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➤ Wits Transplant Procurement Handbook

A Practical Guide to Organ Donor Procurement

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Donald Gordon
Medical Centre

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Foreword

It is our pleasure to introduce the Wits Transplant Procurement Handbook.

This handbook is the culmination of our efforts since 2016, when our procurement team at Wits Transplant made a commitment to increase referrals to our procurement coordinators, and then increase 'conversion' of these referrals into consents for organ donation. This handbook details the practical aspects of our Wits Transplant Procurement Model, which has been successful in our setting. We also compiled this handbook because there are none easily accessible for South African healthcare providers working in organ procurement. Through this handbook, we offer our processes as guidance to the wider transplant community.

It is well known that donor organs are scarce, and that even with living donors, we still lose many patients each year because there aren't enough organs to transplant everyone who needs them. Moreover, the procurement coordinator's job is complicated by South Africa's unique healthcare context. We have 11 official languages, and patients come from a multitude of socio-cultural backgrounds. We have two disparate health provision sectors, with state patients often struggling to negotiate access to services from a position of disempowerment.

Procurement in this setting is not "one size fits all". Through our work, we have had to critically respond to many of these contextual challenges; and develop systems that "work for us". Our systems are described in easy, practical terms in this handbook, and we really hope that this information is helpful.



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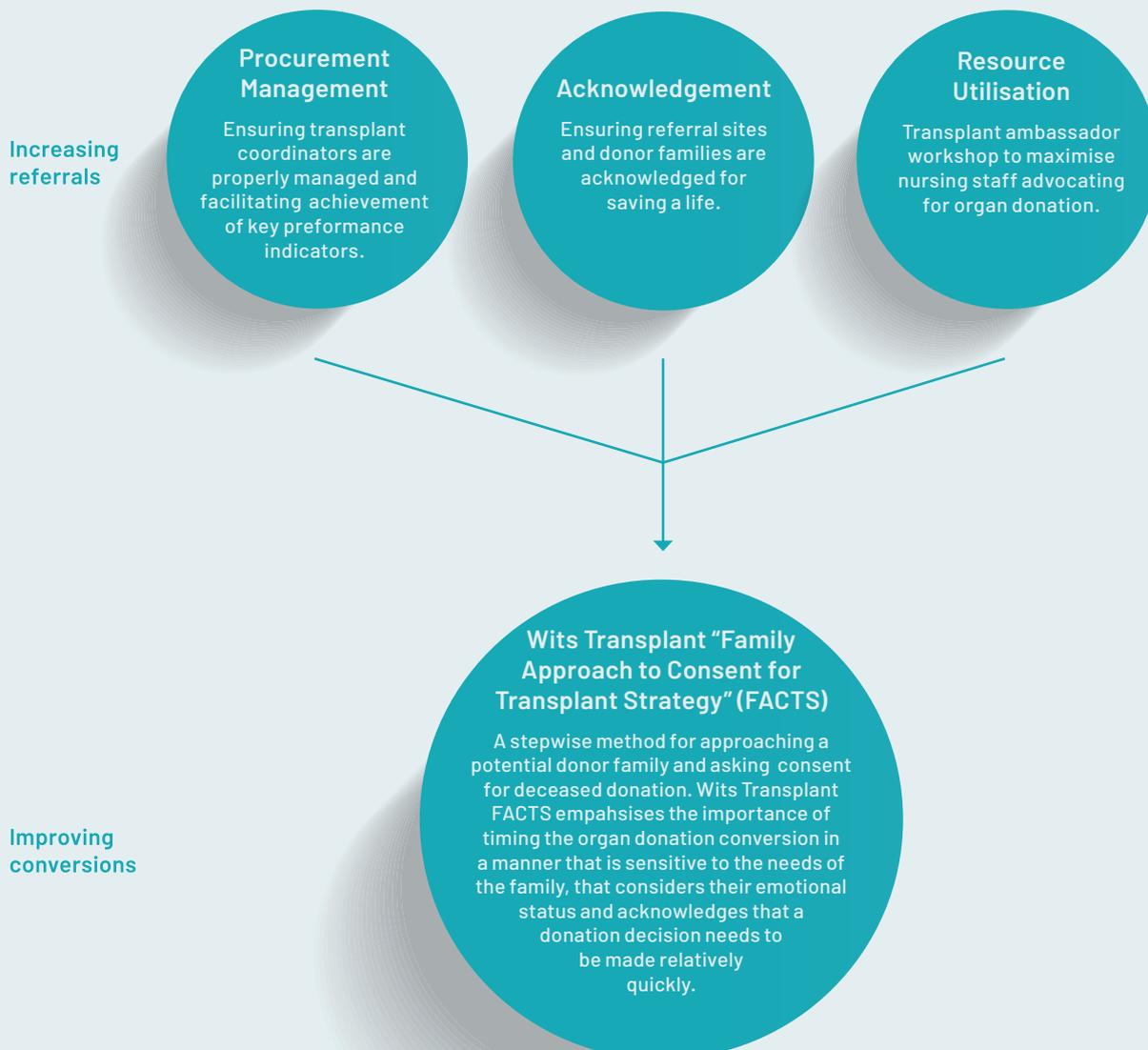
How to use this handbook

