 7 - Final discussion	
Do explore initial family negative responses, as these may be based on misunderstanding, poor information or on remarks taken out of context.	Don't stop supporting the family.
Do obtain written consent for donation.	
Step 8 - Family follow-up, feedback and support	
Do send thank you letters and follow up with families and referring hospital.	

Wits Transplant FACTS Trouble-shooting

Sometimes, even if you follow Wits Transplant FACTS as closely as possible, you'll still run into situations where you need to improvise – **a lot**. Here are some common scenarios that we have experienced.

Scenario 1 – Family is under the impression that they must make the decision to switch off the life support machines.

Although there are different approaches in private and state sectors on when a ventilator is switched off, it is not the role of the family to make this decision, nor is it fair to expect them to do so. If you have a family who believes that the organ donation conversation is a roundabout way of asking them to decide about the machines, you must correct this misunderstanding. Explain that their loved one is already dead, reiterate that 'brain death is death' and tell the family that they don`t have to make this decision. The reality is that, because their loved one is deceased, the machines will be switched off. The only reason why the machines have not been switched off yet is to give the family some time to say their goodbyes and to make a decision on the possibility of organ donation.

By taking this approach, you remove the pressure that families may feel if "we must make a decision to switch off the machines". This leaves families free to consider the possibility of organ donation without feeling guilty that their decision might contribute to their loved one`s ultimate demise. Even if a family has accepted their loss, it is still very difficult to see a loved one on a machine. The loved-one still feels warm, has a heartbeat and passes urine. When the machine is turned off, the loved-one will go cold. So it's understandable that families find this situation difficult, and it's best if they know it's not their decision to make.

Scenario 2 – The family is in dispute about organ donation

In South Africa we often see very big families, and they don't always agree with each other. It's very possible that you will find yourself in a situation where some family members agree to organ donation and others do not.

⚠ **In this situation, it's very important that you help the family to reach a decision. Whilst you might be tempted to leave the hospital and give them more time to discuss the matter, this is not a productive approach.**

Disagreement over donation should be sensitively explored, particularly if the disagreement is because of a misunderstanding or family conflict. Families in conflict with each other should be reminded that donation is one decision they need to address now. Make it clear that this decision is about their loved one. What would the loved one have wanted? How would the loved one feel about helping others?

Here is an example of what you can say in this case, from the NHSBT:

> **"It sounds like there are things that you are going to have to sort out in the days and months to come. There are a lot of decisions to be made around Mandla. One of these immediate decisions is about organ donation. Before you leave this hospital today you must come to an agreement on what Mandla would have wanted. This decision is about Mandla and not about any family conflict or family fight. This is not the place or the time for those arguments."**

The Donor Pause

The donor pause is a silent prayer or contemplation and it's often used in South Africa. It`s a humble gesture of respect towards the donor and the donor family, thanks for their selfless decision and acknowledgement of the life of the donor. We usually do two donor pauses, the first in ICU and the second in theatre before organ retrieval starts. The donor family should be invited to be part of the donor pause in ICU. The donor pause is scheduled at a time that suits the family if they want to be there.

Not all donor pauses are alike. Sometimes it`s only a minute or two of silence. In other donor pauses the nursing staff might sing a song. A short poem can also be read before the donor pause. We like to read this poem from **"The Dreamer"** and we have adapted it a little for this purpose:

"In the seconds before sunrise

In the pause before the climax

In the dark before the light

In the bare before the beautiful

In the last quiet breath before the moment that will take our breath away with the miracles that will soon follow,

let`s have a moment of silence in honor of the donor and the donor family as it takes a truly special person and family to think of others when you are in the middle of your biggest tragedy."

8.2 CONSENT FOR TISSUE DONATION

A donation conversation usually occurs at a difficult and intensely emotional time for families.

Specific knowledge is required to support families and their decision-making at this time, and it is critical that information is provided in a clear and sensitive manner that is appropriate to their needs. Supporting families during their time of loss and grief is an important part of the provision of care.

Specialist communication training is provided to tissue donation coordinators so that they can support families to make an informed donation decision that is right for them.

Where a potential organ donor is identified, the transplant coordinator will also discuss tissue donation with the family, and will, once consent is obtained, refer the donor to a tissue coordinator to arrange tissue recovery.

However, as most people are potential tissue donors, you as a medical professional may need to refer the donor at the time of death. We understand that it may be a difficult and uncomfortable conversation to have with the family and we urge you to contact the tissue donation coordinator for your hospital and let him/her initiate the discussion with the family.

The tissue donation coordinator will ask you for next of kin contact details, as well as a few easy questions to assess the donor's suitability, before contacting the family, either in person or telephonically. Families are offered continued support during and after donation.

Some of the ways donors are honoured may include a donor pause (a silent prayer or contemplation as a humble gesture of respect) before organs and tissue are recovered from the donor; donor tribute ceremonies; letters and small commemorative gifts to the families; or the display of donor details on a memorial wall or in a memorial garden.

9. TISSUE DONATION PROTOCOLS

Tissue donation can take place irrespective of the manner and location of death. Except for a limited number of medical conditions which could render someone ineligible to be a tissue donor, most people who pass on, can donate tissue. Very often, potential donations are lost due to ignorance about tissue donation.

To impact the shortage of tissue for transplantation, as many patient deaths as possible should be referred to tissue donation coordinators. They are specially trained to counsel next of kin on - and obtain consent for - tissue donation; and are always available to support and advise you as a medical or nursing professional.

9.1 TISSUE DONATION BY DECEASED DONORS

Deceased donors can donate eye and corneal tissue, skin, bone, cartilage, ligaments, tendons, and heart valves. Tissue is surgically recovered by trained tissue recovery technicians in an ethical and respectful manner. The donor's body is treated with dignity and restored to its original state after tissue recovery with the aid of prostheses.

At the time of recovery, blood samples are obtained from the donor to test for infectious diseases to ensure that donated tissue is safe for use.

9.1.1 LEGAL REQUIREMENTS FOR DONATION

Informed consent (verbal/telephonic consent followed by written consent) for tissue donation is always obtained from the next of kin. In addition, if death was due to unnatural causes, permission from the state pathologist is obligatory for the donation to proceed.

Next of kin can specify which tissue may be donated.

9.1.2 TIME FRAMES FOR TISSUE RECOVERY

While there is typically more time available to recover tissue, prompt referral of potential donors and recovery as early as possible, aids in maintaining tissue viability.

TISSUE RECOVERY TIME FRAMES		
Type of tissue	**Optimal recovery period after death**	**Optimal period between recovery and use**
Bone, tendons, and ligaments	Up to 5 days after death, depending on the conditions under which the donor's body is kept after death.	Processed bone, tendons and ligaments can be used for transplantation and implantation up to two and a half years after recovery.
Skin	Up to 48 hours after death.	Skin that is processed and preserved can be used up to two years after recovery.
Eye tissue and corneas	Up to 24 hours after death. NB: Eye tissue recovery is more time sensitive and ideally, recovery should be as soon as possible after death.	Transplants should ideally take place within 10 days after recovery to increase graft viability.
Heart valves	Within 36 hours after death.	Heart valves are cryo-preserved and can be stored for up to 10 years under the correct conditions.

9.1.3 CRITERIA FOR DONATION

CORNEAS

EYE AND CORNEA DONATION

- Any person between the ages of 6 and 65 years (and even up to 70 years in certain cases), where death occurred because of natural causes (such as heart disease, most cancers* or strokes) or unnatural circumstances (like motor vehicle accident injuries, and gunshot or stab wounds) is a potential cornea donor.

