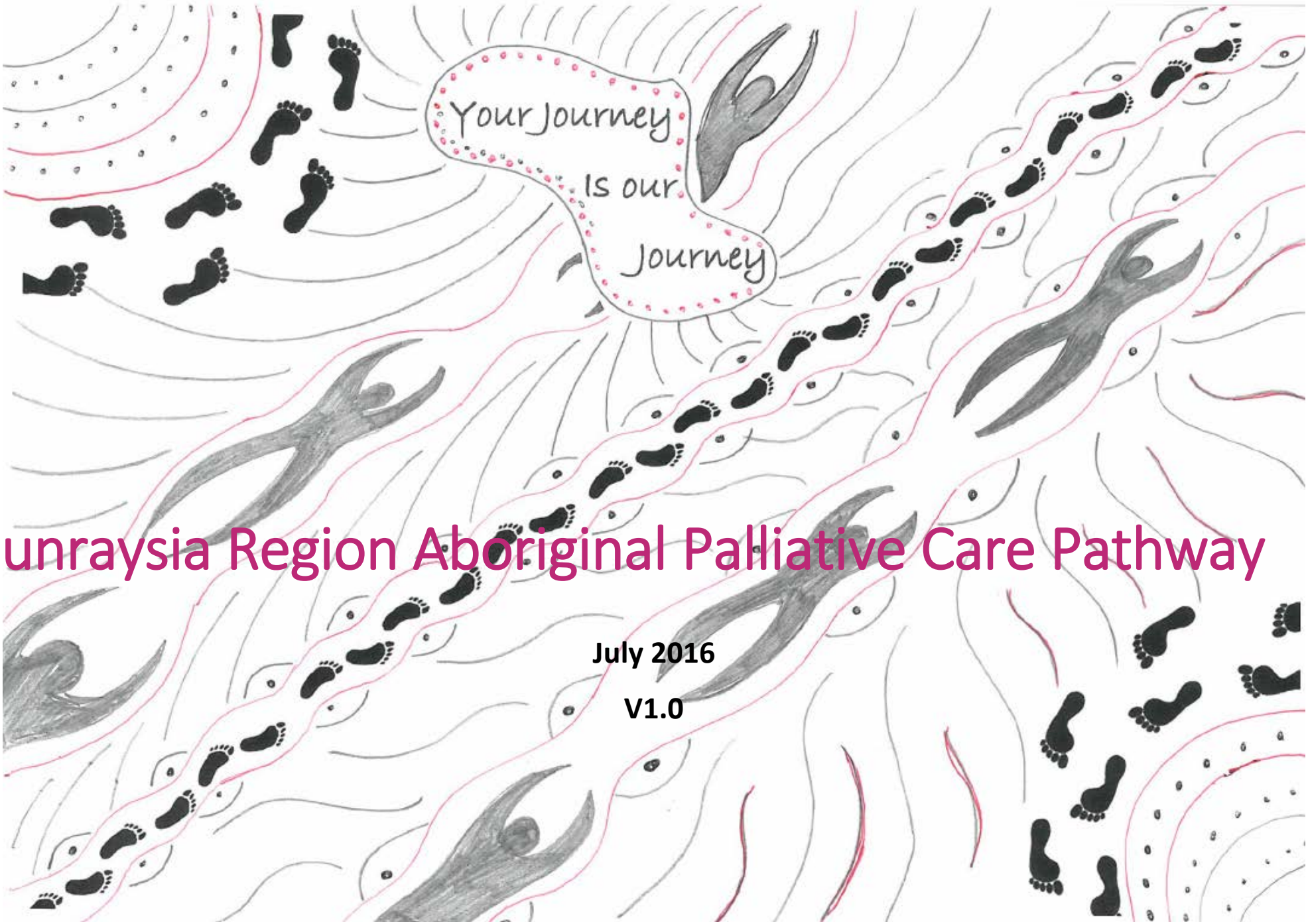


Sunraysia Region Aboriginal Palliative Care Pathway

July 2016

V1.0

Glossary of Terms

AHW: Aboriginal Health Worker

AHP: Aboriginal Health Practitioner at Mallee District Aboriginal Services (Mildura)

ALO: Aboriginal Liaison Officer at Mildura Base Hospital

CPC: Community Palliative Care Services, operated from Sunraysia Community Health Services

ED: Emergency Department at Mildura Base Hospital

EOLC: End of Life Care

GP: General Practitioner across primary health clinics in Sunraysia region

MB AHU: Mildura Base Aboriginal Health Unit

MDAS: Mallee District Aboriginal Services (Mildura)

PEPA: Program of experience in the palliative approach http://www.pepaeducation.com/

SCHS: Sunraysia Community Health Services

The Consortium: Loddon Mallee Regional Palliative Care Consortium, of which both Sunraysia Community Health Service and Mildura Base are members

The Consultancy: Loddon Mallee Regional Palliative Care Consultancy Service (specialist clinical palliative care team operated out of Sunraysia Community Health Service)

Background

Australian studies have found that there is a lack of understanding about palliative care among both Aboriginal Australians and Aboriginal healthcare professionals such as Aboriginal health workers (AHWs)[1] . Similarly, a lack of understanding of Aboriginal belief systems, Dreamtime and spirituality, and our first peoples' links to the land can lead to a 'disconnect' for mainstream clinicians[2].

