



sad news sorry business

Guidelines for caring
for Aboriginal and
Torres Strait Islander people
through death and dying

Acknowledgment

'Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying' was researched and developed by the Aboriginal and Torres Strait Islander Cultural Capability Team. The authors extend their sincere thanks to the Queensland Health staff for generously providing their wisdom, advice and feedback.

Aboriginal and Torres Strait Islander people should be warned that this document refers to the sensitive issue of death and dying.

Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying (version 2.1)

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Purpose

The end stage of life is a very sensitive and significant time for patients and their loved ones. This document aims to provide insight into appropriate cultural knowledge and practices and identify tools that will assist Queensland Health staff in providing culturally and clinically responsive care for Aboriginal and Torres Strait Islander patients and their families through this significant stage of life.

For Aboriginal and Torres Strait Islander people, the time before and following death are subject to a number of customary practices. These practices have meanings that are sacred to Aboriginal and Torres Strait Islander people, and disclosing them is not the intentions of these guidelines. Queensland Health recognises the rights of Aboriginal and Torres Strait Islander peoples to practise their cultural and spiritual traditions and customs without discrimination or judgement.

Aboriginal and Torres Strait Islander peoples are not a homogenous group and must be recognised as two distinct and diverse cultures. Furthermore, customary practices vary between, and within, Aboriginal and Torres Strait Islander tribal groups. There are over fifty Aboriginal language groups in Queensland and two primary languages in the Torres Strait. A single hospital or health service may be accessed by a number of tribal groups, each with their own cultural practices, language and a different view on caring for a person at the end of life stage.

These guidelines are intended to be respectful and sensitive to this diversity; hence aiming to provide general guidance and broad information for Queensland Health staff.

Please note that some generalisations can be made for Aboriginal people and some for Torres Strait Islander people throughout this document. Where possible, guidance will be provided with respect to the two distinct peoples.

About version 2

Sad News, Sorry Business: caring for Aboriginal and Torres Strait Islander people through death and dying was first published in 2011.

In 2014, Queensland Health published the *Aboriginal and Torres Strait Islander Patient Care Guideline* which provides general information with respect to providing healthcare for Aboriginal and Torres Strait Islander people.

In this revision of *Sad News, Sorry Business*, duplication of content which is now available in the patient care guideline has been avoided. It is therefore highly recommended that the patient care guideline be read as a preliminary to *Sad News, Sorry Business*.

Version 2 also includes additional advice, in particular for the time following a person's passing.

Wherever possible, hospital and health services are encouraged, through the guidance and knowledge of their Aboriginal and Torres Strait Islander staff and in partnership with their local communities, to establish specific local guidelines to ensure appropriate, culturally competent care.

Section 1

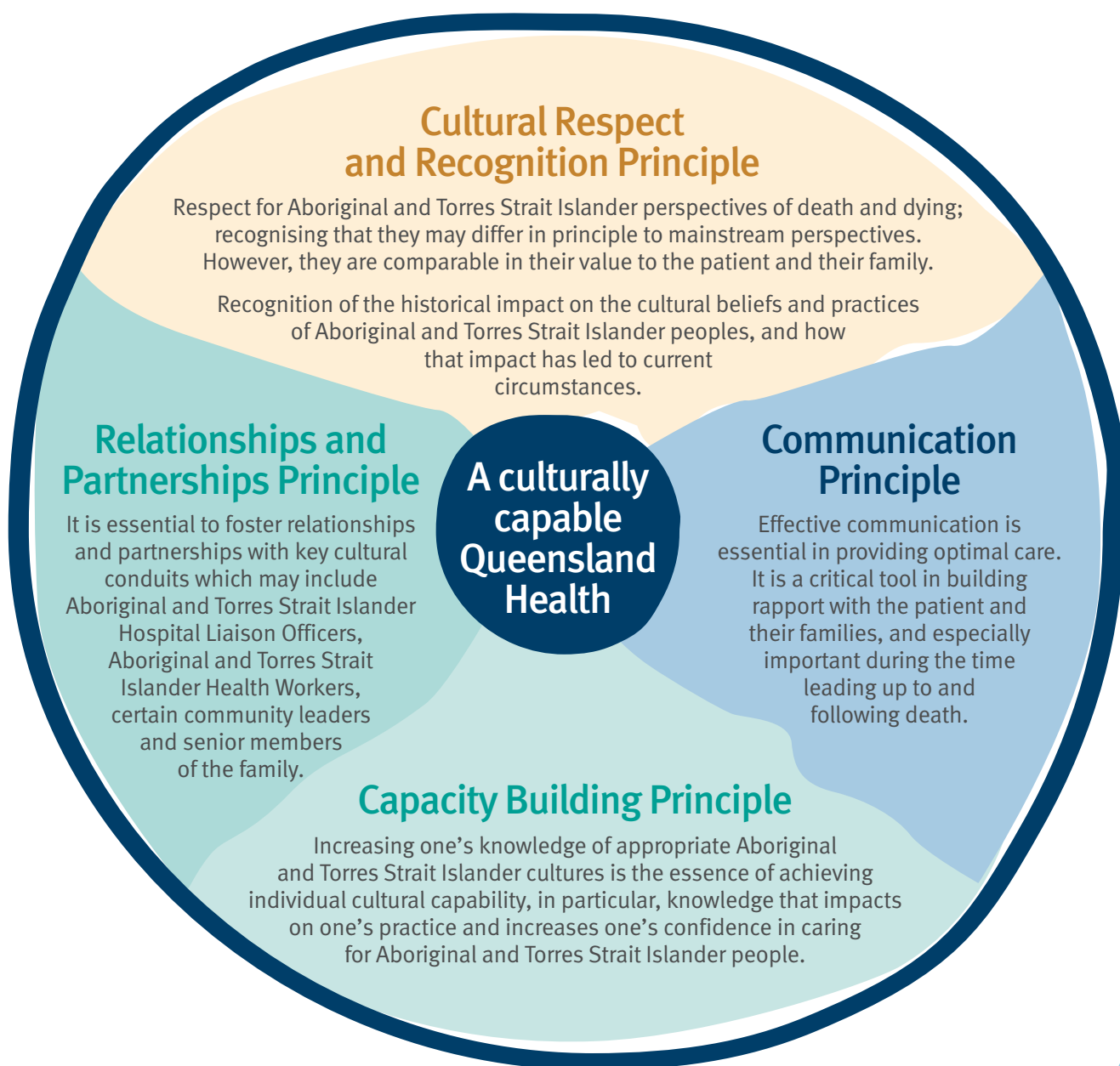
Aboriginal and Torres Strait Islander cultural capability

