Terminal phase and responsibilities after death

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Overview

- Differences of terminal phase
- Withdrawal of non essential treatment
- Appropriate pharmacological management in the last days
- What to consider after death – duties and responsibilities

Terminal phase

- terminal phase is not simply a continuation of what has happened before
- there are new challenges and causes of suffering for patients and their relatives
- plans/goals of care need to be changed to address this suffering
- first challenge is to recognise features of the terminal phase
- Help to prepare family/carers/staff for this phase and what is needed after death

Terminal phase

- the patient may become;
- weary, weak and sleepy
- less interested in getting out of bed or having visitors
- less connected with surroundings
- confused and may have agitation
- less interested in food or fluids
- gaunt from progressive weight loss
- unable to swallow

Terminal phase

- prognosis, though, remains notoriously difficult
- the patients' condition can oscillate
- sharing uncertainties is important – dying is an unstable and deteriorating process
- the most important things is to focus on the goals of care in line with the wishes of the patient and family

Is this person dying?

- Are there signs that this person may die within days?
- Five general signs predictive of death within 3 days;

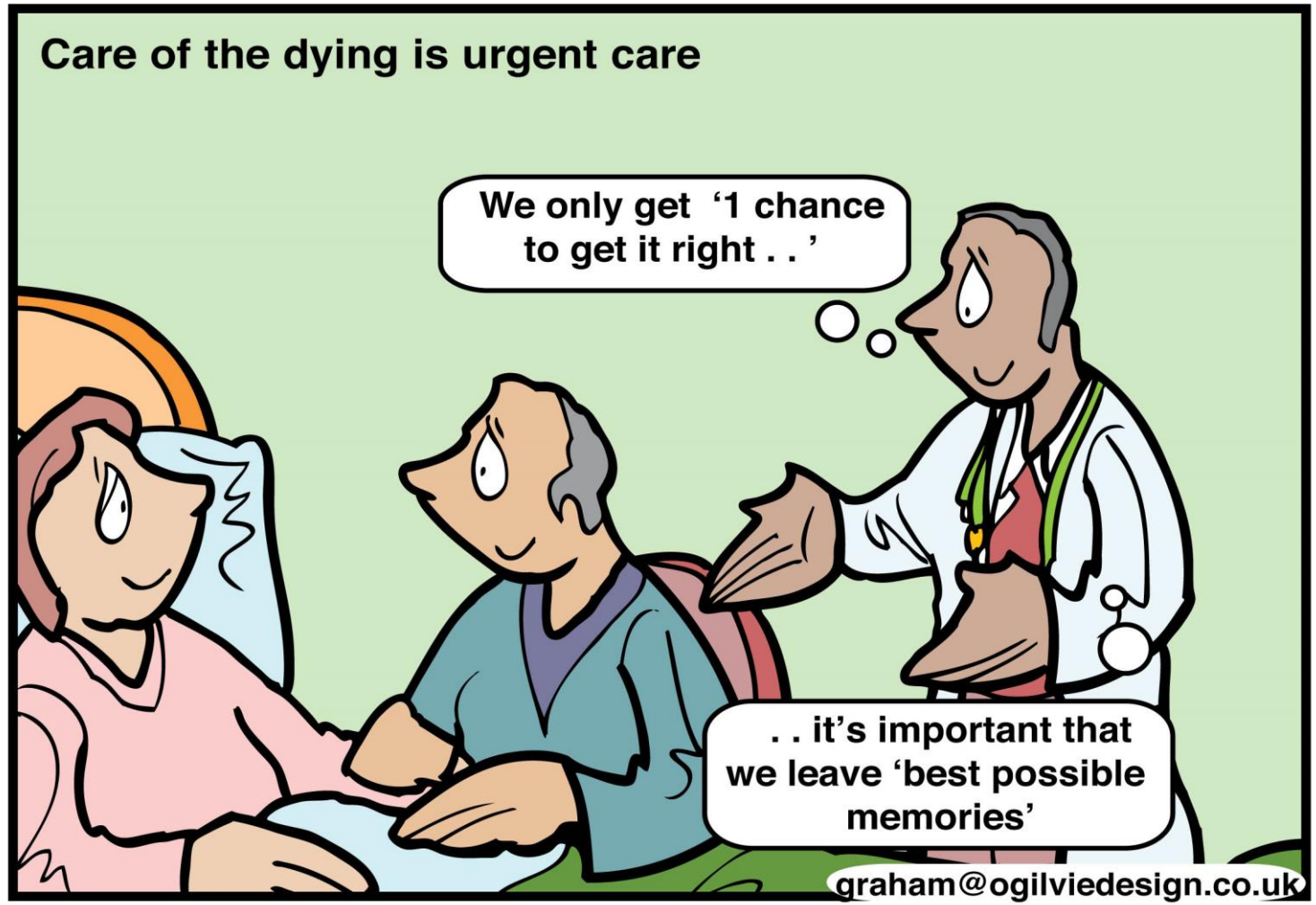
1. No radial artery pulse
2. Decreased urine output
3. Cheyne-Stokes breathing
4. Respiration with mandibular movement
5. not clearing airway secretions (so called ‘death rattle’)