Aboriginal and Torres Strait Islander clients are either not referred to palliative care at all, or are referred at a very late stage in their illness[3]. As a result, Sullivan et al argue that Aboriginal people, who are likely to have complex symptoms, may not be receiving adequate care from generalist healthcare providers[3], and this is despite the evidence that supports the delivery of specialist palliative care.

It is acknowledged that referrals to palliative care services will not be taken up unless supported by cultural advocacy and/or participation by Aboriginal staff. The strong recommendation from the Sullivan study is the need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services[3].

To date in the Sunraysia Region there has been a gap in palliative care service delivery to Aboriginal clients and hence in 2016 a group of local stakeholders came together to determine an Aboriginal Palliative Care Referral Pathway for the Sunraysia Region and also agreed to a set of principles to underpin the service delivery.

Stakeholders who worked up Model Pathway

- Aboriginal Community Representatives
- Sunraysia Community Health Service – Community Palliative Care
- Mildura Palliative Care Consultancy Team
- Mallee District Aboriginal Services
- Mildura Base Hospital – Aboriginal Health Unit
- Mildura Base Hospital – Aboriginal Clinical Project Officer
- Mildura Base Hospital – (Ward 4)
- Primary Health Clinics

[1] McGrath P, Patton MA. Indigenous understanding of hospice and palliative care. Journal of Hospice & Palliative Nursing 2007; 9(4): 189-197.

[2] Department of Health and Ageing. Providing culturally appropriate care to Indigenous Australians: Discussion paper. Canberra, ACT: Commonwealth of Australia, 2004.

[3] Sullivan K, Johnston L, Colyer C, Beale J, Willis J, Harrison J et al. National Indigenous palliative care needs study: Final report. Canberra, ACT: Department of Health and Ageing, 2003.

Agreed Principles to support Aboriginal People accessing Palliative Care Support in Sunraysia Region

- The use of Aboriginal Health Workers (AHWs) for home visits and support is recognised as vital to bridging the cultural divide between mainstream palliative care and Aboriginal culture[4], therefore every effort will be made by the Community Palliative Care Service to work in partnership with an Aboriginal Health Worker. ***The Palliative Care Worker and the Aboriginal Health Worker will discretely identify any culturally specific priorities the patient and family may have in managing the palliative care journey. For example: including a Smoking Ceremony or being buried with the Aboriginal Flag***

- Care delivery will follow a model that works with the Aboriginal population, by respecting the Aboriginal person's link with the land and sense of community and family, and acknowledging cultural and spiritual beliefs about illness, dying and death.

- Palliative care for the Aboriginal person will focus on the individual as part of a larger family/community and kinship network, providing dignified care, support and education that extend beyond the individual.

- Mainstream workers commit to learning the beliefs about death and dying from the Aboriginal perspective and will aim to always deliver a culturally sensitive approach. (This can be supported by annual cultural safety training and mentoring from Mallee District Aboriginal Services (MDAS) and Mildura Base Hospital Aboriginal Health Unit (MB AHU) staff to the Sunraysia Community Health Services Community Palliative Care Team (CPC)

- Aboriginal Health Workers commit to learning about Palliative Care and acting on 'prompts' during health screening (e.g. 'cancer' , ' renal failure) , including alerting the GP or Nurse such that a palliative care referral becomes possible. (This can be supported by annual PEPA training and placements) http://www.pepaeducation.com/

- Yarning will be undertaken with Aboriginal Community representatives to help promote the message about culturally safe ' A Palliative Approach' and 'End of Life Care' Supports that are available in the Sunraysia Region

- All stakeholders commit to continuous improvement in service delivery and cases will be reviewed every 6 months and key learnings shared across all groups.