  * Corneas do not contain blood vessels, eliminating the risk of transmitting most types of cancer.
- Cataracts and poor eyesight do not prevent cornea donation.
- If the patient's medical history includes any of the following, or the cause of death is unknown, the corneas cannot be donated:
  - previous laser surgery to the eye(s)
  - corneal scarring due to disease or trauma to the eye
  - eye diseases such as glaucoma
  - eye conditions such as keratoconus
  - any untreated systemic infection
  - infections such as tuberculosis, syphilis, hepatitis B and C, and/or HIV/AIDS
  - lymphoma and leukaemia

To ensure tissue viability, the eyes need to be kept closed from the time of death and be prevented from drying out. Moisturise the eyes with a saline-based eye drop before closing.

BONE

BONE, TENDON AND LIGAMENT DONATION

- Anyone between the ages of 16 and 80 years, who does not have septicaemia, cancer, or an infectious disease such as hepatitis B and/or C, syphilis, or HIV/AIDS, is a potential donor.
- If the cause of death is unknown, the deceased cannot donate bone, tendons or ligaments.

SKIN

SKIN DONATION

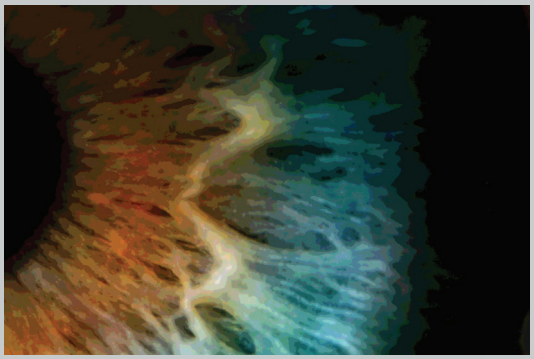
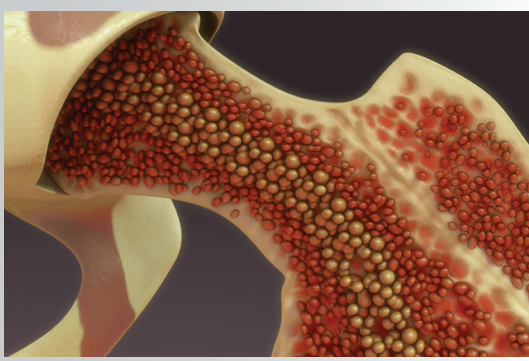
- Anyone between the ages of 16 and 80 years, who does not have septicaemia, cancer, or an infectious disease such as hepatitis B and/or C, syphilis, or HIV/AIDS, is a potential donor.
- If the patient's medical history includes any of the following, or the cause of death is unknown, skin cannot be donated:
  - prolonged steroid therapy
  - chronic skin disease
  - psoriasis

HEART

HEART VALVE DONATION

- Deceased individuals from the age of 6 months, up to and including 55 years, who does not have septicaemia, cancer, or an infectious disease such as hepatitis B and/or C, syphilis or HIV/AIDS can donate heart valves.
- Heart valves cannot be donated if death was caused by any of the following:
  - poisoning
  - blood- borne infections
  - trauma to the heart
- If the cause of death is unknown, heart valves cannot be donated.
- While not common, heart transplant recipients can donate their original hearts after transplant for heart valve recovery, provided that they meet the criteria for donation and that the heart valves of the original heart were not the reason for the transplant.

PLEASE CONTACT THE TISSUE DONATION COORDINATOR TO ASSESS DONOR SUITABILITY IF YOU HAVE ANY QUESTIONS.

9.2 TISSUE DONATION BY LIVING DONORS

The human skeleton contains cancellous bone (also called trabecular bone or spongy bone) which is light, porous bone enclosing numerous large spaces that give a honeycombed or spongy appearance.

Cancellous bone is used in allograft (tissue transplantation / implantation) to stimulate bone regeneration. In the presence of cancellous bone and bone morphogenic proteins (BMPs), the recipient's body creates osteoblasts, which grow into new bone cells.

Cancellous bone is mostly present in the bones close to joints, such as the femoral head at the top of the femur and constitutes 20% of the bone mass in the body.

Patients undergoing primary hip replacement surgery can opt to donate the femoral head, which is removed during surgery and normally discarded as medical waste, through a femoral head collection programme in most major hospitals.

9.2.1 LEGAL REQUIREMENTS FOR FEMORAL HEAD DONATION

The patient is required to sign a consent form prior to surgery which states that:

- the donation process and use of the donated tissue was satisfactorily explained.
- he/she gives consent that the bone removed during surgery may be released to the tissue bank and not be discarded as medical waste.
- three vials of blood may be obtained from him/her to test for infectious diseases.

The participating hospital is required to log the donation to the tissue bank for auditing purposes.

9.2.2 CRITERIA FOR DONATION

BONE

FEMORAL HEAD DONATION

- Male and female primary hip replacement patients between the ages of 18 and 80.
- Patients should not have cancer, or an infectious disease such as hepatitis B and/or C, syphilis, or HIV/AIDS.

10. GLOSSARY, REFERENCES AND RESOURCES

10.1 GLOSSARY

Brain death	Brain death implies that there is no remaining homeostatic function (please note: some hypothalamic function may remain). The patient cannot breathe spontaneously, and support of cardiovascular function is necessary. Some spinal activity may still be present but is compatible with a diagnosis of brain death.
Consent	Before organ and/or tissue donation can take place, voluntary, express consent needs to be obtained from the donor (in the case of a living donor) or from the next of kin (in the case of a deceased donor). Informed consent is the process in which a healthcare provider educates the donor or the next of kin - who must be deemed competent to make a voluntary decision - about the process, risks, benefits of, and alternatives to, organ and tissue donation before donation can take place.
Donation after brain death (DBD)	Organ donation that takes place after a patient who is connected to a mechanical ventilator, is declared brain dead by two independent doctors, is known as donation after brain death.
Donation after circulatory death (DCD)	Donation after circulatory death can occur in palliative care settings where there is planned withdrawal of non-beneficial treatments and imminent death is expected.
Donor database	The donor database, managed by the Organ Donor Foundation (ODF), contains the details of South African individuals who registered as organ and tissue donors.
Femoral head donation	Healthy patients undergoing hip replacement surgery can consent to donate the piece of bone removed during the surgery.
Living organ donor	A living organ donor is an individual who makes a conscious decision to donate a kidney or a liver segment to a patient in need of a kidney or liver transplant.
Organ donation	Organ donation is the act of giving one or more organs (or parts thereof), without compensation, for transplantation into someone else whose own organs are no longer functioning. Most organ donations are from deceased patients, but in certain circumstances, living persons can donate organs such as kidneys and liver segments.
Organ Donor Foundation (ODF)	The ODF is the national umbrella body for the promotion of organ and tissue donation in South Africa and raises awareness of organ and tissue donation through education and publicity programmes.
Recovery / Procurement	Recovery (also known as procurement) refers to the process during which organs and/or tissue is recovered from a donor's body. Organ procurement takes place under sterile conditions in a hospital theatre. Tissue recovery can take place in hospital, in a funeral home or mortuary, or at a forensic pathology facility.
Referral	When a potential organ and/or tissue donor is identified, the potential donation is referred to the transplant coordinator or tissue donation coordinator for evaluation.
Tissue donation	Tissue donation refers to bone, ligaments, tendons, skin, heart valves, corneas, and scleral tissue which can be donated when a person dies. Living tissue donors can donate bone after hip replacement surgery.
Whole body donation	Full bodies can be donated to the anatomy department of a university, exclusively for educational purposes. The donor's body is preserved for a period of 1 to 3 years, after which it is cremated (ashes are returned to the family if requested).

10.2 REFERENCES

The reference material listed below may be helpful educational resources on organ and tissue donation, but is not a comprehensive reference list. If you are aware of other useful resources that should be included, please inform SATCS.

