

Death, Dying, Grieving & Organ and Tissue Donation Awareness - A Cultural Perspective Conference



CONFERENCE REPORT

Australian Multicultural Foundation
02/09/14

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Introduction

The 'Death, Dying, Grieving and Organ and Tissue Donation Awareness - A Cultural Perspective' conference, facilitated by the Australian Multicultural Foundation (AMF) and funded by the Organ and Tissue Authority (OTA) under the Community Awareness Grants program, took place on 19 June 2014 at the Village Roadshow Theatre at the State Library of Victoria. A total of 144 people attended the conference, including 21 speakers and six chairs.

The objective of this conference was to explore the diverse beliefs and practices surrounding death and the dying person, with a particular focus on the important topic of organ and tissue donation, and to provide communities with access to relevant and culturally appropriate information. By addressing these issues, the conference hopes to encourage more open and informed discussion in the wider community and raise greater awareness and understanding to ensure that patients and their families receive the appropriate care.

Cultural and religious beliefs and practices are an important consideration and have significant influence in issues associated with death, dying and grieving. This includes issues such as coping with terminal illness, planning for end of life, coping with sudden traumatic death, or considering whether you wish to become an organ and tissue donor. In some migrant communities in Australia, issues surrounding death, dying and end-of-life care are not openly discussed. Furthermore, many people from culturally, religiously, and linguistically diverse backgrounds are unsure whether their culture or faith supports organ and tissue donation, which can act as a barrier to family discussion and knowledge of donation decisions.

The conference covered a wide range of topics related to death, dying, grieving and organ and tissue donation in culturally, religiously and linguistically diverse communities. Speakers included medical practitioners, religious leaders and community workers, as well as people with personal experiences related to organ and tissue donation. The sessions generated much discussion during the Q&A session, as well as during lunch and breaks.

This report will provide a summary of each of the presentations and panel sessions, giving an overview of each speaker's perspective and documenting some of the key discussions that arose in question and answer sessions. It will do so in chronological order, and will conclude with some recommendations that have come out of the conference.

We would like to sincerely thank the speakers, panellists and chairs for their invaluable contribution to this conference, as well as to the AMF staff and the OTA for their work in organising the day. We look forward to developing the key outcomes of the conference and to implementing these within the community.

Introduction and Welcome

Sir James Gobbo AC CVO

Emeritus Chairman

Australian Multicultural Foundation



Sir James began by highlighting the difficulty of discussing organ and tissue donation in a cultural setting, as it is a relatively new discussion in the wider discussion of death, dying and grieving. He noted that today there is a higher regard for cultural sensitivities from the Australian public than from anywhere else in the world, with studies showing an 88% approval of multiculturalism. This is beneficial when dealing with topics such as death, dying and grieving, as we are willing to talk about it and address cultural sensitivities. We have made a lot of progress in

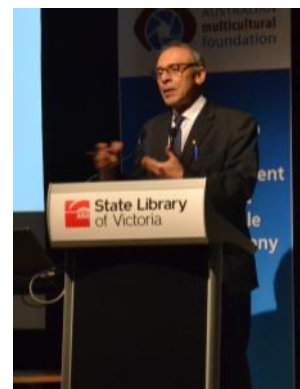
this domain, but there is still more to be done; especially regarding religious diversity and tolerance. Sir James Gobbo then explained that for members of culturally and linguistically diverse (CALD) communities, the religious leader is often the figure that many people go to in order to discuss issues such as organ donation. He then emphasised the significance of palliative care in issues of death, dying and grieving, noting that Victoria has been quite successful in this area. Lastly, Sir James Gobbo welcomed everyone and noted that the conference is the first of its kind in Australia and that the attendees are 'pioneers...taking place in something that's historic'.

Dr Hass Dellal OAM

Executive Director

Australian Multicultural Foundation

Dr Hass Dellal welcomed everyone to the conference on behalf of the AMF and the Organ and Tissue Authority (OTA), and thanked the OTA for their support. He then underlined the aim of the conference; to explore the varying cultural beliefs and practices surrounding death and the dying person, with a particular focus on organ and tissue donation, and to bring together medical experts and religious leaders alongside members of the community to discuss culturally appropriate end-of-life care. Lastly, Dr Dellal raised two key points pertaining to the topic; that issues to do with death, dying and grieving are often not openly discussed in migrant communities, and secondly that the conference aims to encourage discussions regarding organ and tissue donation within families in order to optimise the opportunities for organ and tissue donation.



Keynote Address

Chair: Dr Hass Dellal OAM

Executive Director
Australian Multicultural Foundation

Understanding beliefs and practices about death, dying and grieving for people from culturally, religiously and linguistically diverse backgrounds

Dr Peter Saul

Senior Intensive Care Specialist at John Hunter Hospital
Director of Intensive Care at Newcastle Private Hospital



Dr Peter Saul began his speech by explaining that he was not going to focus on what different people believe, as he preferred to focus on our commonalities rather than our differences. He analysed the presence of values in end of life decision making, contending that we do not inherently have values, but that 'values arise in a context where decisions have to be made', noting that he has seen people take a complete 180 degree turn on their opinion on a topic in the space of one conversation. He then went on to explain that the fundamental issue in end of life decisions is agency, in other words, who is responsible for making such decisions, and that the family is the focus in this process. He said that the cultural beliefs of patients are often presented to clinicians as a 'problem', as though clinicians themselves are part of a dominant group, and that this has unfortunately created an 'us and them' situation. He here mentioned that he feels very challenged by the fact that cultural and religious beliefs of doctors has an influence on the patient's decision, for example, palliative care is 'a very catholic organisation' in Australia, which is admirable but also comes with its belief systems. Dr Saul then asked the audience to respond to some questions by raising their hands, highlighting that even amongst the people in the room there were differing opinions and knowledge regarding organ and tissue donation.

He then provided an anecdote of a young Japanese man visiting Australia who fell out of a window and became brain dead, whose parents were Shinto. He explained that he thought that they would be against organ donation for religious purposes, however they asked about organ donation, saying 'isn't that what you do here in Australia?' They wanted to do what was normal for him. He also spoke of the time he spent living in Spain, where the amount of English people living there donating organs was higher than in England.

Dr Saul then went on to provide some reasons as to why people choose to donate organs, such as giving meaning to the death or allowing the person to live on in

others, or choose not to donate, such as mixed feelings or donating feeling like a distant prospect that needs action now. He said that often people do not feel as though they are in control of their own life. Furthermore, he noted that when religious leaders are faced with the question of donation, they feel a lack of empowerment, as though they don't feel as though they should make this decision as it is in 'the hands of God'. Finally, Dr Saul provided a list of responses he often receives from families regarding the prospect of organ donating, such as 'go away', 'I can't read this' or 'talk to my daughter', and that unfortunately these are more common amongst people from non-English speaking backgrounds (NESB). He ended by saying that what he is aiming to do now is to access the people who provide gateways to these communities and to establish trust, that what we believe is strongly influenced by context, and that the problem is agency.

The importance of organ and tissue donation in relation to people from culturally, religiously and linguistically diverse backgrounds

Ms Yael Cass

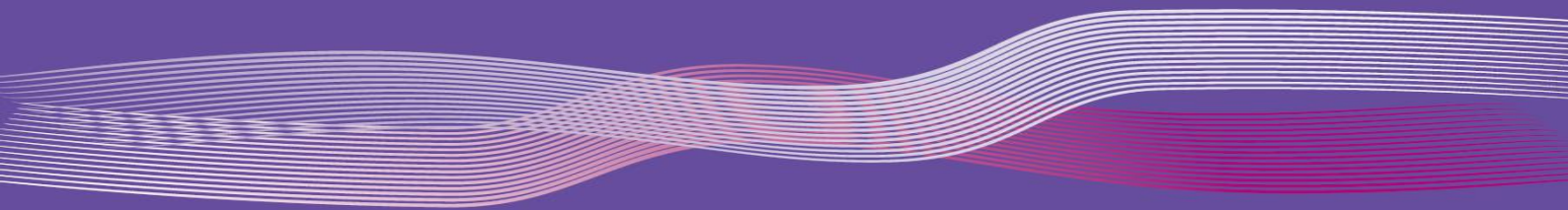
Chief Executive Officer
Organ and Tissue Authority

Ms Yael Cass focused specifically on the current status of organ and tissue donation in Australia. She contended that the needs are not being met in Australia, and emphasised the importance of maximising every opportunity, as organ donation is only possible in certain hospitalised circumstances such as intensive care. She noted that the consent rate was only 62% nationally, with some families refusing even if the patient was registered as a donor. Ms Cass outlined three recurring reasons for this; that the patient didn't want to, that the family did not feel comfortable with it, or for religious and cultural reasons. She stated that while many religious leaders support organ donation, getting the facts and information to the community can take time. For example, many people are apprehensive toward donation as they would like to follow the tradition of having an open casket and are concerned about the appearance of the donor, and are unaware that the appearance does not change after donating.



