

# Palliative care preferences: Place of Death

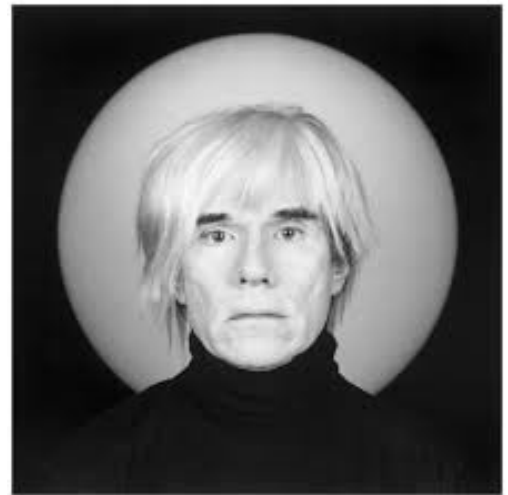
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Dying is the most embarrassing thing that can ever happen to you, because someone's got to take care of all your details. You'd like to help them, and most of all you'd like to do the whole thing yourself, but you're dead, so you can't.

**Andy Warhol**



# Introduction

Place of death (POD) is a palliative care concern

# **The importance of patient choice**

# Advance Care Directives

- South Australia & Northern Territory ratified 'Natural Death Act' 1980's
- In 1990-2000's a mechanism to promote adherence by the health care system to peoples wishes emerged
- Combination of ACD & Enduring Guardianship in NSW – 2005
- Capacity for ACD to be entered on to the electronic medical record - 2014

# **The importance of patient choice regarding place of death (POD)**

# POD

- Used as an outcome measure by palliative care services as a 'good death' measure
- Difficulties remain in attainment of ACD let alone POD decision

**What factors relate to people's  
POD preference**



# Associates of POD preference

- Timing of discussion around POD
- Skilled health professionals
- Role of carer
- Living alone

# **A good death**

# Components of a good death

- A bad death more easily recognisable
- Fundamental collective acknowledgement by all parties that the person is dying
- Providing culturally appropriate EOL care
- Better bereavement outcomes

# Conclusion

- Limited information about why POD is or isn't adhered to
- Dying is a whole of community issue not just a health issue

# **Aims of study**

- To establish the range of rationales for POD preference among a sample of Richmond Network NNSWLHD palliative care clients and their carers
- To establish commonalities in the experience of palliative care patients and their carers as it relates to POD preference
- To track the trajectory of each study subject and establish the barriers and enablers of their POD preference being achieved.



- To derive a theory or theories which explain preference in this very important area of palliative care practice.

# Method

# Method

## Study design

- Grounded theory
- Constant comparison of multiple data sources (interviews, re-interviews, researcher diary, PMR) were employed as the model(s) of preference took shape and emerged from the data (Charmaz, 2006).



# **Ethics Approval**

Ethics approval was received from NSW Health (North Coast NSW HREC) and SCU HREC

# Data collection

- With consent of participants, all data are collected by tape recorded interview.
- There are two points of interview-based data collection.
- Step 1: Interview with patient/principal carer at the time of admission to the service. This is conducted as part of/at the conclusion of the assessment. The goal of this interview is to establish preferences re POD and to explore the reasons behind this from both patient and carer points of view. Questions, fears and anxieties are explored at this time.
- Step 2: A 2nd tape recorded interview is conducted at a point close to the time of the patient's expected death. This interview is focused on how things have progressed in palliative terms, and whether preferences and /or imperatives have changed re POD preference, and if so, why.

# Sample

## *Inclusion Criteria:*

Newly referred patients (and their carers) to the Richmond Network palliative care service

## *Exclusion Criteria:*

- The patient is living alone and has no primary carer
- The patient and/or principal carer has insufficient English
- The patient is socially vulnerable/marginal (based on CNC assessment)
- The patient has significant cognitive impairment (based on CNC assessment)

# Data collection (contd)

- A field note diary of the researcher's observations and situational responses is kept in relation to each participant's death and dying journey.
- Information regarding patient/carer decision making in relation to advance care directives and enduring guardianship, along with ultimate place of death, is also recorded for each participant.