Model Pathways

Scenario A

Palliative Approach (living well with a life limiting illness)	End of Life Care
HOSPITAL TO HOME (Attendance to Emergency Department or discharge from Ward)	**HOME** (supported to die at home)
Mildura Base Ward Staff + support from Aboriginal Health Unit + support from Sunraysia Palliative Care Consultancy Service make referral to Sunraysia Community Palliative Care (+Mallee District Aboriginal Services)	**Sunraysia Community Palliative Care + support from Aboriginal Health Worker**

Scenario B

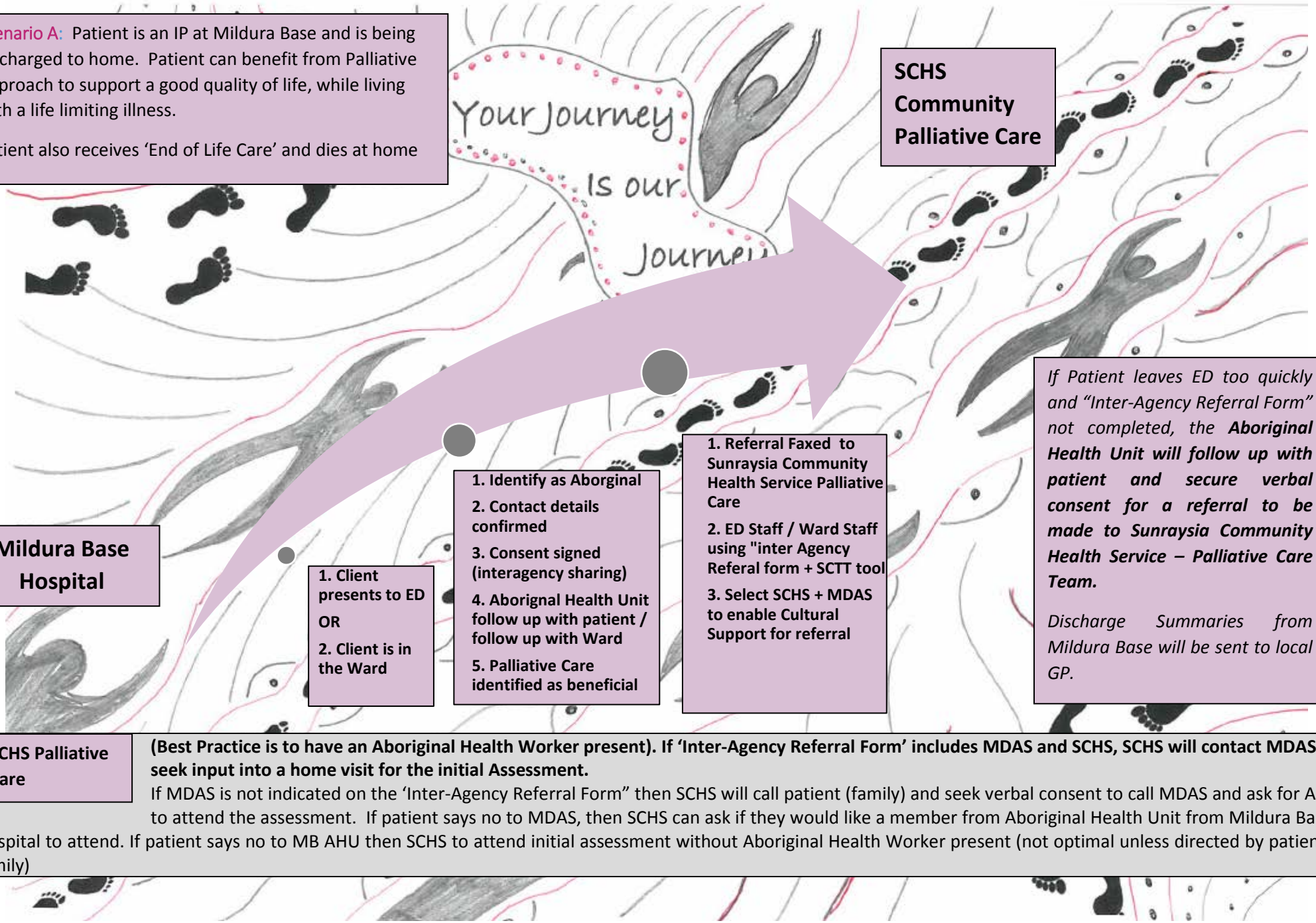
Palliative Approach (living well with a life limiting illness)	End of Life Care
HOME (sporadic attendance at Primary Health Clinic)	**HOSPITAL** (supported to die in hospital)
Sunraysia Community Palliative Care + support from Aboriginal Health Worker	**Mildura Base + support from Aboriginal Health Unit + Sunraysia Palliative Care Consultancy Staff**

Scenario C

Palliative Approach (living well with a life limiting illness)	End of Life Care
HOME (sporadic attendance at Primary Health Clinic)	**HOME** (supported to die at home)
Sunraysia Community Palliative Care + support from Aboriginal Health Worker	**Sunraysia Community Palliative Care + support from Aboriginal Health Worker**

Scenario A: Patient is an IP at Mildura Base and is being discharged to home. Patient can benefit from Palliative Approach to support a good quality of life, while living with a life limiting illness.