Ms Cass then went on to discuss the differences in willingness to donate between English-speaking and people from NESB, with roughly a 10% difference, suggesting the information is less available to these people. She said that while the importance of saving a life is a strong motivator for all cultural groups, awareness of the protocols of organ donation varied among people of different backgrounds regarding misconceptions such as mutilation of the body during the process, or a doctor not trying as hard to save a life if the person is a registered donor.

She then explained the initiatives taken by DonateLife to help support people of culturally and linguistically diverse backgrounds, such as translating their brochure into 18 different languages. Ms Cass concluded by outlining what the next steps are



for the Organ and Tissue Authority; working with religious and community leaders, developing and distributing information resources to communities and supporting staff in hospitals with information so that they can support families from multicultural communities.

Ms Yael Codron

Transplant Recipient

Ms Yael Codron gave the audience an invaluable personal account of how organ donation changed her life. She began by stating that she is a recipient of a kidney, who she calls 'Doris', who came into her life 5 years ago on Good Friday. She explained that she was born with kidney problems but after many operations she was able to have a normal childhood. However, she knew from a young age that she would one day have to be on dialysis as her kidneys would fail. She then went on to explain her experience with dialysis, beginning at age 21 when she was in her second year at university. She explained that her and her mother learned how to do everything themselves, such as setting and packing up the machine, to ensure that she was in control of her own situation. She was able to dialyse on holidays with her family, as her mum made every effort to ensure that she did not miss out on anything.

Ms Codron said that this went on for seven years, and that as she grew older she grew more and more frustrated, as she never felt one hundred percent and was often lethargic, and felt trapped being dependent on her parents in her late twenties while her friends travelled the world. She then went on to state that throughout this period, she was 'waiting for someone else to die in the exact circumstances that would allow their organs to be viable for donation' and 'waiting for an act of altruism' and that eventually that day came. She then showed the audience a short video that her sister took in hospital of her before she went in for the transplant, and after the transplant. Most notably was a video of Yael talking to her 'kidney brother', a man who had received the other kidney from the same donor, and who had also been on dialysis for over seven years. When asked about the donor, the man said that they are 'very generous people' and emphasised his gratitude toward them.

Ms Codron then continued with her story, saying that at the time she didn't want to think too much about organ donation, she just wanted to get on with her life. As time went by however, she discussed it with friends more and more often, asking others if they would donate their own organs. She received a variety of responses, some being 'why not', some having not thought about it, and one particular response being quite surprising, that one friend wouldn't donate their organs because 'Jews are not allowed to donate their organs'. Ms Codron said that she wasn't so concerned by whether Jews could or couldn't donate their organs, more that this friend was not particularly religious, as she didn't keep kosher and didn't keep the Sabbath. Ms Codron went on to explain that when it comes to death, Jews have a religious burial, and there are some important myths regarding organ donation that need to be cleared up, and that one of the most important aspects of Jewish law is the importance of saving a life. However, you cannot take one life to save another, which is the very heart of the debate; is someone dead when their brain stem is dead, or

when their heart stops to beat? As doctors now consider whole-brain death to be irreversible, more and more Rabbis now accept that harvesting organs from people whose brain stem is dead is no longer taking one life to save another. Ms Codron concluded by stating that it is important to get the word out in our communities, so that we can become a 'generation of givers', once again emphasising her gratitude to her donor and their family, and explaining that since receiving her kidney, she has travelled, 'climbed volcanos and jumped out of aeroplanes'.

Plenary Session 1

Chair: Ms Carmen Calleya-Capp

Representative from the Maltese Community

The role of the family in culturally, religiously and linguistically diverse communities in death, dying and grieving

Mr George Lekakis AO

Chief Executive Officer
Froniditha Care



Mr George Lekakis began by explaining the scope of Froniditha care, an aged care facility with 5 centres in Victoria and New South Wales, as well as looking after people in their own homes. The centre mainly looks after members of the Greek community, who were the focus of his presentation. He mentioned that much of this information he was providing came from his senior nursing staff, and that he is extremely proud of the contribution that the facility makes to the community. He focused on the role of the family in a situation when a patient is

in palliative care, and also on the grieving process. He stated that the grieving process begins often when the patient is admitted to a care facility, and begins to experience loss as their memory fades; they lose their relationships or are no longer able to fill their role in the family and community. It also induces sadness and depression in those that love that person, as they hear of and recognise their deteriorating health, or feel a sense of shame that they are putting that person into care. He asserted that as palliative care is such a complex process, as the person receiving palliative care must be involved in the decision making. It is important that the family address the option early on and can make advanced care planning, and encourage such discussion while the resident is still able to have input.

Mr Lekakis then provided information regarding alternatives to hospitalisation, as there are many community supports which assist a residential aged care facility and help the resident in a comfortable and familiar environment to minimise the need for hospital transfers. Hospital in-reach times and palliative care teams support the nursing home staff with the palliation process. He noted that in his experience, it is at this stage when most difficulties arise as families begin to panic and the decision-

making process becomes harder, for example, when people stop eating. Within the Greek community, he mentioned that families often lose sight of importance of the quality of life for their loved one as they are focused on the quantity of their life. For example, if the family try to feed the person once they have stopped eating, this can cause other difficulties for the patient, and thus the key is to educate the family and resident prior to this stage. The purpose of this is to allow the person to pass away with dignity and in comfort, surrounded by loved ones. He explained that when this is achieved, family members are also more likely to cope better after their loved one has passed away.

Throughout this process, the wishes of the resident is paramount, however, if the person is not cognitive, the role of the family and their wishes is important. These decisions can often be very difficult, as they involve what kind of medical treatment will be required, whether they wish to be kept alive, and what their final wishes are regarding family, possessions, experiences and funeral arrangements. He emphasised that it is crucial not to lose your humanity and to remain empathetic, as you generate relationship with both the patient and the family, it must be one based on respect. Lastly, Mr Lekakis explained how Fronditha care address the spiritual issues or the resident, such as the Greek orthodox funeral traditions that are crucial to a family, and that staff also experience emotional difficulties when their patients pass, for which the centre has an employee assistance program.

The role of the family in diverse communities in relation to organ and tissue donation

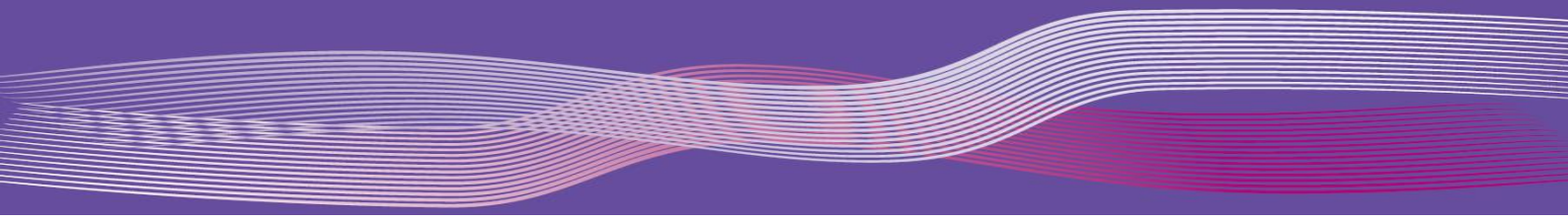
Dr Elena Cavazzoni

Paediatric Intensive Care Staff Specialist
Children's Hospital at Westmead



Dr Cavazzoni began by explaining the importance of the family making the right decision for them at the time of donation, and by reiterating how rare the ideal circumstances for organ donation are. She then introduced herself and her role as a paediatric intensivist at a children's hospital and what kind of services her unit offers, reiterating that among 1300 patients admitted throughout the year, there are 25-40 patients that die each year, and that of those patients, only 3-8 die in a 'situation that allows the family to say yes or no to organ donation'.

