

Advance care planning and Advance Care Plans: pitfalls and progress

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Advance Care Planning: pitfalls and progress

- What is Advance Care Planning?
- Why might Advance Care Planning be beneficial?
- Barriers to Advance Care Planning
- Progress in Advance Care Planning
- Pitfalls in Advance Care Planning
- Recommendations and next steps
- Summary and conclusions



What is Advance Care Planning?

- A process of discussion
 - Individual, parent or guardian
 - Care provider e.g. medical social worker, nurse, doctor
 - May or may not include other family or friends
- Thinking ahead
 - Open questions
 - What is important to child and family?
 - What is important for the future?



What is an Advance Care Plan?

- Advisory document to guide care of the child
- Transferable across care settings, alerts for ambulance and Emergency Department
- Describes child's medical condition and care needs
- Should reduce the need for parents to tell and retell their story
- Cardiopulmonary Resuscitation discussed as part of the process



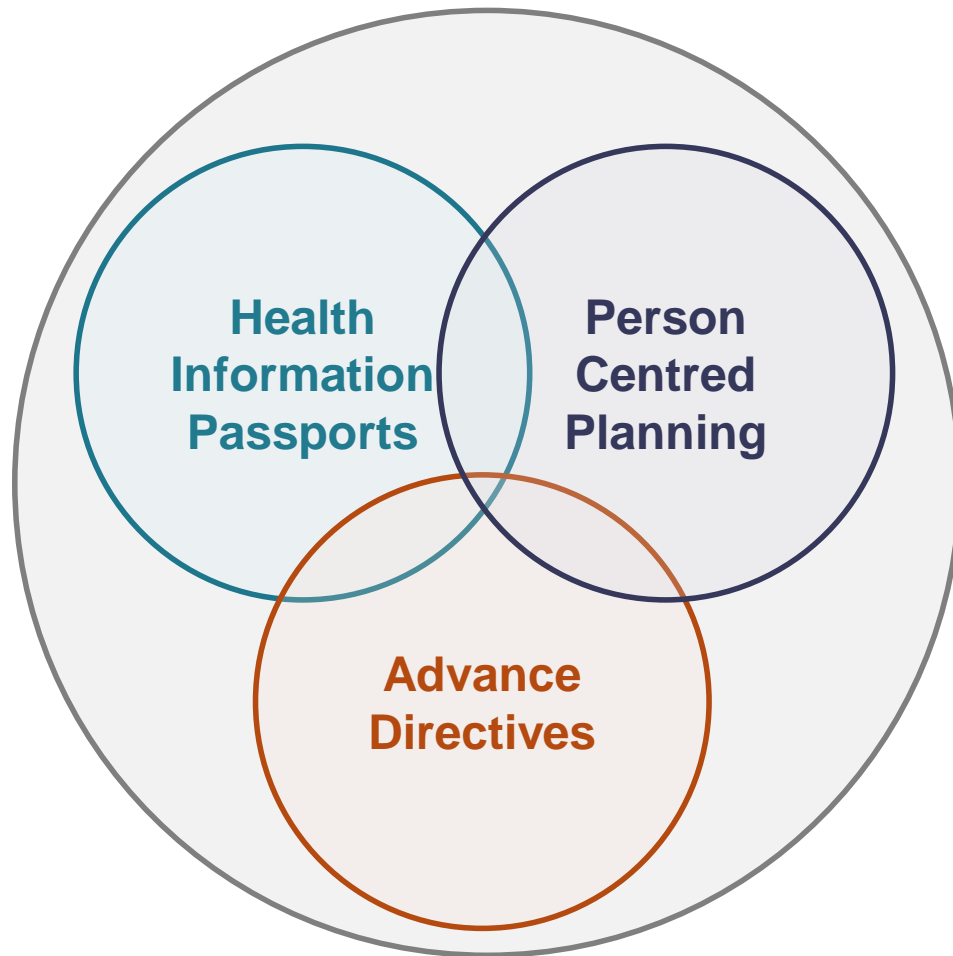
Why might Advance Care Planning be helpful?