In this handbook we will share details of the Wits Transplant Procurement Model. Using this model, we addressed solid organ procurement on two levels (Figure 1). The first level included strategies to increase referrals to our procurement coordinators. The second level aimed to increase conversion rates of referrals to consents for organ donation, using the Wits Transplant “Family Approach for Consent to Transplant Strategy” (FACTS).

- In the first section we describe our initiatives to increase referrals, and explain how you can do them too.
- The second section is devoted to Wits Transplant FACTS.
- The third section of the handbook details some clinical and legal considerations in procurement and medical management of donors.

On the back cover, we have an easy access **Wits Transplant FACTS “Cheat Sheet”** which outlines the main steps of the strategy and can be quickly accessed if necessary. In order to simplify the information in this handbook, we have provided checklists wherever possible.

Figure 1 – The Wits Transplant Procurement Model



Increasing referrals

To increase a procurement coordinator's opportunity to obtain consent for deceased organ donation, there must be a strategy to increase the number of potential donor referrals from hospitals in the region. However, implementing initiatives that facilitate additional referrals can be tricky when there is no clearly defined scope of practice for transplant coordinators, and when there is no nationally endorsed protocol for referring centres. Our core strategy for increasing referrals, with strong leadership and a commitment from the team, included:

1. procurement management
2. acknowledgement and
3. resource utilization.

We identified target hospitals in our region, nurtured relationships, enhanced knowledge and understanding of organ donation and transplantation in order to achieve our goal.

How did we undertake Procurement Management?

Procurement management included in-service education, awareness days, individual doctor appointments and CPD-accredited continuing medical education (CME) meetings. We agreed it was mandatory to follow-up every referral within 45 minutes and to do this by physically visiting the referring hospital. We created a WhatsApp group for our coordinators to notify management and the team about referrals. We felt that assessing and filtering referrals telephonically was a missed opportunity – if not for consent to donation – then for educating nurses and doctors and networking with colleagues.

Acknowledgement

We agreed that increasing referrals was deeply rooted in relationship building, nurturing existing relationships and fostering trust between ourselves and our partner hospitals. At the end of each year

(2017 and 2018) we handed out certificates of appreciation to all nurses and doctors who referred potential donors that progressed to consent for organ donation. This provides continuity and an opportunity for follow-up, perhaps even closure.

Resource utilization – The Transplant Ambassador Programme

We knew we had very few resources to increase organ procurement, but one way around this was to capacitate individual staff at referring hospitals as Transplant Ambassadors – people who promote transplant as they go about their daily work – and who can advocate for organ donation in their setting. Our Transplant Ambassadors are usually professional nurses working in ICU's or trauma/casualty units. These nurses are often in the most appropriate position to suggest referring a potential donor to the team with whom they are working.

To upskill our Transplant Ambassadors, we host an annual workshop on organ donation. We try to hold the workshop off-site with the intention of making the day a bit of an occasion. Through these workshops, we aim to show our Transplant Ambassadors that we believe in them, and appreciate the service they provide. To date, we have hosted two workshops that have been attended by approximately 100 professional nurses. Of course, we need funds to do this, so we secured an educational grant from several pharmaceutical companies.