Patient also receives 'End of Life Care' and dies at home



SCHS Community Palliative Care

Mildura Base Hospital

1. Client presents to ED

OR

2. Client is in the Ward

1. Identify as Aborginal

2. Contact details confirmed

3. Consent signed (interagency sharing)

4. Aborignal Health Unit follow up with patient / follow up with Ward

5. Palliative Care identified as beneficial

1. Referral Faxed to Sunraysia Community Health Service Palliative Care

2. ED Staff / Ward Staff using "inter Agency Referal form + SCTT tool

3. Select SCHS + MDAS to enable Cultural Support for referral

If Patient leaves ED too quickly and "Inter-Agency Referral Form" not completed, the ***Aboriginal Health Unit will follow up with patient and secure verbal consent for a referral to be made to Sunraysia Community Health Service – Palliative Care Team.***

Discharge Summaries from Mildura Base will be sent to local GP.

SCHS Palliative Care

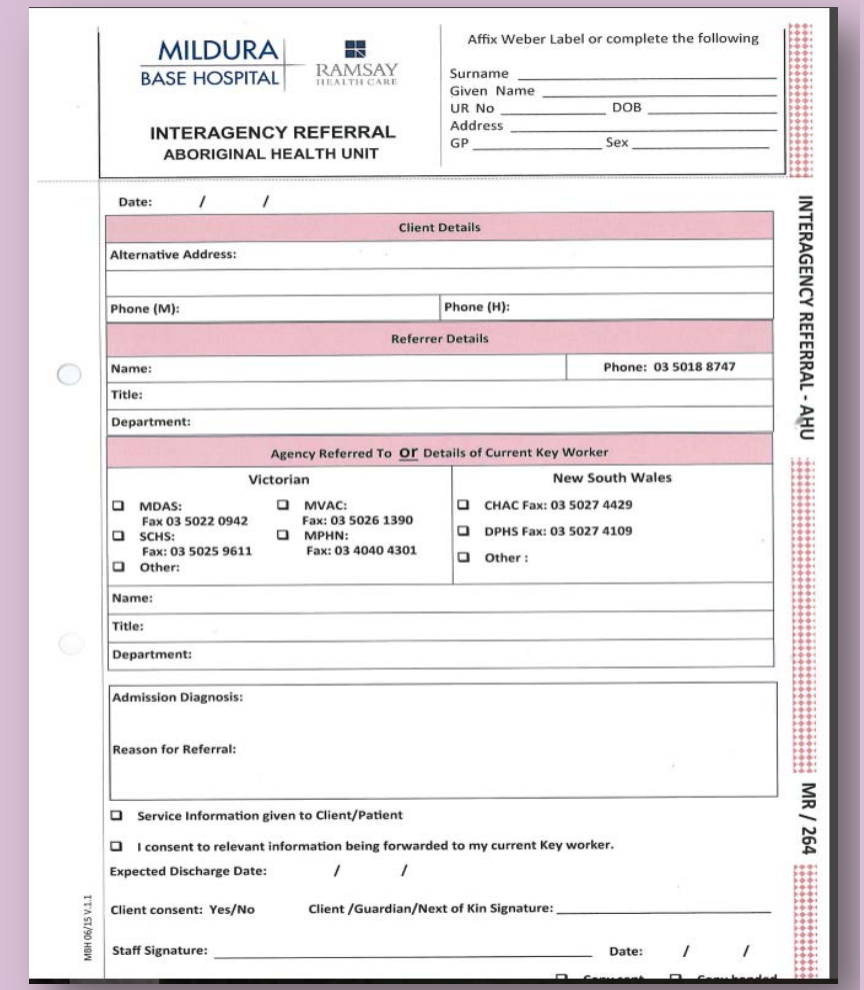
(Best Practice is to have an Aboriginal Health Worker present). If 'Inter-Agency Referral Form' includes MDAS and SCHS, SCHS will contact MDAS to seek input into a home visit for the initial Assessment.

If MDAS is not indicated on the 'Inter-Agency Referral Form" then SCHS will call patient (family) and seek verbal consent to call MDAS and ask for AHP to attend the assessment. If patient says no to MDAS, then SCHS can ask if they would like a member from Aboriginal Health Unit from Mildura Base. Hospital to attend. If patient says no to MB AHU then SCHS to attend initial assessment without Aboriginal Health Worker present (not optimal unless directed by patient / family)

Inter-Agency Referral Form

SCTT Tool

FORM



MILDURA BASE HOSPITAL | RAMSAY HEALTH CARE

INTERAGENCY REFERRAL
ABORIGINAL HEALTH UNIT

Affix Weber Label or complete the following

Surname _____
Given Name _____
UR No _____ DOB _____
Address _____
GP _____ Sex _____

