

Goals of Care, Limitation of Treatment and Advance Care Directives

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Healthy Dying Initiative

Key objective is to make Tasmania a place where:

- Dying is recognised, acknowledged & supported by all parts of the community and its services
- Decision making at the end of life is oriented towards timely and appropriate provision of palliative care for those who need it

Healthy Dying

- Death is inevitable consequence of having life
- Dying days are as valuable as non-dying
- If cure, remission or restoration not possible, responsibility to provide palliation
- Care focussed on needs & wishes of patient
- Acknowledge relationships – impact of End of Life experience for bereaved

Attitudinal barriers to dealing with death – persistent myths

- You cannot initiate talk of death as patients and families do not want this and you run the risk of precipitating it if you do (“don’t talk about death, it will kill him”).
- You have to do everything to maintain and prolong life otherwise you are causing death (“you can never give up on a patient”).
- Use of opioids and sedatives in palliative care can contribute to the cause of death

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RHH focus on Goals of Care:

- Goals of Care Plan form
- Terminal Care Pathway

Community focus

- Advance Care Directive

Personal Perspective

What has happened to clinical leadership in futile care discussions?

Brendan F Murphy

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Treating clinicians need to make and own decisions about withholding futile treatment, instead of delegating them to patients' families who are usually ill equipped to do so

As a specialist physician for more than 20 years and, more recently, as a senior health manager, it has become apparent to me that staff at all levels across the hospital sector believe that they are actively treating a proportion of patients for whom such treatment is clearly futile. In providing this treatment, clinical leaders are on some level aware that they are doing a disservice to these patients, their families and the community, but seem ill equipped or unwilling to deal with the psychological, social and perceived legal challenges encountered in withholding futile treatment.



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Why Goals of Care?

- Patients who lack capacity often get more 'aggressive' care than those who can speak for themselves
- Relatives and doctors tend to choose more aggressive treatment for patients than they would for themselves



Why Goals of Care? (2)

- Discussion of treatment limitation decisions difficult
- Health Professionals are uncomfortable with withdrawal of treatment
- 'Persons Responsible' also struggle with end of life decisions
- It is often hard to find out what people want
- What people want may also be problematical (medical futility)



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Goals of Care Plan

Aims to ensure that patients who are unlikely to benefit from medical treatment aimed at cure, receive care appropriate to their condition, & are not subjected to burdensome treatments, (particularly cardiopulmonary resuscitation), especially where this is, or may be, contrary to their wishes



Goals of Care Plan

- Tool for discussing option of treatment limitations with patients and families
- REPLACES NFR ORDER FORM
- Clear documentation for decision-making
- Improve reach outside of hospital for Palliative and Terminal care



Goals of Care in Community Settings

- Palliative Goals – helps plan ahead for any foreseeable emergencies (eg fracture, UTI, pain and symptom management)
- Terminal Goals – ensure appropriate medications available when needed, and that family and staff understand death is imminent and hospital transfer undesirable

Goals of Care in community settings

- GP can extend the 'life' of the form (90 days from hospital discharge)
- May reduce number of people transferred to hospital when not wanted
- Keep the Goals of Care Plan form in a safe, accessible place for future reference

ACD history in Tasmania

- 1995 - Guardianship and Administration Act
- 2006 - Respecting Patient Choices Project
- 2006 - Clinical Ethics Committee of RHH
- 2009 - Clinical Network Working Party

ACDs in Tasmania

- ACDs have common law status in Tasmania & Australian case law confirming that they should be respected
- The underlying right is that of every competent adult to make decisions for themselves ('respect for autonomy')
- By extension, every competent adult can refuse medical treatment
- Legally, this is not regarded as suicide
- Similarly, the doctor who agrees to withdraw treatment is not assisting a suicide



Who can write an ACD?

- By person themselves (ie 'Person Concerned')
- Can be completed by an appropriate 'Person Responsible' on behalf of person who already lacks capacity
- Need to state:
 - who the ACD is for, and
 - who is filling it in
 - address
 - signature
 - relationship

What to include?

Focus on:

- Values, wishes & beliefs
- Acceptable outcomes rather than specific medical treatments
- End of life decisions
- AVOID AMBIGUITY
- Can include broader care issues
- Name preferred 'Person Responsible'



Person Responsible

Substitute Decision Maker named by the Person Concerned OR

Is an “approved” person under GA Act who is asked to give consent on behalf of Person Concerned.

1. an Enduring Guardian,
2. Spouse,
3. Unpaid carer,
4. Other person with best interests at heart



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Enduring Guardian

- Only those with capacity can appoint EG
- Legally appointed using GAB form
- Only valid once lodged with GAB
- Only used if/when Person Concerned lacks capacity
- **ONLY** for health and life-style decisions

Witnessing

An ACD should be witnessed by an independent adult who:

- has no relationship to Person Concerned or Person Responsible
- has nothing to gain from process
- believes person writing ACD knows what it is, what it means, and that person is not under duress to write ACD



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Role of GP, RACF etc

- Explain what possible events might happen
- Listen and advise on decisions
- Reassure regarding fears
- Support families and others in understanding ACD process and outcomes
- Witness an ACD

Aged Care & ACDs

- Over time, ACDs will be required by RACFs for all residents
- Clear wishes may prevent unnecessary transfers to hospital for dying residents
- Importance of having SDM nominated and **AVAILABLE**



Aged Care & ACDs (2)

- Important that ACD is understood by RACF staff and copy easily found
- GP needs to know ACD has been written, and is able to read it when making treatment decisions
- Clarity re ‘life-threatening illnesses” and symptom management and terminal care

Emergencies and ACDs

- Ambulance officers have duty to respond by CPR etc in emergency situations
- Hospital staff response to ACD – withdraw or withhold treatment as indicated in ACD and by EG/PR
- Keep ACD up to date
- Keep somewhere easy to remember/find



Take home messages

1. Support patients to discuss their wishes with family/carers and to complete an ACD
2. Ensure all documents about end of life care decisions are consistent with one another, clear and unambiguous



Further information

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