Dr Cavazzoni then moved her focus to defining the family, using the phrase 'care, support, protect', to describe what a family does, and linked this to the role of the family in medical decision-making and specifically in end of life discussion. She explained how while autonomy and right of self-determination is big in Western medical practice, this might not fit with all people who are accessing the healthcare system. In many cases, the role of the family members is very influential and it is not necessarily just an individual's decision, therefore it is crucial that medical practitioners include the family in that discussion. Nurses play a pivotal role in this



process of discussion between the families and healthcare providers as they spend more time by the bedside and with the family.

She then went on to mention that end of life effective care includes acknowledgement and respect for different cultures, willingness to negotiate compromise when these views differ, awareness of own values, ability to empathise, knowledge of practice of cultural groups regularly seen, and final understanding that all patients are individuals.

Dr Cavazzoni then outlined the greatest challenges to families who are going through a process that has led to an organ donation decision:

- Comprehension of unexpected death
- Finding meaning in donation: Is the heart the slave of the brain or the brain the slave of the heart? She here provided an anecdote from Barbados where there is no legislation for declaring a person as dead.
- Fear and suspicion: who will actually receive the organs.
- Decisional conflict: I want to do good but do not want to hurt my loved one; what if something goes wrong?
- Vulnerability: sudden grief makes someone unable to make decisions.
- Respecting the donor
- Needing closure

She concluded by saying that it is important for clinicians to allow the family to make the right decision for them, but to understand exactly what is involved. She summarised her presentation by stating that there is no easy formula in how to approach these discussions with families, it is crucial to ensure they are rested and nourished, and to help them understand what is being asked of them, answer their questions, and help them decide what the right decision is for them.

Ms Fulvia Nisyrios

Family member of an organ donor

Ms Fulvia Nisyrios began by reiterating that she uses plain language and 'short words' to make information clear and accessible to all people. She told the audience her story of her family's own experience with organ donation after her mother was hit by a car and spent three days in intensive care. She mentioned that these long three days were spent with her brother and sisters by her mother's side, and that the grieving process was one that brought out a range of different emotions; one minute they would be laughing together and the next they would be crying. After the doctors had tried everything to relieve the pressure off her mother's brain, but on the second night, they were told that there was nothing more that could be done. She went on to explain that upon hearing this news, her father, a 78 year old Italian man, said out of the blue that he wanted to donate her organs. She relived her shock, stating that through all of his grief and agony and after no discussion with the family or hospital staff, he had thought of this. She said that this choice was very amazing to her, the way in which he used his tragedy to give others a chance at life.

She then read a note that she had written to herself a week after her mother had passed away, about the last two hours before she was about to go into theatre to have her organs removed. She relayed that she remembered kissing her mum and telling her how much she loved her before she went in to have her liver and kidneys removed. She was attached to life support so that they could be harvested, and was 'warm and soft, but also dead.' She noted that when she lifted her eyelids, she saw 'death' and that it was nice to know that she would be living on in others.

She then moved on to explaining that while it is very hard to make this decision at the time, when you are sitting by your loved one while they still seem alive, she recalls seeing her mother's body at the funeral, and that it was cold, hard, and just flesh, and thus remembered thinking that she was so glad that they had donated her organs and given them to someone who could use them. Lastly, she mentioned that upon hearing stories from those who have received organs and from knowing that they have helped others, this has helped her family to heal. As a result of her death, two other people are alive and have brought relief to their families and friends and communities, all from her dad choosing to donate her mother's organs. She finished by stating that 'this is part of the great legacy that my mum left behind, and we get a lot of comfort in that'.

Panel Session

Chair: Professor Gary Bouma AM

UNESCO Chair in Intercultural and Interreligious Relations – Asia Pacific
Emeritus Professor of Sociology at Monash University

Religious and spiritual needs in relation to death, dying and grieving including beliefs regarding organ and tissue donation



Reverend John Baldock

Vicar of St John's Anglican Parish, East Malvern

Reverend John Baldock began by stating that there is no existing official opinion of Anglican Church towards organ and tissue donation, and as a result, most clergy would be neutral on this issue. This largely leaves the decision with the individual. He explained that he has been involved in the interfaith movement and that the issue of organ donation is very prevalent, and also mentioned that the Church of England and Catholic Churches in England have a campaign which promotes organ donation.

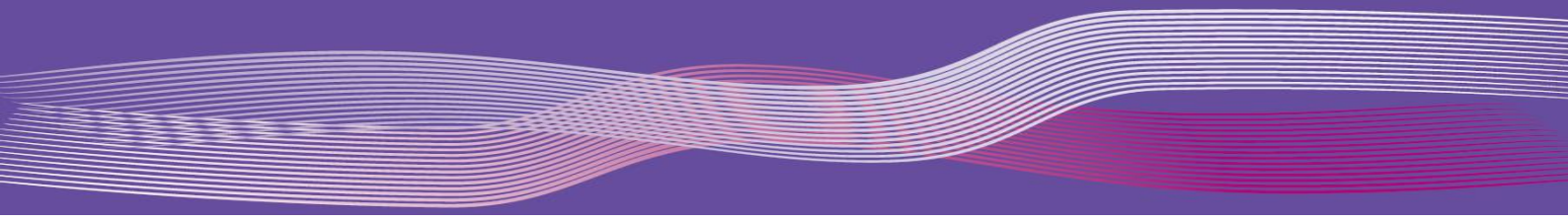
He then spoke about Christian beliefs in relation to organ and tissue donation, outlining that Christians believe in the value of human life and to relieve suffering and care for those in need. They are committed to a culture which affirms healing and which promotes the common good and a fullness of life, having tradition of generosity. He said that on the whole, organ donation would be seen by Christians as an act of sacrifice, giving and care for others. He noted that regarding beliefs and practice of this issue, moment of dying is seen as a moment of great significance, therefore respectful processes must be followed. Christians would not support compensation or coercion for donation, and believe in fair and equitable donation of organs and tissues with no place for wealth or status. Lastly, Reverend Baldock said that the vast majority would see brain death as defining death, and that with the right encouragement the Anglican Church could generate its own official stance on organ and tissue donation, of which the response would be strong as globally the Anglican Church supports it.

Mr Makarand Bhagwat

Representative, Hindu Swayamsevak Sangh Australia

Mr Makarand Bhagwat begun by stating that the Hindu scriptures do not provide specific guidance on modern medical practice or more specifically the issue of organ and tissue transplantation, as when the religion was created, the current medical advances were not seen or heard of. He said that there is no moral or ethical dilemma for Hindus who wish to donate. He then explained some Hindu beliefs regarding death, such as the soul being part of the Brahman and is totally indestructible. In this sense, he said that dying is described as changing from one stage to another, and that death is the most certain fact of life, just as empires rise and fall and cities come and go, everything travels toward death.

Mr Bhagwat explained that men and women think they will never die, although we witness it all the time, which is a wonderful thing. Hindu's rejoice in the setting free of the soul instead of lamenting over the loss of the body. Regarding organ donation, spiritually such an act will create good karma, as the deed will be good for the soul of the family, and the body of the receiver. Furthermore, he explained that different organs hold different emotions of the person, each having a different personality tendency of another, meaning that part of the mind of one person goes to another person. Lastly, he reiterated that it is the will of God to help those in need as helping others is worshipping, and that the human body is indeed perishable and will return



to nature, thus organ donation is a spiritually advantageous thing for the giver and for the receiver.

Dr Diana Cousens

Former Vice-Chairperson of the Buddhist Council of Victoria

Dr Diana Cousens began by emphasising that there is no single view of Buddhists when it comes to organ donation. She explained that Buddhists believe in past and future lives and that nothing arises without causes, in effect, that events in one's previous life have an impact on the current life, however, we may be reborn in any circumstance in the next life. She then told the story of when Buddha cut up his body and fed it to a starving tigress and her cubs, displaying the virtue of generosity, thus the idea of donating parts of the body to help others is deeply entrenched in the Buddhist tradition. For those in countries such as Thailand, Cambodia and Sri Lanka who follow the Theravada tradition, there is likely to be no issue with organ donation. For those in China, Vietnam, Japan, Korea or Tibet who practice Mahayana branch of Buddhism, organ donation is slightly more problematic during the process of death as it questions the journey of qualities of a person such as consciousness and what this would mean for the next life.