Date: / /

Client Details

Alternative Address:

Phone (M): | Phone (H):

Referrer Details

Name: | Phone: 03 5018 8747

Title:

Department:

Agency Referred To or Details of Current Key Worker

Victorian		New South Wales
☐ MDAS: Fax 03 5022 0942	☐ MVAC: Fax: 03 5026 1390	☐ CHAC Fax: 03 5027 4429
☐ SCHS: Fax: 03 5025 9611	☐ MPHN: Fax: 03 4040 4301	☐ DPHS Fax: 03 5027 4109
☐ Other:		☐ Other :

Name:

Title:

Department:

Admission Diagnosis:

Reason for Referral:

☐ Service Information given to Client/Patient

☐ I consent to relevant information being forwarded to my current Key worker.

Expected Discharge Date: / /

Client consent: Yes/No Client /Guardian/Next of Kin Signature: _____

Staff Signature: _____ Date: / /

INTERAGENCY REFERRAL - AHU

MR / 264

MRH 06/15 V1.1

TOOL

https://www2.health.vic.gov.au/Api/downloadmedia/%7B29FEA706-847F-46C3-A940-01D974178846%7D

https://www2.health.vic.gov.au/Api/downloadmedia/%7BC0AE06D3-367A-42A6-934A-8341E870131D%7D

https://www2.health.vic.gov.au/Api/downloadmedia/%7BA5454375-AB8B-42A5-BB72-EAE238008471%7D

https://www2.health.vic.gov.au/Api/downloadmedia/%7B6682A524-2FED-42C0-94D1-452A5BED2170%7D

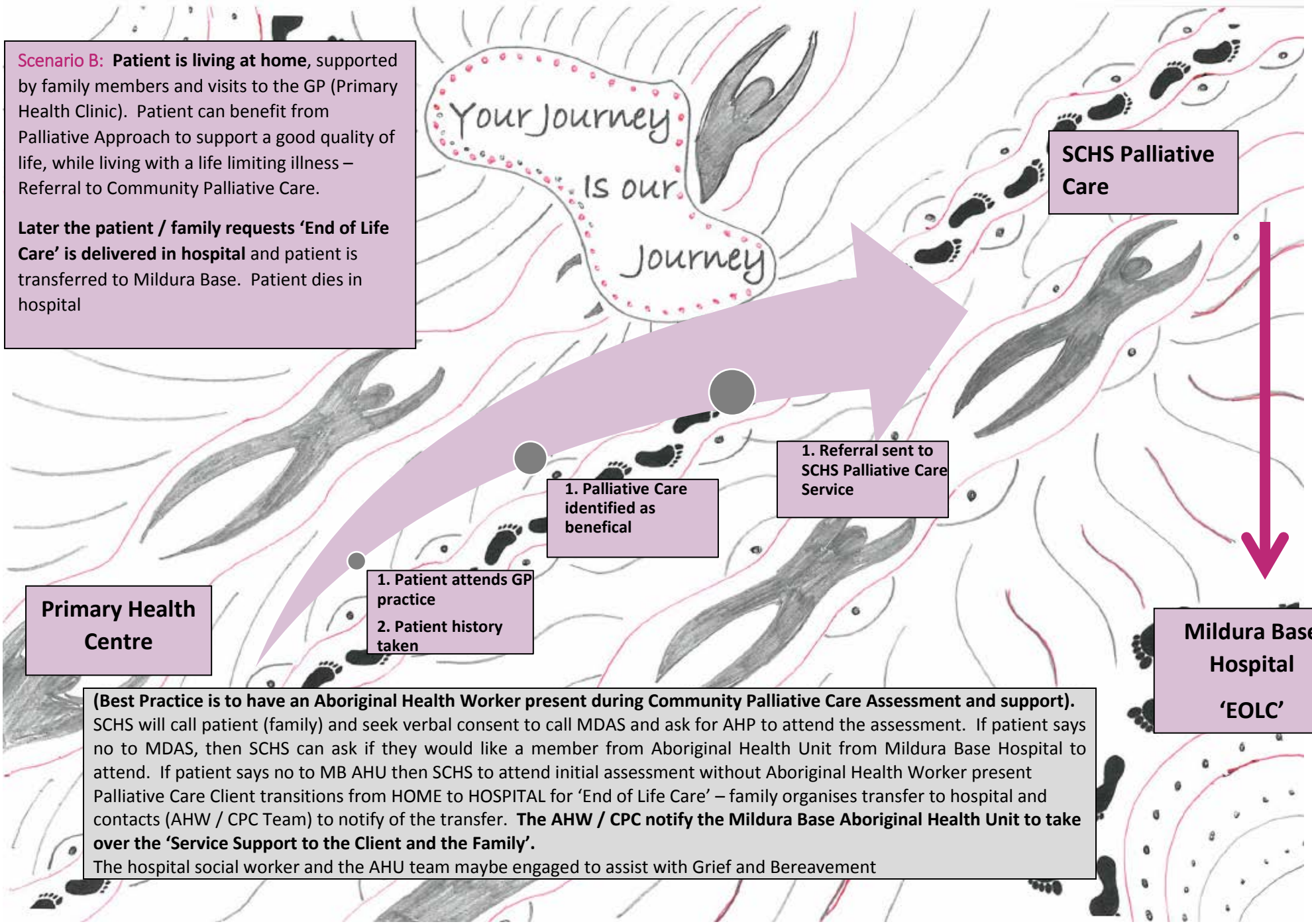
The forms from DHHS should be downloaded from the site to ensure the most up to date form is used.

