

6 April 2018



Ms A. Sanderson, MLA
Chair
Joint Select Committee on End of Life Choices
Parliament House
4 Harvest Terrace
WEST PERTH WA 6005

Dear Ms A. Sanderson,

Re: Questions on notice from public hearing

In reply to your request for further information related to Brightwater's appearance at the Joint Select Committee on End of Life Choices:

1. Where an individual chooses to stop eating or drinking and essentially passes away, what would be recorded on the death certificate?

To respond to this question we reviewed the three most recent death certificates of people living at Ellison House with Huntington's disease who had chosen to not have a Percutaneous endoscopic gastrostomy (PEG) inserted. The PEG would have enabled the individual to have an enteral feeding regime instituted when they were no longer able to meet their full nutritional requirements through oral food intake.

Each of these people had cause of death listed as "cardiopulmonary arrest" with antecedents for all three listed as "palliative". In addition, two of the three had an antecedent of "functional decline", with the third having an antecedent of "emaciation and undernourished (refused oral intake)". All three had Huntington's chorea listed as a significant condition.

2. Provision of the front page framework accompanying the Brightwater Care Group developed Advance Health Directive form and the Advance Health Directive form originally developed to support Mr Christian Rossiter.

Please find both of these documents attached to this response.

I hope that this response provides you with the information that you require. Should you require further information, I am happy to be contacted either by mail or phone on 0409 221 902.

Yours Sincerely,

Janet Wagland
General Manager, Community



Brightwater

ADVANCE CARE DIRECTIVE

LOCATION: _____

SURNAME:

URN:

GIVEN NAME:

DOB:

SEX:

DOA:

NOTE: Tick (✓) or Mark (x), the appropriate response under each section.

A. Cardiac and/or Respiratory Arrest – CPR (Cardiopulmonary Resuscitation)

Should I experience cardiac or respiratory arrest, I request the following guidelines be observed:

- ☐ CPR is to be conducted (basic life support started and the ambulance service called to provide advanced life support)

OR

- ☐ No CPR is to be conducted: (make no attempts to resuscitate me)

B. Medical / Surgical Care – Management of Infection

In the event of infection or suspected infection I request the following guidelines be observed:

- ☐ Medical / surgical treatment or intervention is not to be given

OR

- ☐ Medical / surgical treatment or intervention is to be given as detailed below:

- Being seen by a doctor on site or at another location
- Being prescribed antibiotics that can be administered at the facility where I live or at another location
- Being transferred to acute care hospital, where I may be evaluated including having blood tests and X-rays
- Being treated with intravenous antibiotics. I understand that I will be required to remain in hospital during this treatment

[Delete any of the above (•) which are not authorised]



Brightwater

ADVANCE CARE DIRECTIVE

LOCATION: _____

SURNAME:

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C. Medical / Surgical Care – Other Emergency Situations

If I am in need of emergency medical or surgical care in order to maintain my health or wellbeing, I request that the following guidelines be observed:

- ☐ No emergency medical / surgical treatment or intervention is to be given.

OR

- ☐ Emergency medical / surgical treatment or intervention is to be given as detailed below which I understand may include:

- A tracheostomy tube being inserted
- My existing tracheostomy tube replaced, if it becomes dislodged.
- Artificial ventilation to assist my breathing (this may include a tube being inserted in my throat and connected to a machine).
- Transfer and admission to a hospital (including its ICU) appropriate for my care needs.
- My existing feeding tube be replaced, if it becomes dislodged.
- A blood transfusion
- Renal dialysis

[Delete any of the above (•) which are not authorised]



Brightwater

ADVANCE CARE DIRECTIVE

LOCATION: _____

SURNAME:

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D. Food and Fluids

If I am unable to independently eat or drink by mouth, I request that:

☐

I not be given any food, nutrients or drink by any means

OR

☐

I be given food, nutrients and drink by artificial means, including

- Food via a tube including, but not restricted to, a nasogastric (nose or mouth) or gastrostomy (stomach) tube
- Drink via a tube
- Nutrients (water, salt, carbohydrate, protein and fat) by intravenous infusions

[Delete any of the above (•) which are not authorised]



Brightwater

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DOA:

E. Palliative Care – Comfort and Pain Relief

“Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual”.

World Health Organisation (<http://www.who.int/features/factfiles/palliative-care/en/>)

If I require palliative care, I request the following guidelines be observed:

- I remain at the facility where I live
- I be transferred to hospital
- I be kept comfortable and pain free
- I have an intravenous line started, if I need fluids
- I have an intravenous line started to deliver medication for pain, if I can't swallow or don't have a gastrostomy tube
- I be given medication to minimise pain and discomfort, e.g. Morphine
- I be given treatment to manage a deep vein thrombosis or pulmonary embolism

[Delete any of the above (•) which are not authorised]



Brightwater

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DOA:

F Other Procedures (Optional)

I agree to the following procedures after my death:

☐ Yes ☐ No Organ Donation

☐ Yes ☐ No Cremation

☐ Yes ☐ No Burial



Brightwater

ADVANCE CARE DIRECTIVE

LOCATION: _____

SURNAME:

URN:

GIVEN NAME:

DOB:

SEX:

DOA:

Dated

Name

Signature

Medical Practitioner

Name: _____

Address: _____

Contacts: _____

Signature: _____

Witnesses – Persons not directly involved in providing care

Witness 1

Name: _____

Address: _____

Contacts: _____

Signature: _____

Witness 2

Name: _____

Address: _____

Contacts: _____

Signature: _____



Brightwater

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Life-Prolonging Treatments

I have been advised that this advance care directive has been developed within the framework of contemporary standard medical practice. It enables me to state my wishes for my health and personal care, should the time ever come when I am not able to communicate or make decisions on account of incapacity, illness or injury. While I am able to decide for myself, I ask that I am consulted directly regarding my health and personal care.

I understand that I am able to change my preferences at any stage.

It is my overarching wish that I be provided with:

- ☐ All treatment necessary to keep me alive

OR

- ☐ Reasonable treatment, having regard to the guidelines detailed below, to keep me alive

OR

- ☐ Treatment that is aimed at maintaining my comfort, but not treatment that is aimed at prolonging my life

I request that regard be had to the following guidelines with respect to my health and personal care.