Dr Cousens explained that it is believed that a calm transition is needed to ensure a good rebirth. This often involves having Monks chanting in the room at the time of death, giving away all possessions prior to death and having the body undisturbed for at least 8 hours after death. Western medical practice declare brain death to be death, however the Mahayana tradition and the Tibetan beliefs in particular have a more detailed understanding of this process, including many different stages, meaning that brain death does not look like death to Mahayana Buddhists. As Tibetan Buddhism is the most common form of Buddhism in Western cultures, this issue is prevalent in Western countries as well. Chinese and Vietnamese Buddhists are trying to adapt their views to view organ donation as a compassionate process and to allow for the saving of other lives. Those with attachment to their body, however, may be disturbed as the spiritual consciousness will be aware of what is happening and could distress the calmness of this stage, and thus the person must stop breathing to be considered as dead. She then raised the concern of organ trafficking, vulnerable populations include young, unemployed, refugees, those in debt, disabled. Lastly, Dr Cousens outlined the proposed Buddhist protocol regarding organ donation:

- Buddhists may elect to have their organs donated after death is medically determined
- Potential donor must have identified themselves during their lifetime or advised their family.
- At least 8 hours should be allowed for chanting near the body prior to the organs being removed.
- Doctor must say out loud that they are fulfilling their vow.
- Deceased person must be treated with respect.
- Must have a bill of rights and an advocate to ensure that they are not being exploited.

- Must receive same standard of medical care as recipients so as to minimise harm.

Father Chris Dimolianis

Parish Priest at the Greek Orthodox Parish of St. Eustathios

Father Chris Dimolianis began by saying that while he represents the Greek Orthodox Church, what he says will be on behalf of all orthodox churches. He then addressed the question of what death is, and that is the separation of the body from the soul. The body is considered something very holy, even after death. This is why there are many traditions where the body is not only respected but venerated, such as having an open-coffin funeral, and is also why members of the Greek Orthodox faith do not cremate.

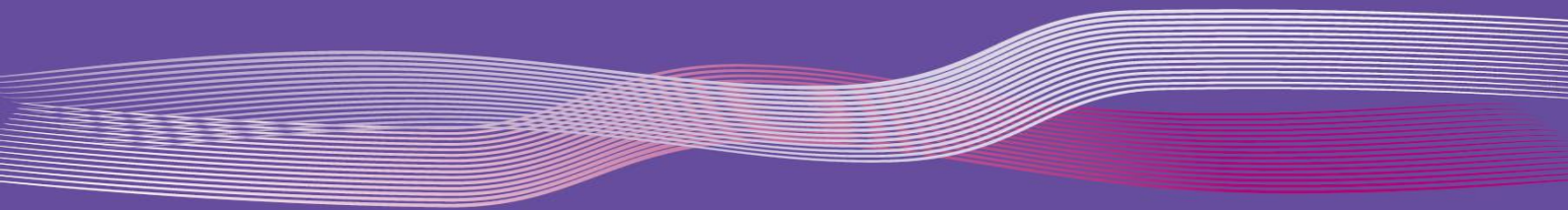
Regarding organ and tissue donation, although there are individuals within the orthodox traditions who do believe that organ and tissue should not be donated, due to the sacredness of the body, generally speaking the concept of transplants are seen upon very favourably. Father Dimolianis then read parts of a statement just recently made in Australia by all orthodox traditions, such as Russian, Romanian, Serbian and Greek orthodox bishops, mentioning the practice of organ and tissue transplants as an 'honourable effort of science'. The statement basically asked all to support and encourage those who are considering becoming donors, in order to 'aid the suffering of fellow human beings'. The choice to become a donor is left up to the individual in consultation with their spiritual fathers and medical doctors. He explained that this statement also mentioned that in the case of a living donation for organs such as kidneys, the physical appearance of the donor should not be unacceptably compromised. Post mortem donation must follow 'full biological death' and the process of harvesting organs must still allow for a proper burial.

Lastly, he addressed those working in the health sector in the room, providing them with some information about practices that they are likely to see when dealing with orthodox Christian patients, such as having a priest come to the bedside to say some prayers, or the Holy Communion. There is often a paradox among Greek orthodox families when a member is dying, between the fear of having a priest come in as this will signal to the person that they are dying, or whether it will help them. He believes that this has compounded a fear of death. He then briefly explained the funeral service and stages of memorials in orthodox traditions.

Rabbi Meir Shlomo Kluwgant

President, Rabbinical Council of Victoria

Rabbi Meir Shlomo Kluwgant began by emphasising that Jewish culture and tradition believe that words have real implications, which is why there is a propensity in being hesitant to discuss topics such as death. He then outlined another tradition, that even if a sharp sword is placed at your throat, you never give up, every life being precious irrespective of its condition, which creates quite a harsh approach toward issues such as terminal illness, creating ethical and practical dilemmas in hospitals.



He then went on to explain that from the Jewish perspective, there is no greater level of impurity than attaching oneself to the dead body, no greater respect must be paid than to the body of a dead person. The burial process, for example, is the same for everybody, with the same clothing and coffin. This process helps the deceased to find peace, which is why the body is buried as quickly as possible after death unless there is a legal reason as to why not. Furthermore, grieving is fundamental, as it is important to miss somebody and to cry. He explained that there is a 7 day period where the family will stay at home and spend time together remembering the deceased and celebrating them in happiness and sadness. Flowers are not placed on the grave, so as to make the death real so that loved ones can grieve and get closure. He said that death is an 'ugly and sad situation' that we need to acknowledge.

Rabbi Klugant then explained that the greatest level of kindness on earth is to assist someone who is dying or who has passed away, as it is absolutely voluntary. He then mentioned that 'one who saves a single life is considered to one who is saving the entire world' as every life is precious and valued in the same way. He then explained the dichotomy when discussing organ and tissue donation; one hand, saving a life is invaluable, and on the other hand, the sixth commandment states that one shalt not take a life. This has troubled members of the Jewish community for a long period of time. He concluded by stating that ultimately, there are two schools of thought today, and that generally the Jewish community accept whole brain death as actual death, therefore there is now a greater capacity for Jewish people to support the initiative of organ and tissue donation, and to choose to donate to save other people's lives.

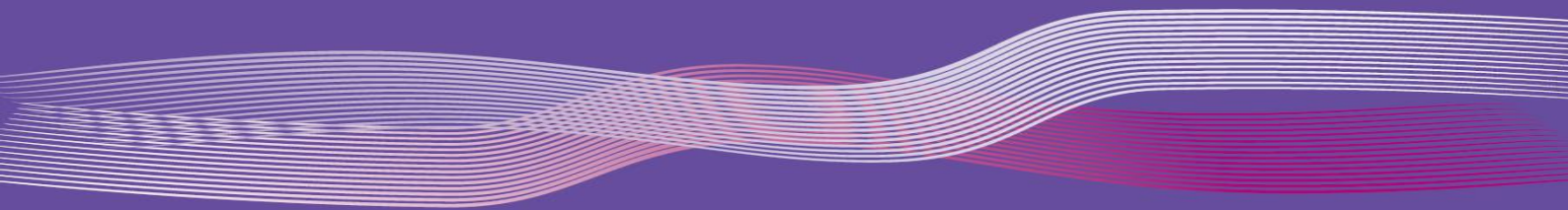
Father Brian Lucas

General Secretary, Australian Catholic Bishops Conference

Father Brian Lucas opened by providing an anecdote from a cemetery in Rome, in which the monks decided to exhibit the bones of the deceased. Some words appear on the exit of the cemetery, 'what you are now, we once were, what we are now, you will be'. He explained that while this is quite confronting, it is a belief within the Catholic Church that death ought not to be a source of fear and terror. However, our experiences with death with our own loved ones brings about the complexities of dealing with death and the level of sensitivity required.

He then gave another anecdote of a member of his own family passing away after being on life support, and how there is a misconception of the theological position of the Catholic Church toward taking someone off life support. He addressed the question of how we determine when treatment is futile and the time has come to embrace death, drawing a comparison between when someone is brain dead, and the more complex situation when someone is beyond all reasonable hope and treatment is futile.

Father Brian Lucas then briefly explained Catholic rituals for when a person is dying, such as having the priest come to pray by the person and anoint them with oil to help them heal and be forgiven for their sins. He then stated that the Catholic position on



transplantation is very clear and a number of statements have been made on the topic; that organ donation is seen as an act of generosity. This has to be managed very carefully in the clinical setting, not to put guilt upon a person who chooses not to. He then finished with a story of a parishioner whose daughter was in hospital with not much hope, and who instantly upon hearing that she had died, asked about filling in a form for organ donation, exemplifying the generosity shown by someone in grief and shock.