Procurement management

So, let's get you started

This section details activities for procurement coordinators to implement when they visit hospitals. These are based on our experiences, and you may have to tweak what we have done to work in your setting. It may take a few tries until you hit on a winning formula.

Before you start planning your hospital activity, it is important to remember that each hospital has different potential to refer. This means that you should carry out more activities at the larger hospitals, and fewer at the smaller ones. We found that it helps to plan your approach by ranking your hospitals based on the number and size of trauma/casualty units and ICU's from biggest to smallest. You can then create a working spreadsheet (a template for which can be found in **Appendix 1** of this handbook) and list the hospitals in ranking order from the greatest potential to refer donors (the biggest hospitals) to the smallest ones. Set monthly targets for the number of proposed visits per hospital and plan what activity will be performed at each visit in your spreadsheet.

Next, set a target for the number of referrals you would like to receive each month from each hospital. At the end of each month, capture the actual visits completed versus the planned number of visits. Also capture the actual number of referrals versus the target set for referrals. This gives each procurement coordinator a monthly, realistic overview of how effectively they are performing and where they could improve. It is very important not to neglect the smaller hospitals – **a referral is a referral, and a chance to save lives, no matter where it comes from!**

Checklist – Planning Hospital Activities

✓	Rank all hospitals from highest to lowest potential to refer
✓	Create a spreadsheet and enter hospitals in ranking order
✓	Set a target for the number of hospital visits per month
✓	Specify what activity is to be performed at each visit
✓	Set a target for the number of referrals per hospital per month
✓	At the end of each month capture actual versus planned activities, and actual versus planned referrals

Once you have your targets in place, it's time to get out there and start the hard work. Here are some details to guide you in the planning of hospital activities that we have found effective at Wits Transplant. In a hospital setting, any activity you undertake should have an educational element that creates the opportunity to talk about organ donation and transplantation. We identified four such activities:

- (i) **an in-service education meeting for an identified group of nurses,**
- (ii) **awareness days for the general hospital staff,**
- (iii) **a one-on-one appointment with an appropriate doctor eg. neurosurgeons, intensivists, trauma physicians,**
- (iv) **CME meetings.**

We discuss each in turn.

Hospital activity: In-service education

This activity is booked with the manager of the ICU or trauma/casualty unit where information and education in organ donation is shared with the nurses on shift for the day. Generally, you should book two appointments to ensure that nurses on both shifts are included. The content should focus on:

- The current status of transplantation in South Africa, highlighting the number of recipients on waiting lists.
- How deceased donors can save the lives of those waiting for a transplant and discuss how many lives just one donor can save.
- How tissue, bone and corneas can be used.
- The process of what happens when a deceased donor is taken to theatre and organs are retrieved. Emphasize that this process is very dignified and respectful towards the donor and their family.

Encourage discussion and questions throughout the session and clarify any misunderstandings. Remember there is no such thing as a “stupid question” – treat the staff in the hospital with respect, be approachable, give them your time and attention and you may just get a referral.

Hospital Activity - Awareness Days

Set aside a full day to spend at one hospital to focus on creating awareness about organ donation and transplantation. People targeted at these awareness days are all nursing staff and all medical practitioners at the hospital as well as members of the public who are visiting the hospital. It is important to arrange awareness days in advance with either the Hospital Manager, Nursing Matron or Clinical Facilitator. This is generally a very busy day so please ensure that you have support from other transplant coordinators or from NPO’s like **TELL** or the **Organ Donor Foundation**

When you get to the hospital on the day, set up a display table in the reception area. This table must have someone there all the time as this is where members of the public will come and find out about organ donation and transplantation. It is important that the person working at this display table is knowledgeable about the topic so it should be a procurement coordinator or a volunteer from one of the NPO’s. Have Organ Donor Foundation brochures at the table so if anyone wants to register as a potential organ donor, they can do so immediately. Remember, the most important thing is that people share their donation preferences with their families – so be sure to give them this vital information.