## Interview Protocol

- *Interview One* On admission (patient & carer)
  - 1. Have you thought about where you would like cared for in your last days of life?
  - 2. Why have you decided you would like to die – at home ? in hospital ?
  - 3. How does your family feel about your decision to die - at home ? in hospital ?
  - 4. Are there any particular types of treatments you do not want to have in your last days of life?
  - 5. How do you feel about the questions I'm asking you?
  - 6. Would you mind if for unexpected reasons your wishes couldn't be for filled?
  - 7. Who would you like to have with you when you die?

## Interview Protocol

- *Interview Two* (patient & carer)
- 1. Have you changed your mind about where you wanted to be cared for in the last days of life?
- 2. What were the reasons for you changing your mind? Or what were the things that made it possible for you to achieve your goal?
- 3. How does your family feel about your decision to die - at home ? in hospital ?
- 4. Are there any particular types of treatments you do not want to have in your last days of life?
- 5. How do you feel about the questions I'm asking you?
- 6. Would you mind if for unexpected reasons your wishes couldn't be for filled?
- 7. Who would you like to have with you when you die?

# Data Analysis

- All interviews are transcribed and textual data analysed for themes.
- Both open and axial coding are undertaken.
- The thematic analysis employed seeks commonalities in the experience and rationales of people who are going through the end of life process. Barriers and enablers to congruence between preference and actuality are specifically sought.

Progress so far

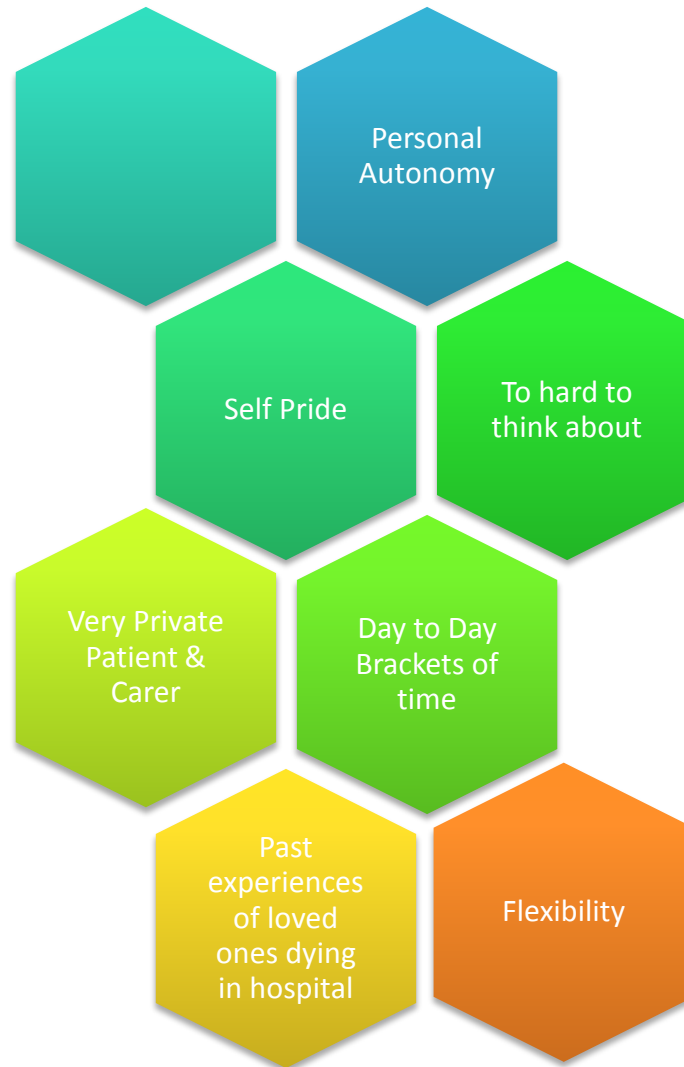


# Progress

- 10 participants have been interviewed on admission (step 1)
- 8 participants have been interviewed at a point close to death (step 2)
- The interview process has been therapeutic for multiple participants

# Results

# Drivers of choice in favour of home



“I guess it all centres on the comfort zone; I think I’ll live a whole lot longer if I stay here rather than go to hospital this is where my darling is and this is where I’m comfortable; if my darling doesn’t mind, this is the best place”