Consumer Information: Gives adequate details of the information required by the person receiving the referral to enter details into a computer system.

Consent to share information: Is the evidence of permission sought to undertake the referral.

Referral cover sheet and acknowledgment: Acts for both parties – a cover sheet for the referral and the receiver can also use it to acknowledge to the referee that they have received the referral.

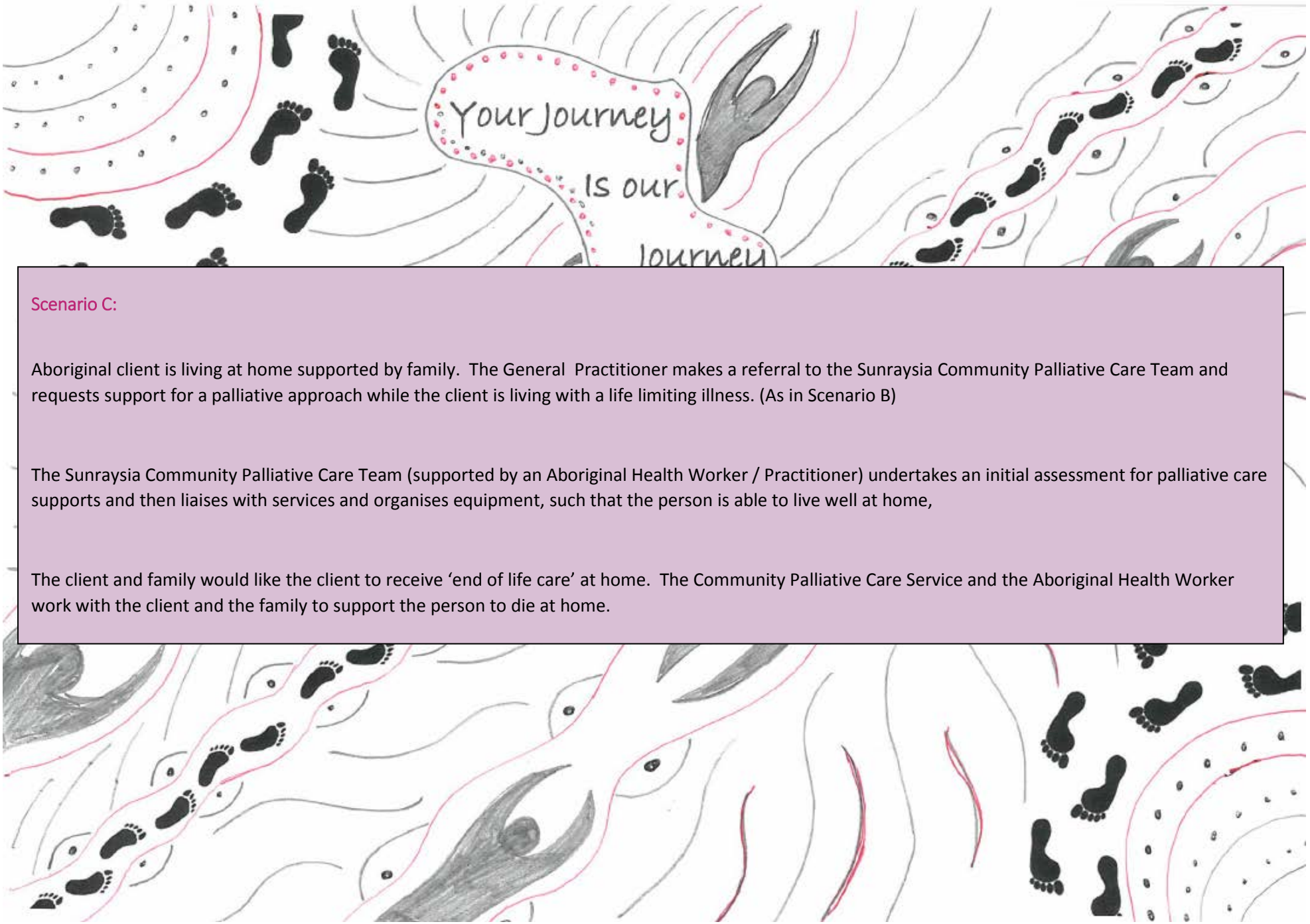
Palliative care supplementary information: Gives more specific information about diagnosis / prognosis / client knowledge of both of these.