Book two formal education sessions as part of your awareness day. This can usually be done with help from the Hospital Manager, Nursing Matron or Clinical Facilitator. One session should be in the early morning and one early afternoon. Invite all hospital staff to attend. You can ask the appropriate person email the invite to all staff ahead of time so that the session can be diarized. Keep an attendance register so that you have a record of those who were there. This session should be 60 -90 minutes long. It’s been our experience that you only need two speakers for these sessions. The first is the procurement coordinator, who covers topics like brain stem death,

which organs and tissue can be donated, nursing a potential donor, the process of procuring organs in theatre and, very importantly, who and when to call if there is a potential donor the hospital wishes to refer. The second speaker could be a transplant recipient who can share their own transplant journey.

It is very powerful to have a transplant recipient join you at the awareness day and to speak at the education sessions. This shows the other side of organ donation, the “lives saved”. It also gives staff a firsthand account of what it is like to be gravely ill and waiting on a list for an organ. The transplant recipient can talk about what it felt like to receive the call that there was a donor for them and to show nurses and medical practitioners what life is like after transplant. Involving a transplant recipient in the education session has high impact, it’s very moving and it highlights the power of referring a potential donor.

TIP! – When planning an awareness day, especially when you are going to be interacting with the public – ask yourself: “Who is my audience? What language do they speak? How much medical knowledge do they have?” The answers to these questions will help you ensure you have the best people on your team. If you are going to a state hospital where many languages are spoken, and you can’t speak these languages, try to get a multilingual volunteer to assist you in connecting with the public at a more meaningful level. Of course you’ll need to make sure this is someone you trust, for instance a Transplant Ambassador – **more on page 9**. If there are going to be children coming past your display table, think of ways to make your presentation more interesting for them. Maybe use pictures or props.

Checklist – Planning an Awareness Day

	Book a full day at the hospital
	Book two education sessions, one morning and the other afternoon
	Ask the Hospital Manager, Nursing Matron or Clinical Facilitator to send out invitations

✓	Enlist someone to help you, for instance from one of the NGO's
✓	Set up your display table in reception
✓	2 speakers at each formal session – you, and a transplant recipient or other interesting speaker

Hospital activity - Individual doctor appointments

Identify key doctors like neurosurgeons, trauma physicians and intensivists who would be crucial in referring potential donors. Set-up a one-on-one appointment either in the unit where they work or in their consulting rooms. This creates an opportunity for you to have a more in-depth discussion about organ donation and transplantation. At this appointment it is important to find out as much as possible about what experience the doctor has had with referring potential donors and with organ transplantation. It is an opportunity to explain your role as a procurement coordinator, as well as the process that needs to be followed from referral, through consent to transplantation of organs and tissue. This is a critical relationship building opportunity and will pave the way for long-standing working collaborations. As a coordinator, this is a great way of getting onto a doctors' radar.

Hospital activity - Continuing Medical Education (CME) meetings

It's best to arrange this meeting at least a month in advance to allow sufficient time for invites to be circulated to the doctors or nurses who you would like to attend. The meeting is usually hosted at a specific hospital, most often in the early evening. Doctors, nurses and paramedics from that hospital are invited.

The CME meetings we have run through Wits Transplant generally involve a talk by the procurement coordinator entitled: "Doing good with giving bad news". The talk focusses on some of the main ethical and practical challenges facing procurement transplant coordinators in South

Africa. It emphasizes elements of ethically robust practice such as clear communication from the healthcare team, the importance of timing, the structure of sensitive conversations in which we 'break bad news' and the importance of follow-up. The talk explores some of the primary challenges affecting donor numbers and referrals in South Africa, and it presents a pathway for working together in order to increase donor numbers.

There is often a second talk by one of the medical practitioners from the hospital focusing on a clinical topic of their choice. Otherwise, the hospital may request a second talk on another aspect of transplant, or a different topic. Here, you have an opportunity to engage the services of another speaker, which can add something meaningful to the conversation. Consider getting a lawyer, a community member or an ethicist – or someone else who can give a different perspective on organ donation and transplantation.

It is very beneficial to have these talks CPD accredited so that attending doctors can earn CPD points. The hosting hospital will usually be able to do this for you. An example of a CME programme can be found in **Appendix 2**, and can be customised to suit your needs.