- Three neurological signs predictive of death within 3 days; Decreased response to visual stimuli, Hyperextension of the neck, Drooping of nasolabial fold
- Four neurological signs predictive of death within 24hours; Non-reactive pupils, Decreased response to verbal stimuli, Grunting of vocal cords, Inability to close eyelids.

"Don't freak out—it's just a save-the-date."

Now what?

- Clarify patient and carer expectation
- Assess the situation at home or RACF
- Plan for symptom management – anticipatory prescribing
- Information for families and care staff


Care of the dying is urgent care
We only get ‘1 chance to get it right . . ’
. . it’s important that we leave ‘best possible memories’
graham@ogilviedesign.co.uk

Basics of care

- Dignity and privacy
- Sensitively address concerns
- Explore with person and their family whether they have an advanced care directive (hopefully this has already been done!)
- Encouraging family members to stay with the patient as much as they wish but with permission to take regular rests

Common symptoms at end of life

- Noisy breathing
- Pain
- Nausea and vomiting
- Agitation/delerium
- Anxiety
- Dyspnoea

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Prescribing Guidelines for the Pharmacological Management of Symptoms for Adults in the Last Days of Life

All patients at the end of life are entitled to treatment at optimising their comfort and dignity. The treating team – doctors, nurses and other clinicians - responsible for the care of a dying patient must work together with the patient and their nominated carers/family members to ensure that the patient receives appropriate, timely and adequate treatment to prevent and relieve distress. This will usually include the prescribing of medications for symptom management.

Anticipatory prescribing

There are several common symptoms that may cause distress in dying patients. Ordering medications ahead of time, 'anticipatory prescribing', is required so that prompt management of these symptoms can occur.

When to use these guidelines:

These guidelines outline recommended initial medications, doses and administration regimens for the management of common symptoms in the last days of life. The guidelines can be used:

- in response to a patient suffering from distressing symptoms, and/or
- in anticipation of distressing symptoms developing.

These guidelines have been developed for use in SA Health inpatient settings.

BEFORE WRITING UP MEDICATION ORDERS

- Discuss the need for medications to support symptom management with the patient and/or substitute decision maker(s). Record shared decisions made in the case notes.
- Review the patient's **current medications** and consider:
  - ceasing any non-beneficial or burdensome medications and continuing essential medications via the subcutaneous route where possible
  - the potential development of distressing withdrawal symptoms if specific medications are abruptly ceased (refer to *Medication Cessation for Adults in the Last Days of Life fact sheet*).
- Be aware that the medications and doses outlined in these guidelines may be inadequate if the patient is already prescribed analgesics (particularly moderate to high dose opioids), anxiolytics, anti-emetics or anticonvulsants.
- Check for **allergies** and for potential **contraindications, interactions or side effects**.

WHILE WRITING UP THE MEDICATION ORDERS

- Ensure that the **reason** for administering the medication is documented in the **'indication'** box of each medication, using terms consistent with those used in the table overleaf.