10.2.1 Government of the Republic of South Africa. National Heath Act No. 61 of 2003. Chapter 8: Government Gazette, Vol. 469, No. 26595.

* Available for download at: https://www.gov.za/documents/national-health-act

10.2.2 Thomson, D. Organ donation and transplantation. In the Open Access Textbook of General Surgery.

* Available form: https://vula. uct.ac.za

10.2.3 Wits Transplant Procurement Handbook A Practical Guide to Organ Donor Procurement. September 2019.

* Available for download at: http://www.dgmc.co.za/docs/Wits-Transplant-Procurement-Handbook.pdf

10.2.4 Thomson, D. Organ donation: From death to life. Offered free of charge through Coursera.

* Access the course here: https://www.coursera.org/learn/organ-donation

10.2.5 Thomson, D et al. South African Guidelines on the Determination of Death. South African Medical Journal, [S.l.], p. 367-380, apr. 2021. ISSN 2078-5135.

* Available for download at: http://www.samj.org.za/index.php/samj/article/view/13264

10.2.6 Checklists for brain death and circulatory death determination.

* Available for download at: https://criticalcare.org.za/wp-content/uploads/2021/02/Death-Determination-Checklists-South-African-Guidelines-Brain-Death-and-Circulatory-Death.pdf

* Available for download at: https://www.sats.org.za/about/sa-transplant-coordinators-society

PLEASE NOTE: Printed copies of the checklists are included on the following pages.

10.3 RESOURCES

We include a few printed resources for ease of use on the following pages:

- **South African Guidelines on the Determination of Death**
- **Brain Death Certification Checklist**
- **Brain Death Clinical Testing Checklist**
- **Apnoea Testing Checklist**
- **Circulatory Death Certification Checklist**
- **Information Checklist for Potential Organ Donor Referral**

Display posters are included at the back of the file.

South African guidelines on the determination of death

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Death is a medical occurrence that has social, legal, religious and cultural consequences requiring common clinical standards for its diagnosis and legal regulation. This document compiled by the Critical Care Society of Southern Africa outlines the core standards for determination of death in the hospital context. It aligns with the latest evidence-based research and international guidelines and is applicable to the South African context and legal system. The aim is to provide clear medical standards for healthcare providers to follow in the determination of death, thereby promoting safe practices and high-quality care through the use of uniform standards. Adherence to such guidelines will provide assurance to medical staff, patients, their families and the South African public that the determination of death is always undertaken with diligence, integrity, respect and compassion, and is in accordance with accepted medical standards and latest scientific evidence.
The consensus guidelines were compiled using the AGREE II checklist with an 18-member expert panel participating in a three-round modified Delphi process. Checklists and advice sheets were created to assist with application of these guidelines in the clinical environment (https://criticalcare.org.za/resource/death-determination-checklists/).

Key points

- Brain death and circulatory death are the accepted terms for defining death in the hospital context.
- Death determination is a clinical diagnosis which can be made with complete certainty provided that all preconditions are met.
- The determination of death in children is held to the same standard as in adults but cannot be diagnosed in children <36 weeks' corrected gestation.
- Brain-death testing while on extra-corporeal membrane oxygenation is outlined.
- Recommendations are given on handling family requests for accommodation and on consideration of the potential for organ donation.
- The use of a checklist combined with a rigorous testing process, comprehensive documentation and adequate counselling of the family are core tenets of death determination. This is a standard of practice to which all clinicians should adhere in end-of-life care.

S Afr Med J 2021;111(2b):xx-xx. https://doi.org/10.7196/SAMJ.2021.v111i2b.15200

Death is a medical occurrence that has social, legal, religious and cultural consequences requiring common clinical standards for its diagnosis and legal regulation.[1] There is no documented case of a person who fulfils the preconditions and criteria for brain death ever subsequently developing any return of brain function.[2,3]

Clear medical standards for death certification augment the quality and rigor of death determination.[4-6] Currently there are no clinical guidelines on death determination in South Africa (SA), with clinicians using available international guidelines, which vary markedly and are not always applicable to the SA context.[7-10] The World Federation

of Societies of Intensive and Critical Care Medicine (WFSICCM) recently published a document, based on current literature, aiming to standardise terminology and establish minimum testing standards across the world.[5] In order to be applicable over a range of legal jurisdictions, some sections of this document are necessarily broad, making application to the local context challenging. There is therefore a need to align the WFSICCM document with the SA context and legal system, and to provide clear guidance to SA practitioners and the public.

The aims of this document are to provide guidelines for healthcare providers for the testing process, and to answer key questions that commonly arise when medical professionals are called upon to determine death in SA.The objectives are to:

- provide clear medical standards for healthcare providers in the determination of death, in order to promote safe practice and avoid diagnostic errors in the determination of death
- provide assurance to patients, their families and the SA public that determination of death is undertaken with diligence, integrity, respect and compassion and in accordance with accepted medical standards and societal expectations
- create a checklist for brain death and circulatory death determination.

Methods

An expert panel was constituted and reviewed current evidence and compiled consensus-based recommendations for the minimum standards required for death determination, applicable in the SA context, using a modified Delphi process. All statements in this guideline are considered strong recommendations. In cases where evidence is less strong, the term 'suggested' is used to indicate a lower level of evidence. Statements are intentionally similar to international documents in the interests of commonality of approach. Recommendations are aligned with the best interests of patients and their families.

Panel recruitment

Expert panel members were recruited through the Critical Care Society of Southern Africa (CCSSA) as experts in the field of death determination and end-of-life care representing a broad range of disciplines within critical care (neurosurgery, paediatrics, obstetrics and gynaecology, surgery, anaesthesiology, nursing, ethics). Informed consent was given by the expert panel with acknowledgement that they would be identifiable in the publication (Appendix 1 - 3: http://samj.org.za/public/sup/15200-1.pdf). The study methodology was approved by the University of Cape Town Human Research Ethics Committee (HREC 476/2019).

Delphi process

A literature search of Pubmed, Web of Science, SCOPUS and the grey literature was conducted by the steering committee of the expert panel and a professional librarian to identify national and professional society guidelines in death determination, and their supporting evidence, for review (http://samj.org.za/public/sup/15200-2.pdf). A modified Delphi approach was used with adherence to the Appraisal of Guidelines for Research and Evaluation (AGREE II) instrument to compile the guidelines.[11]

Key questions related to current principles and practice regarding death certification were drafted by the meeting steering committee. During three rounds of a modified Delphi process[12] using Surveymonkey (SVMK Inc., USA), a web-based application, the expert panel progressively modified, deleted or added questions and components. Participants were asked to rate agreement with each component between 1 and 9 on a Likert scale, with 1 - 3 being 'not important', 3 - 6 being 'important but not critical' and 7 - 9 being 'critically important', or state if they were unable to comment. This scale is recommended by the Grading of Recommendations Assessment, Development and Evaluation working group.[11,13] Participants were invited to suggest additional questions for consideration for the round table in each round using free-text responses. Although five to 10 experts are considered adequate for content validation, we used 18 to ensure a broadly representative group.[14]

Precise terminology was reviewed and finalised in order to improve clarity in death determination discussions and debate. We defined consensus for the Delphi *a priori* based on guidance in *The COMET Handbook*.[15] For inclusion in the consensus outcome statement (COS), outcomes required at least 70% of participants in each stakeholder group to score the outcome as critically important and <15% to score the outcome as not important. Outcomes excluded from the COS required at least 70% of participants in each stakeholder group to score the outcome as not important and <15% to score the outcome as 'critical'. If outcomes did not meet either criterion, they were presented at the round-table for discussion. The expert panel members summarised the responses and the available evidence and formulated draft recommendations that were presented and discussed at a face-to-face round table meeting prior to the CCSSA national conference in Cape Town, SA, in 2019. The results were presented at a plenary meeting of the conference.

