TRANSITION POINTS FOR CARE IN PATIENTS WITH ADVANCED DISEASES

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NEED FOR PALLIATIVE CARE WHO ALTAS

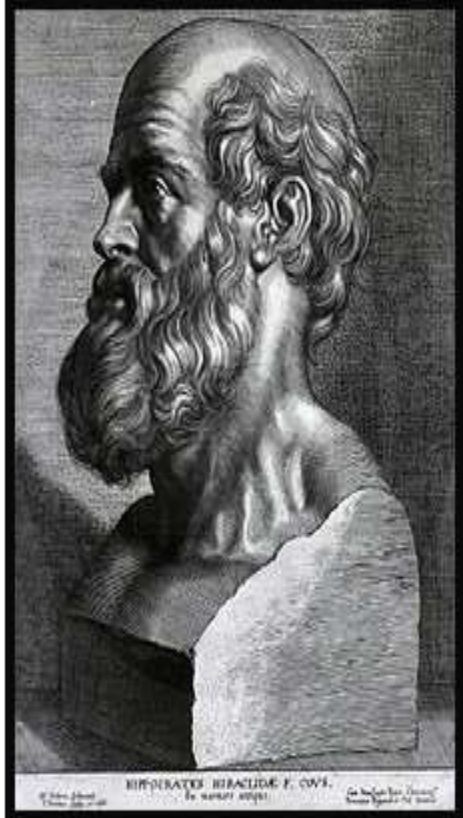
GLOBAL

- 20 million patients need Palliative Care
- Equal number of families
- 69% are over 60 years of age
- 6% are children.
- About 78% of adults in need of palliative care at the end of life live in low and middle-income countries.

INDIA

- 3 million patients with cancer at any point of time.
- 3 million cardiac, respiratory, neurological
- 5.1 million with HIV/AIDS
- Children with HIV, Thalessemia, Neurological, Sickle cell etc
- Aged population with morbidities

ROLE OF A PHYSICIAN

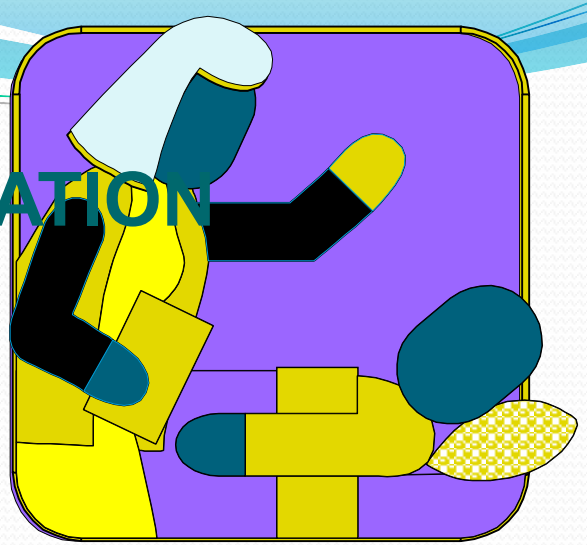


Cure sometimes, treat often, comfort always.

(Hippocrates)

izquotes.com

THE WORLD HEALTH ORGANIZATION (WHO) DEFINES PALLIATIVE CARE AS:



Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

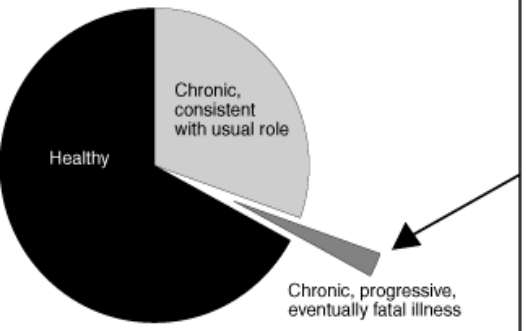
GOALS OF PALLIATIVE CARE

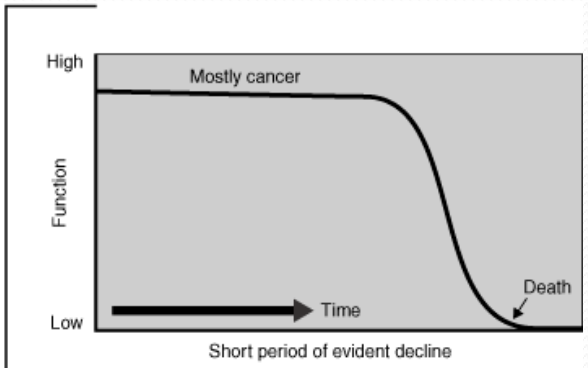
- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;

Cont.

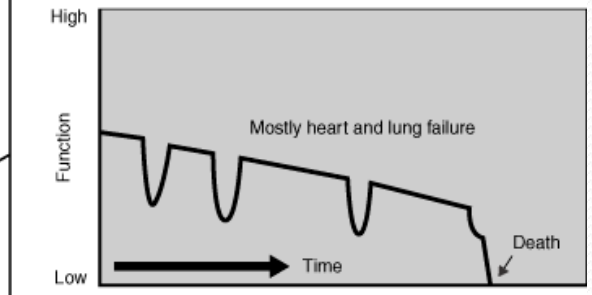
- **Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;**
- **Will enhance quality of life, and may also positively influence the course of illness;**
- **Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.**

TRAJECTORY OF ILLNESSES

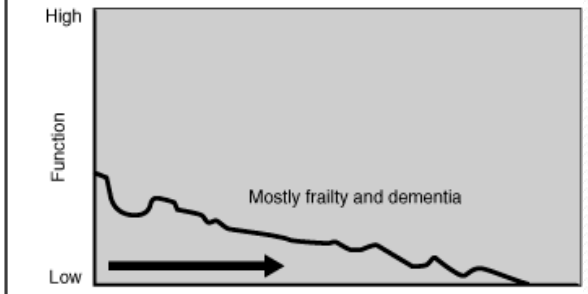




Short period of evident decline



Long-term limitations with intermittent serious episodes



Prolonged dwindling

Living Well at the End of Life

Adapting Health Care to Serious Chronic Illness in Old Age

Joanne Lynn, David M. Adamson

Rand Health White Paper WP-137 (2003)

CANCER

SUMMARY RECOMMENDATIONS

- Advanced cancer can take many trajectories; understanding the trajectory of illness is key to understanding the goal of anticancer treatment.
- Performance status can help guide treatment decisions, as well as provide important information about prognosis.
- Treatment of symptoms (physical, social, psychological, and spiritual) is important when treating advanced disease.
- An integrated palliative care and oncology approach is best practice to provide quality care that is in line with patient-centric goals and values.