Positive and negative axes around  
place of death choice

Hospital

Home

Unpredictable  
nature of disease

Carer Strain

Privacy

Comfort Zone

Intimacy

# Positive Axes - Hospital

**Clinical  
necessity**

Symptoms  
uncontrolled

No carer

**Reduce  
burden on  
family**

Not wanting  
family to care

Family and  
patient difficult  
relationship

**Carer not  
capable**

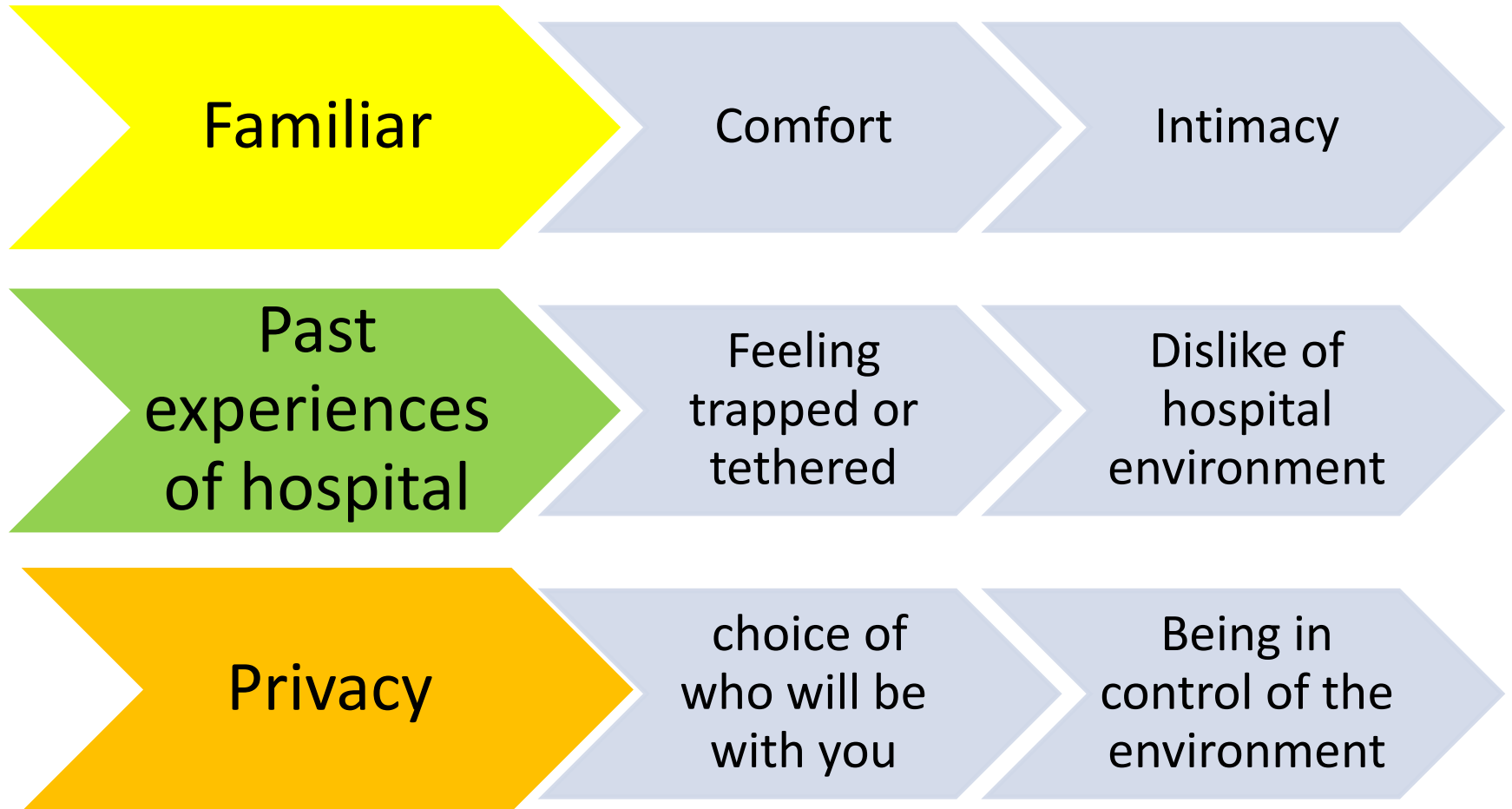
Elderly or very  
young carer

No other  
family support

“Yes, I have thought about POD for me it’s what is most comfortable for me and my family; rather than just thinking about me I know that sounds interesting but hospital might be the right place for me rather than being at home; due to my circumstances not having lots of family close by I can’t expect a teenager to give the kind of care necessary at the end of someone’s life”