All questions and feedback from this meeting were then reviewed with the steering committee. The combined consensus statement and proposed guideline were circulated to all society members for comment over three months. All expert panel members approved the final document for publication. The guidelines were then submitted for external review and endorsement by other South African professional medical societies (Table 1).

Updating of the guidelines

A review period of five years was set after publication of this document, the review to be undertaken by the guideline development group of the CCSSA, unless an earlier revision is mandated by emerging high-quality medical evidence or legislative changes.

South African guidelines on the determination of death

1. General statements

Death is the clinical point of irreversible loss of the capacity for consciousness and the irreversible loss of the capacity to breathe.[16]

Death is determined by either neurological or circulatory criteria and must be made in accordance with accepted medical standards.[1]

A correctly performed clinical examination can determine the point of death with complete certainty. It is not necessary to wait for pathognomonic signs of death (hypostasis, rigor mortis, decay) to be present in the healthcare setting.[16,17]

Table 1. List of endorsing societies

Trauma Society of Southern Africa
The Association of Surgeons of South Africa
Radiology Society of South Africa
Southern African Transplantation Society
Islamic Medical Association
South African Medical Association
Resuscitation Council of South Africa
South Africa Thoracic Society
The Colleges of Medicine of South Africa - Committee of Critical Care
Neurological Association of South Africa

In cases where there are confounders affecting the clinical examination, testing should be deferred until such confounders are resolved or ancillary testing confirms the diagnosis of death.[17]

2. Definitions

Ancillary test: an additional test that can assist with the clinical diagnosis of brain death.[18]

Accommodation: a period of somatic support to allow for family to process the diagnosis of death.

Brain death/death by neurological criteria: the preferred term when death is determined on neurological grounds. (This is in preference to the term brain-stem death and is in alignment with the latest guidelines.)[5]

Circulatory death/death by circulatory criteria: the preferred term when death is determined on circulatory grounds. (This is in preference to terms such as cardiac or cardiorespiratory death and is in alignment with the latest guidelines.)[1]

Coma: the absence of wakefulness, awareness and the capacity for sensory perception and responsiveness to the external environment.[1]

Confounder: a situation during which a diagnostic test may be unreliable. Repeat testing when the confounder is no longer present, or ancillary testing, is required to diagnose death in these settings.

Somatic support: management to support the body and organs, excluding the brain, after brain death has been confirmed.

3. Brain death

3.1 Preconditions for brain death testing

There must be an established aetiology compatible with complete and irreversible loss of all brain function prior to commencement of the determination of brain death.

Preconditions for brain-death testing to be valid are:

- a minimum temperature of 36°C[2,5]
- a systolic blood pressure (BP) ≥100 mmHg or a mean arterial pressure (MAP) ≥60 mmHg (or age-appropriate haemodynamic targets in the paediatric population)
- exclusion of the influence of central nervous system (CNS) depressing drugs. This is done by at least one of the following:
  - allowing five elimination half-lives of the drug to pass before making an evaluation of brain death (taking into consideration the dose and the elimination half-life, which may be influenced by age, organ dysfunction or prior hypothermia)[5]
  - administering an appropriate drug antagonist
  - measuring drug levels[5]
  - performing ancillary testing in addition to a complete clinical examination if there is concern about prolonged or unknown drug elimination
- intact neuromuscular function
  - If doubt exists regarding the effects of pharmacological paralysis, a train-of-four nerve stimulator can be used. A normal response to stimulation should be observed.[3]
- correction of severe metabolic, acid-base and endocrine derangements that could affect the examination
  - If these derangements cannot be corrected and are judged to be potentially contributing to the loss of brain function, ancillary testing must be used after a clinical examination of brain death has been completed.

3.1.1 Additional remarks: Preconditioning[5]

Neuroimaging is recommended when available to assist with establishing an aetiology and confirming brain injury.

Neuroimaging is not required for the diagnosis of brain death where an obvious cause is known.

Drug levels should not exceed the therapeutic range and, if within a therapeutic range, not be associated with an altered level of consciousness.

Barbiturates have long and variable elimination half-lives, so blood levels should be measured and documented to be below that of clinically significant effects (<10 mg/L) or alternatively ancillary testing should be used to diagnose brain death.

If there is concern about severe alcohol intoxication being the primary cause of coma, the blood alcohol level should be shown to be <80 mg/dL.

Consensus was not achieved on a standardised observation period prior to brain-death testing. The appropriate observation period was felt to be specific to each individual case. However:

- in cases of anoxic brain injury, this observation period should be 24 hours
- in cases where therapeutic hypothermia was used, there should be a 24-hour period of normothermia prior to an examination for brain death
- in paediatrics, a cautious approach is advised, given the frequent presence of confounders in this group.

It must be possible to adequately examine the brain-stem reflexes. It must be possible to examine at least one eye and one ear and safely perform apnoea testing.[3,5]

Apnoea testing may be precluded by severe hypoxic respiratory failure or a high cervical cord injury, in which case ancillary testing can be used after confirming that brain-stem reflexes are absent.[3,5]

While trying to provide broad guidance on the magnitude of metabolic and endocrine disorders which are likely to influence the testing of brain-stem reflexes, it is essential to bear in mind that the most important factor is the establishment of an unequivocal cause for the individual's coma.[17]

It is recognised that circulatory, metabolic and endocrine disturbances (e.g. hypotension, hypernatraemia, diabetes insipidus) are likely accompaniments of death as a result of cessation of brain-stem function. It is important to emphasise that these may be the effect rather than the cause of cessation of brain function and do not preclude the diagnosis of death by neurological testing.[17]

It is recognised that:[17]

- Sodium can cause unresponsiveness at levels <115 or >160 mmol/L.
- Serum potassium levels can cause flaccid paralysis below 1 mmol/L. Therefore, we recommend a level >3 mmol/L be confirmed.
- Profound elevation or lowering of phosphate or magnesium can be associated with severe neuromuscular weakness at levels <0.5 or >3.0 mmol/L and may need to be corrected.
- Hyperglycaemia in diabetic ketoacidosis or hyperosmolar non-ketotic coma may cause a state of unresponsiveness which mimics irreversible cessation of brain-stem function, but this state is extremely unlikely with blood glucose levels <20 mmol/L.
- Severe hypoglycaemia is associated with coma or stupor and testing of brain-stem reflexes should not be undertaken if the glucose level is <4 mmol/L. As blood glucose concentrations change rapidly in critically ill patients, a blood glucose measurement should always be made immediately prior to the testing of brain-stem reflexes.

The following endocrine conditions are extremely rare and unlikely to co-exist in the presence of known primary pathologies. If there is any clinical reason to expect these disturbances, then it is obligatory to ensure appropriate hormonal assays are undertaken.

- Myxoedema may cause a deep unresponsive coma.
- An Addisonian crisis may be associated with severe neuromuscular weakness, causing an acute ascending paralysis or encephalopathy proceeding to coma.

3.2 Braindeath testing[3,5,17]

The testing process comprises assessment for:

1. coma
2. absence of brain-stem reflexes
3. inability to breathe.

Detailed explanation of the testing process is outlined (Table 2).