NON-CANCER

COMMON SYMPTOMS IN PATIENTS WITH ADVANCED CONGESTIVE HEART FAILURE

- Shortness of breath
- Fatigue
- Lower extremity swelling
- Decreased mobility
- Cough
- Dry mouth
- Pain, noncardiac and cardiac
- Difficulty sleeping
- Anxiety
- Depressed mood
- Decreased sexual interest
- Cachexia
- Confusion

MANIFESTATIONS OF ADVANCED DEMENTIA

Neurocognitive

Progressive worsening of memory and other cognitive deficits
Confusion and disorientation become profound
Behavioral changes: agitation, combativeness, resistance to care, apathy
Progressive deterioration of speech, ability to communicate; patient eventually becomes incoherent, mute, unresponsive

Functional

Independent mobility progressively lost; patient becomes bed-bound
Capacity for self-care and performance of independent activities of daily living progressively lost; patient becomes totally dependent

Nutritional

Progressive loss of appetite
ogressive loss of capacity to swallow; ability to eat independently almost invariably declines
spiration increasingly becomes a risk

Complications

owel and bladder incontinence
vers and infections (e.g., pneumonia, urinary tract infections, sepsis)
ecubitus ulcers
eight loss and malnutrition

Adapted from Shuster JL. Palliative care for advanced dementia. *Clin Geriatr Med* 2000;16:373–386, with permission.

1. Symptom management and personal care
2. Preparation for the end of life
3. Achieving a sense of completion in patients' lives
4. Treatment preferences
5. Treating the patient as a whole person
6. Relationship between patients and professionals

Indications of a Good Death in Chronic life limiting Conditions incl Renal Failure

RADBOUD INDICATORS FOR PALLIATIVE CARE NEEDS (RADPAC)

Congestive heart failure

- The patient has severe limitations, experiences symptoms even while at rest; mostly bedbound patients (NYHA[a] IV)
- There are frequent hospital admissions (>3 per year)
- The patient has frequent exacerbations of severe heart failure (>3 per year)
- The patient is moderately disabled; dependent; requires considerable assistance and frequent care (Karnofsky score ≤50%)
- The patient's weight increases and fails to respond to increased dose of diuretics
- A general deterioration of the clinical situation (oedema, orthopnoea, nocturia, dyspnoea)
- The patient mentions 'end-of-life approaching'

Chronic obstructive pulmonary disease

- The patient is moderately disabled; dependent; requires considerable assistance and frequent care (Karnofsky score ≤50%)
- The patient has substantial weight loss (±10% loss of body weight in 6 months)
- The presence of congestive heart failure
- The patient has orthopnoea
- The patient mentions 'end of life approaching'
- There are objective signs of serious dyspnoea (shortness of breath, dyspnoea with speaking, use of respiratory assistant muscles and orthopnoea)

Cancer

- Patient has a primary tumour with a poor prognosis
- Patient is moderately disabled; dependent; requires considerable assistance and frequent care (Karnofsky score ≤50%)
- There is a progressive decline in physical functioning
- The patient is progressively bedridden
- The patient has a diminished food intake
- The presence of progressive weight loss
- The presence of the anorexia-cachexia syndrome (lack of appetite, general weakness, emaciating, muscular atrophy)
- The patient has a diminished 'drive to live'

Ref: Thoonsen B, Engels Y, van Rijswijk E, Verhagen S, van Weel C, Groot M, et al.
Early identification of palliative care patients in general practice: development of RADboud indicators for PAlliative Care Needs (RADPAC).
Br J Gen Practice. 2012 Sep;62(602):e625-31.

PROGNOSTIC INDICES

Gold Standards Framework, Prognostic Indicator Guidance (PIG)

The 'surprise question': For patients with advanced disease of progressive life-limiting conditions - Would you be surprised if the patient were to die in the next few months, weeks, days?

The answer to this question should be an intuitive one, pulling together a range of clinical, co-morbidity, social and other factors that give a whole picture of deterioration. If you would not be surprised, then what measures might be taken to improve the patient's quality of life now and in preparation for possible further decline?

GOLD STANDARDS FRAMEWORK, NHS

Thomas K. Prognostic Indicator Guidance (PIG). 4th ed. The Gold Standards Framework Centre in End of Life Care. 2011 Oct [cited 2014 Sep 29]. (642kb pdf)

PALLIATIVE PROGNOSTIC INDEX

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days (a)	(b)	(c)
100	Full	Normal *No Disease*	Full	Normal	Full	N/A	N/A	108
90	Full	Normal *Some Disease*	Full	Normal	Full			
80	Full	Normal with Effort *Some Disease*	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work *Some Disease*	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework *Significant Disease*	Occasional Assistance Needed	As above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work *Extensive Disease*	Considerable Assistance Needed	As above	Full or Confusion	30	11	41
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	As above	Total Care	Reduced	As above	8	5	
20	Bed Bound	As above	As above	Minimal	As above	4	2	6
10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma	1	1	
0	Death	-	-	-	--			

(a) Survival post-admission to an inpatient palliative unit, all diagnoses (Virik 2002).
(b) Days until inpatient death following admission to an acute hospice unit, diagnoses not specified (Anderson 1996).
(c) Survival post admission to an inpatient palliative unit, cancer patients only (Morita 1999).

Anderson F, Downing GM, Hill J. Palliative Performance Scale (PPS): a new tool. J Palliat Care. 1996; 12(1): 5-11.

