



GRUP DE TREBALL FINAL DE VIDA

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Marc conceptual

Identificació més precoç
de persones amb
necessitats pal·liatives

perfil geriàtric i amb
multimorbiditat

marc col.laboratiu entre
el coneixement geriàtric
i pal·liatiu

Bodenheimer T, Berry-millett R, Francisco S. Care management of patients with complex health care needs. *Synth Proj Res Synth Rep* 2009;**19**:1–39.



Model d'atenció



Meier DE. Focusing Together on the Needs of the Sickest 5%, Who Drive Half of All Healthcare Spending. *J Am Geriatr Soc* 2014;62:1970–2.



De la visió pronòstica a la visió centrada en necessitats



context assistencial que faciliti una relació directa i dinàmica entre els professionals i els pacients i família / cuidadors



valoració més individualitzada i multidimensional



24è congrés Societat Catalana de Geriatria i Gerontologia

NOT DO



American Academy of Hospice and Palliative Medicine

[View all recommendations from this society](#)

Released February 21, 2013

Don't delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.

Five Things Physicians and Patients Should Question

by
Canadian Society of Palliative Care Physicians
Last updated: June 2017

- 1 **Don't delay palliative care for a patient with serious illness who has physical, psychological, social or spiritual distress because they are pursuing disease-directed treatment.**

BMJ 2014;349:g7817 doi: 10.1136/bmj.g7817 (Published 29 December 2014)

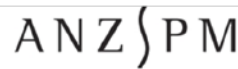
Page 1 of 1

NEWS

Massachusetts requires doctors to inform patients about end of life options

Michael McCarthy

Seattle



5THINGS

CLINICIANS AND CONSUMERS SHOULD QUESTION

Developed by the Australian and New Zealand Society of Palliative Medicine and the Australasian Chapter of Palliative Medicine

- 1 **Do not delay discussion of and referral to palliative care for a patient with serious illness just because they are pursuing disease-directed treatment.** Palliative care provides an added layer of support to patients with life-limiting disease and their families. Symptomatic patients can benefit regardless of their diagnosis, prognosis or disease treatment regimen. Studies show that integrating palliative care with disease-modifying therapies improves pain and symptom control, as well as patient quality of life and family satisfaction. Early access to palliative care has been shown to reduce aggressive therapies at the end of life, prolong life in certain patient populations, and significantly reduce hospital costs.

- 2 **Do not delay conversations around prognosis, wishes, values and end of life planning (including advance care planning) in patients with advanced disease.** Advance care planning is a process, which includes choosing a surrogate or alternate decision-maker and communicating values or wishes for medical care. Evidence shows that advance care planning conversations improve patient and family satisfaction with care and concordance between patients' and families' wishes, reduce the likelihood of unnecessary hospital care and increase the likelihood of receiving hospice care.

www.choosingwisely.org.au





- ❖ No retardar **atenció pal·liativa**, encara que hi hagi tractament actiu
- ❖ No retardar les converses sobre pronòstic, desitjos, valors i **planificació del final de la vida**
- ❖ No retardar la **informació a la persona i família**
 - Millor control símptomes
 - Augmenta qualitat vida i satisfacció de la persona i família
 - Redueix teràpies invasives
 - Pot augmentar supervivència
 - Disminueix costos

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NOT DO

Opinion

TEACHABLE MOMENT

LESS IS MORE

Sense and Nonsense of Treatment of Comorbid Diseases in Terminally Ill Patients

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Story From the Front Lines

A 69-year-old woman was diagnosed as having metastatic pancreatic cancer. She had a history of type 2 diabetes mellitus, which was diagnosed 7 years earlier. Initially, her diabetes was controlled by strict adherence to a healthy lifestyle. For example, she had stopped eating ice cream, which she was very fond of. Two years prior to the cancer diagnosis, she had started metformin therapy, and her hemoglobin A_{1c} level measurements of 6.8% were achieved.

Teachable Moment

Pharmacotherapy is the appropriate use of drug therapy aimed at preventing and treating a disease or to relieve symptoms. In the final phase of life, the goals of treatment change, and drugs used to prevent or treat chronic diseases need to be reconsidered.¹ In diabetic patients without complications, no benefit of tight glucose control can be expected for at least a decade.² In addition to limiting burden and adverse effects, discontinuing drug use in patients with limited life expectancy may actually improve quality of life and survival. In a recent randomized trial, discontinuation of statins in patients with a life expectancy of less than 1 year led to improved quality of life and a trend toward longer life span compared with continued use of these drugs.³ Continuing medication use at the end of life also has important impacts on health care costs. Discontinuing statin therapy alone in patients with a life expectancy of less than 1 year could save the US health care system \$603 million annually.³

General considerations when prescribing medication for patients at the end of life include the patient's life expectancy, time until potential benefit of treatment,

Tsun van Gelder, MD, PhD
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She was treated with palliative chemotherapy, and during each cycle she received dexamethasone to reduce associated nausea. During the first 2 cycles, her blood glucose level rose as high as 288 mg/dL (to convert to millimoles per liter, multiply by 0.0555), for which she received short acting insulin.