AFTER MEDICATION ORDERS ARE WRITTEN UP

- Ensure the patient is monitored and commence medications as soon as symptoms are identified
- Review treatment outcome for **effectiveness** and **side effects**
- Regularly review the management plan with the patient and/or substitute decision maker(s).
- Ensure **handover** to all medical and nursing staff involved in the care of the patient; for example, at shift changes, on transfer of the patient to another ward or facility, or on discharge of the patient.

URGENT CLINICAL REVIEW is required if:

- there is **inadequate relief** of a symptom despite three maximum doses administered in succession at the shortest specified time interval, or
- there is any clinical concern.

Further information about symptom management, prescribing or administering medications, or other related issues may be obtained from:

- [illegible]

Urgent phone advice can be obtained from Specialist Palliative Care Services: contact via the relevant hospital switchboard.

INDICATION	MEDICATION	DOSE	ROUTE	FREQUENCY	PRACTICE POINTS *Dosing should begin with the lower dose in any given range.*
Pain or Dyspnoea	*Morphine*	2.5mg to 5mg	Subcut	every hour as required	• Doses listed are for opioid naïve patients. • Where opioids are already prescribed, convert regular oral opioid dose to the appropriate 24hour subcutaneous dose and administer by a continuous subcutaneous infusion. • HYDROmorphone is approximately **FIVE** times more potent than morphine
	If the patient has a contraindication to morphine such as: • ***known or suspected renal impairment, or*** • ***an allergy to morphine*** ***then give either:***				
	Fentanyl	25microgram to 50 microgram	Subcut	every hour as required	
	OR				
	Hydromorphone	0.5mg to 1mg	Subcut	every hour as required	
Anxiety or Terminal Restlessness	*Clonazepam*	0.25mg to 0.5mg	Subcut	every 12 hours as required	• Clonazepam has a long duration of action and is prone to accumulate and lead to over sedation • Midazolam has a very rapid onset and short duration of action. It is preferred if amnesia and sedation are required. A subcutaneous infusion is required to achieve sustained effect.
	OR				
	Midazolam	2.5mg	Subcut	every hour as required	
Delirium or Agitation	*Haloperidol*	0.5mg to 1mg	Subcut	every 2 hours as required, to a maximum of 10mg per 24 hours	• Avoid haloperidol in Parkinson's Disease - olanzapine is preferred. • A benzodiazepine may be used in addition to an antipsychotic but should not be used alone.
Nausea	*Metoclopramide*	10mg	Subcut	every 4 hours as required, to a maximum of 30mg per 24 hours	• Metoclopramide is contraindicated in suspected bowel obstruction • Avoid using metoclopramide and haloperidol in Parkinson's Disease or if extrapyramidal side effects are distressing - ondansetron is preferred • Haloperidol is useful in patients with or at risk of concurrent delirium or agitation
	OR				
	Haloperidol	0.5mg to 1mg	Subcut	every 4 hours as required	
Gurgly / Noisy Breathing	*Hyoscine butylbromide*	20mg	Subcut	every 4 hours as required	• Start early and evaluate response. Cease therapy if ineffective after 3 consecutive doses

Required ward imprest list

Clonazepam 1mg/mL injection	Midazolam 5mg/mL injection or 15mg/3mL injection
Haloperidol 5mg/mL injection	Metoclopramide 10mg/2mL injection
Hyoscine butylbromide 20mg/mL injection	Morphine 10mg/mL injection
Fentanyl 100microgram/2mL injection **OR** Hydromorphone 2mg/mL injection	

For further information, refer to the *Clinical Guideline for the Pharmacological Management of Symptoms for Adults in the Last Days of Life*

Withdrawing medications

- Consider withdrawing oral medicines but be aware of possible rebound effects
- Antidepressants – agitation, headache
- Betablockers – rebound tachycardia, palpitations, angina
- Nitrates - angina
- Anticonvulsants - seizure
- *SA Health Fact Sheet on medication cessation*
- *Rebound effects can mostly be dealth with with either opioid or benzodiazepine or both*