Morita T, Tsunoda J, Inoue S, et al. Validity of the Palliative Performance Scale from a survival perspective. J Pain Symp Manage. 1999; 18(1):2-3.

Virik K, Glare P. Validation of the Palliative Performance Scale for inpatients admitted to a palliative care unit in Sydney, Australia. J Pain Symp Manage. 2002; 23(6):455-7.

Myers J, Kim A, Flanagan J. Palliative performance scale and survival among outpatients with advanced cancer. Supportive Care in Cancer 2015; 23.4: 913-918.

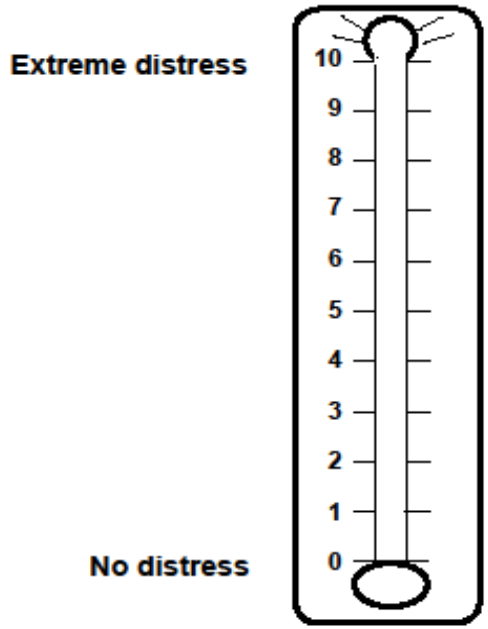
HOLISTIC ASSESSMENT- DISTRESS THERMOMETER

National Comprehensive Cancer Network®

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.



PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.

Be sure to check YES or NO for each.

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions
		Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues
		Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities
❑	❑	**Spiritual/religious concerns**

YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Substance abuse
❑	❑	Tingling in hands/feet

Other Problems: _____

_____

COMMUNICATING AT TRANSITIONS

Communication About Diagnosis: Giving Bad News

Recommendations

Find a comfortable and private place to talk
Ask whether the patient would like to have others present
Minimize interruptions
Assess the patient's understanding of the situation
Let the patient know explicitly that bad news is forthcoming
Provide information honestly and in simple language
Give time for questions
Encourage patient to express emotions and respond empathically
Check understanding
Arrange a clear follow-up plan

Communication About Cancer Near the End of Life. Anthony L. Back, Wendy G. Anderson, Lynn Bunch, Lisa A. Marr, James A. Wallace, Holly B. Yang , Robert M. Arnold,
Cancer Volume 113, Issue Supplement 7, 2008

Table 3. Content-Based Codes for Transitions to Palliative Care

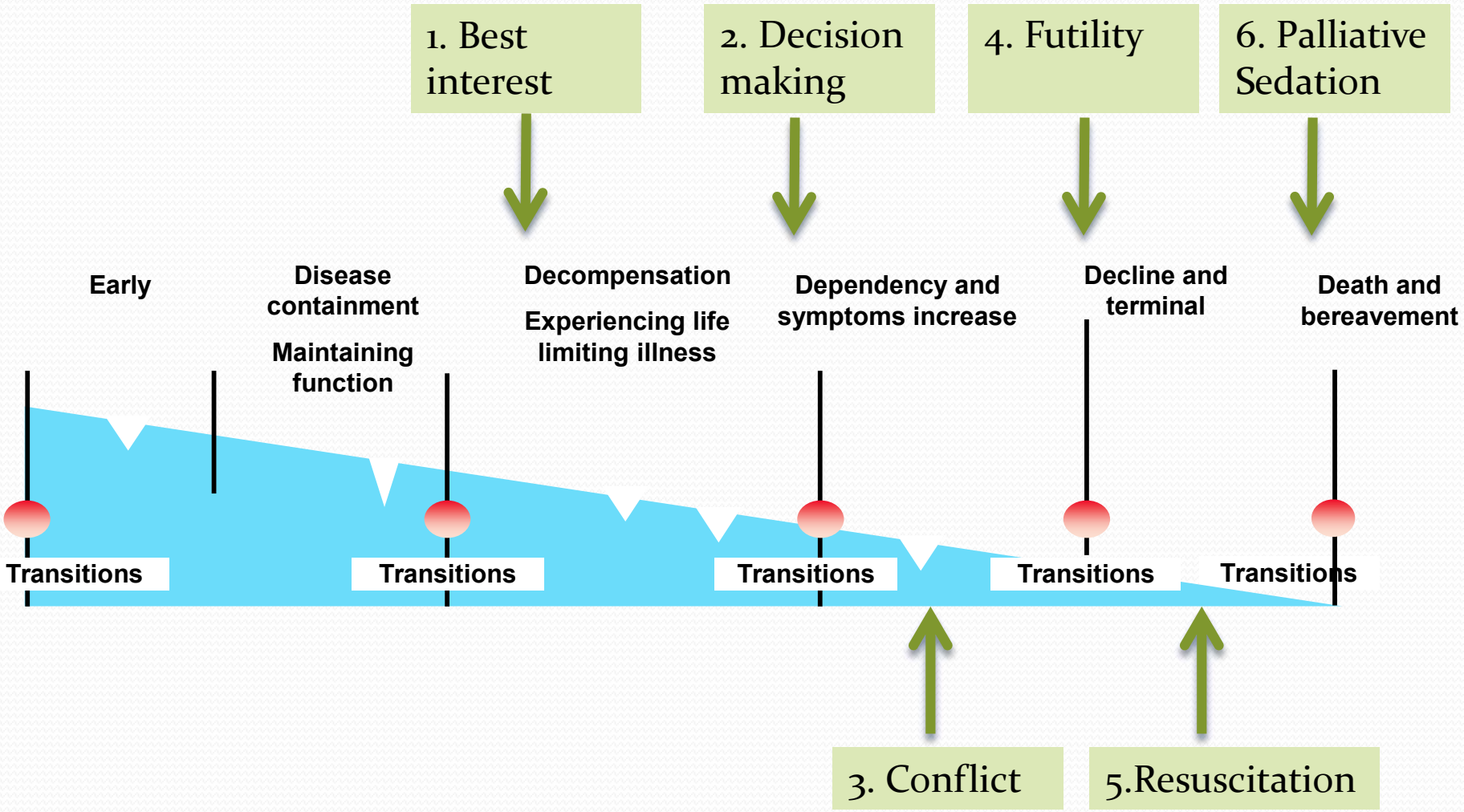
Step	Participant Behavior Code	Example of Dialogue Coded Positively
Assess perception	Assesses the patient's perception of the situation	"Tell me what your understanding is at this point."
Discuss big picture	Elicits the patient's values or goals	"What is most important to you now?"
Ask about worries	Asks about worries, fears, or concerns	"Do you have any particular concerns?"
Respond to emotional content of difficult questions	Responds to the question "How much time do I have?" including an empathic response	"Is there anything in the future you are thinking about specifically?"
	Responds to the question "Isn't there anything more you can do?" including an empathic response	"There are many things we can do to help."
Propose care plan	Not assessed	
Checks for understanding	Checks that the patient has understood the conversation	"Tell me what you are taking away from our talk."