Lia van Zuylen, MD, PhD
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At home, without dexamethasone use, her measured blood glucose levels were occasionally slightly above the upper limit of target values. During the third treatment cycle, the patient's husband told the ward physician that his wife treated the slightly high blood glucose levels by not eating until the levels came down to normal. The physician—who had an

JAMA Internal Medicine March 2015 Volume 175, Number 3

Research

Original Investigation | LESS IS MORE

Use of Medications of Questionable Benefit in Advanced Dementia

Jennifer Tjia, MD, MSCE; Becky A. Briesacher, PhD; Daniel Peterson, MA; Qin Liu, MD, PhD; Susan E. Andrade, ScD; Susan L. Mitchell, MD, MPH

JAMA Intern Med. 2014;174(11):1763-1771. doi:10.1001/jamainternmed.2014.4103
Published online September 8, 2014.



LESS IS MORE

Inappropriate Drug Use in Advanced Dementia

JAMA Internal Medicine February 2015 Volume 175, Number 2

PERSPECTIVES

LESS IS MORE

Pain as a Cause of Agitated Delirium

ARCH INTERN MED/VOL 172 (NO. 15), AUG 13/27, 2012 WWW.ARCHINTERNMED.COM
1130

PERSPECTIVES

LESS IS MORE

Pharmaceutically Less and Holistically More

JAMA INTERN MED/VOL 173 (NO. 11), JUNE 10, 2013 WWW.JAMAINTERNALMED.COM
948



- ❖ No cal **tractar** sempre les comorbiditats
- ❖ No utilitzar **fàrmacs d'escàs valor**, en demències avançades com: inhibidors de la colinesterasa, memantina, hipolipemians
- ❖ No oblidar que el **dolor** mal controlat pot ser causa d'agitació
 - adaptar els tractaments als nous objectius
 - qualitat en la prescripció i administració
 - ús racional dels medicaments ha d'anar lligat a adequació esforç terapèutic
 - abordatge holístic del dolor/ mesures no farmacològiques

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NOT DO

Long Term Care

Six Things Physicians and Patients Should Question

by
Long Term Care Medical Directors Association of Canada
Last updated: January 8, 2017

- 1 Don't send the frail resident of a nursing home to the hospital, unless their urgent comfort and medical needs cannot be met in their care home. ▲



American College of Emergency Physicians

[View all recommendations from this society.](#)

October 14, 2013

Don't delay engaging available palliative and hospice care services in the emergency department for patients likely to benefit.



AMDA – The Society for Post-Acute and Long-Term Care Medicine

[View all recommendations from this society.](#)

Released March 20, 2015

Don't recommend aggressive or hospital-level care for a frail elder without a clear understanding of the individual's goals of care and the possible benefits and burdens.

Critical Care

by
Canadian Critical Care Society
Canadian Association of Critical Care Nurses
Canadian Society of Respiratory Therapists
Last updated: March 22, 2017

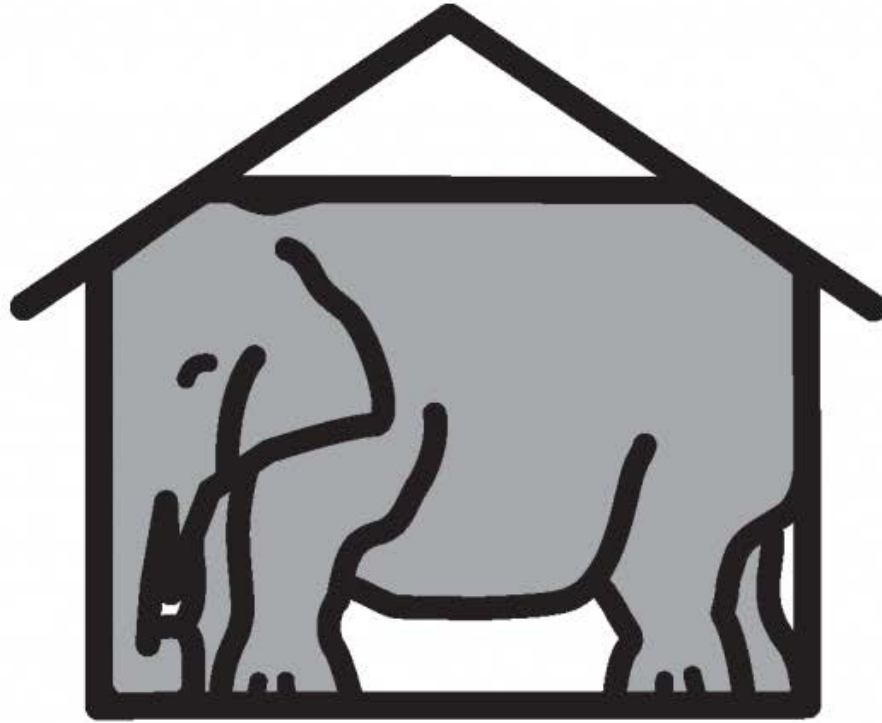
- 1 Don't start or continue life supporting interventions unless they are consistent with the patient's values and realistic goals of care. ▲