Withdrawing medication – some examples

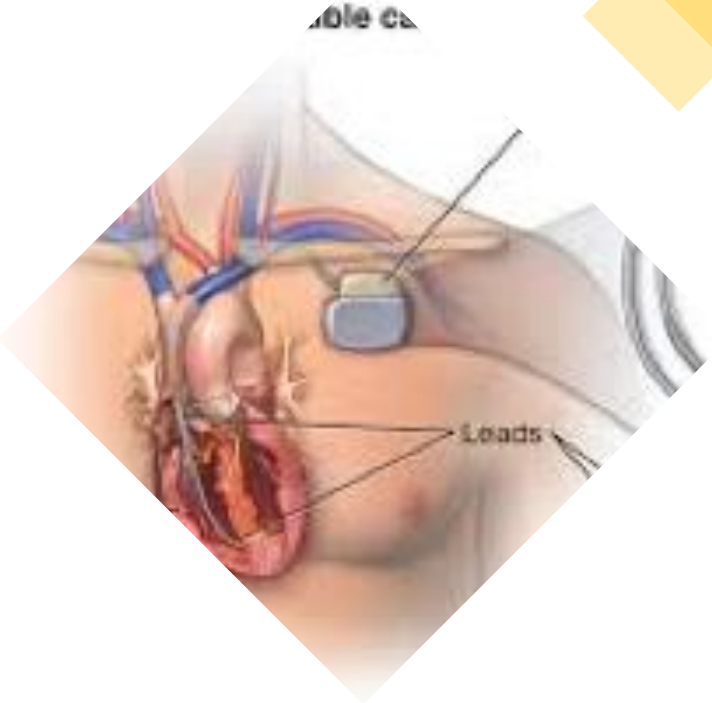
- Anticonvulsants - re-emergence of seizures benzodiazepines such as clonazepam or midazolam can be used SC , Keppra (leviteracetam) may be converted to CSCI
- Antidepressants - dysphoric mood, agitation, headache → treat symptomatically with opioid or benzodiazepine.
- Antipsychotics - dyskinesia, nausea, vomiting, agitation - convert to equivalent dose of regular parenteral antipsychotic. Seek specialist advice.
- Parkinsons – rotigotine patch, apomorphine SC, benzodiazepine may help relieve muscle rigidity (antiemetics least likely to exacerbate PD are domperidone, ondansetron and possibly levomepromazine) – ie this is a bit tricky so seek specialist advice

Diabetes

- A special case, acceptance of much higher glucose levels
- Type I – use once daily basal insulin at 50% of pre terminal dose, BSL daily, check for hypo
- Type II – cease oral hypoglycaemics, stop monitoring

ICDs

- Implantable cardioverter defibrillators (ICD) should be disabled
- If activated they may cause unnecessary distress and produce no benefit
- Try and anticipate this early
- Hopefully patient has details of device, if not contact cardiologist then relevant manufacturer



- A quick reminder
- Although it feels like you may be working with limited supports and need to rely on all your guile and street smarts there is help out there!!!!
- On call Pall Care Registrar, Consultant or Nurse from the specialist services
- Advanced care paramedics

After death

- Sensitivity to cultural and religious beliefs and requirements
- At the time of death and dying different cultures have different customs that loved ones and family may expect to follow
- If possible clinical staff should consult with the patient and family so that areas of significance and sensitivity can be recognised and addressed
- Funeral homes – lists available from afda.org.au (funeral directors association)

Declaration of life extinct

- Can help during ‘unsociable’ hours
- RNs who have been trained
- Extended care paramedics
- Obviously formal certification still needs to be completed
- However there is no rush – family can be reassured that they can stay with their loved one over night

Calvary

Health Care Adelaide

DECLARATION OF LIFE EXTINCT PALLIATIVE CARE

Unit Record Number _____

Family Name _____

Given Names _____

Address _____

_____

Date of Birth ☐☐☐☐☐☐☐☐ Age ☐

Sex ☐ Room No. _____ OR USE LABEL

Date of Death: __ __ / __ __ / __ __ __ __ Time of Death: _____ AM / PM

Assessment of Clinical Determinants to Verify Death

1. No palpable carotid pulse: ☐
2. No heart sound heard for 2 minutes: ☐
3. No breath sound heard for 2 minutes: ☐
4. Fixed (non-responsive to light) and dilated pupils: ☐
5. No response to centralised stimuli (e.g. trapezius muscle squeeze, supra-orbital pressure, mandibular pressure or the common sternal rub: ☐
6. No motor (withdrawal) response of facial grimace in response to painful stimulus (e.g. pinching inner aspect of elbow): ☐

Why death certificates?