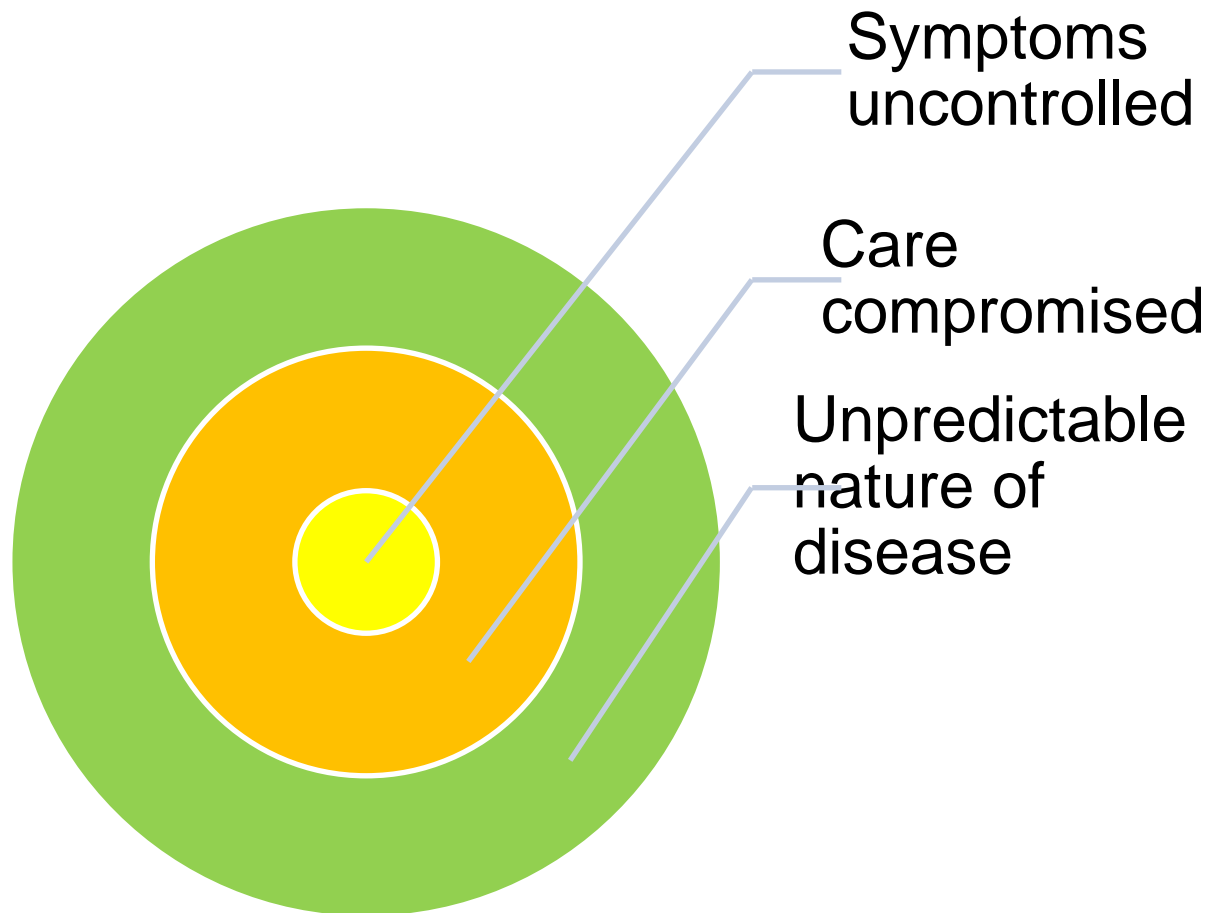


# Positive Axes - Home



- “But it’s what to expect, I don’t know what to expect some people just go to sleep don’t they, bathing may become more difficult , yeh that’s what happened with Dad yeh Yes I’d just rather stay here so the family don’t get stuck in hospitals its easier here especially with the kids”