Efficacy of Communication Skills Training for Giving Bad News and Discussing Transitions to Palliative Care

Anthony L. Back, ; Robert M. Arnold,; Walter F. Baile, ; Kelly A. Fryer-Edwards,D; Stewart C. Alexander, ; Gwyn E. Barley, ; Ted A. Gooley, James A. Tulsky

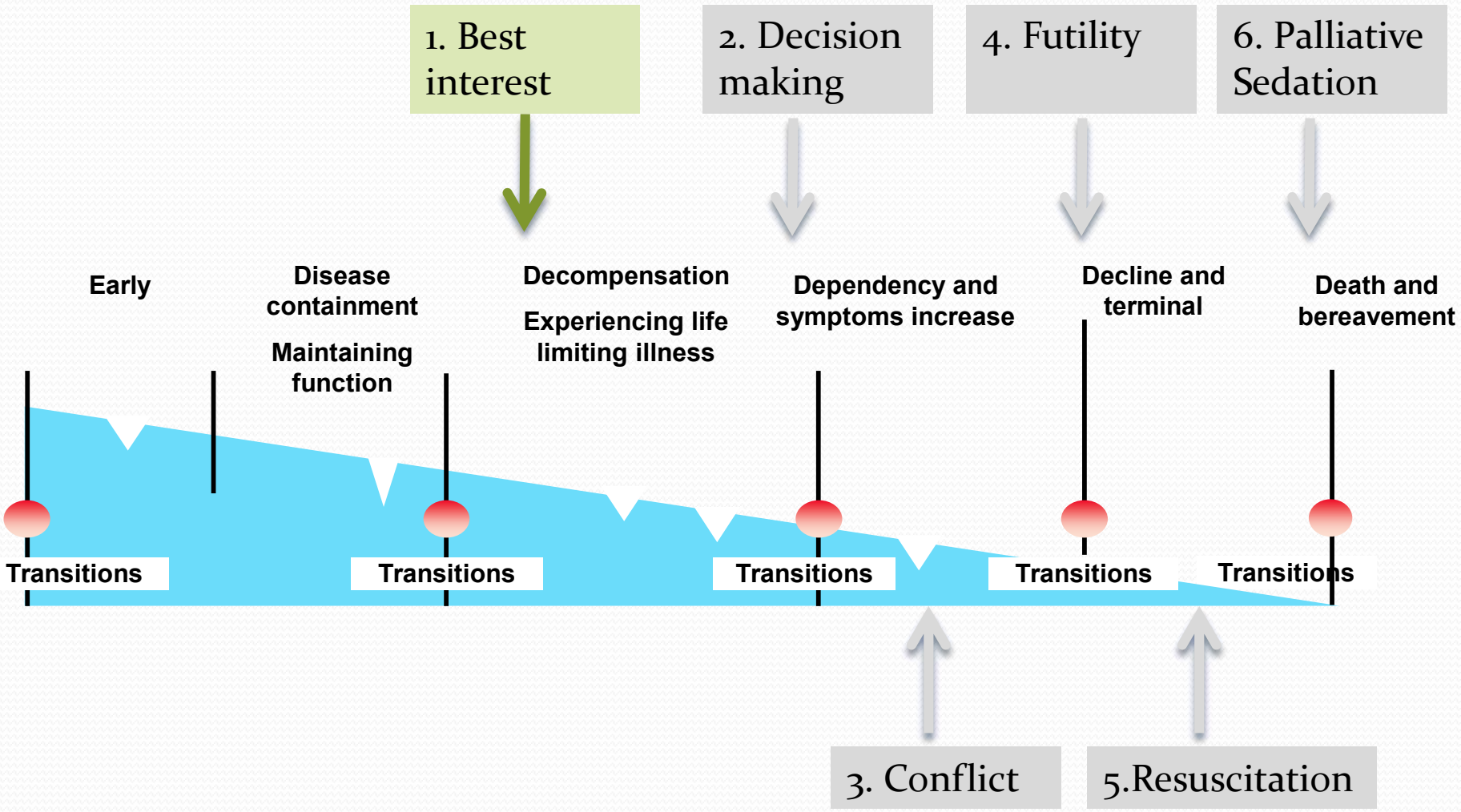
ARCH INTERN MED/ VOL 167, MAR 12, 2007

TRANSITIONS IN LIFE-LIMITING ILLNESS



Beauchamp TL, Childress JF.
Principles of Biomedical Ethics, 6th ed, Oxford University Press, 2009. p.336.