- An important legal document
- Advice to births, deaths and marriages
- provides authority to funeral home to dispose of body
- Necessary for determination of settling estate etc
- ABS data/mortality statistics, patterns of disease

Why death certificates?

- So family members can understand cause of death – this is very important
- They will see what you write so be very clear about this when you talk to the them
- It may cause distress if they see multiple comorbidities that they weren't aware of or not advised of
- The spouse, parents, children and non-parental legal custodians/guardians (documentary evidence needed) have access to the death certificate.

Who can fill out the death certificate

- The medical practitioner who was responsible for the deceased's care during their last illness or immediately before death
- Or; who examined the body of the deceased person after death
- The doctor must be 'comfortably satisfied' as to the cause of death and there are NO circumstances which require reporting the death to the Coroner
- If the regular treating GP is away when the patient dies another GP from the practice can fill in the form ONLY if they have enough information to do so. It is preferable that they view the body. If they have any doubt they shouldn't complete the form.
- Medical Certification of Cause of Death should, at all times, be based on your BEST MEDICAL OPINION
- However there is some guidance available: Cause of Death Certification Australia, Aust Bureau of statistics, ausstats.abs.gov.au – a good overview of wording to use

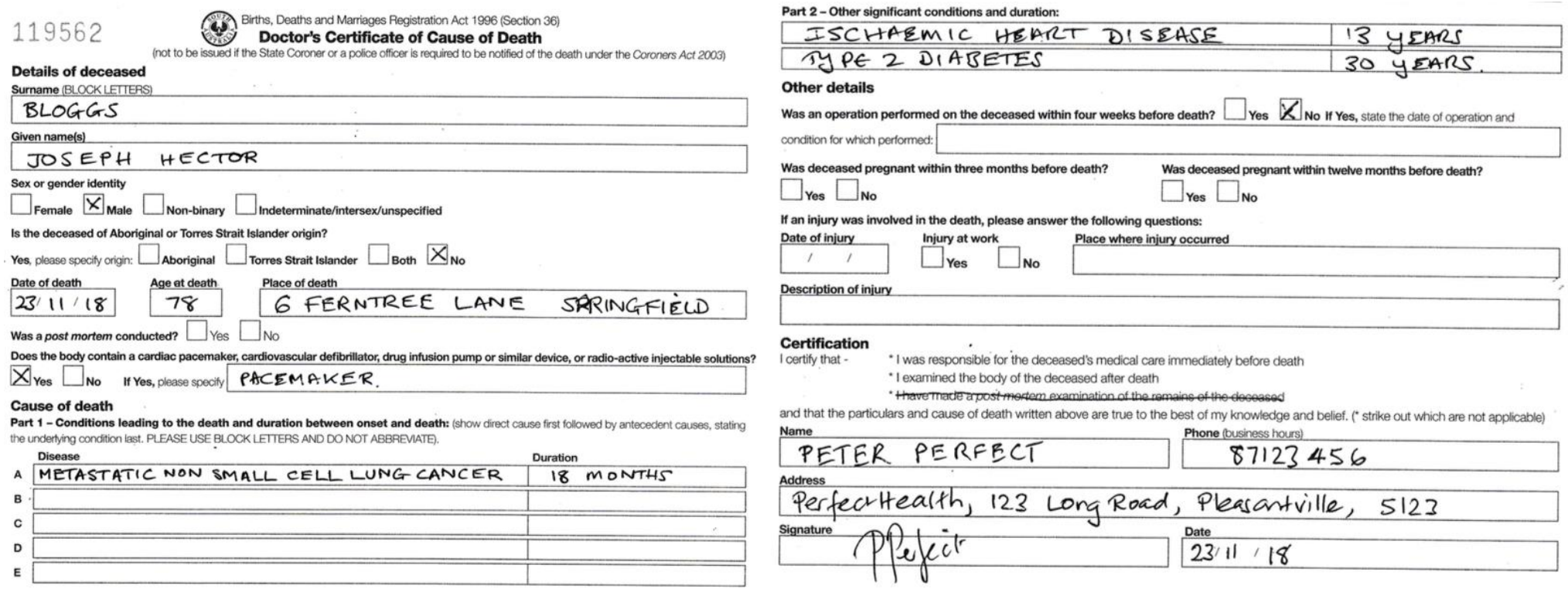
An example

78 year old married man Mr Joe Bloggs, not ATSI, diagnosed with metastatic (stage IV) non small cell lung cancer in May 2017

PHx of T2DM diagnosed over 30 years ago, IHD - STEMI 2005 with coronary artery stenting, AF, pacemaker, asthma, cholecystectomy, chronic low back pain. No recent surgery.

Failed response to immunotherapy and cytotoxic chemotherapy. Decision to proceed to palliative care in the home with you as the GP. He develops increasing shortness of breath, weakness and progression to terminal phase. End of life care in home. Dies peacefully at 6 Ferntree Lane, Springfield at 0700 on 23rd November 2018 and you visit at lunch to certify him.