Scenario B: **Patient is living at home**, supported by family members and visits to the GP (Primary Health Clinic). Patient can benefit from Palliative Approach to support a good quality of life, while living with a life limiting illness – Referral to Community Palliative Care.

Later the patient / family requests 'End of Life Care' is delivered in hospital and patient is transferred to Mildura Base. Patient dies in hospital

(Best Practice is to have an Aboriginal Health Worker present during Community Palliative Care Assessment and support). SCHS will call patient (family) and seek verbal consent to call MDAS and ask for AHP to attend the assessment. If patient says no to MDAS, then SCHS can ask if they would like a member from Aboriginal Health Unit from Mildura Base Hospital to attend. If patient says no to MB AHU then SCHS to attend initial assessment without Aboriginal Health Worker present Palliative Care Client transitions from HOME to HOSPITAL for 'End of Life Care' – family organises transfer to hospital and contacts (AHW / CPC Team) to notify of the transfer. **The AHW / CPC notify the Mildura Base Aboriginal Health Unit to take over the 'Service Support to the Client and the Family'.**
The hospital social worker and the AHU team maybe engaged to assist with Grief and Bereavement



Scenario C:

Aboriginal client is living at home supported by family. The General Practitioner makes a referral to the Sunraysia Community Palliative Care Team and requests support for a palliative approach while the client is living with a life limiting illness. (As in Scenario B)

The Sunraysia Community Palliative Care Team (supported by an Aboriginal Health Worker / Practitioner) undertakes an initial assessment for palliative care supports and then liaises with services and organises equipment, such that the person is able to live well at home,

The client and family would like the client to receive 'end of life care' at home. The Community Palliative Care Service and the Aboriginal Health Worker work with the client and the family to support the person to die at home.

End of Life: Mildura Base Hospital

Sorry Day – day the patient dies.

Sorry Time – time the family spends with the patient before and after death (Can be all day or longer).

Eye Contact – Families will not make eye contact during sorry time, be respectful of this, make eye contact comfortable for the family, be seated and silent.

Mildura Base Hospital will accommodate requests from patients on an individual basis.

- Hospital staff must show respect and understanding to the family during sorry time.
- It is essential to ask the family who the family spokesperson is (usually an Uncle or Aunty).
- When passing is close arrange with the Hospital Co-ordinator-ALO to have the patient's room available for an extended period (all day).
- If the patient is in a 4 bed bay – move to a single room if possible.
- **Family are welcomed to use the Aboriginal Healing Centre as a waiting area for family to gather. (Note: this can be opened for extended hours to support family members)**
- Be aware that family may remain at the hospital while the patient's body is at the hospital. Family members will travel to be with the patient, there are no timeframes for this.
- Viewings of the patient can be organised.
    - Hospital staff will be required to be present at viewings (ALO and Hospital Co-ordinator). Families will have access to viewings for 1-2 weeks post passing.

- Contact the Triage team at MHS (or other counselling services) after discussion with the ALO if any support is required to support the family.
- In the death is a coroners case there are additional precautions;
- ***Discuss the barriers of viewing the patient with the nominated family spokesperson, before the family view the patient to decrease distress for the family.***
    - The body cannot be touched and tubes etc. cannot be removed
    - Viewing of the body can be immediate 1-2 hours in the Emergency Department; however the Hospital Co-ordinator, ALO, and Police will be present.
    - The body can be viewed in the mortuary after transfer from Emergency Department with the same restrictions.

- The Aboriginal Health Unit will fly their flags at half-mast until the burial.
- **Do not discuss funeral arrangement or funeral parlour details with the family before death.**
- Ask the family if they wish to have referral to social work, ALO to support them in their decisions post death.