Two doctors are required to confirm the diagnosis of brain death. One of the doctors must have more than five years' experience (since qualification as a medical practitioner). Neither doctor must be involved with a transplantation team.[19]

Two doctors should perform the brain death testing together. If testing is done separately, there is no need for a delay between the tests; however, it is strongly advised that a single apnoea test should be done by the two doctors together.[5,20]

Table 2. Clinical testing for brain death – coma, brain stem reflexes, apnoea test

Clinical testing for	Test and interpretation	Cautionary remarks
1. Coma	***Test***: Assess both centrally and peripherally. Apply deep pressure to all of the following: • the condyles at the level of the temporomandibular joints • the supra-orbital notch bilaterally • the sternal notch • all four extremities, via deep nail bed pressure. ***Interpretation***: Noxious stimuli should not produce grimacing, facial muscle movement or a motor response of the limbs other than spinally mediated reflexes. Any non-spinal reflex response is incompatible with a brain death diagnosis.	A multilevel assessment of motor function is important to exclude focal lesions. The clinical differentiation of spinal responses from brain-mediated motor responses requires expertise. Consultation with an experienced practitioner is recommended if the origin of a response is unclear. Alternatively, if interpretation is unclear, ancillary testing is recommended.
2. Brain-stem reflexes	Testing of the brain-stem reflexes comprises examination of the cranial nerves: pupils, ocular movements, facial sensation and movement, pharyngeal and tracheal response. These are tested sequentially and bilaterally when possible. All brain-stem reflexes must be absent to determine brain death.	
2.1. Pupillary light reflex – cranial nerves II and III	***Test***: Shine a bright light into the eye and look for a pupillary constrictor response. ***Interpretation***: There should be no pupillary response.	The pupils should not be pinpoint. Pupils do not have to be fully dilated. Anticholinergic drugs such as atropine can cause pupillary dilatation. Cataract or iris surgery is not a contraindication to clinical testing.
2.2. Corneal reflex – cranial nerves V and VII	***Test***: Touch the corneas with soft cotton wool or gauze and examine the eyes for blinking or a withdrawal response. ***Interpretation***: No blinking or withdrawal response.	Touching the sclera is not sufficient. Remove contact lenses. Examine the cornea gently as it is easily damaged.
2.3. Response to pain in the trigeminal distribution – cranial nerves V and VII	***Test***: Apply pain over the trigeminal distribution with deep pressure over the supra-orbital nerve bilaterally and to the condyles at the level of the temporomandibular joints. ***Interpretation***: No grimacing, facial muscle movement or motor response of the limbs other than spinally mediated reflexes.	In patients with spinal cord injuries, peripheral sensation and motor function can be lost and it is essential to adequately assess response to stimuli through brainstem-mediated sensation and motor response.
2.4. Vestibulo-ocular reflex – cranial nerves III, IV, VI and VIII	***Test*** (cold caloric): Inspect the external auditory canal with an otoscope to confirm that the eardrum is visible. If the eardrum is not visible, the canal must be cleared before testing can occur. Elevate the head to 30° to align the semi-circular canal and generate a maximal response. Flush 50 mL of ice-cold water into the ear canal using a syringe. Hold eyelids open and observe for eye movement for a minimum of 60 seconds. ***Interpretation***: No eye movement in response to the cold water; the eyes remain in the midline within the socket.	Presence of a ruptured eardrum does not invalidate the test. Fractures to base of skull or petrous temporal bone may obliterate the response on the side of the fracture. Testing should not proceed on that side if there is cerebrospinal fluid (CSF), blood or brain tissue in the external auditory canal.
Vestibulo-ocular reflex – cranial nerves III, IV, VI and VIII	***Not required/recommended***: Testing for the oculo-cephalic (head turning/doll's eye) reflex examines the same reflex pathways as cold caloric testing but is a sub-maximal stimulus and is not recommended. It may also aggravate a pre-existing cervical spinal injury.	

...continued

Table 2. (continued) Clinical testing for brain death – coma, brain stem reflexes, apnoea test

Clinical testing for	Test and interpretation	Cautionary remarks
2.5. Gag reflex – cranial nerves IX and X	***Test***: Stimulate the posterior pharyngeal wall, on both sides, with a tongue depressor or Yankauer suction. ***Interpretation***: No gag response seen.	
2.6. Cough reflex – cranial nerve X	***Test***: Stimulate the tracheobronchial wall with a soft suction catheter. ***Interpretation***: No cough response seen.	The efferent limbs for this reflex are the phrenic nerve and the innervation of the thoracic and abdominal musculature. Therefore, it cannot be assessed in patients with a complete high cervical injury.[21]
3. Apnoea test	Only proceed with the apnoea test if all above reflexes are absent. Apnoeic oxygenation is used to demonstrate lack of ventilatory drive. This involves the supply of 100% oxygen to the trachea, without providing ventilatory assistance. Through mass-movement, oxygen reaches the alveoli, allowing for transfer to the blood. In the absence of ventilation, p_aCO_2 rises and stimulates the brain-stem respiratory centres, causing spontaneous breathing. As the p_aCO_2 rises, the ventilatory centre is maximally stimulated by a p_aCO_2 >60 mmHg (8 kPa) and pH <7.30. An attempt at breathing is defined as any respiratory muscle activity that results in abdominal or chest excursions or activity of accessory respiratory muscles.	
	Test: Pre-oxygenate the patient with 100% oxygen for 10 minutes to allow for elimination of nitrogen and to prevent hypoxaemia during the test. Perform a baseline blood gas measurement. Disconnect the patient from the mechanical ventilator. Supply continuous oxygen via a T-piece (preferred) or through a catheter inserted through the endotracheal tube and placed above the carina.	Throughout the procedure, monitor the patient's S_pO_2. An option to minimise the time required for the p_aCO_2 to rise to the desired level, is to adjust the minute ventilation to mild hypercarbia (p_aCO_2 ~45 mmHg (6 kPa)) before disconnecting the patient from the ventilator.
	Observe continuously for any spontaneous breathing. At the end of the period without mechanical ventilation, apnoea must persist in the presence of an adequate stimulus to spontaneous ventilation, i.e. an arterial p_aCO_2 >60 mmHg (8 kPa) and an arterial pH <7.30. Take an arterial blood gas to document the rise in p_aCO_2 and change in pH. At the end of the test, reconnect the patient to the mechanical ventilator.	If using a catheter, supply oxygen at 4 - 6 L/min. The diameter of the catheter must be <70% of the diameter of the endotracheal tube. When using the tracheal insufflation method, care should be taken to avoid high oxygen flows and wedging of the catheter insufflating oxygen as high intrapulmonary airway pressure may cause barotrauma. The period of observation to achieve an adequate threshold of stimulus of the respiratory centre is variable. Usually p_aCO_2 rises by ~3 mm Hg (0.4 kPa) for every minute of apnoea. If starting from normocapnia, the p_aCO_2 is likely to be >60 mmHg (8 kPa) after 10 minutes. If this is not the case at 10 minutes and the patient is stable, wait a further 5 minutes and repeat the arterial blood gas. In patients with pre-existing hypercapnia, it is recommended to wait for a p_aCO_2 rise >20 mmHg (2.7 kPa) above the chronic level, with a pH <7.30. Failure of the p_aCO_2 to rise is most likely due to an inappropriately high oxygen flow rate via a tracheal catheter.
	Interpretation: No breathing effort is seen at any point. Apnoea testing should be aborted if: • spontaneous respirations are witnessed during apnoea testing • systolic blood pressure becomes <100 mmHg or mean arterial pressure becomes < 60 mmHg despite titration of inotropes/vasopressors (age-appropriate targets for paediatrics) • there is sustained desaturation below 85% • an unstable arrhythmia occurs. It is suggested that prior to aborting the apnoea test because of cardiorespiratory instability, an arterial blood gas (ABG) be sent for testing. If the p_aCO_2 target is met, the apnoea test can be considered positive (consistent with brain death).	If hypoxia occurs, 1 - 2 positive pressure breaths can be given, and apnoea testing continued. Adequate pre-oxygenation and recruitment usually avoids this problem.