What evidence is there?

- Reduces the number of times families have to tell and retell their story ✕
- Improves professionals confidence when caring for patients at end of life ✕
- Facilitates discussion about end of life choices
- Facilitates shared decision making
- Alignment of aims of treatment
- Optimum use of resources
- Cost effectiveness



Evidence for Advance Care Planning



Advanced communication skills

- Different outcome measures based on different models and concepts
 - Advance Directive
 - Facilitated reflection and communication, completion of documentation, fundamental changes to the provision and culture of healthcare
- Potential impact of
 - Timing of discussions
 - Wording and communication



Does advance care documentation engage healthcare professionals in end-of-life discussions?

- Systematic review: 24 eligible articles from 10 countries including 23,914 subjects
- Mostly qualitative or mixed methods studies
- Advance care planning documentation influences attitudes, beliefs and personal experience
- Little evidence for documentation as a trigger for discussion
- Health professionals reported positive perceptions of the use of advance care documentations (18/24 studies)
- Little evidence for benefits of accessing previously formulated wishes in Advance Care Plan documentation

Lewis E et al. *Palliat Med.* 2016 Mar 7.
[Epub ahead of print]



Family-centred Advance Care Planning for teens with cancer.

- Randomized controlled trial in paediatric oncology (USA)
- Thirty adolescents aged 14 to 21 years (mean 16 years) with cancer and their parents or surrogates
- Intervention
 - Lyon Family-Centred Advance Care Planning survey
 - Respecting Choices Interview
 - Five Wishes
- Significantly increased congruence for intervention compared with controls for 4 of the 6 disease-specific scenarios
- 100% intervention adolescents wanted their families to do what is best at the time versus 62% controls
- Intervention adolescents significantly better informed about end-of-life decisions
- Intervention families more likely to concur on limiting treatments than controls.



Impact of involvement in end of life decision making

- Qualitative analysis of interviews with surrogates approximately 4 weeks after a patient's death
- Participating in decision making allowed surrogates to
 - Regain control
 - Counteract feelings of helplessness
 - Reduce their empathic suffering.



Nunez ER et al Crit Care
Med. 2015 43(11) 2387-93



Tools to promote shared decision making in serious illness

- Systematic review
- Six randomised controlled trials tested four different Advance Care Planning tools, including:
 - A short video
 - A low-health-literacy print tool
 - A workbook
 - A website
- All but one tool improved patient knowledge
- Two tools had an effect on clinical decisions

Austin CA JAMA Intern Med. 2015; 175(7): 1213–1221



Estimating the effect of palliative care interventions and Advance Care Planning on ICU utilization



- Systematic review
- Nine randomised controlled trials and 13 controlled trials identified. All adult studies.
- 37% (SD, 23%) reduction in the relative risk of ICU admission for patients at high risk of death (3 papers)
- 26% (SD, 23%) relative reduction in length of stay in ICU with palliative care interventions



Does Advance Care Planning reduce costs of care near end of life?

- Systematic review
- 7 studies: 4 randomised controlled trials, 1 before and after design, 2 observational studies
- All studies only involved adult patients
- 6 studies found reductions in costs of care (£722 – £44,990 per patient depending on study period and cost measurement)
- Ethical concerns regarding reduction in costs of care as a driver to Advance Care Planning

Klinger C et al Palliat Med 2016: 30(5): 423-33



U.S. News News

Is the 'Death Panel' Debate Dead?

There's far less commotion about a proposed Medicare rule regarding end-of-life care than six years ago, but opponents are still out there.