GUIDE - Cultural protocols for working with Aboriginal & Torres Strait Island people (prepared by Cherie Waight VACCHO)

- Many Aboriginal people will not tell you if they do not understand what you are saying and will not ask questions out of politeness
- Many Aboriginal people have a very different spiritual reality from most westerners. Do not assume that what the family or client is telling you is due to medication or pathology. Many Aboriginal people see previously deceased family around them when they of their families are close to death
- Do not make assumptions about the roles and relationships of family members (e.g. carer decision makers, advocate.) They may be complex cultural issues involved in who takes what role and when.
- Aboriginal people are generally not used to having non-Aboriginal visitors in their homes and may still have strong fears of outside visitors because of a long history of stolen children

Cultural Awareness

- All non – indigenous service providers should undertake cultural awareness training
- Please do not assume that you will understand 'Aboriginal culture' because you have had cultural awareness training – there are many variations across Victoria and Australia. Be aware that there is a different cultural reality to your own
- Seek development and inclusion of palliative care component or focus into existing cultural awareness training
- History plays an important role in how Aboriginal people perceive what happens in society today
- Aboriginal people have been traditional owners of this land long before European settlement of this country
- Aboriginal people are disadvantaged compared to the general population and this is the result of past and present injustices
- Aboriginal people believe their origins come from the dreamtime and creative ancestors. It was the time when patterns of life were established and lores were laid down

Relationships and continuity

- Build relationships with Aboriginal health workers / hospital liaison workers; this is important for cultural safety
- Where possible and appropriate make sure there is an Aboriginal community representative, liaison person or advocate present at the initial meetings. Wait until the client and family are comfortable before their presence is withdrawn. The Aboriginal community representative should be acceptable to the client and family and may be a family member.
- Allow sufficient and appropriate time for early meetings and be prepared to revisit, sometimes several times. Several shorter visits may be better than a longer visit
- Be prepared to re-schedule meetings or visits if family or community business is happening for the client and family

Consistency

- Be consistent with the team member who visits and limit the number of new faces, especially early in the relationship
- Introduce all the team members
- Remember that many faces can be confusing for the person and family members
- A good idea is to leave a phot behind so that the face becomes familiar to the person and family
- If someone new is visiting, forewarn the person or family

Trust

- Be aware you will have to earn and build the trust of an Aboriginal person and their family
- Explain to the person and the family who the team is and where they come from and what services will be provided
- Explain clearly what to expect and what not to expect from the services (remembering to be sensitive)
- Be clear and sensitive in helping the person and family understand the disease progression and ask if they would like to have an Aboriginal health worker of family member present when discussing this
- Ask about their expectations and hopes

Language

- Using plain language is important and just be yourself
- Use active listening skills
- Ask for feedback to check that the information has been understood by the person and/or family members
- Check the information given previously is understood
- If the person is very unwell and unstable, leave written information behind that enables the carer/family to remain informed
- Remember there is a lot of information to be taken in and it is likely to sound complicated
- If there is a language barrier, discuss this with the Aboriginal health worker or family member, including what resources can be provided to assist in helping the person to understand
- Provide copies of care plans or a letter clearly stating the expectation and agreements. The care/family can then share this information appropriately

Referrals and assessment

- When making a referral or receiving one ensure you ask about whether the person or their family is Aboriginal or Torres Strait Islander
- Inform the person/s of their options to have an Aboriginal community liaison representative and family members involved from the start
- Ask if an Aboriginal representative is already involved and seek permission to contact that person
- Be aware that the main carer, family / contact person, Aboriginal community representative and decision maker/s may be different people
- In making bereavement risk assessments, be aware of the likelihood of multiple losses
- Be prepared to revisit to get all the information required for an assessment

Service Coordination

Simplifying 'service coordination' for the client and family has been identified as a priority action.

There are often many services involved with supporting the Aboriginal person with a life limiting illness and many more that may be utilised / needed throughout the course of the illness. Having a way to capture all of these services succinctly is difficult. Case Management services may be involved and of course would then take the lead for communication and coordination. The GP is well placed also to ensure services communicate.

The SCTT template has the components of being able to record services that are involved with the client and therefore could be utilised to capture this information and therefore facilitate coordination and communication.

https://www2.health.vic.gov.au/Api/downloadmedia/%7B6ED6787C-300E-42F8-B143-A0163100A63F%7D

Advanced Care Planning – '50 +' Health Check

It is recognised that having an Advance Care Plan well in advance of any crisis situation can support the patient and family members during 'End of Life Care' and after the passing.
Mallee District Aboriginal Service is working to include Advanced Care Planning in the '50+ health check' to support Aboriginal people to make an Advanced Care Plan

Recommendations for future

1. Culturally safe Bereavement Support has been identified as a gap and might be a focus of future work
2. If and when demand for palliative care support for Aboriginal clients increases, consideration might be given to a 'joint appointment' of a Palliative Care Aboriginal Health Worker – between Sunraysia Community Health and Mallee District Aboriginal Service.
3.

If you have any questions regarding this pathway, please contact any of the following:

- **The Loddon Mallee Regional Palliative Care Consultancy Team: 03 5025 9028**
- **The Aboriginal Health Unit Mildura Base Hospital: 03 5018 8741**
- **Mallee District Aboriginal Service (Mildura): 03 5018 4141**
- **Ward 4 Mildura Base Hospital: 03 5022 3281**