TRANSITIONS IN LIFE-LIMITING ILLNESS



1. Determining the best interest

- **Autonomy versus Palliative Paternalism**

Health care professionals sharing the burden of responsibility

- **Autonomy and Beneficence**

Patient's right to choose

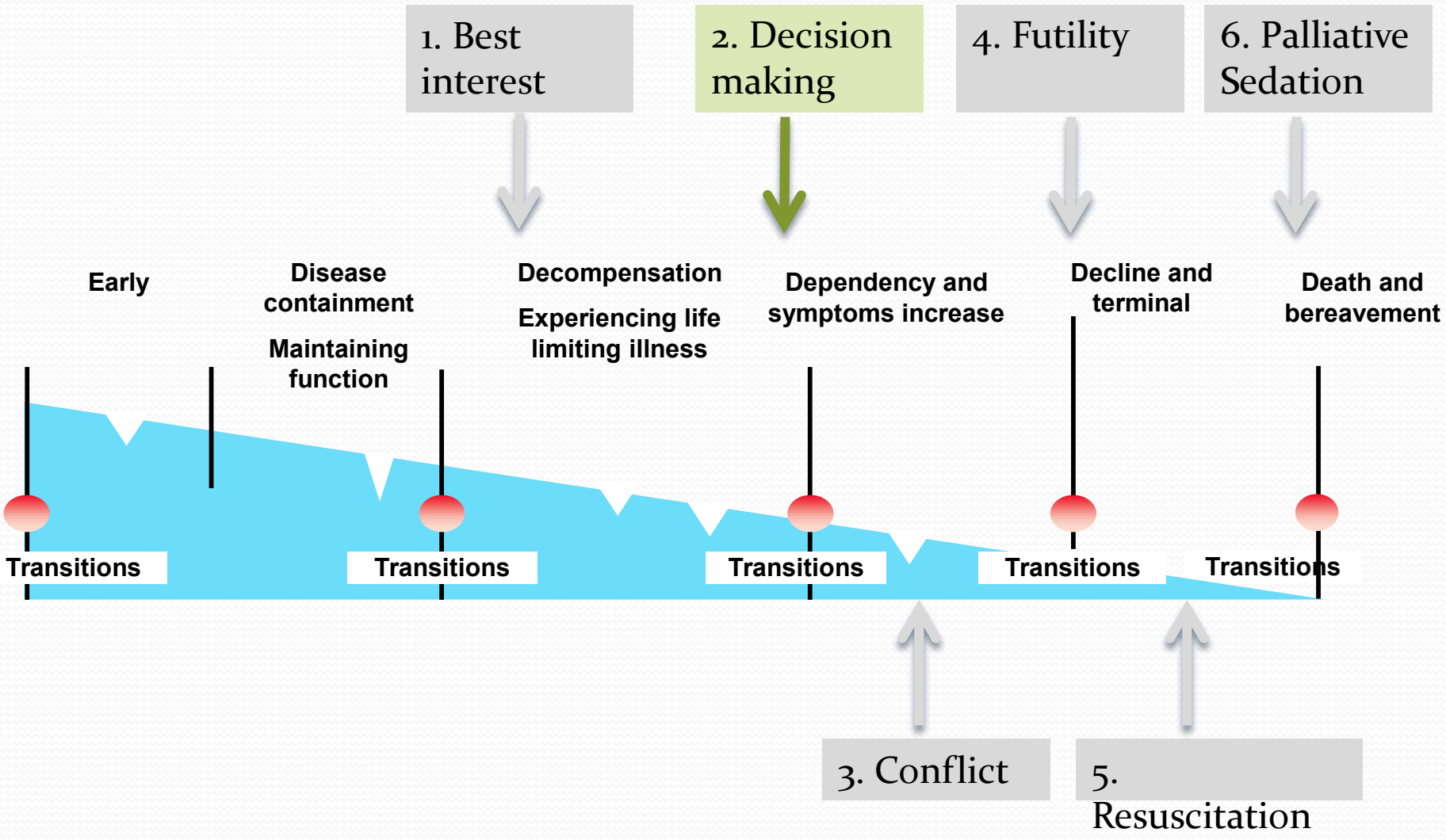
- **Autonomy and Non-Maleficence**

Doctor's right to refuse

- **Non-Maleficence and Non-Abandonment**

Continue to treat even if the physician feels that health demands are inappropriate

TRANSITIONS IN LIFE-LIMITING ILLNESS



2. Decision making

Jonsen's four box model for medical decision making

Medical Indications What is the prognosis? What are the treatment options? Benefits/burden of treatment?	**Patient/Family Preference** Decision making capacity Surrogate decision making Expressed wishes/Preferences
Quality of Life Appropriateness for the patient Trade offs Patient hopes/fears/expectation	**Contextual factors** Resources/Economic/Religious Legal factors Conflict/Conflict of interest