Patients and their families often value the avoidance of invasive or overly aggressive life-sustaining measures when they are at the end of life. However, many dying patients receive aggressive life-sustaining therapies, in part due to clinicians' failures to elicit patients' preferences and to provide recommendations.



- ❖ **No derivar hospital d'aguts a pacients fràgils**
 - **Tenir en compte sempre el risc i el benefici del trasllat**
 - **Risc delírium, infeccions, esdeveniments adversos fàrmacs, pèrdua funcional**
 - Donar a l'hospital objectius d'atenció segons necessitats
 - Tenir en compte els seus valors i les seves preferències
- ❖ **No retardar atenció pal·liativa als serveis d'urgències**
- ❖ **No iniciar o mantenir mesures de suport vital al final de la vida**

24^è Societat Catalana
congrés de Geriatria i Gerontologia



**ELEPHANT
IN THE ROOM**

WHAT WE'RE NOT
TALKING ABOUT

24^è congrés

Societat Catalana de Geriatria i Gerontologia

DO

PERSPECTIVE

LESS IS MORE

The Elephant in the Room—Your Patient Is Dying A Teachable Moment

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Timothy J. Moynihan, MD
Division of Medical Oncology, Mayo Clinic College of Medicine, Rochester, Minnesota.

A 55-year-old man was referred to our institution for outpatient evaluation of several long-standing symptoms, including fatigue, numbness, tingling, and weakness in his extremities; diffuse abdominal pain; watery diarrhea; unintentional weight loss; and orthostasis with recent syncopal episodes. He was extensively evaluated by colleagues in various medical specialties. On day 11 of outpatient evaluation, his first cardiac arrest occurred, requiring several minutes of resuscitation.

Testing on hospital admission included a transthoracic echocardiography, which revealed findings consistent with amyloidosis. The hematology service was consulted and recommended further invasive testing. Diagnostic studies ultimately confirmed amyloid light-chain lambda amyloidosis with cardiac involvement.

to deactivate the ICD. The following day he died peacefully in the presence of loved ones.

When caring for patients with a terminal illness, physicians are challenged with difficult discussions and decisions, and many times these ignore the “elephant in the room”—the fact that the patient is dying. There are multiple drivers for this evasiveness, including lack of physician training and preparedness, the patient’s and family’s denial or wish to avoid difficult or painful news, and attempts to maintain hope for a different outcome.^{2,3}

As exemplified in the case we describe, physicians sometimes focus solely on the disease process and how it can be treated while consciously or unconsciously avoiding the true overall prognosis and outcome, ignoring what is obvious—that the patient is dying. In fact,

Opinion



TEACHABLE MOMENT

LESS IS MORE

What Are the Patient’s Wishes?

Joshua Feblowitz, MS
Harvard Medical School, Boston, Massachusetts.

Jeremy Richards, MD, MA
Harvard Medical School, Boston, Massachusetts; and Division of Pulmonary, Critical Care, and Sleep Medicine, Beth Israel Deaconess Medical Center, Boston, Massachusetts.

Story From the Front Lines

An 83-year-old man with coronary artery disease and chronic renal insufficiency underwent a pylorus-preserving pancreaticoduodenectomy (Whipple procedure) for a pancreatic tumor. Although the patient was not considered an ideal surgical candidate given his comorbidities, he strongly favored undergoing the procedure, and his surgeon agreed to proceed after comprehensive preoperative evaluation. Prior to surgery, the patient told both his surgeon and his wife—also his health care proxy—that he wished to be “full code,” but if he could not be “brought back to [his] normal self,” he did not want to be “kept alive artificially” or have a feeding tube.

that were potentially inappropriate based on his circumstances and prognosis. Evidence suggests that this situation is common; in a study of patients older than 60 years, more than 70% lacked decision-making capacity at a time when care decisions were required.¹

Multiple—albeit imperfect—tools exist to preserve a patient’s voice in such decisions, including selecting a health care proxy, creating an advance directive, or discussing goals of care. Such tools are frequently underused even when they are clearly indicated. Tan and Jatoi² demonstrated that only 15% of patients with unresectable pancreatic cancer had an advance directive documented.² Furthermore, even when such tools are used, they may be insufficient to guide care.