Sheikh Mogamat Majidih Essa

Imam of ISOMER Mosque

Sheikh Mogamat Majidih Essa introduced his presentation by stating that Muslims believe that death is an eternal, truth, and that there is life after death. Muslims base their lives expecting that death could approach at any time, as no one knows when it will come. For the family of the deceased, it is a time of sadness, but for the person who has died, it is a happy time as the soul is in rest and satisfaction.

He then explained that when a Muslim person is dying, the family and friends gather around them and assist in spiritual comfort in 'preparation for the soul to depart with peace' and recite particular verses from the Koran and pray for their welfare in the life to come. Grieving and weeping is normal, however it is prohibited to grieve in a loud manner such as wailing or beating of the chest. Mourning is allowed for three days, except for the wife of a deceased person, which is four months and ten days.

Regarding organ and tissue donation, Sheikh Essa explained that these practices are permissible in Islam based on the following beliefs:

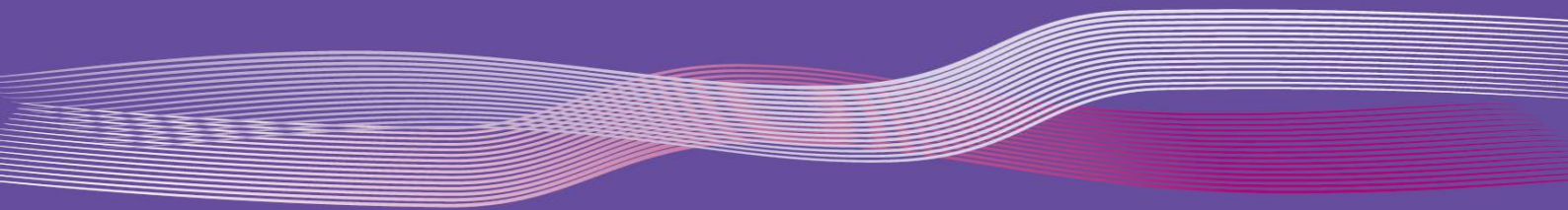
- 'Whoever saved the life of one, it shall be as though he has saved the life of all mankind'
- Necessity permits prohibited matters
- Organ donation saves lives, and preserving life is one of the five Sharia objectives.
- Organ transplant is a means available to mankind to overcome hardship.

Lastly, he outlined the various Fatwas that have been passed in organ donation, and the majority of the Muslim community agree with its practice. There are some general conditions for these decrees, such as absolute respect for the human body, explicit consent, no buying and selling of the organs, no sexual organs involved, genuine clinical need for transplantation.

Mr Jasbir Singh Suropada

Vice-Chairperson, Sikh Interfaith Council of Victoria

Mr Jasbir Singh Suropada firstly explained the basics of Sikhism, the three basic messages being, truthful earning, care and share (looking after fellow human beings and share what you have earned) and meditation upon God's name. He explained that Sikhism is strictly monotheistic and Sikhism believes that truth is the highest virtue. Furthermore, Sikhs do not cut or shave any hair on the body from birth, and



do not use tobacco or alcohol. Service to humanity is considered the highest service in Sikhism.

When a person is dying, Mr Suropada explained that family or friends read prayers to him or her, or they are played on an audio player if they are unavailable. Life is considered temporary in Sikhism, nothing is permanent and everything has a life span, and therefore it is important to be mindful about death, as we are all here as transit passengers. He said that it is very important to be aware when dealing with a deceased body of Sikh person, providing an example of when a coroner accidentally shaved the beard off someone, which was seen as sacrilege to the Sikh community.

In terms of healthcare, he listed that medication is permitted within Sikhism, as is blood transfusion and organ and tissue donation. Euthanasia however, is not encouraged, nor is keeping someone on life support for long periods of time. Moreover, abortion is seen as 'wilful destruction of human life', artificial reproduction is permitted within a marriage, and circumcision is prohibited. Regarding treatment, it is important that the turban is not removed, and that the patient or family is consulted before removing any hair from the body, unless it is in a life-threatening circumstance. It is also preferable that the practitioner is of the same sex as the patient. Regarding the funeral, the body is washed and dressed with the turban, and placed in an open coffin. All bodies are cremated and disposed of in flowing water. He lastly explained that during the final moments, there is a focus on prayers and spirituality such as chanting, to prepare the dying person to be dethatched from this world and to focus on where their soul is going. There is no restriction to the period of grieving.

Q&A

The short question and answer session between the audience and the panel of religious leaders both clarified some of the theological positions outlined in the presentations, and generated some dynamic discussion. Topics covered were:

- Implications in terms of karma for good and bad outcomes of an organ transplant.
- How do we define a 'clinical need' for an organ transplant?
- Issues to do with organ and tissue donation are not widely spoken of in some religious communities.
- Education in religious schools regarding organ and tissue donation.
- The definition of death varying across religions as opposed to the medical 'brain death'.

Plenary Session 2

Chair: Monica Dowling
Nurse Donation Specialist
DonateLife Victoria

The organ and tissue donation process and respect for cultural and religious sensitivities

Dr Gopal Taori
Intensive Care and Medical Donation Specialist
Monash Health Network

Dr Gopal Taori started his presentation by speaking to the audience in another language to exemplify the complexity of the organ and tissue donation process in the context of cultural and linguistic diversity. He then told explained that at Monash Health, the rate of organ donation has been quite significant and that many of these cases have been from people of culturally and linguistically diverse backgrounds, and that it is a strong belief there that every potential organ donor family should have access to information on the topic so that they can make an informed choice.



He went on to explain that when the conversation of organ and tissue donation is raised, one of the questions that often appears is whether the patient is really dead. This is due to the two different meanings of death, when the heart stops, or when the brain has stopped functioning and they are on a breathing machine. For families, this is very difficult to accept. This is not necessarily to do with the religion of the family, but often to do with something personal. In some cases, it may be too difficult to explain to family or communities overseas. Furthermore, he explained that many of the family members of patients are first generation migrants, who have come from autocratic countries or from a corrupt medical system, making it a challenge for medical staff here to gain the trust of the family. Therefore, he said that the staff tries to convince them of the robustness of our system, of the process of diagnosing someone as brain dead and of the fairness of the organ donation system.

Dr Taori went on to outline the collaborative approach taken at Monash Health in aiming to connect with people of diverse backgrounds. This involves combining social workers with cultural competencies with donation specialists, and connecting with their own communities via outreach programs. This means that these community members are able to sit in on the organ donation conversation and explain the process in a much better environment. He then referred to a study conducted in the UK, which concluded that ethnic minority populations such as African and South-east Asian people make up about one third of the kidney transplant waiting list, however the same groups make up only 3% of donors and are

less likely to actually receive a donation as they wait much longer to find a compatible kidney.

Lastly, Dr Taori outlined that in the context of so many different cultural and religious rituals regarding the body of the deceased, it is a challenge to incorporate organ and tissue donation into this process. He mentioned that the donation specialists spend a lot of time talking with the family in a sensitive manner, trying both to facilitate their traditions while also ensuring that organs donated are in the best possible condition. He concluded by saying that 'this whole culture thing' is very complex and often counter intuitive, not all people of one group have the same traditions, therefore the best we can do is to not assume.

Plenary Session 3

Chair: Mr Ross Barnett

Executive Officer
Ethnic Communities' Council of Victoria

Services and support for issues related to death, dying and grieving, including organ and tissue donation, for culturally and linguistically diverse communities

Mr Michael Bramwell

Chairman of Palliative Care Victoria
Director of Aged & Palliative Care at Melbourne City Mission



Mr Michael Bramwell began with the question; what is palliative care? He mentioned that people often associate palliative care with 'giving up hope', however the actual definition is to 'improve the quality of life for people of all ages who have a life-limiting illness' aiming neither to hasten or postpone death. He explained that it is multidisciplinary and is delivered to people where they are located, mentioning that they provide to the homeless as well. Furthermore, palliative care considers the physical, social, spiritual, cultural and emotional needs of the client and their family and that the service is often free. He reiterated that it is not only for people who are about to die,

some clients live for a very long time and move in and out of palliative care as their needs change.