3.2.1 Additional remarks: Apnoea testing

We do not recommend using a spontaneous breathing mode and remaining connected to the ventilator during apnoea testing. Performing testing in such a manner typically requires turning off the ventilator's default safety features to prevent back-up apnoea ventilation. If a patient remains connected to a mechanical ventilator, auto-triggering can give a false impression that a person is breathing spontaneously. This occurs when the ventilator is set on a spontaneous breathing mode (pressure support ventilation) and either extrinsic or intrinsic factors generate sufficient change in airflow or negative pressure that exceeds the trigger threshold, leading to a mechanically delivered breath. Extrinsic causes for auto-triggering include excessive condensation in ventilator tubing, endotracheal tube leak, chest tubes, and random artefacts or noise in the ventilator circuit, while intrinsic causes include cardiogenic oscillation, especially in a hyperdynamic cardiovascular state.[5]

3.2.2 Additional remarks: Clinical observations

Observations compatible with a diagnosis of brain death are:[3]

- spinal reflexes (which can be spontaneous or elicited by stimulation)[22,23]
  - extension-pronation movements of the upper limbs
  - nonspecific flexion of the lower limbs
  - presence of deep tendon reflexes
  - plantar responses, either flexor or extensor
  - respiratory-like movements (shoulder elevation and adduction, back arching or intercostal expansion) without significant tidal volume
  - undulating toe reflex (plantar flexion of great toe, followed by brief plantar flexion sequentially of second to fifth toes)
  - Lazarus sign (bilateral arm flexion, shoulder adduction, hand raising to above the chest, and may include flexion of trunk, hips and knees)
  - head turning
- sweating, blushing, tachycardia
- normal blood pressure without the need for pharmacological support
- absence of diabetes insipidus (DI) (preserved osmolar control mechanism).

Observations incompatible with brain death are:

- decerebrate or decorticate posturing
- true extensor or flexor motor responses to painful stimuli
- witnessed seizures.

3.3 Ancillary testing

The clinical exam is considered the most sophisticated way of testing neurological function in that it deliberately delivers a stimulus to provoke central processing followed by an efferent response. All ancillary tests infer the integrity of this stimulus-integration-response arc, but do not observe it directly.[5]

It is recommended that the clinical exam be completed to the fullest extent possible prior to conducting an ancillary test.[5]

Making an appropriate choice of an ancillary test depends on the clinician and the clinical circumstances. The most effective method to address a confounder must be identified using an educated appraisal of the strengths and weaknesses of those tests that are readily available.[5]

It is recommended that ancillary testing is required in the following circumstances:[5]

- inability to complete a clinical neurological determination of death, including the apnoea test
- confounding conditions which would invalidate clinical testing that cannot be resolved
- uncertainty regarding interpretation of spinal-mediated motor reflexes
- pre-existing severe neuromuscular disorder, such as amyotrophic lateral sclerosis or a pre-existing severe sensory neuropathy.[24,25]

Ancillary testing which establishes the absence of intracranial blood flow is the preferred method of testing where available.[5]

- radionuclide studies
- conventional four-vessel cerebral angiography
- transcranial Doppler.

It is suggested that electrophysiological testing with an electroencephalogram (EEG) not be utilised routinely as an ancillary test, given its low specificity.[5,26] EEG testing may, however, be preferred where craniovascular impedance has been affected by an open skull fracture, decompressive craniectomy, or an open fontanelle/suture in infants.[5,27]

It is suggested that computed tomography angiography (CTA) and magnetic resonance angiography (MRA) which may be used in the investigation of these patients not be used in isolation to support a diagnosis of cerebro-circulatory arrest at present, pending further research into the sensitivity and specificity of these modalities.[5,28-35]

3.3.1 Technical aspects of ancillary testing

Radionuclide/brain scintigraphy studies

To confirm brain death with radionuclide/scintigraphic techniques, the study must demonstrate absence of intracranial isotope.[5,36-38]

- Diffusible radiopharmaceuticals (brain-specific tracers) should be used preferentially.
- Single photon emission computed tomography (SPECT) is preferred over planar imaging.
- If SPECT is not available, perfusion scintigraphy with anterior and lateral planar imaging should be used with appropriate time intervals to demonstrate static filling of the posterior fossa.

Cerebral angiography

If used as an ancillary test to confirm brain death, four-vessel cerebral angiography must demonstrate absent filling at the points where the internal carotid and vertebral arteries enter the skull base, with demonstration of patent external carotid circulation.[39]

Transcranial doppler

Transcranial doppler testing is operator training dependent, needs specialised probes and requires that:[40,41]

- two examinations be performed ≥30 minutes apart
- the examinations be performed bilaterally, anteriorly and posteriorly to include both internal carotid arteries as well as the vertebrobasilar circulation
- the exams illustrate biphasic oscillating flow and systolic spikes with reversal of flow in diastole in order to make a declaration of brain death.

Transcranial doppler testing is not validated in paediatrics[42] and is not widely available in SA.

Electroencephalography (EEG)

If EEG testing is used, it should be used in conjunction with somatosensory and brainstem auditory evoked potentials.[43]

EEG should be interpreted as demonstrating absence of brain activity when a 30-minute study is isoelectric above 2 microvolts with

a sensitivity of 2 microvolts/mm and filter of 0.1 or 0.3 seconds and 70 Hertz.[5,44]

3.4 Paediatric considerations in brain death

A cautious approach with a low threshold for serial examinations is recommended in this population group.[5,45]

Brain death cannot be diagnosed in neonates <36 weeks' corrected gestation.[3,4]

Clinical assessment of brain death in neonates and the paediatric population is the same as in adults, with age-appropriate haemodynamic targets,[46,47] except that in neonates (<4 weeks) the sucking and rooting reflex should be absent in addition to the other brain-stem reflexes.[5]

Ancillary testing (as with adults) is not routinely required in this population group when clinical testing confirms brain death.[45]

A T-piece should be used for oxygenation during the apnoea test in paediatric patients in preference to the tracheal insufflation method, owing to the risk of barotrauma with this method.[5]

In patients with chronic hypoxaemia owing to cyanotic heart disease, apnoea testing should not be performed and instead an ancillary study be conducted to assist with the determination of brain death.[5]

3.5 ECMO and brain death[48-50]

The same fundamental principles of brain-death testing apply to patients on extracorporeal membrane oxygenation (ECMO).

The apnoea test should be performed in patients on veno-arterial (VA) or veno-venous (VV) ECMO unless unable to be completed owing to haemodynamic instability.

In VA ECMO, the flow rate may be adjusted to maintain a MAP ≥60 mmHg during testing.

Preoxygenation prior to apnoea testing should be done by increasing the inspired oxygen via the mechanical ventilator to 100% and to the membrane lung of the ECMO machine to 100% for 10 minutes. The sweep gas flow should be titrated to <1 L/min while maintaining oxygenation in order to allow a rise in carbon dioxide (CO_2). Apnoea must persist in the presence of an adequate stimulus to spontaneous ventilation, i.e. an arterial p_aCO_2 >60 mmHg (8 kPa) or 20 mmHg above the patient's baseline and an arterial pH <7.30. Serial blood gases may be required as achieving the rise in CO_2 may take longer to achieve than in a person without ECMO support.

3.6 Pregnancy and brain death[51-54]

If a decision is made to offer somatic support to a brain-dead pregnant patient, it is recommended that a multidisciplinary team of intensivists, obstetricians, social workers, psychologists and neonatologists be involved.

The consent to continue providing somatic support to a brain-dead pregnant patient should be made in keeping with the HPCSA professional rules on consent.[55] Due consideration to duration of support required, the high-risk nature of the delivery and an assessment of the home and legal circumstances needs to be conducted by a multidisciplinary team.

The fetus should be routinely monitored with at least daily heart rate checks, given that fetal health may affect decision-making.