# Hospital positives as a back up or plan B - for those who wish to die at home.



# Negative Axes - Hospital

Feelings of  
sterile  
environment

Unfamiliar

Strangers  
caring for you

Lack of  
privacy

Made to fit  
in with the  
system

Dehumanising

Constantly  
being told  
what to do

You are not  
you in  
hospitable

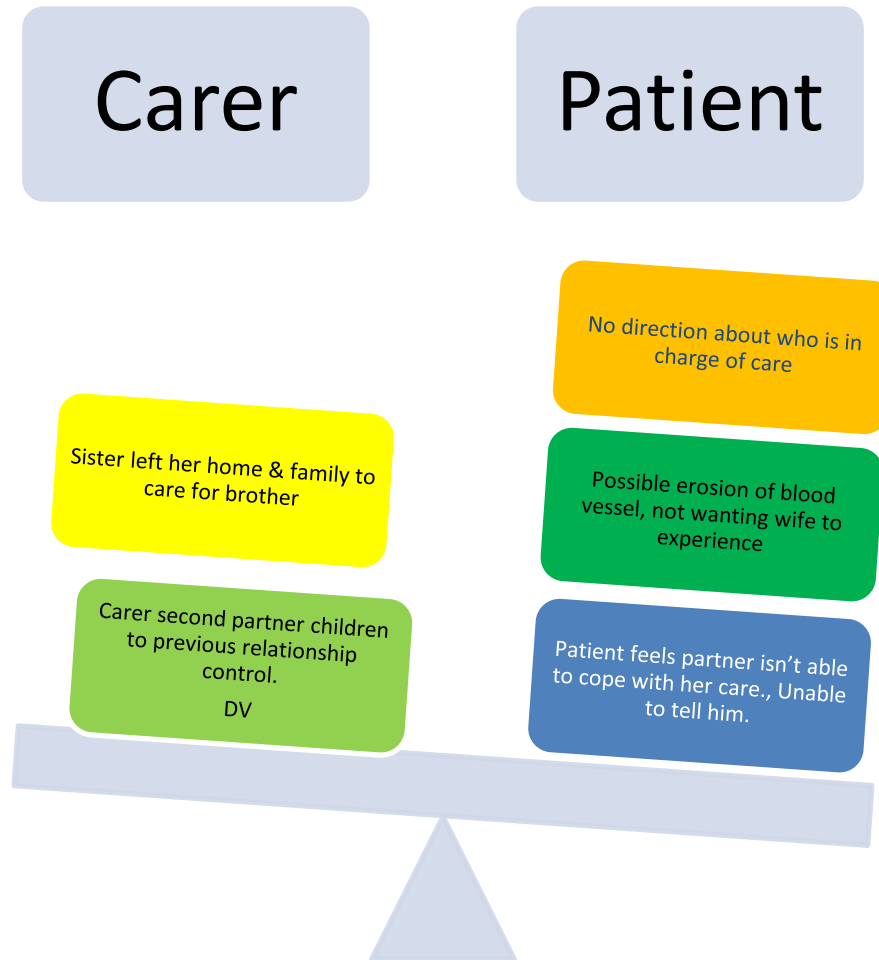
Being defined  
by your disease  
process

“Living with an illness you don’t have to let it define you, in hospital you can’t get away from it so it does tend to define you it’s not good for your head, any bodies head yours or mine”

“I just find hospitals depressing and I don’t think I’ve ever been in hospital where I’ve been too sick that it doesn’t worry me being there too much.

I’ve always had a negative or there’s always been a negative knock on, I don’t like going to them at all, there is a whole lot of things. Just going there just being there waiting, the whole lot of it is just waiting you can’t get up you don’t have the flexibility of just getting up and doing things, that you do at home”

# Complex family relationships



Family 1

Brother & Sister

Rented accommodation

- Children of Hungarian immigrants – Sister left her family in Sydney and travelled (over 800kms) to care for her brother in a remote community for his last 4 months of his life. So he could die at home.

(Issues she faced - financial burden, sister's children feeling neglected, a long distance from her support network).

Died at Home

## Family 2

Defacto couple

Rented Accommodation

- Immigrants (South African) – Husband second relationship - two daughters from a previous marriage.
- Although patient wanted to die at home, his daughter's drove the decision making process. They were in denial about their father's prognosis, daughters didn't live in the area or contribute to the care of their father.
- Carer – Felt powerless to achieve POD choice.  
DV – Carer reported after husband died.