The *Queensland Health Aboriginal and Torres Strait Islander Cultural Capability Framework 2010–2033*:

- articulates the requirements of achieving successful provision of culturally appropriate health services to and with Aboriginal and Torres Strait Islander individuals and communities
- is the overarching framework to guide every aspect of health service delivery for and with Aboriginal and Torres Strait Islander Queenslanders.

“This will require all Queensland Health staff, individually and collectively, to understand and respect cultural differences and needs, and apply this understanding in their various roles.”

The framework’s four guiding principles will be applied to caring for an Aboriginal and/or Torres Strait Islander person and their family faced with death.



Cultural respect and recognition

Death, a confronting certainty of life, varies in meaning between all cultures. Appreciating the differences in the meaning of death is essential for providing the best care for all patients at their final stages of life. The term 'passing' is generally more accepted and sensitive terminology to use when discussing death or dying with Aboriginal and Torres Strait Islander people due to the spiritual belief around the life cycle.

Prior to colonisation, Aboriginal and Torres Strait Islander traditional cultures had well established beliefs and practices that had been handed down through the generations. The country was home to hundreds of different traditional groups with their own language, customs, relationship with their environment and beliefs. Some traditional groups shared similarities, reflecting their inter-tribal relationships.

Three significant factors dramatically altered Aboriginal and Torres Strait Islanders customs.

1. Colonisation and religion

Traditional cultures were significantly impacted by colonisation and the introduction of Christianity. Traditional people and cultures were systematically suppressed as Western lifestyles and religions were imposed. Almost all aspects of Aboriginal and Torres Strait Islander cultures were forbidden or discouraged, including practices associated with death and dying and the sharing and passing down of this knowledge.

2. Past government policies

Past policies including dispossession, dislocation, segregation, assimilation, removal of mixed race children and integration greatly impacted traditional Aboriginal and Torres Strait Islander cultures and customs.

3. Immigration

Australia has seen an influx of people from a variety of nations since colonisation. Each nationality came to Australia with their culture, inclusive of beliefs and practices associated with death and dying, which their descendants may still practise today. Some beliefs and practices have impacted on Aboriginal and Torres Strait Islander cultures, for example as a result of intermarriage with people of other cultures. Beliefs and practices for Aboriginal and Torres Strait Islander people may therefore vary considerably.

Today in Queensland these impacting factors mean that many cultural practices have been modified or lost. However, some Aboriginal and Torres Strait Islander people still maintain traditional beliefs and practices that are an essential part of the life and death cycle.

Culture and healthcare

It is our professional duty to deliver care that is appropriate to our patient including care that is responsive to our patients' needs as expressed in their way and from their perspective. Differences exist between non-Indigenous and Aboriginal and Torres Strait Islander Australians' perspectives on healthcare, wellbeing, death and dying. A common contrast in perspective is the meaning of a hospital admission.

- For non-Indigenous people the hospital is a place to heal, to fix health problems, and to rehabilitate.
- For Aboriginal and Torres Strait Islander people, the hospital may be seen as a place one goes to die.