The certificate



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Births, Deaths and Marriages Registration Act 1996 (Section 36)

Doctor's Certificate of Cause of Death

(not to be issued if the State Coroner or a police officer is required to be notified of the death under the *Coroners Act 2003*)

Details of deceased

Surname (BLOCK LETTERS)
BLOGGS

Given name(s)
JOSEPH HECTOR

Sex or gender identity
☐ Female ☒ Male ☐ Non-binary ☐ Indeterminate/intersex/unspecified

Is the deceased of Aboriginal or Torres Strait Islander origin?
Yes, please specify origin: ☐ Aboriginal ☐ Torres Strait Islander ☐ Both ☒ No

Date of death 23/11/18 **Age at death** 78 **Place of death** 6 FERNTREE LANE SPRINGFIELD

Was a *post mortem* conducted? ☐ Yes ☐ No

Does the body contain a cardiac pacemaker, cardiovascular defibrillator, drug infusion pump or similar device, or radio-active injectable solutions?
☒ Yes ☐ No **If Yes,** please specify PACEMAKER.

Cause of death

Part 1 – Conditions leading to the death and duration between onset and death: (show direct cause first followed by antecedent causes, stating the underlying condition last. PLEASE USE BLOCK LETTERS AND DO NOT ABBREVIATE).

	Disease	Duration
A	METASTATIC NON SMALL CELL LUNG CANCER	18 MONTHS
B		
C		
D		
E		

Part 2 – Other significant conditions and duration:

ISCHAEMIC HEART DISEASE	13 YEARS
TYPE 2 DIABETES	30 YEARS.

Other details

Was an operation performed on the deceased within four weeks before death? ☐ Yes ☒ No **If Yes,** state the date of operation and condition for which performed:

Was deceased pregnant within three months before death? ☐ Yes ☐ No

Was deceased pregnant within twelve months before death? ☐ Yes ☐ No

If an injury was involved in the death, please answer the following questions:

Date of injury / / **Injury at work** ☐ Yes ☐ No **Place where injury occurred**

Description of injury

Certification

I certify that -
* I was responsible for the deceased's medical care immediately before death
* I examined the body of the deceased after death
* ~~I have made a *post mortem* examination of the remains of the deceased~~

and that the particulars and cause of death written above are true to the best of my knowledge and belief. (* strike out which are not applicable)