Response to Referrals

Our 'Hospital Activities' are substantially aimed towards providing educational opportunities and information that will ultimately result in increased referrals. But what should you do when you get these referrals? Part of the Wits Transplant Procurement Model is mandatory follow-up of every referral. It's best that you physically respond to every referral within 45 minutes, by visiting the referring hospital. Create a WhatsApp to notify management and the team about the referral.

Acknowledgement

An example of the certificate of appreciation can be found in **Appendix 3**, and you can easily customize it to meet your needs.

Resource utilization

The Transplant Ambassador Programme

Once a year, try to host a full day “Transplant Ambassador Workshop”. The programme should cover all relevant topics about organ donation, and an example can be seen in **Appendix 4**. Try to host the workshop offsite. A budget of R25 000-00 is sufficient to cover costs of venue hire, catering, certificates and badges. It’s a good idea to approach pharmaceutical companies for funding.

To ensure nurses can attend the workshop, a letter is sent to the Nursing Manager of each targeted hospital outlining the content of the workshop and requesting permission for two professional nurses to attend. Once permission is granted from the Nursing Manager, a formal invite is then extended to the two identified nurses – an example of this invite is in **Appendix 5**.

At the end of each Transplant Ambassador Workshop, each delegate receives a certificate of completion as well as a Transplant Ambassador badge which they are encouraged to wear to work. The badge identifies them amongst their colleagues and within their hospital as being Ambassadors and supporters of organ donation and transplantation. The badge also helps to spark conversations about this topic. Easily adaptable examples of the badge and the certificate can be found in **Appendices 6 and 7**.

Checklist – Transplant Ambassador Workshop

✓	Book venue, catering, AV equipment and parking
✓	Send invite to Nursing Manager, asking for 2 staff members to attend
✓	Send invite to the two identified staff members once the Nursing Manager has approved
✓	Secure your speakers
✓	Print certificates
✓	Get badges made

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: <ul style="list-style-type: none">• 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 is 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 just 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 - 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"

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."

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 possibly 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."**

↑ Clinical and legal considerations

Determination of Brain Stem Death

Brain Stem Death is legally recognized as constituting death in South Africa. The National Health Act [2], our main piece of legislation regarding the provision of healthcare, stipulates the circumstances under which a person may be considered as a deceased organ donor. In this case, brain stem death needs to be certified by two registered doctors independent of the transplant team, one of whom must have been registered for 5 years or more. [3].

Checklist - Initial clinical assessment of a potential donor is done by evaluating the following key factors

✓	Is hemodynamic stability and maintenance satisfactory?
✓	What is the cause of brain-stem death?
✓	When last did the patient receive any analgesic or sedative agents?
✓	<p>Even if brain-stem death testing according to the National Health Act was already performed, what is your professional opinion? It is always good to do your own quick assessment and double check if there is any brain stem activity still present. Assess for any pupil, corneal, gag, cough and pain reflexes and for spontaneous breathing.</p> <p>⚠ Remember that if a patient is sedated or on analgesia, this might affect the results of brain-stem death testing. In this case, stop the infusion and repeat brain stem death testing.</p>

✓	Has a clinical history of the patient been obtained from the treating team, and are there any concerns with the case?
✓	Have you discussed the patient's potential for organ donation with a member of the transplant team at your transplant centre?

Even if you use the list above to guide you in your clinical evaluation, it is important to remember that other essential clinical factors might be present. You will need to consider these even though they are not mentioned here. You can find out much more about the exact clinical evaluation [here](#).

Legislation and logistics regarding unnatural deaths

According to SA law - a forensic autopsy is carried out when the cause of death is considered unnatural or possibly unnatural. This is relevant to all unnatural death cases even if the family gives consent to organ donation. Unnatural deaths can be grouped as deaths due to violence and the consequences of injuries that result in death. A postmortem examination will be done to determine the cause of death following an unnatural death.

In the event of an unnatural death, where the family has consented to organ donation, the Forensic Pathologist's telephonic consent must be obtained to proceed with the retrieval process. The Forensic Pathologist will give permission for the retrieval of specific organs and tissue that will not influence the outcome of the postmortem.

The Forensic Pathology Laboratory will collect to body after the retrieval process has been completed. Copies of the relevant donor documents, completed D28 and other relevant forms will be collected with the body. These documents differ depending on whether you're in the state or private sector, but the nurses at the hospital will be able to help you.