Returning to Country

Aboriginal and Torres Strait Islander patients may request to return to their homelands and to be close to their family and country for the final stages of their life. This is an understandable request; however, it may be complicated if the patient is on chronic therapy such as renal dialysis, or receiving palliative care. The desire to return to country will be more important to them than treatment of their disease. Work in partnership with the primary health service, families and the community. Contact the local hospital and health service to investigate possibilities.

Communication

Effective communication is an essential element to ensuring the right care for the patient and their family. Often taken for granted, it is not until we reach a barrier that we realise how vital communication is to healthcare delivery, and to supporting a patient and their family through end of life.

Language

Verbal language was vital to Aboriginal and Torres Strait Islander cultures pre-colonisation. Languages were rarely written down. Knowledge was verbally handed down from generation to generation and embedded through storytelling, depiction through art, songs, dance and other ceremonies.

Despite being suppressed to near extinction, some Aboriginal and Torres Strait Islander languages are still spoken. Speaking a traditional language and recognising it as your first language is more common for Aboriginal and Torres Strait Islander people residing in remote areas. Some Aboriginal and Torres Strait Islander people identify English as a second or third language, therefore experience difficulty understanding both Standard English and medical terminology. Using appropriate language can reduce the level of misunderstanding, and confusion for patients and their families.

Traditional languages

Over one-third of Aboriginal people (39%) and over half of Torres Strait Islander people (56%) speak or have spoken some words of their traditional language. One in nine Aboriginal and Torres Strait Islander people aged 15 years and over do not identify English as their first language.

In Queensland, there are over 50 Aboriginal languages that are still spoken or being revitalised. Torres Strait Islander people have two distinct traditional language groups: Meriam Mer (Eastern Island group) and Kalaw Lagaw Ya (Western Island group).

Body language

Body language expectations vary amongst Aboriginal and Torres Strait Islander cultures. It is important to acknowledge that there are local practices which can be learned with experience. Speak with your local Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker who can advise on local practices, or source information to guide you if the patient is from another community.

Be guided by the non-verbal and body language cues demonstrated by the family members.

For further advice and information, refer to the *Aboriginal and Torres Strait Islander Patient Care Guideline*.

Communicating a diagnosis and prognosis

Delivering a diagnosis and prognosis to Aboriginal and Torres Strait Islander patients can be difficult considering the cultural and communication barriers. Understanding and demonstrating respect for the beliefs of the patient and their family will assist with developing trust and rapport.

The following difficulties may be encountered.

- The patient and their family may be reluctant to acknowledge bad news or may not understand what it immediately means for themselves or their kin.
- The patient and their family may need time to discuss the information to gain a complete understanding for all involved.
- Some Aboriginal and Torres Strait Islander people maintain their cultural beliefs, which is inclusive of spiritual beliefs about the causes of poor health. These beliefs generally may conflict with Western explanations and diagnosis of illnesses.

Section 1 Aboriginal and Torres Strait Islander cultural capability

Pain and its management

We are all susceptible to pain. However, we differ in the way pain is experienced and expressed, for example, contrast in pain thresholds and levels of analgesic effect. Misinterpretation of the intensity and severity of pain can lead to insufficient pain management.

Aboriginal and Torres Strait Islander people may be reserved and unobtrusive when in pain and may not openly complain. This is often due to embarrassment or reluctance to be any trouble to healthcare staff. This is in contrast to inaccurate social stereotyping which sometimes leads to labelling Aboriginal and Torres Strait Islander people as difficult patients or sometimes drug seekers.

Patients' understanding of pain management medications may vary also. As the health care provider, it is imperative to inform patients of their informed options for pain management while in our care. Patients' assumptions about the strength and immediacy of the analgesic effects, and their side effects are common issues for health care providers.

Be mindful that Men's and Women's Business and the protocols surrounding these may cause barriers for the patient to openly talk about pain. Be sure to ask the patient if they prefer to consult with someone of their own gender.

Relationships and partnerships

Forming positive relationships with key people associated with the patient is essential in providing optimal care. Establishing and maintaining relationships and partnerships will ensure delivery of quality healthcare and assist community engagement. When possible, these meaningful relationships should be developed proactively and as early as possible. During the time of death is a difficult and inappropriate time to do so.

Rapport with the patient and family

Establishing rapport is a key element for building relationships with any patient and their family. Patients and family members are vulnerable during the final stages of life, so absolute sensitivity and diligence are required of health care providers.

Aboriginal and Torres Strait Islander people may have a general feeling of distrust of non-Indigenous health staff. This may be due to historical factors, or possibly feelings of being judged or being treated unfairly in unfamiliar environments, such as mainstream health services.

Building rapport is therefore especially important when caring for an Aboriginal and/or Torres Strait Islander patient as this is an opportunity to prove one's credibility and trustworthiness. Building rapport with the patient and their family is not necessarily time consuming, as it is the quality of communication that is most valuable rather than the amount of time.