Name PETER PERFECT **Phone** (business hours) 87123456

Address PerfectHealth, 123 Long Road, Pleasantville, 5123

Signature PPerfect **Date** 23/11/18

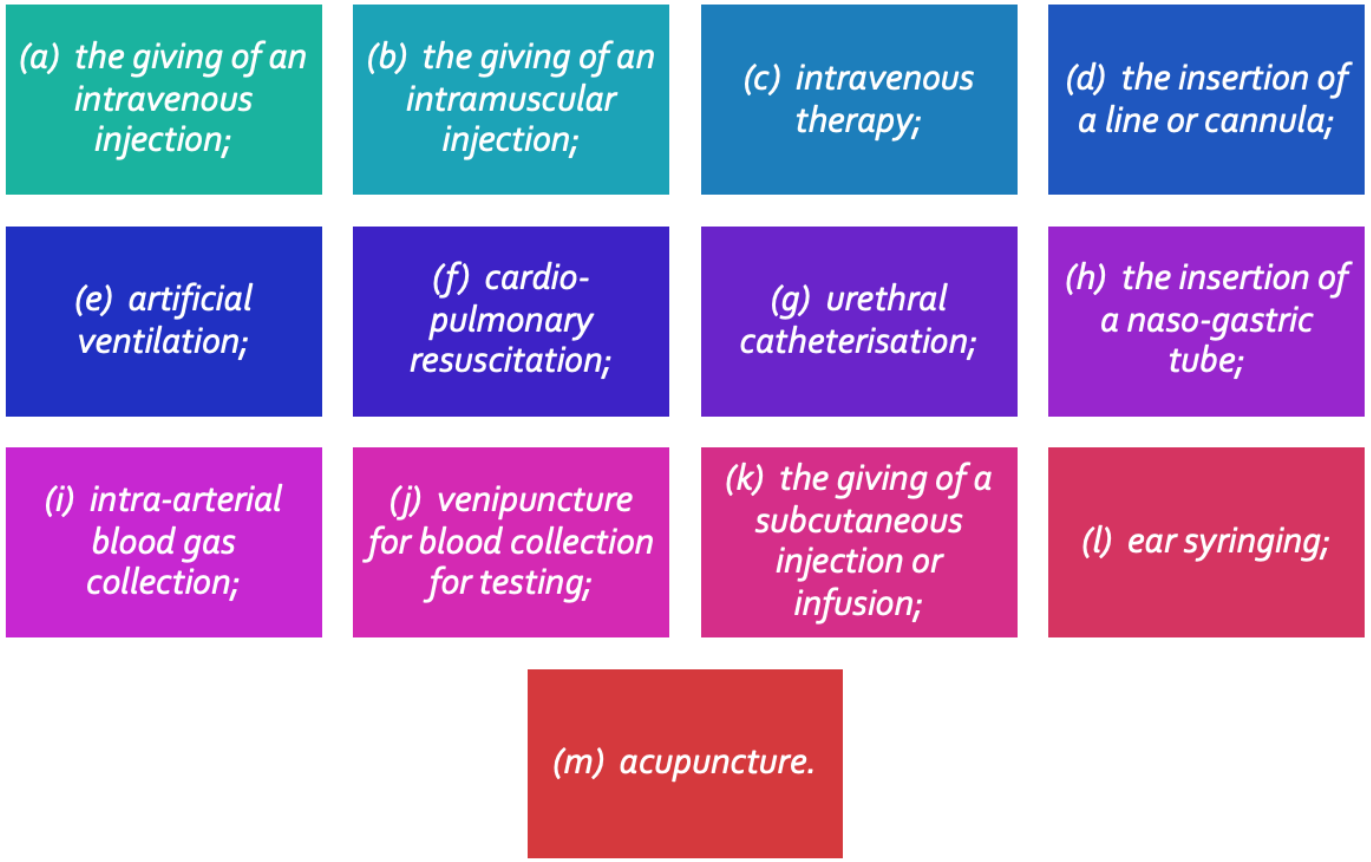
What to do with certificate

- The Doctor's Certificate of Cause of Death consists of three pages:
- **white copy** – (Notice of Death) deliver to the Registrar of Births, Deaths and Marriages, GPO Box 1351, Adelaide 5001 (Chesser House, 91-97 Grenfell Street, Adelaide 5000) **within 48 hours** of the death. Do not give this copy to the funeral director.
- **yellow copy** – give to the funeral director or person who is arranging burial or cremation. They are responsible for sending it to the Registrar with the Death Registration Statement.
- **Blue copy –** must be retained by the doctor.