Antenatal steroids should be administered to facilitate fetal lung maturation with preparations for delivery made between 26 and 33 weeks when fetal lung maturity is reached.

3.7 Family accommodation in brain death

While it is reasonable to provide accommodation for a finite period of time, assuming that the specific timeframe for doing so is brief, that resources allow, and that a family is informed of the timeframe in advance, accommodation ordinarily should not be provided for a period greater than 24 hours.

It is ethically and legally appropriate for the treating team to end somatic support for a body when the family has been adequately counselled on the diagnosis of death and the option of organ donation explored.

An additional clinician in the hospital can provide the family with a second opinion regarding determination of brain death if it is felt that this may assist the family in accepting the person's death.

Even in the setting of requests for accommodation, support should be discontinued if a person has been declared brain-dead and the hospital bed is required for a living patient where no other bed is available.[5]

4. Circulatory death

4.1 Preconditions for circulatory death testing

To declare death on circulatory grounds, one of the following criteria must be met:

- it is inappropriate to attempt cardiopulmonary resuscitation
- attempts at cardiopulmonary resuscitation have failed
- treatment aimed at sustaining life has been withdrawn.

Treatment may be withdrawn because:[56]

- it has been assessed to be of no further benefit to the patient (non-beneficial/futile) and is not in his or her best interest to continue
- it is in respect of the patient's wishes via an advanced directive to refuse life-sustaining treatment
- it is in respect of the patient's wishes as expressed by their legal surrogate decision-maker.

4.2 Circulatory death testing

The patient should be observed by the person responsible for confirming death for a minimum period of five minutes to establish that irreversible circulatory arrest has occurred.[57]

The absence of mechanical cardiac function should be confirmed using a combination of the following:

- absence of a central pulse on palpation
- absence of heart sounds on auscultation.

In the hospital setting, clinical assessment of absent mechanical cardiac function can be supplemented by one or more of the following:

- absence of pulsatile flow using direct intra-arterial pressure monitoring
- absence of contractile activity using echocardiography.

Once mechanical cardiac function is confirmed as absent by clinical assessment, intra-arterial pressure monitoring or echocardiography, the five-minute waiting period can begin.

Any spontaneous return of circulatory or respiratory activity during the five-minute observation period should prompt a reset of the observation period from this point.[58]

Spontaneous return of circulatory or respiratory activity is not an indication to begin resuscitation efforts in a context where this has been determined to be inappropriate.

After the five-minute period of continued circulatory arrest has passed, the absence of pupillary responses to light and of any motor response to supra-orbital pressure should be confirmed.[59-61] The time of death is recorded as the time at which these criteria are fulfilled.[1]

It is inappropriate to initiate any intervention that has the potential to restore cerebral perfusion after death has been confirmed.[3,62]

In cases where organ donation after circulatory death takes place, a second doctor is required to certify the death.[19]

5. Organ donation

End-of-life care should, as standard of care, explore the patient's wishes regarding organ and tissue donation.[63]

The recommended time for a clinical assessment of organ donation potential (with the transplant co-ordinator) is when the treating team makes a decision to perform brain-death testing or to initiate discussions with the family to withdraw life-sustaining treatment. This allows clarification of the potential for organ and tissue donation prior to end-of-life discussions, and an informed approach for consent from the family.[64]

Somatic support of a brain-dead patient is appropriate to allow the possibility of organ and tissue donation to be fully explored with the family.[3]

6. Training and documentation

All doctors should be trained in the determination of death. It is recommended that a standardised checklist be used for death determination and its documentation.[65,66]

Consultation with a medical practitioner experienced in the diagnosis of brain-death is advised in situations where the diagnosis and testing are uncertain.

All doctors training in disciplines that manage patients with severe brain injuries should receive detailed training in the preconditions for brain-death testing, clinical testing procedures, indications for and utility of ancillary testing, somatic support of the brain-dead patient, and techniques for effective counselling of families.[5,65,67]

All phases of the brain death determination should be documented in the medical record, including:[5,68]

- aetiology of the coma
- absence of confounders
- full details of the clinical testing performed, including apnoea testing and laboratory values
- neuroimaging results if done
- the reason for ancillary testing if performed and the findings
- time and date of death
- identity of the practitioners performing the evaluation, with their HPCSA numbers.

In cases where brain death can be determined with a neurological exam and ancillary testing is not needed, the time of death must be documented as the time the arterial p_aCO_2 reaches the target, with no spontaneous respirations seen, during the apnoea test confirmed by two doctors.[3,5]

In cases where the doctors were not able to complete the apnoea test together, the time of death will be upon completion of the second apnoea test.[3,5]

In cases where ancillary testing is performed, the time of death must be documented as the time that the ancillary test results are formally interpreted and documented.[3,5]

Determination of death on the basis of circulatory criteria should be documented in the medical record, including:

- in cases where resuscitation was attempted, a record of the resuscitation attempts and the time resuscitation was stopped
- in cases where resuscitation was not attempted, the rationale
- confirmation of absent pupillary and pain response, respiratory effort and circulation after a five-minute period
- time and date of death
- identity of the practitioner/s performing the evaluation, with their HPCSA number/s.

7. Strengths and limitations

This guidance document offers clear, pragmatic evidence-based medical guidance in the determination of death in the SA context. The provided checklists (Figs 1 - 4) offer a summary of the recommendations for clinical application. A limitation of this document is that a lack of high-quality data from large randomised clinical trials prevented the use of formal analytical techniques (GRADE, AGREE) in the literature appraisal. It is also acknowledged that these recommendations were developed without direct patient, cultural and religious input; however, the panel of experts did represent a broad range of cultural and religious viewpoints from across South Africa.

7.1 Applicability, barriers, facilitators and cost implications of these guidelines

Barriers to effective implementation of death determination guidelines include a lack of uptake and acceptance by both clinicians and the public as well as the challenge of ensuring cultural and religious engagement and support for the medical determination of death. The endorsement and application of these guidelines is to be formally encouraged across all healthcare disciplines. Undergraduate and postgraduate teaching should consider these guidelines as the standard of care for the determination of death in South Africa and incorporate them into their training programmes. Hospital policies and standard operating procedures should similarly align themselves with the guidelines to prevent differing practices across institutions, which can cause confusion among clinicians, families and the general public.[9,69] Use of the provided checklists is expressly recommended in the guidelines to facilitate clinicians to apply them in their daily practice. Continuing professional development programmes should incorporate these guidelines in the education of practising clinicians.

Pursuing a diagnosis of brain death may entail additional resources, and the clinician must judge the appropriateness in each clinical context. The beneficial effects of organ and tissue donation to the South African public and healthcare system are large. Exploring the option of organ and tissue donation at the end of life is a standard of care that should be fully assessed and appropriately explored with all patients and their families. Folder reviews and audits of documentation completed at end of life to assess compliance with these guidelines will assist in improving standards in death determination and end-of-life care.[70]

8. Conclusion

Death can be determined with complete certainty by medical professionals adhering to these guidelines which offer the clinician the latest evidence in best practice for determining death by either neurological or circulatory criteria. Use of the attached checklists is recommended.

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IJ, DG, FP, KDV chose the participants, developed and supervised the

methodology, participated in the Delphi process and face-to-face round-table meeting, performed literature searches, participated in manuscript drafting and revisions to the drafts, and approved the final manuscript.

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IC participated in the Delphi process, drafted and graded associated recommendations; participated in revisions to the drafts and approved the final manuscript.