Essential elements of building rapport

- Be respectful of the patient's cultural requirements and ask questions about their culture. Mutual respect and reciprocity is a common cultural value for Aboriginal and Torres Strait Islander people.
- Be honest.
- Be proactive in providing orientation and clear and simple explanations for treatments and daily routines, e.g. why procedures have been postponed or cancelled, where the patient kitchen is, where waiting areas are located etc.

Do not underestimate the power of conversation that occurs in Aboriginal and Torres Strait Islander communities. Aboriginal and Torres Strait Islander people talk about their health experiences to family and community members, such as how they were treated and interactions with staff. If it is a positive experience, this will benefit the reputation of the organisation as well as your own; however, a negative experience will reinforce barriers between the service and Aboriginal and Torres Strait Islander people.

Working together with family members

Establish rapport and understanding with family members as early as possible.

In Aboriginal and Torres Strait Islander cultures, certain family members hold specific roles and responsibilities and will be able to assist with delivery of care at this time. Understanding their cultural roles and responsibilities will help ensure culturally appropriate care is received by the patient. Displaying respect for cultural values serves as a positive for the service.

Patient escort

Some Aboriginal and Torres Strait Islander patients who are transferred between remote, regional and metropolitan Queensland communities may be accompanied by an escort. The patient escort is usually a close family member who plays an important role supporting the patient and sometimes interpreting.

For both the patient and the escort, transferring away from their own community and family to a city environment may add significantly to their anxiety. The escort may also require support and assistance, for example, to overcome language barriers. Ensure that their emotional needs are met as well, as they are not only caring for a sick member of their family, but they may have family at home, children and grandchildren, that they may be missing or worried about.

Professional interpreters

Queensland Health acknowledges that individuals and groups from diverse cultural and linguistic backgrounds utilise the health service. The importance of interpreter services is recognised for ensuring informed patients that participate in personal health care decisions as well as planning and review of all aspects of health. Queensland Health policy is to use interpreters who are NAATI (National Accreditation Authority for Translators and Interpreters Ltd) accredited or recognised. There are however very few accredited or recognised interpreters for any Aboriginal or Torres Strait Islander languages in Queensland. The Indigenous Hospital Liaison Officer or Indigenous Health Worker within your service may be able to assist.

Consent should be sought from both the patient and healthcare staff before involving interpreters in the care of a patient. It is possible that there may be distrust between groups.

Section 1 Aboriginal and Torres Strait Islander cultural capability

Family interpreters

If a family member were to provide interpreter assistance, consider the following.

- Certain topics are taboo and cannot be discussed between certain family members, e.g. information regarding women's health cannot be discussed with a male family member.
- Some subjects may be embarrassing to certain members of the family, especially younger members.

How can you ensure family interpreters are interpreting accurately?

- Ideally, one member of the family should be identified upfront as the spokesperson/contact family member for the patient's matters.
- Identify what needs to be translated prior to speaking with the family spokesperson.
- If there is not one spokesperson, clarify to the family what needs to be discussed with the patient, and have the family decide who will help interpret.
- Strongly emphasise the importance of accurate information.
- Limit the use of medical jargon. Use diagrams to assist with complex medical explanations.
- Most medical problems do not have a traditional name, e.g. cancer; be mindful of this and explain in simple language.

Aboriginal and Torres Strait Islander Hospital Liaison Officers (liaison officers)

Aboriginal and Torres Strait Islander Hospital Liaison Officers can be found in major Queensland Health hospitals. They provide emotional, social and cultural support and assistance to Aboriginal and Torres Strait Islander inpatients and their families.

The liaison officer should be contacted on admission, and their advice should be sought when planning care for the patient during their stay and on discharge. They will be able to determine the cultural appropriateness of care and provide a vital medium between the health care team, the patient and their family. Liaison officers can play an extremely important role when caring for a patient who is dying, or has passed.

Aboriginal and Torres Strait Islander Health Workers (health workers)

Aboriginal and Torres Strait Islander Health Workers are key conduits between the health care team and the patient and their family. Health workers can be found in Aboriginal and Torres Strait Islander community health services throughout Queensland.

If a patient is transferred to your hospital from a remote community, the health worker from that community will be your best contact to assist with communication with the patient. Seek assistance from your Aboriginal and Torres Strait Islander Hospital Liaison Officer, or search for the contact details of the community health service in the community that the patient is from. Be sure to ask the patient or escort where they are from, as sometimes a patient is transferred multiple times, and the medical notes may not reflect this.

The health worker can also assist with explaining any cultural expectations on behalf of the patient, contacting family support for the patient, clarifying the patient's medical or family history, or dietary requirements, and providing advice on discharge planning i.e. what services are available to the patient in the community.