Died in Hospital



## Family 3

### Elderly Couple

#### Rented accommodation

- Elderly couple, live in remote community.

Husband caring for wife, wife feels that husband can't think independently from her, and that he can't anticipate her needs if she can't direct him.

She feels she can only voice her opinion to me.

Other family members live hundreds of kms away, and have their own personal problems and elderly couple won't ask children for help.

Husband is in denial about his wife's prognosis,

Wife wanting to prepare for dying, husband blocking preparations.

Died in Hospital

Family 4

Mother & daughter

Rented accommodation

- Mother lives in a rural area, daughter is studying for HSC. Other family members live overseas.
- Mother and daughter having relationship difficulties, daughter spending more and more time away from home.

Died in Hospital

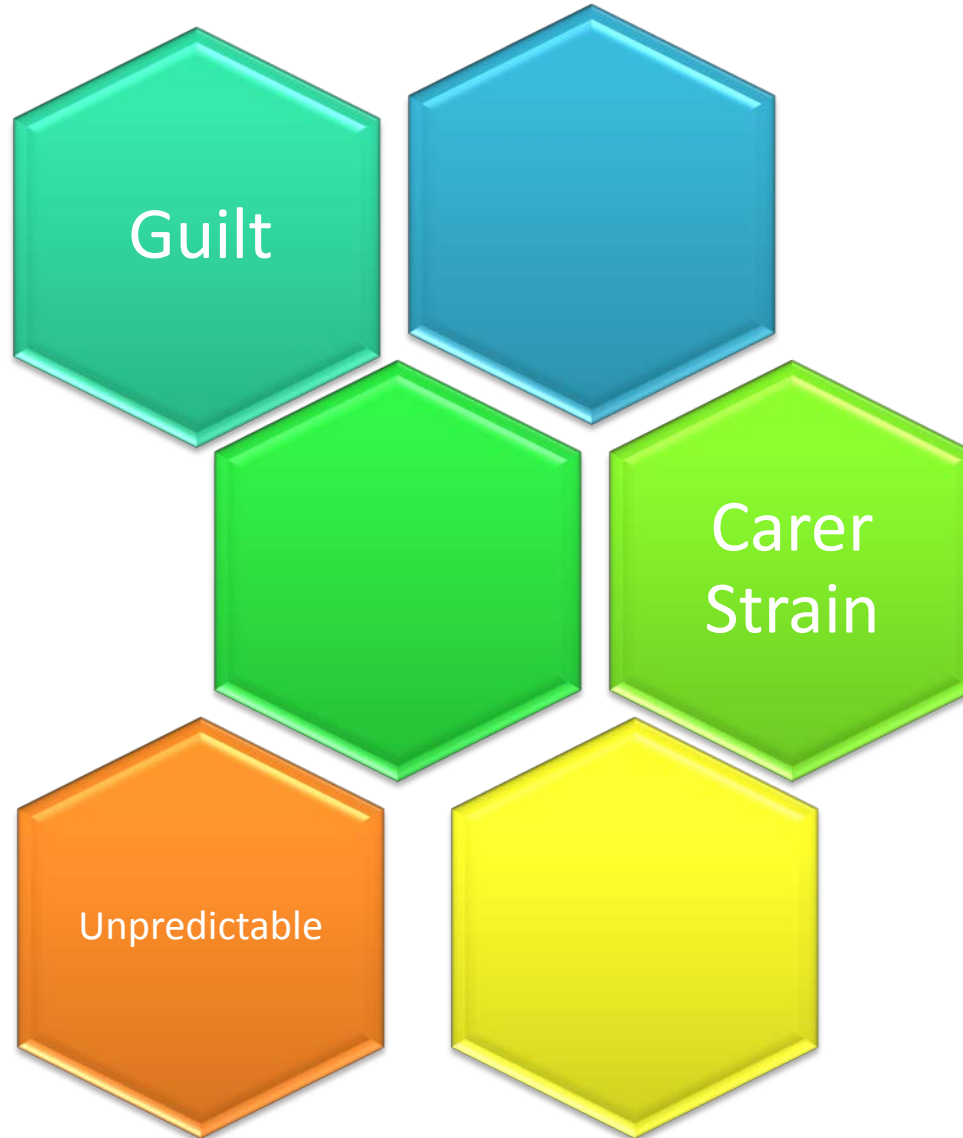
# Unexpected benefits of research for families

- Opportunities for further education and clarification. Able to support and explain which lead to feelings of greater security by carer and patient.
- Patients able to express reasoning behind decisions making process more deeply a with third party. Lead to a feeling of being less isolated, expressed by patient.