The postmortem is done at a Forensic Pathology Laboratory in the area where the death took place. The pathologist will issue a death certificate and the body will be released for burial on completion of the postmortem. This may take some time and must be explained to the donor family, and you should be doing this in Steps 5 and 7 of Wits Transplant FACTS.

Thank you

To the NHSBT for producing the document that inspired this work, and making it public. We hope that through publishing this Handbook, we have been able to “pay it forward”.

To Dr Sue Tager, CEO of Wits Donald Gordon Medical Centre, who’s unwavering support and vision for Wits Transplant has made this programme, and this Handbook, possible.

To the Wits Transplant Team based at Wits Donald Gordon Medical Centre, without each one of you, the work we do would not be possible. Thank you for seeing our organ procurement through to lifesaving transplant operations for recipients.

The editors would like to thank Sr Heather Maher – and the Clinical Research Team at Wits Donald Gordon Medical Centre – for all their hard work and support through this project. Sr Heather Maher took the beautiful author photos for this Handbook.

To every donor family who has made the decision to save lives in their moment of grief. We acknowledge that it takes an incredibly special family to nurture seeds of hope amongst the ruins of tragedy. We would like to thank you for your generosity, for changing peoples lives and giving them hope. May the constant love of caring friends soften your sadness, cherished memories bring you moments of comfort and lasting peace surround your grieving heart.

To every treating doctor, ICU -, trauma - and theatre sister, Transplant Ambassador, trauma counselor, translator, nursing matron and hospital team who refer and assist with the management of all potential and consented organ donors. Our accomplishments would not be possible without your support - and that first phone call.

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APPENDIX 1 – HOSPITAL RANKING SPREADSHEET



Hospital Activity	Planned activities	In-service training	Awareness Day	Doctor visit	CME meeting	Target referrals	Actual referrals
Hospital 1	10		1	3	0	4	2
ICU		2					
Trauma		2					
Neonatal ICU		2					
Hospital 2	6		1	0	1	4	1
ICU 1		2					
ICU 2		2					

APPENDIX 2 – EXAMPLE OF A CME INVITATION AND PROGRAMME

ETHICAL CPD INVITATION

1. Doing good with giving bad news

2. The healthcare professional and social media use

Mediclinic Potchefstroom invites you to an ethical CPD function presented by:

Session 1: Marlize de Jager
Session 2: Adv. Bonnie Venter

Date: 28 May 2019
 Venue: Mediclinic Potchefstroom Management Board Room
 Time: 18:30

You will receive two ethical CEU points on level 1 for attending this CPD function.

Please confirm your attendance before/on 12 May 2019 at elmari.snoer@mediclinic.co.za





Certificate of appreciation

This certificate is proudly presented to:

In appreciation for your contribution towards Wits Donald Gordon Medical Centre completing 132 transplants in 2018.

Wits Donald Gordon Medical Centre Transplant Unit would like to acknowledge the pivotal role you played in saving these lives.

“Without the organ donor there is no story, no hope and no transplant. But when there is an organ donor, life springs from death, sorrow turns to hope and a terrible loss becomes a gift.” UNOS

Without your outstanding dedication, commitment and support, no sorrow would have turned into hope and many recipients would not have had a second chance.

Prof Jean Botha

Director of Transplant

Carla Wilmans

Transplant Manager



APPENDIX 4 – SAMPLE TRANSPLANT AMBASSADOR WORKSHOP PROGRAMME



WDGMC Transplant Ambassador

Workshop Program

Date: Thursday 30 May 2019

Chairperson:

Venue: Wits Club, Wits West Campus, Parktown, North Gate Entrance 7

Time	Topic	Speaker	
08:30 – 09:00	Registration		
09:00 – 09:10	Opening and Welcoming		10 min
09:10 – 09:20	Status of Transplantation in Gauteng		10 min
09:20 – 09:50	Identification of a potential donor and BSD testing		30 min
09:50 – 10:20	Haemodynamic management of a donor		30 min
10:20– 10:50	Morning tea		30 min
10:50 – 11:20	Pathophysiology of Brain Stem Death		30 min
11:20 – 11:40	Legal aspects of organ and tissue donation in SA		20 min
11:40 – 12:10	Conversations about Organ and Tissue donation		30 min
12:10 – 12:50	Lunch		40 min
12:50 – 13:00	Donor family experience		10 min
<u>13:00 – 13:30</u>	Organ harvesting in theatre		30 min
13:30 – 14:00	After harvesting – what now?		30 min
14:00 – 14:30	Certificate ceremony		15 min
14:30 – 15:00	Afternoon tea		30 min