Medical Decision Making

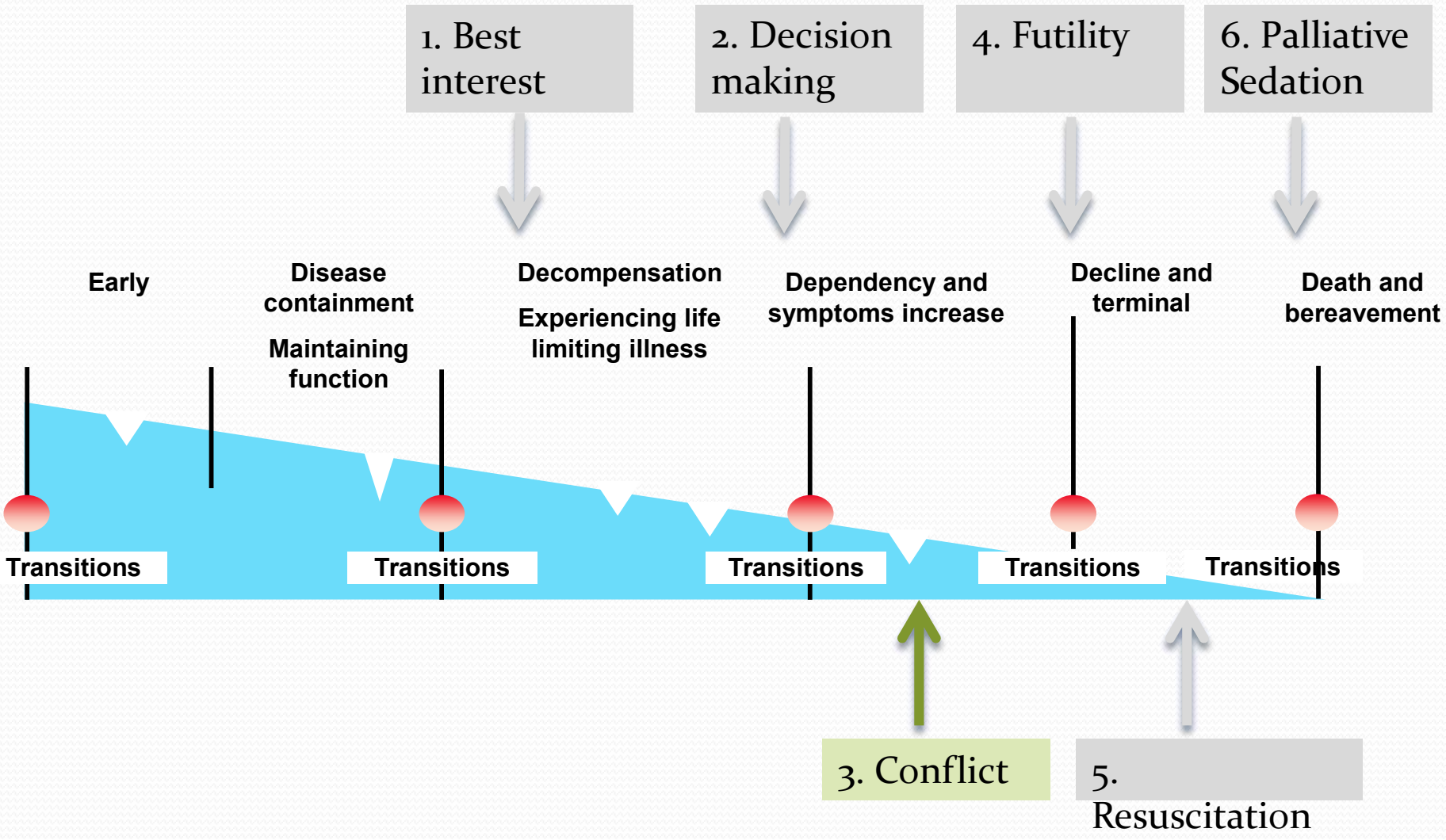
2. Decision making contd.

Surrogate Decision making – Ethical Dilemmas [1, 2]

- Surrogate not aware of patient wishes
- Surrogate not competent to make/participate in medical decision making
- Surrogate not acting in accordance to patient wishes
- Surrogate not acting in best interest of patient's clinical situation
- Surrogate has a conflict of interest
- Surrogate facing conflict
- Surrogate feeling burdened

1. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med 2006; 166:493.
2. Kelly B, Rid A, Wendler D. Systematic review: Individuals' goals for surrogate decision-making. J Am Geriatr Soc 2012; 60:884.