By [Kimberly Leonard](#) | Staff Writer



Some remain skeptical of a proposal that would reimburse doctors for discussing end-of-life medical care with patients. GETTY IMAGES

Barriers to Advance Care Planning

- Patient
- Parent or surrogate
- Professionals
- Awareness
- Attitudes, religious and cultural barriers
- Skills, literacy and language



Barriers to Advance Care Planning at the end of life

- Systematic review of Advance Care Planning implementation studies
- 13 papers identified from 166 abstracts
- Implementation was facilitated by
 - Staff training
 - Structured approach to Advance Care Planning interactions
- Barriers to implementation included
 - Competing demands of other work
 - Emotional and interactional nature of patient-professional interactions around Advance Care Planning
 - Problems in sharing decisions and preferences within and between healthcare organizations



Paediatric advance directives: parents' knowledge, experience and preferences

- Prospective, cross-sectional survey of parents and caregivers of children with chronic illness (USA)
- 307 participants surveyed
 - 117 (38.1%) were aware of advance directive
 - 54 (17.6%) had discussed an advance directive
 - 77 (25.1%) had known someone who had an advance directive
 - 151 (49.2%) participants expressed an interest in an advance directive
 - Significantly more likely if frequent Emergency Department visits over the previous year



Advance Care Planning in Paediatric Intensive Care

- Qualitative one-to-one, semi-structured interviews
- Eight Paediatric Intensive Care Unit consultants and six senior nurses
- Four main themes
 - Recognition of an illness as 'life-limiting';
 - Advance Care Planning as a multi-disciplinary, structured process
 - The value of Advance Care Planning
 - Adverse consequences of inadequate Advance Care Planning.
- Barriers to timely Advance Care Planning
 - Failure to recognise an illness as life limiting
 - Lack of medical consensus
- Recommendations for
 - Education and training
 - Awareness raising amongst patients, parents and professionals
 - Societal debate



Barriers to Advance Care Planning for Children

- Survey of 107 physicians, 159 nurses (54% response rate) working in environments where paediatric Advance Care Planning typically takes place
- The top 3 barriers were:
 - Unrealistic parent expectations
 - Differences between clinician and patient/parent understanding of prognosis
 - Lack of parent readiness to have the discussion.
- Nurses more frequently identified lack of importance to clinicians ($P = .006$) and ethical considerations ($P < 0.001$)
- Physicians more frequently cited not knowing the right thing to say ($P = .006$)
- 71% of all clinicians believed that Advance Care Planning happened too late



Parent and clinician perspectives of paediatric advance directives

- Survey of 96 professionals in the USA
 - 72% physicians
 - 28% nurse practitioners.
- Professionals felt able to lead discussions about limiting therapies “most “ or “all of the time”
- 75% of physicians 37% of nurse practitioners led such a discussion
- in the prior year.
- >80% clinicians agreed limitation discussions were warranted only when children were predicted to die within 30 days (Spectrum of Palliative Care Needs – Red)
- 100% of parent focus group participants, but 17% of physicians and 33% of nurse practitioners, thought that all paediatric inpatients warranted Medical Orders for Life-Sustaining Treatment discussions.
- Medical Orders for Life-Sustaining Treatment communication skills training was recommended by all.



Progress in Advance Care Planning

- Increased awareness
 - 100% increase in publications
 - Media coverage
- Standardised documentation
- Electronic alerts
- Education and training





Standardized documentation

Anytown Hospital **NHS**
NHS Foundation Trust

ALLERGIES

Name		Date:	
Address			Post code:
Hospital No.		NHS No.	