Mr Bramwell then discussed palliative care in the context of diversity, noting that 25% of Victorians are from CALD backgrounds, 15% don't speak English well, and that this group is very underrepresented in accessing palliative care services. He explained that the Melbourne City Mission provides 24/7 home care to residents in certain areas, of which 35% above the age of 65 don't speak English. He then showed the audience a long list of languages for which interpreters were used, the interpreting bill of the company last year being around \$75 000.

He highlighted that it was due to the multicultural presence in their clients that the Melbourne City Mission agreed to participate in the Culturally Responsive Palliative Care Community Education Project, to ensure that they are meeting the needs of the patients at such an important stage of their lives. Mr Bramwell then shared some of his learnings from the program, for example, that often palliative care workers would keep their shoes on in a home for health and safety purposes, however, this was not agreeable for some Buddhist communities, so they discussed this with members of the community in order to find out a solution. Another example provided was that sometimes it was deemed inappropriate for a female carer to be present in the bedroom or bathroom of a patient. The program itself had two key aims; raising awareness of palliative care in some target communities, and improving responsiveness to diversity and developing trust between the palliative care services and the CALD communities. He identified the target communities of this year; Chinese, Italian, Maltese, Turkish and Vietnamese, and of next year; Arabic, Greek, Croatian, Polish and Macedonian.

Mr Bramwell explained the program to be a three-stage process, including community identification, bi-lingual peer education, and providing material such as brochures in both the target group language, as well as in English. He mentioned that over 1000 people have attended the education sessions from the five different language groups. Simultaneously, the palliative care services themselves were undergoing an education program surrounding providing effective care for these groups. Lastly, he thanked some of their partners for their support, and acknowledged the hard work of the bi-lingual educators in discussing such a difficult topic within these communities.

Mr David Marlow

Executive Director

Jewish Community Council of Victoria



Mr David Marlow firstly echoed the point made by Dr Gopal Taori, that one should not assume that all people of one religion will have the same values or beliefs. He then gave an overview of the Jewish Community Council of Victoria, indicating that they are an overarching organisation with 60 affiliate organisations and that they represent the Jewish community to the police and state and federal governments, as well as being involved in advocacy and social justice work. He provided the example of the Pastoral Care project in which the ultra-religious, orthodox, progressive, conservative, and secular

Jews all working together in the same direction, which would not have happened in the past. He then provided some background information on the Jewish community in Victoria, with roughly 52 000 people making up this community according to census data. He mentioned that a majority of these are secular Jews, but when it comes to issues of death and grieving, all of a sudden a lot of them 'find God'.

Mr Marlow explained that the Jewish community is quite decentralised, each different group deciding on their own views and regulations, unlike Catholicism there is no 'Pope' in Judaism. On the topic of organ and tissue donation, Mr Marlow said that the progressive Rabbi's in Victoria have agreed that there are no issues and that it is considered a good thing, with only some restrictions such as not donating for personal gain. The conservatives are of a similar view, which has evolved in the past few years. Within the orthodox tradition, this is not as clear, as there are debates as to what constitutes as death, however, there are currently efforts being made to clarify what the rules are for organ donation.

He then outlined the support and services providers involved in the death, dying and grieving process within the Jewish community, including:

- Psychologists
- Rabbis and other volunteers in pastoral care process
- Jewish Care, a health and aged care provider which have about 1500 residents, and also provide services such as a crisis centre which provide counselling. This is important as the Jewish community is ageing faster than the general Australian community.
- Burial societies; Chevra Kadisha is the largest funeral provider for the Jewish communities, as most Jews would identify as orthodox regardless of how practicing they are and would want to go to an orthodox synagogue and be buried orthodox, while Bet Olam look after the progressive Jews. He here mentioned that the best thing to do is to ask the family what they would prefer.

Lastly, Mr Marlow reiterated what Rabbi Kluwgant explained in regards to the grieving and death processes and traditions, and went on to explain that last year there was an organ donation conference involving the progressive, conservative and orthodox groups as well as the Halachic Organ Donor Society, a US group promoting donation among the Jewish international community.

Plenary Session 4

Chair: Ms Lynn Cain

Project and Training Manager
Australian Multicultural Foundation

Communication strategies for talking about issues related to death, dying and grieving, including organ and tissue donation with culturally, religiously and linguistically diverse communities

Dr Ranjana Srivastava

Medical Oncologist at Southern Health
Author

Dr Ranjana Srivastava began by identifying that ten or so years ago, such a conference may not have attracted such a large audience, but that this is a topic whose time has truly come, and she seems to do these talks more and more. She went on to say that her and her colleagues often struggle to communicate with

patients who speak English and who are articulate, meaning that when it comes to people of NESB, healthcare providers often do not do them justice, although she is optimistic that 'we are getting better'.

She then provided a case study of a 49-year-old Turkish woman who was dying of advanced cancer and who had failed two rounds of chemotherapy. The extended family were always at her bedside, and as such, offers for an interpreter were often politely declined as there was almost always someone who could speak Turkish there. The family then requested that the practitioners not tell the patient that she was dying as it was culturally insensitive, and that if she were to find out it would distress her and the family. The healthcare providers made assumptions that this was consistent with Muslim culture, that the men were the decision-makers, and that the level of education of the patient would be lower than the husband or sons and that any final decision would therefore be left up to them, in order to best act in accordance with family wishes.



Dr Srivastava then provided a second example, of a 78 year old Chinese man that had severe heart failure. The doctor suggested after much medical treatment, that palliative care was now the best option, however the family declined consent and insisted on telling the patient that he has bronchitis. Assumptions made here by the healthcare providers were; that this was consistent with Asian culture, that Asian patients often avoid the truth, that Asian patients cope differently, and therefore that it was acceptable for the family to speak for the patient and that 'we had done our best in trying'.

She then outlined, how in both of these instances, the assumptions had been wrong:

- The Chinese patient was used to be a physiotherapist in China who had very firm beliefs in the patient's right to know about his disease, and who objected to family speaking for him, and wished to clarify his end of life plans via an interpreter.
- The Turkish patient left Turkey at age of three, was educated in London working as a senior academic, had co-founded women's health literacy group, had recently completed an advance care directive but had not told her family.

Dr Srivastava then provided some guiding principles for dealing with patients and families from different backgrounds in light of the fact that the assumptions were profoundly wrong, including:

- Autonomy of the patient and their 'right to know'
- The patient often knows or suspects anyway
- Informed consent is important to deliver and withdraw care
- Healthcare professionals face an ethical dilemma between pleasing the family and doing right by the patient.
- Culture does not have a single meaning, influenced by many factors. There is no one uniform thing that defines 'Asian culture' or 'Middle-Eastern culture'.

- Listen without overreacting; acknowledge a difficult conversation is coming up, listen to the family's reasons, and don't pass moral judgement.
- Probe family concerns via questions such as: What are you most worried about? Have you had a bad experience before?
- Gently point out the practicalities of withholding information from the patient via questions such as: How can you explain transfer to a different kind of care? How would they react to the palliative care nurse coming to give pain relief? Do you think they wonder why everyone looks so worried?
- Empathy is critical.
- Our views are our own and we cannot always impose those onto others.
- Finding a middle ground.

Dr Srivastava concluded by stating that end of life care is vital, it is important to listen, avoid making broad cultural assumptions, be a partner not an opponent, and lastly said that 'patients don't care how much you know until they know how much you care'.

Associate Professor William Silvester

Director of the Respecting Patient Choices Program
The Austin Hospital



Associate Professor William Silvester noted that he would be focusing on advanced care planning throughout his presentation. He initiated this discussion by showing a picture of an elderly man, suffering from severely from dementia, bed-bound, cannot communicate with family or friends whatsoever anymore and who was admitted to hospital from a nursing home as he had pneumonia. He explained that at this point, the medical staff could either stabilise and return him to the home where he would return to his original state, or could have a conversation with the family regarding what is best for

them and the patient.

He then mentioned that he often gets challenged on this, as people misinterpret the Hippocratic oath that doctors sign to mean 'do everything possible', when it actually reads 'I will prescribe regiments for the good of my patients according to my ability an my judgement and never do harm to anyone.' He explained this to mean 'do good, do not harm' and that health professionals should take reasonable steps to save or prolong life, or to act in the patient's best interests; in the case of the man mentioned above, prolonging his life would not be acting in his best interests. He emphasised that the most effective way to act in a patient's best interest, is to know what they would have wanted, when they are in a condition when they cannot express this, and that is the essence of advanced care planning.