Supporting the patient and family

Support is essential for a person in the final stage of life. For Aboriginal and Torres Strait Islander people the family and kinship system provide a wealth of support. However, this support may be difficult if the patient is not in their home town, and away from their family. In such circumstances the involvement of the local liaison officer or health worker could be beneficial.

There are also some Indigenous-specific social and emotional well-being community organisations throughout Queensland that can be suggested to family and friends. Please contact your local liaison officer or health worker to identify these services.

Capacity building

In order to deliver care that is responsive to a patient's cultural needs, one must have some understanding of the cultural knowledge and skills that impact on one's practice. There are several ways to further increase cultural knowledge and skills.

Aboriginal and Torres Strait Islander cultural training programs

The Queensland Health Aboriginal and Torres Strait Islander Cultural Practice Program aims to enhance the knowledge and skills of all staff. The training provides staff with the opportunities to learn about local Aboriginal and Torres Strait Islander cultures and their practical relevance to health care. The training also provides staff with opportunities to identify the important Aboriginal and Torres Strait Islander services and staff in their health services, such as Aboriginal and Torres Strait Islander Hospital Liaison Officers and Health Workers.

Find out more from your local Cultural Practice Program Coordinator within your HHS.

Local staff

Aboriginal and Torres Strait Islander Hospital Liaison Officers, Health Workers and staff in Aboriginal and Torres Strait Islander Health Services hold valuable, locally relevant cultural knowledge. However, they are not the only people that can help. Aboriginal and Torres Strait Islander people also participate in other health or hospital roles, including nursing, midwifery, medicine and allied health. There may be Aboriginal and Torres Strait Islander people employed in operational roles. People employed as gardeners, cleaners and orderlies may hold significant roles within their communities.

Establishing rapport with Aboriginal and Torres Strait Islander staff within your facility is the best way to identify important human resources to assist your learning of local cultural knowledge that impact on your practice.

Working in community

A relationship with the local Aboriginal or Torres Strait Islander community is an imperative for healthcare providers working within Aboriginal and Torres Strait Islander communities. Established groups such as the Community Health Council or Community Council are important stakeholders. These individuals and groups can inform service delivery that is locally appropriate, as well as drive local health initiatives and strategies.

Learning the lingo

The most crucial point in communication is that it is not just what is said, but what the patient hears and interprets. The best way of ensuring the quality of patient's understanding is by speaking the language. However, unless you were working in a community and saturated in the culture, learning the language is difficult. If you do reside in an Aboriginal or Torres Strait Islander community, you are encouraged to learn the language.

Please seek assistance from your local Aboriginal and Torres Strait Islander health workers or health service in the community.

Seeking assistance or advice

Many Aboriginal and Torres Strait Islander patients are transferred to metropolitan hospitals from remote and regional locations to obtain appropriate medical services.

The local Aboriginal and Torres Strait Islander Hospital Liaison Officer may not be familiar with the language spoken by the patient, but may be able to contact someone more appropriate.

Be mindful that liaison officers may have cultural obligations that will conflict with the professional role. Be sure to consult the liaison officer regarding his/her involvement in the care of each patient.

Section 2 The final stages of life

Before the passing

In the lead up to an expected death, there is usually a gathering of immediate and extended family and friends. This will likely take place at the family home but hospital staff should anticipate a large number of visitors to see the patient. Groups may also congregate in the hospital or nearby. Based on the belief that life is a part of a greater journey, it is cultural practice to prepare the person for the next stage in their journey. The gathering is a mark of respect for the patient.

What care of planning should be considered in anticipation for this?

- Consider providing a larger private room for the patient.
- Due to the distance from possible remote and interstate locations that family members will travel from, special considerations for visiting hours should be factored in for an Aboriginal or Torres Strait Islander patient.
- A family member may request to stay overnight with the patient. When allocating patients, consider how you can accommodate this request.
- Develop rapport and work with the family. This is very important in providing the best care possible to the patient, ensuring cooperation and mutual understanding.
- Anticipate many questions. Some people may however be very quiet; they may have many questions to ask but may be shy or intimidated and not know how or what to ask.
- With the consent of the patient and/or their family, ensure the involvement of the Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker in caring for the patient.
- Some Aboriginal and Torres Strait Islander families may request a visit from the clergy or chaplain. Ensure that you have chaplain support services information readily available.
- Refer the family to a local Aboriginal and Torres Strait Islander social and emotional wellbeing organisation, if possible.

Time of passing

The time of passing is very traumatic for family and friends of the deceased. In rural and remote areas, the whole community will experience grief and mourning and business may shut down for a period of time out of respect for the loss. This time will set certain cultural protocols in motion, requiring sensitivity and understanding.

Cultural duties for the extended family and relatives following the death include supporting the immediate bereaved family, as well as feeding, transporting and housing mourners. Such support requires the cooperation of the extended family and friends to share the load, to help the bereaved family have the time to pay respect to the deceased.