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BRAIN DEATH CERTIFICATION

Summary Recommendations - South African Death Determination Guidelines Checklist

Name: _____ Hospital Number: _____ Date of Birth: _____

Doctor 1	Prerequisites	Doctor 2
	Coma, irreversible and cause known	
	Normothermia (> 36^{0}C)	
	Systolic blood pressure ≥ 100 mmHg*	
	Significant metabolic, electrolyte, endocrine abnormality excluded	
	Sedative/analgesic/neuromuscular drug effect excluded	

	Examination**	
	Pupils fixed and non-reactive	
	Absent corneal reflex	
	No gag reflex	
	Absent cough reflex on deep suctioning down tracheal tube	
	No facial grimace to supra-orbital pain	
	Absence of motor response in all limbs (spinal reflexes may persist)	
	Oculovestibular (cold caloric) reflex absent	
	Apnoea testing - no spontaneous respiration	

Doctor 1

Name: _____

HPCSA Number: _____

Signature: _____

Date and time: _____

Doctor 2

Name: _____

HPCSA Number: _____

Signature: _____

Date and time: _____

* or mean arterial pressure ≥ 60 mmHg / in paediatrics age appropriate haemodynamic targets apply

** One doctor with more than 5 years experience, tests may be done by both doctors simultaneously, no doctor may be involved with the transplant team

BRAIN DEATH CLINICAL TESTING

Summary Recommendations - South African Death Determination Guidelines Checklist

Coma	Apply deep pressure to: the temporomandibular joints, the supraorbital notch bilaterally, the sternal notch and all four extremities via deep nail bed pressure. There should be no true motor response.
Pupillary light reflex	Shine a bright light into the eye and look for a pupillary constrictor response. There should be no pupillary response.
Corneal reflex	Touch the corneas with soft cotton wool or gauze and examine the eyes for blinking or a withdrawal response. There should be no blinking or withdrawal response.
Response to pain in the trigeminal distribution	Apply pain over the trigeminal distribution, e.g. pressure over the supra-orbital nerve and to the condyles at the level of the temporomandibular joints. There should be no facial or limb movement.
Gag reflex	Stimulate the posterior pharyngeal wall, on both sides, with a tongue depressor or Yankauer suction. There should be no gag response.
Cough reflex	Stimulate the tracheobronchial wall with a soft suction catheter. There should be no cough response.
Vestibulo-ocular reflex (cold caloric)	Inspect the external auditory canal with an otoscope to confirm that the eardrum is visible. If the eardrum is not visible, the canal must be cleared before testing. Elevate the head to 30° to align the semi-circular canal and generate a maximal response. Flush 50 mL of ice-cold water into the ear canal using a syringe. Hold eyelids open and observe for eye movement for a minimum of 60 seconds. There should be no eye movement in response to the cold water; the eyes remain in the midline within the socket.
Apnoea test	See separate advice sheet.

Observations that are incompatible with a diagnosis of brain death:

Decerebrate or decorticate posturing. True extensor or flexor motor responses. Witnessed seizures.

Observations that are compatible with a diagnosis of brain death:

Spinal reflexes, sweating, blushing, tachycardia, and a normal blood pressure.

APNOEA TESTING

Summary Recommendations - South Africa Death Determination Checklist

Background:

Only proceed with the apnoea test to confirm brain death if all other brainstem reflexes are absent and patient is haemodynamically stable (may be on inotropes).

Two doctors should perform a single apnoea test together.

Testing procedure:

Pre-oxygenate the patient with 100 percent oxygen for 10 minutes to prevent hypoxaemia during the test.

Perform a baseline ABG.
Assess baseline CO_2 level (p_aCO_2 35 - 45 mmHg, 4.6 - 6.0 kPa).

Disconnect the patient from the mechanical ventilator and supply continuous oxygen via a T-piece (preferred) or through a catheter inserted through the endotracheal tube and placed above the carina*.

Observe continuously for any spontaneous breathing.

Halt testing if:

- Spontaneous respirations are witnessed;
- Systolic blood pressure < 100 mmHg or mean arterial pressure < 60 mmHg despite titration of inotropes/vasopressors;
- Sustained oxygen desaturation < 85%;
- An unstable arrhythmia occurs.

It is suggested that prior to aborting the apnoea test due to cardiorespiratory instability, an arterial blood gas (ABG) be sent for testing. If the p_aCO_2 target is met, the apnoea test can be considered positive (consistent with brain death).

Interpretation:

In cases of brain death, apnoea must be demonstrated in the presence of an adequate stimulus to spontaneous ventilation, i.e. an arterial p_aCO_2 > 60 mmHg (8 kPa) and an arterial pH < 7.30.

In patients with pre-existing hypercapnia, it is recommended to wait for a p_aCO_2 rise of > 20 mmHg (2.7 kPa) above the chronic level, with a pH < 7.30.

Attempt at breathing is defined as any respiratory muscle activity that results in abdominal or chest excursions or activity of accessory respiratory muscles.

Duration (Target p_aCO_2)

The period of observation to achieve an adequate threshold of stimulus of the respiratory centre is variable.
Usually p_aCO_2 rises by ~ 3 mmHg (0.4 kPa) for every minute of apnoea.
If starting from normocapnia, the p_aCO_2 is likely to be > 60 mmHg (8 kPa) after 10 minutes.

If this is not the case at 10 minutes and the patient is stable, wait a further 5 minutes and repeat the arterial blood gas.

An option to minimise the time required for the p_aCO_2 to rise to the desired level, is to adjust the minute ventilation to mild hypercarbia (p_aCO_2 ~ 45 mmHg [6 kPa]) beforehand.

If unable to complete testing consider:

If hypoxia occurs 1–2 positive pressure breaths can be given, and apnoea testing continued.
Adequate pre-oxygenation and recruitment usually avoids this problem.

*If using a catheter through the endotracheal tube supply oxygen at 4 - 6 l/min.

CIRCULATORY DEATH CERTIFICATION

Summary Recommendations - South African Death Determination Guidelines Checklist

Name: _____ Hospital Number: _____ Date of Birth: _____

Prerequisites

Inappropriate to attempt cardiopulmonary resuscitation or attempts at cardiopulmonary resuscitation have failed	

Intensive support (ventilation, inotropes) withdrawn at _____ (time) on _____/_____/_____ (date)

Examination

Absence of mechanical cardiac function confirmed by one of the following: - Absence of central pulse / heart sounds on auscultation - Absence of pulsatile flow on intra-arterial BP monitoring - Absence of contractile activity on echocardiography	
Patient observed for 5 minutes with no respiratory or circulatory activity seen*	
At end of 5 minutes observation period lack of pupillary response to light and motor response to supraorbital pain confirmed	

Death certified at _____ (time) on _____/_____/_____ (date) by

Doctor 1	Doctor 2 (in case of organ donation**)
Name: _____	Name: _____
HPCSA Number: _____	HPCSA Number: _____
Signature: _____	Signature: _____

*Any spontaneous return of circulatory or respiratory activity during the 5 minute observcation period requires a reset of the observation period from this point

** In cases of possible organ donation after circulatory death one doctor with more than 5 years experience, neither doctor may be involved with the transplant team.

INFORMATION CHECKLIST FOR POTENTIAL ORGAN DONOR REFERRAL

This checklist is intended as a guideline only when collating information to refer a potential donor. PLEASE REFER ALL POTENTIAL DONORS regardless of how much information you have on hand. The transplant coordinator will add any missing information during the evaluation.

Name of person referring

Hospital

Ward

Telephone no

Cell no (Referrer)

Name of donor Title Initial(s) Surname

Age Gender M F Ethnicity

Diagnosis/Injury

Brain death certified? YES NO Time Date

CONDITION OF DONOR

BP

Pulse

Temperature

Urine Output

Height (Estimated)

Weight (Estimated)

HIV Status

Hepatitis B

Blood Group
(If results are available)

BLOOD ELECTROLYTES

Na K+ UREA CREAT CHLOR

Relatives available? YES NO