Associate Professor Silvester then defined advanced care planning as a process whereby a patient, in consultation with health care professionals, makes decisions about future health care. It is supported by the principle of autonomy, particularly of informed consent, and about dignity and the prevention of suffering. He then

provided a case study to explain the process in detail: an 81-year old man, newly diagnosed with lung fibrosis, was not responding to steroids had been introduced to prospective patient choices but refused to discuss it as he was sure he was going to get better. However as his condition deteriorated, he communicated what he did and didn't want in regards to intensive care and treatment. He discussed his options with his GP, documented it on a Discussion Card, but did not appoint his wife as a substitute decision-maker or complete an Advanced Care Directive. However, the next time he became breathless, he asked his wife to call the GP as opposed to the ambulance, and died peacefully at home, with his doctor and family by his bedside. Professor Silvester explained that the significance of this story is that it was all about the conversation he had with his GP, and the time that he had to reflect on what he wanted for his end of life care, as opposed to a discussion of forms and legalities.

He then mentioned that a lot of statutory law does support advanced care planning throughout Australia, with many other common laws supporting it as well. He provided an unfortunate example of when a brain-damaged man was in a vegetative state and his family wanted treatment to be withdrawn but when the doctor asked the coroner, he was told that if he did so he could be charged with murder.

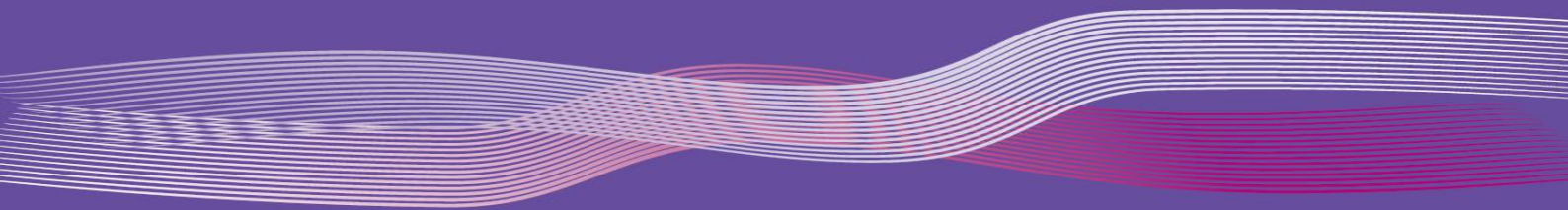
Associate Professor Silvester then began to explain what this has to do with CALD communities, and that originally Advanced Care Planning was offered to English-speakers to ensure that it worked, however that they felt that it was important to make available to a wider range of people, and that it was important to not make any assumptions about the decision making process in end-of-life care. He then described a study conducted at his hospital comparing conversations had with people over 65 from Greek and Italian speaking backgrounds with English speaking backgrounds, which concluded that ACP is both viable and appreciated by both groups, and that it has the same outcomes with people of NESB in terms of acceptability. Lastly, he emphasised the importance of effective communication by touching on a study that looked at the responses of people to the words 'do not resuscitate' as opposed to 'allow natural death', the latter of which was much better received.

Ms Paula Masselos

Director of Strategic Marketing and Communication
Cultural Partners Australia

Ms Paula Masselos acknowledged the importance of the conference and explained that her focus was to be on the engagement with the religious leadership by the Organ and Tissue Authority on this issue. She then described the campaign that the OTA came up with, entitled 'Discover, Decide, Discuss' which aimed to overcome barriers that prevent open discussion of organ and tissue donation. She said that a great benefit of the campaign was that it not only required people to consider what their position on donation in their cultural or religious context was, but it encouraged them to become active in researching the issue and





discussing it with others. She noted that these were the two key messages of the day; do not assume and talk to people. She then provided an overview of the four key pillars of the campaign: the engagement of religious and community leaders, the development of culturally appropriate resources, community engagement and ethnic media engagement. She noted that engagement with community and leaders was essential both to ensure that they were not making any assumptions, and that the program was robust as it was supported by the religious leaders themselves.

Ms Masselos then acknowledged the challenge faced when marketing the campaign to communities, as there are over 200 languages spoken in Australia. She explained that they came up with criteria for deciding which languages the material would be available in, the first seven being Arabic, Chinese, Greek, Italian, Vietnamese, Spanish and Turkish, but that some materials were being offered in a wider range of languages and that this is continuing to expand. A religious framework was also overlaid in deciding these language groups, as some religious groups were of particular interest, including Buddhism, Catholicism, Greek Orthodox, Hinduism, Judaism and Islam. She noted that much research was undertaken by the authority to understand the key issues and barriers regarding organ and tissue donation in different religious communities, and to ensure that the OTA was on track with these issues. In summary, the research found that CALD communities were less aware of the information available, less willing to become donors and less aware of the importance of family discussion.

She then emphasised the influence that religious leaders can have, that being why they wanted to develop relationships with them, two Greek women completely changing their perception of organ donation after being told that the Church allowed it, for example. She explained that part of the campaign involved identifying hierarchies in religious groups, with many faiths having overarching representative bodies which the authority could contact, and having discussions with these leaders in order to identify whether their religion has a position on organ and tissue donation, and if not, how they could go about defining one. She said that the next step was to go about identifying the key areas of concern so that they could be addressed. They also ensured that the religious leaders had input into materials and resources that were being developed by the OTA, including a booklet that was signed by Yael Cass as well as many of the leaders which became a very potent tool. Long form rulings were also instated as a result of the program, such as a Fatwa that was developed to explain the acceptance of organ and tissue donation, as well as statements that have been made by various religious leaders to their own communities which endorse organ and tissue donation. She lastly explained the significance of the media in the campaign, providing an example of a forum in which the religious leaders and authority were on stage together declaring their support for donation which the media promoted extensively. Ms Masselos concluded by stating that the religious leadership are a key stakeholder in promoting organ and tissue donation.

Q & A Session

Chair: Mr Sam Afra

Hon Secretary

Federation of Ethnic Communities' Councils of Australia

All speakers were invited to participate in a panel discussion which gave the audience the opportunity to ask questions. A wide variety of topics were brought up and discussed, including:

- Whether this was the right forum in which to also discuss the engagement of indigenous Australians in organ and tissue donation.
- Existing tensions between religious traditions and Advanced Care Planning
- The length after death in which tissue donation can occur and the types of tissues that can be donated.
- Comparing the practice of donating tissue with donating organs in a cultural/religious context.
- The dichotomy between keeping a patient alive at all costs and deciding when treatment is futile, and how to approach these issues with the patient's family.
- The use of Advanced Care Planning with child patients.
- How to help nurses deal with situations in which families change their mind despite having made Advanced Care Planning.



Close

Chair: Dr Hass Dellal OAM

Executive Director

Australian Multicultural Foundation

Dr Hass Dellal concluded by thanking the speakers, delegates and audience members, mentioning that we could not have had a more distinguished group in Australia on this very important topic. He said it was fantastic to see so many sides, and that there are still many more sides to hear. He thanked everyone for their commitment and consistent involvement throughout the day, particularly thanking Yael Cass and the Organ and Tissue Authority for their support and the AMF staff for coordinating the conference. He concluded by saying that this was just the beginning, that a working group was going to be held on the following day to identify the outcomes from the conference and that the information will be made available to everyone.

Conclusion and Recommendations

Overall, the conference was very productive and successful in generating much discussion and addressing the key issues regarding organ and tissue donation in CALD communities. The participants indicated that they gained a better awareness and understanding about issues surrounding death, dying, grieving and organ and tissue donation, which is a very positive outcome. The themes discussed throughout the conference were relevant to the audience members, who also expressed a willingness to promote the conference themes and implement some of the strategies gained from the speakers' presentations themselves. The day following the conference, a forum was held in which 18 key stakeholders formulated key learnings and recommendations from the conference. The key learnings included:

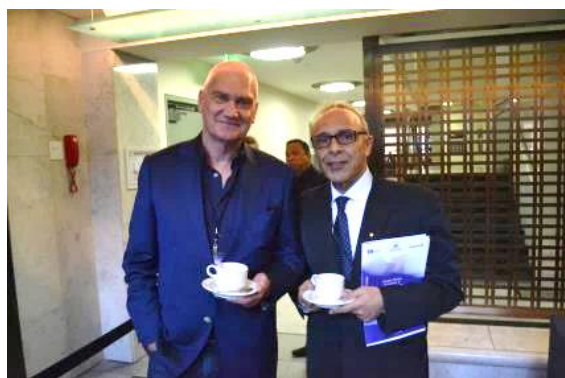
- Accommodating the needs of the family
- Accommodating the needs of the patient
- Training and support for health professionals and service providers
- Wide dissemination of information through education programs and public awareness campaigns
- Increasing opportunities for joint collaborations
- The importance of not making assumptions
- The importance of increased and ongoing engagement with culturally, religiously and linguistically diverse communities

In response to these learnings, the following recommendations were made:

- It is recommended that information about organ and tissue donation be disseminated to professionals outside the intensive care unit, e.g. to emergency department staff and GPs, so that they can also guide families and patients and provide them with the correct information.