 Child and Young Person's Advance Care Plan Collaborative



Collaborators: Alder Hey Children's Hospital, Dorset County Hospital, Gloucestershire Hospitals NHS Foundation Trust, Helen & Douglas House Hospices, Kent & Medway C&YP Palliative Care Network, Naomi House & Jacksplace, North Hampshire NHS Trust, North West Children's Palliative Care Network, Oxford University Hospitals NHS Trust, Poole Hospital, Portsmouth Hospitals NHS Trust, Royal Berkshire NHS Foundation Trust, Royal Manchester Children's Hospital, Solent NHS Trust, Southampton Children's Hospital, St Mary's Hospital Isle of Wight, Together for Short Lives, West Midlands Paediatric Palliative Care Network

- Increased standardization across UK
 - CYPACP (South Central)
 - Deciding Right
 - CYPADM
- Range of formats
 - Paper
 - Electronic
 - Web based e.g. Coordinate My Care



Standardised documentation

Recommended Summary Plan for Emergency Care and Treatment for:

1. Your details

Full name	Date of birth	Date completed
NHSCCHI number	Address	

2. Summary of relevant information for your chosen plan

Including diagnosis, communication needs (e.g. interpreter, communication aid) and reasons for the preferences and recommendations recorded.

Details of your other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan, paediatric care plans. Also include known wishes about organ donation)

3. Your personal preferences to guide your care and treatment plan

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Priorities prolonging life, even at the expense of comfort	Priorities comfort, even at the expense of prolonging life
--	--

Considering the above priorities, what is most important to you is: (optional)

4. In view of the above, clinical guidance for treatment options

Focus on life-sustaining treatments...	or	Focus on comfort treatments...
clinician signature		clinician signature

Please provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate in community, hospital and critical care settings:

For attempted CPR Adult and child	For modified CPR Child only. Refer to summary above.	Not for attempted CPR Adult and child
clinician signature	clinician signature	clinician signature

- ReSPECT: Recommended Summary Plan for Emergency Care & Treatment.
(Emergency Care and Treatment Plan)
- Response to multiple different Advance Care Plan/ Health Information Passport formats across the UK
- Single document for adults and children
- Signposts to other documents
- Paper format



Advance care planning alerts

- Hand held copy held by parents
- Individual patient records
 - GP
 - Hospice
 - Hospital
 - Ambulance Service
- Multiple systems
- Time-consuming to set up
- Poor levels of responsiveness if circumstances change



Advance care planning training and implementation

- Connected Advanced Communication Skills Training
- Northwest Children's Advance Care Planning Training and implementation programme:
 - Introductory session at each paediatric centre
 - Identify medical and nursing leads
 - Advance Care Planning training day (identified leads)
 - Local Policy Implementation
 - Develop local Standard Operating Procedure
 - Awareness-raising training for all staff who are taught advanced paediatric life support (e-learning)
 - Incident and near miss reporting
 - Ongoing monitoring and continuous quality improvement



Pitfalls in Advance Care Planning

- Advance Care Planning for everyone?
- Whose plan is it? Is the child really at the centre?
- Insufficient resources
 - For all children with life limiting conditions to have Advance Care Plans
 - To deliver requested care e.g. end of life care at home
- How many plans are actually used in an emergency
 - Do families remember to show them?
 - Do professionals recognise them?
 - Do professionals understand the difference between Advance Care Plans and other end of life care alerts?
 - Can professionals navigate and interpret them?



Standardized documentation doesn't always mean information is clear

Regardless of the patient's resuscitation status, the following immediately reversible causes should be treated: **choking, anaphylaxis, blocked tracheostomy tube, other** (please state):

RESUSCITATION STATUS

Resuscitation status has not been discussed – attempt full resuscitation

Resuscitation status has been discussed and the following has been agreed:

* DNR PLAN AS OF 26-1-12 *

Clearly DELETE actions NOT required

15 MINS of CHEST COMPRESSION + BMV *

For full resuscitation	Attempt resuscitation with modifications below:	Do not attempt cardiopulmonary resuscitation DNACPR
<p>Attempt resuscitation as per standard RC(UK) guidelines</p> <p><i>Handwritten notes:</i> m. have to complete plan for bag mask use & conduct updated review managed base 24/11/10 Only oxygen and suction, no bag mask or cardiac compression 23/11/10 managed base Neurology Reg.</p>	<p>Patient-specific modifications to standard resuscitation guidelines</p> <p><i>Handwritten notes:</i> AIRWAY: Bag & Mask Oxygen for 15 min BREATHING: 20% O2 CIRCULATION: - Cardiac Compression for 15 min DRUGS: → NIL (Not for IV resus medications) OTHER: PICU/HDU: → No PICU admission</p>	<p>Patient-specific supportive care is documented on pages 3 and 4</p> <p>In the event of sudden death 24 hour emergency number for doctor who knows the child:-</p>

- A nurse tried to refer professionals to Iftab's Resuscitation Plan
- Professionals had no choice other than to provide resuscitation



What next?