JAMA Internal Medicine February 2014 Volume 174, Number 2

JAMA Internal Medicine April 2015 Volume 175, Number 4

Clinical Review & Education

Special Communication

Communication About Serious Illness Care Goals A Review and Synthesis of Best Practices

Rachelle E. Bernacki, MD, MS; Susan D. Block, MD; for the American College of Physicians High Value Care Task Force

1994 JAMA Internal Medicine December 2014 Volume 174, Number 12





❖ Establir **COMUNICACIÓ**

- S'ha d'informar de **manera precoç** i quan hi hagi **estabilitat**
- Ha d'informar qui millor **conegui a la persona**

- Què entén per qualitat de vida
- Què ha entès del pronòstic i de les opcions de tractament
- Què en sap i què en vol saber
- Quines són les seves preocupacions i els seus temors
- Quins són els seus valors i les seves preferències





❖ Establir RELACIÓ:

- **Planificació avançada** de l'atenció
 - Presa de **decisiones compartides**
-
- Les preocupacions de la persona
 - Els seus valors o objectius personals pel pla de cures
 - El grau de comprensió sobre la seva malaltia i el pronòstic
 - Les preferències sobre el tipus de cures o tractaments, el lloc i el moment d'atenció

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Box 1. Summary of the American College of Physicians (ACP) High Value Care Advice on Communication in the Care of Patients With Serious and Life-Threatening Illness

Disease or Condition

Communication for patient with serious and life-threatening illness.

Target Audience

Internists (including oncologists, cardiologists, nephrologists, and intensivists), family physicians, and other clinicians who care for patients with serious and life-threatening illness.

Target Patient Population

All patients with serious and life-threatening illness.^a

Indications for Communication

Examples:

Solid tumor with metastases, hypercalcemia, or spinal cord compression.

CHF, class III or IV with 2 or more hospitalizations.

CKD, on dialysis, age 75 years or older.

COPD, on home oxygen with FEV1 less than 35% predicted.

All patients whose physicians answer "no" to the following question: "Would you be surprised if this patient died in the next year?"

Evidence That Early Communication About Goals of Care and End-of-Life Preferences Improves Care

End-of-life conversations are associated with better quality of life, reduced use of life-sustaining treatments near death, earlier hospice referrals, and care that is more consistent with patient preferences.

Patients who received early palliative care showed significant improvements in quality of life and mood, and survived 25% longer.^b

Patients who engaged in advance care planning were more likely to have their wishes known and followed.

Preparation for the end of life is associated with improved bereavement outcomes for family.

Potential Harms of Communication

Strong preponderance of evidence shows no increased depression, anxiety, hopelessness.

Potential Costs of Communication

Increased clinician time.

Harms of Failure to Address Goals of Care and/or End-of-Life Issues

Patient receipt of care not consistent with personal goals.

Worse quality of life.

Prolonged death with increased suffering.

Worse bereavement outcomes for family members.

Increased costs without benefit to patients.

Barriers to Communication

Patient factors: anxiety, denial, desire to protect family members.

Clinician factors: lack of training, comfort, and time, difficulties in prognostication.

System factors: life-sustaining care is the default, no systems for end-of-life care, poor systems for recording patient wishes, ambiguity about who is responsible.

Approaches to Overcome Barriers to Communication About Patient Values and Goals

Provide communication training for clinicians, especially about prognostication.

Improve documentation and exchange of information about patient values and goals through information technology.

Create real-time monitoring and feedback on performance for clinicians.

ACP High Value Care Advice

Communication about goals of care is a low-risk, high-value intervention for patients with serious and life-threatening illness; these discussions should begin early in the course of life-limiting illnesses. Ideally, communication about serious illness care goals should come from the patient's primary clinician even when a team of clinicians is involved with the patient's care. Early discussions about end-of-life care issues are associated with improved patient outcomes, including better quality of life, reduced use of nonbeneficial medical care near death, and care more consistent with patients' goals. This approach is also associated with improved family outcomes and reduced costs. Key elements of a system to help assure that every patient has a personalized serious illness care plan include training clinicians, identifying patients at risk of dying, preparing and educating patients, "triggering" physicians to conduct discussions at the appropriate time, having a structured communication format for goals of care discussions, establishing a system to assure documentation of these discussions, and using metrics to measure performance. The ACP supports the need for improving our approach to serious illness and end-of-life care, as well as the system changes needed to assure thoughtful and timely communication with patients and their family members across all health care settings.