TRANSITIONS IN LIFE-LIMITING ILLNESS

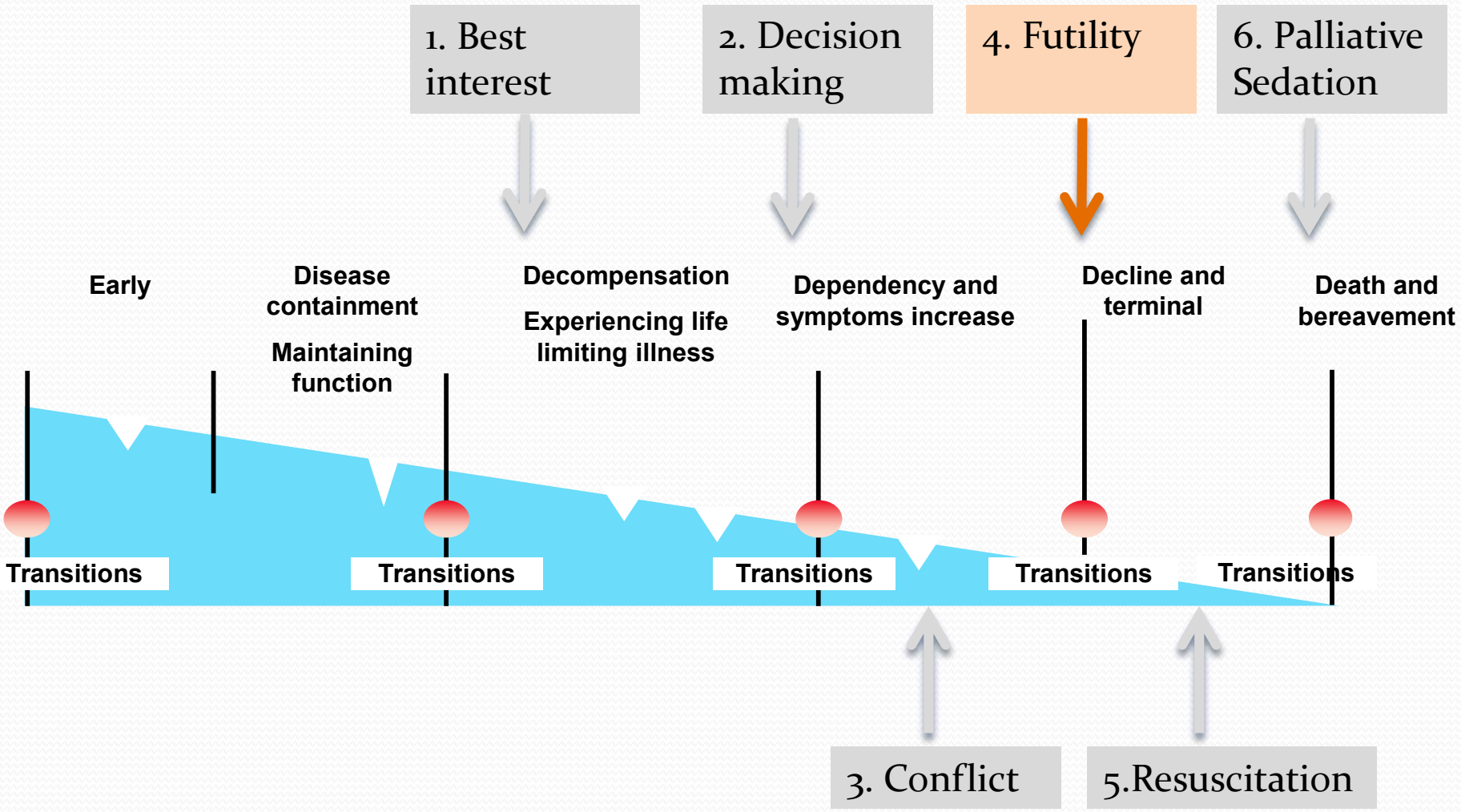


3. Conflict

- Demand for a specific medical therapy that is devoid of clinical evidence in that given clinical situation. What should the doctor do? [1]
- Request from family to withhold medical information from the family? How to respond to these demands?
- Conflict of opinion among the family
- Conflict of opinion among health care providers

1. The Hastings Center. Guidelines on the termination of life-sustaining treatment and the care of the dying, The Hastings Center, Briarcliff Manor, NY 1987. p.32.
2. When the family requests withholding the diagnosis: who owns the truth? McCabe MS, Wood WA, Goldberg RM. J Oncol Pract. 2010 Mar;6(2):94-6.

TRANSITIONS IN LIFE-LIMITING ILLNESS



4. Futility

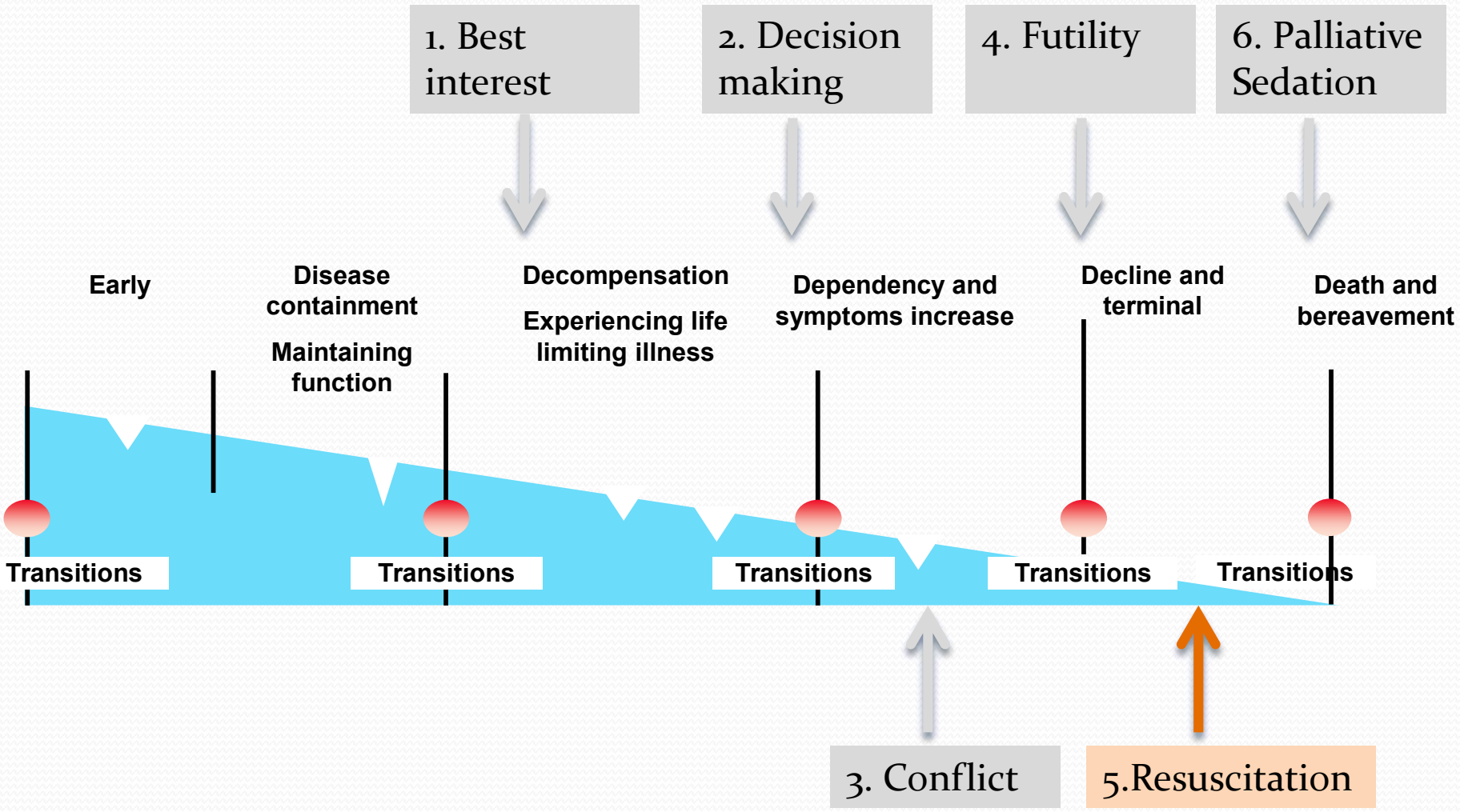
Excessive/Aggressive medical interventions in terms of efforts and resources utilized having little or no clinical outcomes.

Ethical Dilemmas [1]

- **How to know that an intervention is futile?**
- **Who should determine futility?**
- **Should patients and families participate in futility discussions?**
- **How to adhere to institutional policy/standpoint on futility?**

Swetz KM, Burkle CM, Berge KH, Lanier WL. Ten common questions (and their answers) on medical futility. Mayo Clin Proc 2014; 89:943.