The legal requirements of death (i.e. death certificate, notification of reportable deaths) are followed as per usual.

Communication following the passing

In Aboriginal culture it is taboo to mention (or in some cases write) the name of a deceased person. Aboriginal people believe that if the deceased person's name is mentioned, the spirit is called back to this world. Images (film and photographs) or broadcasting the voice of the deceased person may also be against protocol and may cause serious offence.

Contacting the next of kin following the death is not always correct practice for Aboriginal and Torres Strait Islander people.

It is **culturally inappropriate** for a non-Indigenous health staff member to contact and inform the next of kin of a person's passing. This breach of cultural protocol may cause significant distress for Aboriginal and Torres Strait Islander families connected to the person who has passed.

In the Western Island group of the Torres Strait, cultural protocol will require certain in-law relatives to assume a role known as the '*Marigeth*' (*Spirit Hand*). This role supports the grieving family by caring for the needs, informing family (immediate and extended) of the person's passing, acting as family spokesperson (communication in and out) and coordinating funeral arrangements. These relatives will be the people to contact when organising open disclosure interviews, for example.

Note that a different process or protocol may occur for other families and communities in other areas of the Torres Strait and direct advice must be sought from representatives of those communities. Remember also that there is a significant population of people from Papua New Guinea that reside within the Torres Strait.

As a matter of best practice, seek cultural guidance from the local Aboriginal and Torres Strait Islander Hospital Liaison Officer, the Aboriginal and Torres Strait Islander Cultural Practice Coordinator, Health Worker, the family group or the wider community.

Notifying Aboriginal and Torres Strait Islander staff

Be mindful of any Aboriginal or Torres Strait Islander staff that may be related to the patient. This can be established proactively by asking the patient or the family if they have family working in your facility. Ensure that respect is given to those staff members by allowing cultural protocol to inform them.

Prepare for these cultural implications.

- Early in admission identify whether the patient is of Aboriginal and/or Torres Strait Islander origin. Then identify who would be the correct person to contact in the event of deterioration in health and passing of the patient.
- Death is a taboo topic, so ensure that you respectfully ask the patient or one of the senior members of the family in private about who would be the contact person in case of health deterioration or passing.
- Ask the local Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker for the appropriate word to use in substitute for the patient name following passing. Also be attentive to the deceased person's family to what words they use.

Traumatic or sudden death

Slow deterioration of health and expected deaths are more readily accepted by Aboriginal and Torres Strait Islander families and communities than sudden deaths.

Sudden death in Aboriginal and Torres Strait Islander cultures may be associated with sorcery and blame, which can lead to payback. These issues are essential to understand, especially for Queensland Health staff working in remote and regional areas. Sorcery is believed to be a contributing factor in many sudden deaths. It is as real to many Aboriginal and Torres Strait Islander people as a blocked artery or a diabetic ulcer and should not be dismissed as mere superstition.

Whenever possible, build rapport with your local Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker or community leaders (if working in community). These people are the medium between health professionals, patients and family. The relationships should be proactively developed and maintained and will be beneficial if caring for Aboriginal and Torres Strait Islander people who find themselves in highly distressing situations.

Consider the following in the event of a traumatic or sudden death.

- Anticipate that there could be strong reactions. Maintain respect and professionalism. It is important to appreciate and respect differences in perspective to avoid aggravating situations.
- Be honest and sincere when supporting the family.
- Coordinate care with the Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker.
- Practise good communication skills.
- Open disclosure should be practised sensitively and confidently.

Section 3 Time after passing

The time following the passing requires continuing support, sensitivity and respect for family and friends, and respect for cultural protocols and practices. Refer to Aboriginal cultural protocols and practices below. Additional guidance is also provided for the formal processes of open disclosure and coronial investigations.

Sad News, Sorry Business

Family and friends may continue to arrive for some time after the person has passed. On arrival, the newcomers are usually ushered in to see the family; often the partner, siblings and other immediate family. The arrival of a new relative is often accompanied by a revival of loud mourning.

Following the passing of a patient, some general protocols are advised when communicating with the family.

- In some communities, it is advisable to avoid eye contact with the family members and friends as a mark of respect.
- If staff wish to express their condolences, a silent hand shake, without eye contact will suffice.

In some instances the family may request a priest or chaplain to visit the deceased person's room or home, which is believed to evoke the spirit from the house. Traditionally in Aboriginal culture, this may include a smoking ceremony.

Customary practices following death differ between Aboriginal and Torres Strait Islander people, some of which are described.

Aboriginal cultural protocols and practices

Aboriginal cultural protocols following death generally have two purposes:

- sending the spirit onto the next world
- identifying the cause of death.

Many Aboriginal tribal groups share the belief that this life is only part of a longer journey. When a person passes away, the spirit leaves the body. The spirit must be sent along its journey; otherwise it will stay and disturb the family.