- Awareness raising
 - Professionals
 - Patients and families
- Offer Advance Care Planning discussions as standard for all children with life limiting conditions
- Formal implementation and monitoring
 - Standardised documentation
 - Professional training
- Evaluation
 - Simulation to explore how it Advance Care Plans work in practice
 - Inter-organisational incident and near miss reporting
- Research
 - Complex intervention
 - Randomised controlled trials

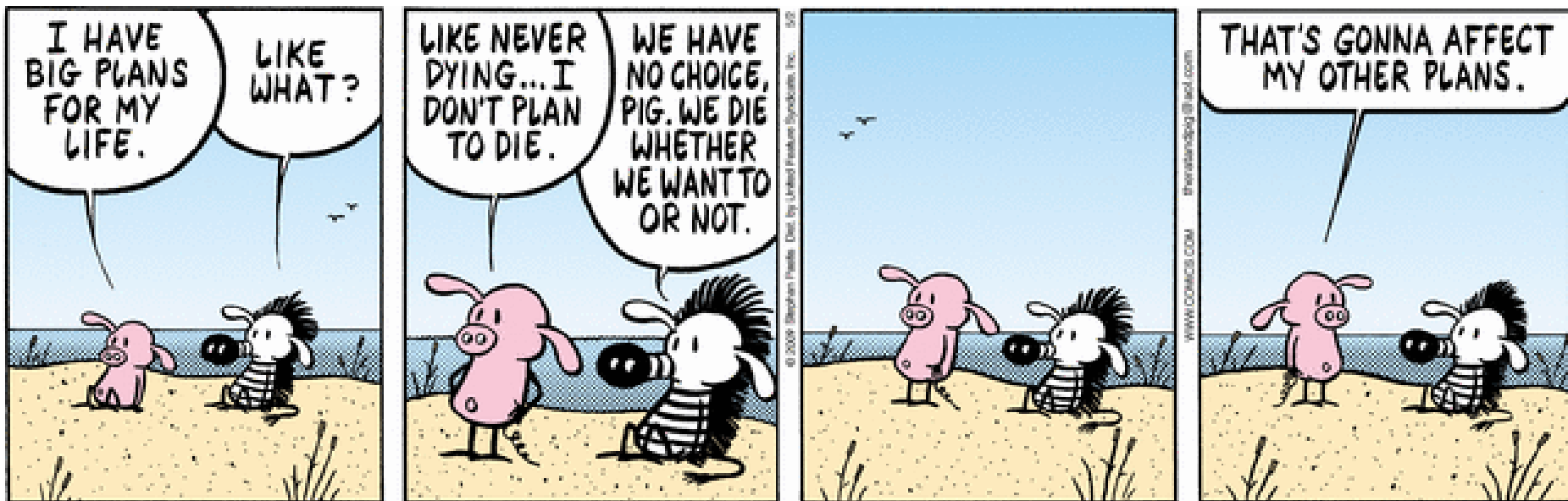


Summary and conclusions

- Advance Care Planning appears to offer significant benefits to patients and their families
- Advance Care Planning appears to facilitate discussion about end of life choices and shared decision making
- Advance Care Planning may be cost effective but the primary driver for implementation of Advance Care Planning must not cost improvement
- The presence of an Advance Care Plan, even with appropriate alerts does not necessarily mean that it can, or will be followed



Any questions?



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