# Unexpected benefits

- Creating an occasion to discuss wishes at a forum were neither patient or carer has had to initiate, but both realise the need (safe).
- Being able to look at issues that may help or hinder being able to achieve POD choice.

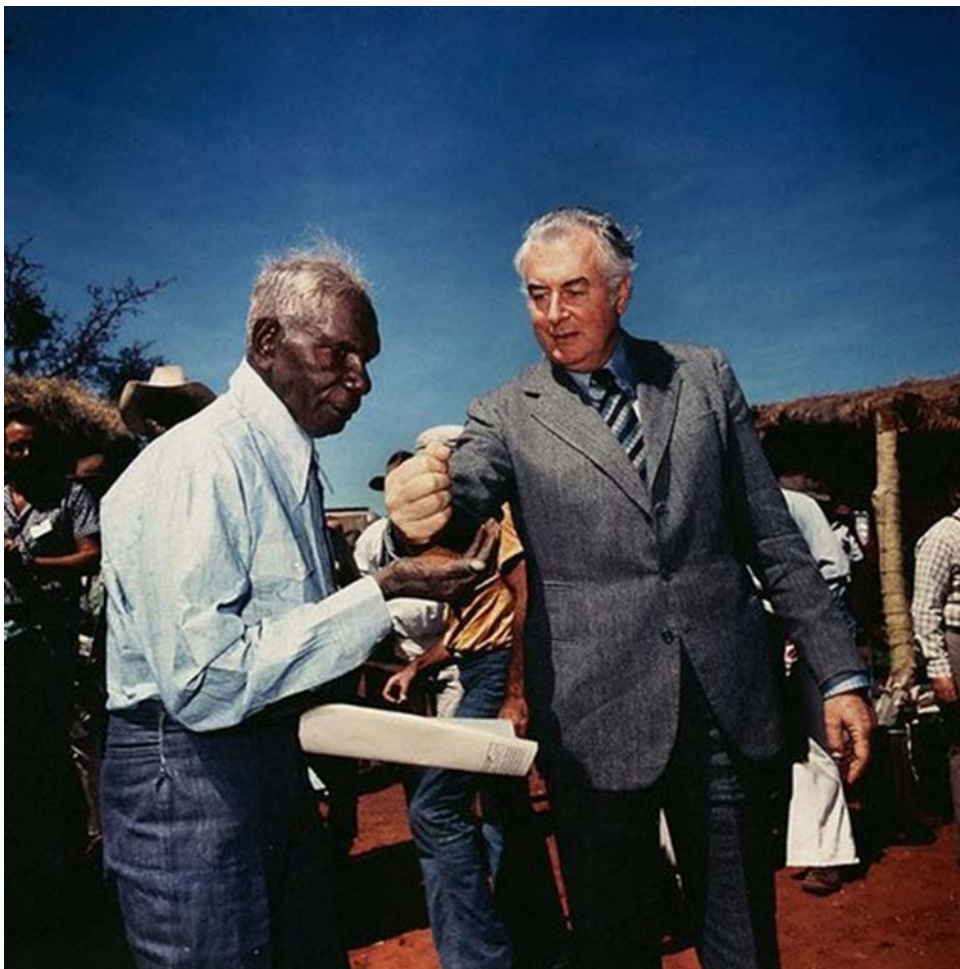
# Impact of choice for carer



“With all my reservations,” Gough Whitlam said on his 80<sup>th</sup> birthday, “I do admit I seem eternal.”

He warned, however: “Dying will happen sometime. As you know, I plan for the ages, not just for this life.”

“You can be sure of one thing,” he said of a possible meeting with his maker, “I shall meet him as an equal”



Prime Minister Gough Whitlam pours soil into the hand of  
Vincent Lingiari NT – 1975  
Photograph by Mervyn Bishop

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