There are two significant practices that occur following death that assists with the journey of the spirit.

- The name of the deceased is not mentioned for a long period of time, from several months to years. This is to ensure that the spirit is not held back or recalled to this world.
- A smoking ceremony is conducted. The smoking of the deceased person's belongings and residence also assists with encouraging the departure of the spirit.
- Some Aboriginal groups also practise means of identifying causes of death. These are practised by Elders who hold the cultural authority to do so, and the causes in question are usually of a spiritual nature. The ceremonies are likened to an autopsy of Western practice.

These practices may be sacred in nature and therefore not discussed openly. Queensland Health staff should not dismiss the need to perform these practices and ceremonies and should allow appropriate time and privacy.

Pending the smoking ceremony and investigations, family and friends are sometimes relocated away from the deceased person's house. In some areas, the family resides in sorry camps which can be some distance from modern amenities and services.

How can cultural wishes of the family of a deceased Aboriginal patient be respected?

Be aware that the practices described above may occur. There can be restrictions to interfering with the deceased person's body which deem traditional investigations impossible. However, a report of the post-mortem investigation or coronial inquest should be discussed with and made available to the family as soon as possible.

Family members may request a lock of hair from the deceased person's body. This is usually done in private, so avoid drawing attention to it.

- Speak to the treating doctor to determine if this is possible.
- Document this in the patient notes.

How can the cultural wishes of the family of a deceased Torres Strait Islander patient be respected?

Torres Strait Islander beliefs and practices following death have more religious implications, and involve many family members.

- Prepare for many people and loud mourning, particularly if the deceased is a long way from their home or community.
- Consider the use of a single room for the family to mourn.
- Consult with the Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker or family representative to manage the mourning period in the facility.

Sometimes in Torres Strait Island culture, the day before the burial, the family arrives at the morgue to 'dress' the deceased person. If it is a female family member, only females will be allowed inside and vice versa. The family will fully dress the deceased person including shoes, a tie and sometimes their cologne.

- Be respectful of the cultural protocols.
- Be aware of the religious implications.
- Listen to the family; they will identify what is required.

Remote and discrete communities

Discrete communities can effectively close for business under some circumstances, including Sad News and Sorry Business. Contact must be made with the council prior to any visit; the council will advise on local protocols. Contact the council again prior to your visit before commencing travel. If there is a death in the community you may need to reschedule your visit. Every community is very different.

If you are in working in the community, it may be respectful for you to participate if you know the deceased person. Please be guided by your health workers or prominent members of the community. It is critical to follow protocol.

Family escort for the deceased

One particular family member may be the appropriate person to escort an Aboriginal or Torres Strait Islander deceased person from a metropolitan or regional hospital back to their community. Communicate with the family to ensure that the right person has been identified and that the health service has their name and contact details. This will ensure smooth operations for transferring the deceased person back to their community.

Postponing the burial

The burial may require the presence of certain family members. This may result in delays due to appropriate negotiations amongst family members.

Financial barriers

Some families cannot afford the cost of a funeral. However, Aboriginal and Torres Strait Islander people can apply for financial assistance (Burials Assistance) at their local courthouse or Office of the State Coroner. Seek assistance from your local Aboriginal and Torres Strait Islander Hospital Liaison Officer or Health Worker.

A hospital autopsy request in a remote location can be expensive for the family, as the family will have to pay for the transfer of the deceased body to and from the nearest health service that can provide such services.

Aboriginal and Torres Strait Islander staff attending funerals

Please remember that Aboriginal and Torres Strait Islander staff members also have obligations to attend funerals as members of the family and community. This applies in all settings.

Open disclosure

The technical aspects of the open disclosure process should be maintained, as per the Queensland Health advice, and practised sensitively with Aboriginal and Torres Strait Islander families.

Factors to consider

- Plan the open disclosure session with the family; identify what will be shared; how and in what order. Your confidence and preparedness will be viewed as your professionalism and trustworthiness.
- Consult your local cultural conduit in planning the open disclosure session. These conduits may include the local liaison officer or health worker or a prominent member of the family; or in a Torres Strait Islander family, the senior in-laws.

Guidance notes

- Ensure that all the required family members are invited and present on the day.
- Check the appropriateness of setting and environment for a family gathering, to ensure privacy and comfort of family.
- Discuss alternative locations as the health facility may not be the best location.
- Seek guidance in anticipation of very emotional family members. Identify collaborative strategies to best support grieving families and also minimise or prevent potentially harmful situations from occurring.
- Clarify whether or not you can use the name of the deceased person, and identify what 'name' is suitable.