- It is recommended that hospital staff discuss and establish the patient's next of kin early during the admission process in order to avoid confusion later on.
- It is recommended to continue to promote and support the work of the OTA and DonateLife in encouraging families to discuss donation wishes in advance.
- It is recommended that cultural competency training and training in how to sensitively work with families and patients from CALD backgrounds be provided for health care professionals and service providers so that they can best serve members of CALD communities.
- Greater engagement with interpreters and translators will help them to better understand and communicate information about patient treatments and the organ and tissue donation process to patients and their families.
- It is recommended to focus on developing more education programs and supporting other key professional advisors in communities such as high profile community leaders, personal advisors, GPs, teachers, and other relevant health care professionals involved in areas such as the emergency department, palliative care, oncology and renal failure, to disseminate information about organ and tissue donation.
- It is recommended that a public awareness strategy around organ and tissue donation, which takes into account low health and language literacy rates, be developed in order to correct misperceptions and further publicise this topic to a larger audience. It is important that the public awareness strategy on organ and tissue donation include the following:
 - a) More personal stories and testimonies: this makes it more heartfelt, as people can put a face to a name and engage more with the story.
 - b) More opportunities for discussion and engagement with communities.
 - c) The use of case studies to illustrate a range of situations which links to information about the process.
 - d) Emphasise that if a person expresses a willingness to become an organ and tissue donor, it is the medical professionals that will determine whether the individual is a suitable donor and what they can actually donate.
 - e) Emphasise to communities that Australia has strict laws with regard to the commercial trafficking of organs, in order to correct misperceptions about the process.
- Greater engagement with faith and community groups/organisations can help to disseminate information in the most appropriate way to CALD communities at the grassroots level.
- It is important to understand the culture and values of the target audience, as well as establish the most effective forum to communicate the information, e.g. through movies, Q&A sessions, plays, community working groups, etc.
- It is recommended that the Australian Multicultural Foundation (AMF) and SBS develop a documentary which includes interviews with faith leaders about their support for organ and tissue donation which can be used as a resource for the community.
- The information in sacred texts is very important for members of faith communities. It is recommended that this information be part of the general communication to those faith communities.

- Increased networking with like-minded organisations can provide an opportunity for more cohesion between service providers. This can lead to the active sharing of more resources within the health network and bigger funding pools.
- Cultural competency training for health care professionals and service providers can result in a greater understanding and awareness about different cultures and lead to fewer assumptions.
- Encouraging families to have discussions about end of life care and donation wishes earlier will also help reduce assumptions and concerns about what our loved ones want.
- It is important to continue to discuss and work with CALD communities on these important issues to build trust in communities and disseminate the information widely at the grassroots level. It is recommended to have a communication channel in which people can ask questions and have their concerns addressed.
- It is recommended to look into more research and funding opportunities to support activities and the development of more resources which increase awareness and understanding about organ and tissue donation in CALD communities.



Appendices

Appendix 1 – Conference Program

Thursday 19 June	
8.30am – 8.45am	Registration
8.45am – 9.00am	<p>Introduction and Welcome</p> <p>Dr Hass Dellal OAM Executive Director Australian Multicultural Foundation</p> <p>Sir James Gobbo AC CVO Emeritus Chairman Australian Multicultural Foundation</p>
9.00am – 10.00am	<p>Keynote Address</p> <p><i>Understanding beliefs and practices about death, dying and grieving for people from culturally, religiously and linguistically diverse backgrounds</i></p> <p>Dr Peter Saul Senior Intensive Care Specialist at John Hunter Hospital Director of Intensive Care at Newcastle Private Hospital</p> <p><i>The importance of organ and tissue donation in relation to people from culturally, religiously and linguistically diverse backgrounds.</i></p> <p>Ms Yael Cass Chief Executive Officer Organ and Tissue Authority</p> <p>Ms Yael Codron Transplant Recipient</p> <p>Chair: Dr Hass Dellal OAM Executive Director Australian Multicultural Foundation</p>
10.00am – 11.00am	<p>Plenary Session</p> <p><i>The role of the family in culturally, religiously and linguistically diverse communities in death, dying and grieving.</i></p> <p>Mr George Lekakis AO Chief Executive Officer Fronditha Care</p> <p><i>The role of the family in diverse communities in relation to organ and tissue donation.</i></p> <p>Dr Elena Cavazzoni Paediatric Intensive Care Staff Specialist Children’s Hospital at Westmead</p> <p>Ms Fulvia Nisyrios Family member of an organ donor</p> <p>Chair: Ms Carmen Calleya-Capp Representative from the Maltese Community</p>

11.00am – 11.15am	Morning Tea
11.15am – 1.00pm	<p>Panel Session</p> <p><i>Religious and spiritual needs in relation to death, dying and grieving including beliefs regarding organ and tissue donation</i></p> <p>Reverend John Baldock Vicar of St John’s Anglican Parish, East Malvern</p> <p>Mr Makarand Bhagwat Representative, Hindu Swayamsevak Sangh Australia</p> <p>Dr Diana Cousens Former Vice-Chairperson of the Buddhist Council of Victoria</p> <p>Father Chris Dimolianis Parish Priest at the Greek Orthodox Parish of St. Eustathios</p> <p>Sheikh Mogamat Majidih Essa Imam of ISOMER Mosque</p> <p>Rabbi Meir Shlomo Kluwgant President, Rabbinical Council of Victoria</p> <p>Father Brian Lucas General Secretary, Australian Catholic Bishops Conference</p> <p>Mr Jasbir Singh Suropada Vice-Chairperson, Sikh Interfaith Council of Victoria</p> <p>Chair: Professor Gary Bouma AM UNESCO Chair in Intercultural and Interreligious Relations – Asia Pacific Emeritus Professor of Sociology at Monash University</p>
1.00pm – 2.00pm	Lunch
2.00pm – 2.30pm	<p>Plenary Session</p> <p><i>The organ and tissue donation process and respect for cultural and religious sensitivities.</i></p> <p>Dr Gopal Taori Intensive Care and Medical Donation Specialist Monash Health Network</p> <p>Chair: Ms Monica Dowling Nurse Donation Specialist DonateLife Victoria</p>

2.30pm – 3.20pm	<p>Plenary session</p> <p><i>Services and support for issues related to death, dying and grieving, including organ and tissue donation, for culturally and linguistically diverse communities.</i></p> <p>Mr Michael Bramwell Chairman of Palliative Care Victoria and Director of Aged & Palliative Care at Melbourne City Mission</p> <p>Mr David Marlow Executive Director Jewish Community Council of Victoria</p> <p>Chair: Mr Ross Barnett Executive Officer Ethnic Communities' Council of Victoria</p>
3.20pm – 3.35pm	<p>Afternoon tea</p>
3.35pm – 4.45pm	<p>Plenary Session</p> <p><i>Communication strategies for talking about issues related to death, dying and grieving, including organ and tissue donation with culturally, religiously and linguistically diverse communities.</i></p> <p>Dr Ranjana Srivastava Medical Oncologist at Southern Health and Author</p> <p>Associate Professor William Silvester Director of the Respecting Patient Choices Program The Austin Hospital</p> <p>Ms Paula Masselos Director of Strategic Marketing and Communication Cultural Partners Australia</p> <p>Chair: Ms Lynn Cain Project and Training Manager Australian Multicultural Foundation</p>
4.45pm – 5.30pm	<p>Q & A session</p> <p>All speakers are invited to participate in a panel discussion which gives the audience the opportunity to ask questions that have arisen during the conference</p> <p>Chair: Mr Sam Afra Hon Secretary Federation of Ethnic Communities' Councils of Australia</p>
5.30pm	<p>Close</p> <p>Dr Hass Dellal OAM Executive Director Australian Multicultural Foundation</p>