^a Serious illness (life expectancy <1 year).

^b Evidence shows that palliative care consultation is approximately 50% communication and patient education.

Abbreviations: CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; FEV1, forced expiratory volume in the first second.

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DO

Rev Esp Geriatr Gerontol. 2018;53(5):245-246



Revista Española de Geriatria y Gerontología

www.elsevier.es/regg



EDITORIAL

Armonización terapéutica: la necesaria alineación de los sistemas de salud con los resultados que importan a las personas



Therapeutic harmonization: the necessary alignment of the healthcare systems with the results that matters to the patients

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^b Grupo de investigación en Cronicidad de la Cataluña Central (CJRC), Vic, Barcelona, España

^c Cátedra de Cuidados Paliativos / Centro de Estudios Sociales y Sanitarios (CESS), Universitat de Vic-Universitat Central de Catalunya, Vic, Barcelona, España

^d Programa de Prevención y Atención a la Cronicidad, Departament de Salut, Generalitat de Catalunya, Barcelona, España

SPECIAL COMMUNICATION

Quality End-of-Life Care Patients' Perspectives

Peter A. Singer, MD, MPH, FRCPC
Douglas K. Martin, PhD
Merrijoy Kelner, PhD

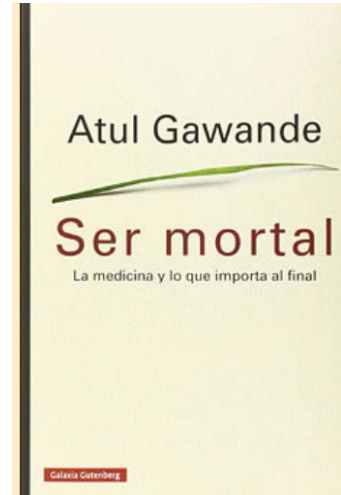
Context Quality end-of-life care is increasingly recognized as an ethical obligation of health care providers, both clinicians and organizations. However, this concept has not been examined from the perspective of patients.

Objective To identify and describe elements of quality end-of-life care from the patient's perspective.

BECAUSE EVERYONE DIES, END-OF-LIFE CARE IS AN ETHICAL OBLIGATION OF HEALTH CARE PROVIDERS, BOTH CLINICIANS AND ORGANIZATIONS. HOWEVER, THIS CONCEPT HAS NOT BEEN EXAMINED FROM THE PERSPECTIVE OF PATIENTS. TO IDENTIFY AND DESCRIBE ELEMENTS OF QUALITY END-OF-LIFE CARE FROM THE PATIENT'S PERSPECTIVE.

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JAMA, January 13, 1999—Vol 281, No. 2 163





HARMONITZACIÓ
TERAPÈUTICA

Indicadors que es basin en
el valor de les intervencions

Són els que realment
importen a les persones



QUÈ IMPORTA

PROFESSIONALS

- Control símptomes
- Mantenir autonomia
- Planificació
- **resultats**
- Continuitat d'atenció
- Reduir costos
- Atenció al dol

PACIENTS

- Rebre adequat control dels dolor i dels símptomes
- Evitar la càrrega de la família
- **procés**
- Alleugerir la càrrega
- Enfortir les relacions



PER REFLEXIONAR

- Estic tractant de manera adequada el dolor i altres símptomes?
- Estic prolongant de manera inapropiada la vida?
- Estic ajudant als pacients a tenir un bon control de la seva vida?
- Estic ajudant a alleugerir la càrrega de la seva família?
- Estic ajudant a enfortir les seves relacions amb els seus éssers més propers?



«Creiem que la medicina consisteix en garantir la salut i la supervivència. Però en realitat, és molt més que això, perquè qui pateix una malaltia greu té unes altres prioritats, al marge de prolongar la seva vida. Entre les principals preocupacions hi ha evitar els llaços amb els seus familiars conscients, no ser una càrrega, la sensació que la seva vida no té sentit, i la possibilitat de compartir els seus records, treure els seus objectes personals, deixar el seu llegat i assegurar-se que les persones que deixa estaran bé. El nostre sistema d'atenció sanitària tecnològica ha fracassat totalment a l'hora de satisfer aquestes necessitats.»

moltes gràcies!

Atul Gawande