TRANSITIONS IN LIFE-LIMITING ILLNESS

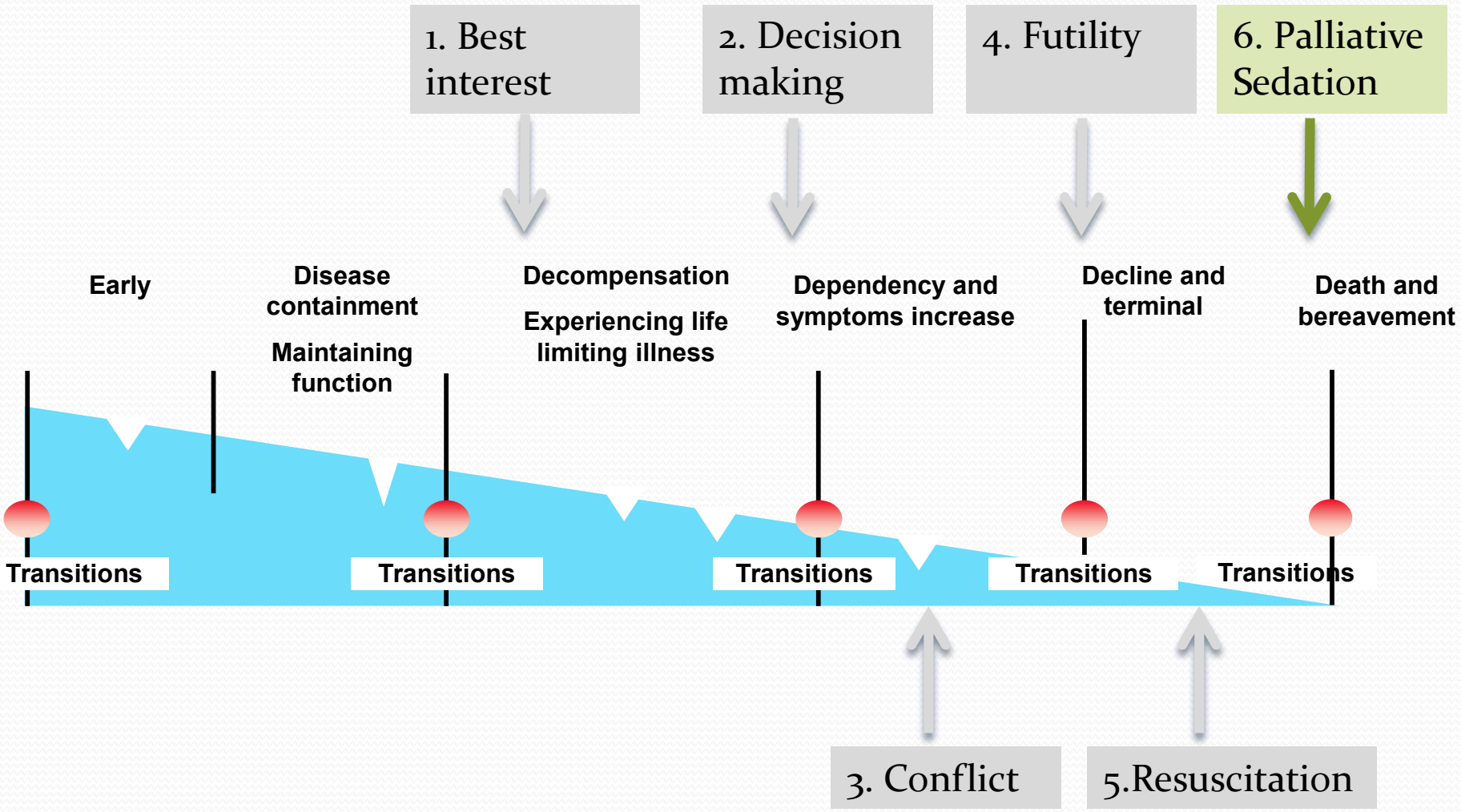


5. Resuscitation

- **Discussion and application of anticipatory not for resuscitation orders – When to discuss and how to discuss?** [1]
- **Withholding versus withdrawing life sustaining treatment** [2]
- **Time limited trial (middle path)** [3]
- **Discontinuation of life sustaining treatment (pace makers/defibrillators, dialysis, NIV etc.)**
- **Hydration and Nutrition**

1. 2005 American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care. Part 2: Ethical issues. Circulation 2005; 112:IV.
2. Ditto PH, Jacobson JA, Smucker WD, et al. Context changes choices: a prospective study of the effects of hospitalization on life-sustaining treatment preferences. Med Decis Making 2006; 26:313.
3. Quill TE, Holloway R. Time-limited trials near the end of life. JAMA 2011; 306:1483.

TRANSITIONS IN LIFE-LIMITING ILLNESS



6. PALLIATIVE SEDATION

- **Is it Euthanasia? No it is not Euthanasia**
- **Management of intractable refractory symptoms in terminally ill dying patients who otherwise would have died with poorly controlled symptoms and distress [1]**
- **Palliative sedation is a humane, ethical and moral approach towards relief of severe uncontrolled symptom and distress by lowering consciousness with one and only intent of relief of symptoms and distress**
- **Founded on principles of doctrine of double effect where the positive outcomes of intervention outweigh the negative consequences.**
- **Extent of sedation proportional to severity of symptoms with a scope for reversibility of sedation [2]**

1. Maltoni M, Pittureri C, Scarpi E, Piccinini L, Martini F, Turci P, et al. Palliative sedation therapy does not hasten death: results from a prospective multicenter study. Annals of oncology : official journal of the European Society for Medical Oncology / ESMO. 2009;20(7):1163-9.
2. Cherny NI, Radbruch L. European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care. Palliative medicine. 2009;23(7):581-93.

CONCLUSIONS

- Different diseases have different trajectories of illness
- It is important to recognize when the transitions are occurring
- At this point , different decisions are appropriate
- These should be guided by principles of Medical Ethics
- Death and bereavement are also part of Comprehensive Palliative Care