When not to issue a death cert

- any violent or unnatural death
- sudden death of unknown cause
- death under suspicious or unusual circumstances
- if the deceased person was a child or person in care or custody
- where a doctor has been unable to sign a death certificate giving the cause of death
- where the identity of the person who has died is not known
- death while under, or as a result of, or within 24 hours of administration of anaesthetic
- death during a medical procedure (see next slide***)
- death following a medical procedure where the death was not the reasonably expected outcome of the procedure (24 hours).

Procedures excluded from reportable death



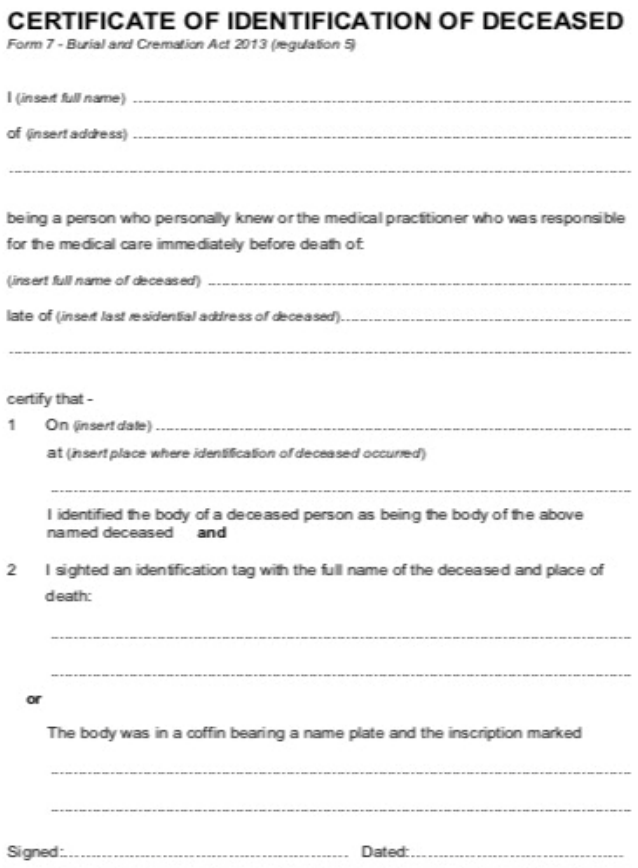
Burial and cremation forms

- Completed forms must be forwarded to the funeral director or the person arranging the cremation or burial.
- Form 3 – Death from natural causes – certificate of treating of the examining doctor – for cremation
  Form 4 – Death from natural causes – certificate of a second doctor for cremation
  Form 5 – Death from natural causes – certificate of the doctor conducting post-mortem (non-coronial)
  Form 6 – Partial certificate of cause of death – for burial
  Form 7 – Certificate of identification of deceased
  Form 8 – Certificate of doctor dispensing with identification of the deceased

- cbs.sa.gov.au

Form 7

- It is an offence to bury or cremate a body unless a certificate of identification has been sighted



CERTIFICATE OF IDENTIFICATION OF DECEASED

Form 7 - Burial and Cremation Act 2013 (regulation 5)

I (*insert full name*) .....

of (*insert address*) .....

.....

being a person who personally knew or the medical practitioner who was responsible for the medical care immediately before death of:

(*insert full name of deceased*) .....

late of (*insert last residential address of deceased*).....

.....

certify that -

1 On (*insert date*) .....

at (*insert place where identification of deceased occurred*)

.....

I identified the body of a deceased person as being the body of the above named deceased **and**

2 I sighted an identification tag with the full name of the deceased and place of death:

.....

.....

or

The body was in a coffin bearing a name plate and the inscription marked

.....

.....

Signed:..... Dated:.....

Useful resources

- Therapeutic guidelines Pall Care version 4
- Caresearch.com.au
- palliAGEDgp app developed by decision assist and available from the app store
- eviQ: Cancer Treatments Online has an opioid conversion calculator available online only, access is open and registration is free
- FPM/ANZCA opioid calculator app
- Your local specialist Pall care service
- https://www.cbs.sa.gov.au/assets/files/death_infosheet.pdf
- Sara Bird. How to complete a death certificate. A guide for GPs. AFP, 2011, 40:6; 446-449

Goodbye Everybody!