APPENDIX 5 – TRANSPLANT AMBASSADOR WORKSHOP INVITE



APPENDIX 6 – TRANSPLANT AMBASSADOR BADGE



APPENDIX 7 – TRANSPLANT AMBASSADOR WORKSHOP CERTIFICATE



WITS TRANSPLANT FACTS CHEAT SHEET

Coordinators involvement – ⚠️ Coordinators are trained in organ donation conversations, and they are the best people to lead these conversations. Involve coordinator as early in the process as possible, this allows coordinator to develop relationship with family. It allows staff to ask questions and discuss concerns in order to have a common goal of requesting organ donation at the right time and in the right way. It allows time to plan a strategy for the family approach where everyone understands who is going to do what and when. Introduce the coordinator as, “a nursing sister who supports families in these situations”

1. PLANNING

- Key stage in the process. Allows you to formulate a strategy with the multi-disciplinary team
- Done before speaking to the key-family members
- Ensure hemodynamically stability and maintenance
- Involve treating doctor, coordinator, nurse & other relevant health professionals
- Assess & confirm brain-stem death tests
- Assess & confirm patients donation potential
- Identify key family members and get a sense of family dynamics
- Explain approach strategy to healthcare team

2. BREAKING BAD NEWS

- Meet with the family in a private room away from bedside
- Dr breaks bad news and hands over to coordinator.
- ⚠️ Introduce coordinator by name, do not use the words ‘transplant coordinator’
- Use words that leave no room for doubt that brain-stem death is death
- Use visuals to demonstrate the extent of injury
- Allow moments of silence and time for questions
- Offer support
- DO NOT mention anything about organ donation
- Avoid words or phrases like ‘life-support’ or ‘the machines are keeping him alive’

3. TIME-OUT BREAK

- Give family some privacy and time to process the news that was given to them. They need time to reflect on the reality of the situation
- Encourage family and those close to patient to spend as much time as needed with their loved one

4. ASSESSING UNDERSTANDING AND ACCEPTANCE OF LOSS

- Arrange a second family meetings
- Check key-family members level of understanding
- Observe body language and listen carefully to words used and questions being asked
- Move forward to step 5 if all key-family members accept that their loved one has died
- If family member has not accepted, go back to step 2 ⚠️ The possibility of donation should not be discussed until you are confident that all family members have come to terms with the loss of their loved one

5. CONSENT CONVERSATION

- Led by coordinator
- Use positive language
- Give specific information about the patient’s donation potential and emphasise benefits for recipients, their families and the community
- Provide information of the process of organ donation before expecting a response
- Use OPEN ended questions
- Never use negative or apologetic language
- Emphasise that care, and respect will be given to the donor at all times, and the family will be informed every step of the way
- Listen carefully for common concerns that the family may have at this time. (These concerns are often the reasons for refusal.)
- Address these common concerns in a knowledgeable and sensitive way

6. TIME-OUT BREAK

- Allow family to discuss the option of organ donation in private and come to a decision
- The foundation of the “consent conversation” and the “time-out break” to ensure that any decision a family makes is done in a unhurried fashion, based on sound information and in a supportive atmosphere

7. FINAL FAMILY DISCUSSION

- Family will inform coordinator about their final decision
- Family support at the bedside should continue irrespective of final decision
- Answer questions and respect family requests
- Verbal consents must be followed by written consent
- Sensitively explore initial family refusal

8. FAMILY FOLLOW-UP FEEDBACK AND SUPPORT

- Inform referring team about the family’s final decision
- Regular telephonic updates to be given to family spokesperson
- Follow-up thank you letters given to the referring team
- Follow-up thank you letters given to the donor family from the transplant team
- Recipients are encouraged to write anonymous thank you letters