- If you ensure that the conduits understand, they may be able to assist with explanations and provide constant support for the family following the open disclosure session in regards to explaining the situation.
- Consider the use of teleconference or video conference facilities if family members cannot be physically present.
- Practise appropriate communication skills.
- Give the family time to understand the information that you are sharing.
- If a hospital post-mortem report is available at this time, use the opportunity to explain the content of the report to the family. The report may also provide structure for the open disclosure process.
- If a death is reportable and awaiting coronial investigation, ensure that the family is made aware of the coronial process.
- Essentially, families just want to hear the truth; be genuine and confident.

Coronial investigations

The unforeseen nature of a reportable death that may lead to a coronial investigation is often associated with highly emotional reactions from family and friends. Considering the lack of trust that may exist between Aboriginal and Torres Strait Islander people with non-Indigenous people and the extensive family system, the reaction has potential to be large and quite negative.

Refer to the Information for Health Professionals, which outlines the professional, legal, cultural and ethical responsibilities of Queensland Health and staff members involved. A good understanding of the process is essential to educate the family about the process.

Refer to Open Disclosure (Australian Commission on Safety and Quality in Health Care) to assist with managing this process with Aboriginal and Torres Strait Islander patients and their families.

Glossary

Aboriginal (adjective): A person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Australian continent and surrounding islands).

Coronial autopsy: Post-mortem investigation on a reportable death.

Death: Death may also be referred to as 'passing' of a patient in this document.

Dying: Dying may also be referred to as the final stage/journey of life in this document.

Patient escort: A family member who escorts the patient between health facilities.

Family: In Aboriginal and Torres Strait Islander culture the term family may vary in definition to non-Indigenous culture. This is illustrated in the use of immediate family titles being used across the extended family sphere, i.e. brother and sister are all the males and females of the same generation.

Hospital autopsy: Post-mortem investigation on a non-reportable death.

Aboriginal and Torres Strait Islander Health Worker (Indigenous Health Worker): Person who works within a primary health care framework to achieve better health outcomes and better access to health services for Aboriginal and Torres Strait Islander individuals, families and communities; required to hold the specified Aboriginal and Torres Strait Islander primary health care qualification. There is a genuine occupational requirement that the occupants of these positions are of Aboriginal or Torres Strait Islander origin.

Aboriginal and Torres Strait Islander Hospital Liaison Officer: Person in position usually based in regional and metropolitan hospital to provide a range of support for staff, patients and their families. There is a genuine occupational requirement that the occupants of these positions are of Aboriginal or Torres Strait Islander origin.

Open disclosure: The open discussion of an incident that results in harm to a patient while receiving healthcare. The elements of open disclosure are an expression of regret, a factual explanation of what happened, the potential consequences and the steps being taken to manage the event and prevent recurrence.

Formal open disclosure is the structured process to ensure communication between the patient, senior clinician and the organisation executive. The process consists of an open disclosure team involving a clinical team, a senior clinician trained as an open disclosure consultant, and hospital executives.

Sad News: Torres Strait Islander term that refers to the passing of a person.

Senior member of the family/senior in-law: The family members to go to for advice on matters surrounding the death of an Aboriginal or Torres Strait Islander person.

Sorry Business: Aboriginal term that refers to the passing of a person.

Sorry camps: Temporary camps often away from original dwellings that are used by the wider family during the initial time following the death of a person in Aboriginal culture.

Torres Strait Islander: A person of Torres Strait Islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Torres Strait Islands).

Resource list

Aboriginal and Torres Strait Islander Patient Care Guideline

https://www.health.qld.gov.au/__data/assets/pdf_file/0022/157333/patient_care_guidelines.pdf

Funeral Assistance Scheme - Coroners Court of Queensland

www.coronerscourt.qld.gov.au/for-families/funeral-assistance-scheme

Coronial Investigations Explained

<https://clinicalexcellence.qld.gov.au/sites/default/files/2018-02/coronial-investigation.pdf>

CRANApplus Bush Support Service (for remote health workers)

Bush Support Line 1800 805 391 – open 24 hours

Open Disclosure, Queensland Health (Queensland Health intranet only)

qheps.health.qld.gov.au/psu/od/default.htm

Open Disclosure, Australian Commission on Safety and Quality in Health Care

www.safetyandquality.gov.au/our-work/open-disclosure/

Queensland Health Aboriginal and Torres Strait Islander Cultural Capability Framework 2010–2033

www.health.qld.gov.au/atsihealth/documents/cultural_capability.pdf

Queensland Health Interpreter Service

www.health.qld.gov.au/public-health/groups/multicultural/interpreting-translation

Queensland Health Language Service Policy

www.health.qld.gov.au/public-health/groups/multicultural/policies-plans-strategies/policies

Queensland Nurses and Midwives Union

www.qnmu.org.au

Royal Australian College of General Practitioners

www.racgp.org.au

State Coroner's Guideline Chapter 7.3: Investigating health care related deaths

https://www.courts.qld.gov.au/__data/assets/pdf_file/0017/206126/osc-state-coroners-guidelines-chapter-7.pdf



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