

Round 2

## Delphi-study to formulate guidelines for medication management in the last phase of life - Round 2



For your convenience, we again give the definitions for terms that we use throughout the questionnaire.

Medication management: patient-centered care to optimize safe, effective and appropriate use of prescription and over-the-counter drugs.

Medication review: an assessment of the pharmacotherapy based on a structural and critical evaluation of the medical, pharmaceutical and clinical information.

End of life: the last 3 months of life.

Patient and/or family: indicating the family especially when the patient is not mentally competent.

Palliative care specialist: physician or nurse specialist/practitioner with a formal training in palliative care medicine or equivalent expertise due to clinical experience.

### **Part 1**

Based on the responses from you and other experts we selected 43 solutions, presented in the table on the following pages. A number of solutions were suggested by experts, which were added to the list of solutions presented in round 1. For an overview of added solutions, please refer to page 9. We would like you to select from this list, and then **prioritize**, the ten statements you consider to be **most relevant to your idea to formulate guidelines for medication management in the last phase of life**.

To do this, please would you:

- **Firstly read through all of the statements on the next two pages.**
- Once you have read through all of the statements, choose the 10 statements most relevant to you and rank these from 1 to 10, placing the number of each statement in the respective box provided at the end of this questionnaire. For example if statement 5 is of greatest relevance to your idea of recovery, enter 5 in box 1, if statement 11 is next most relevant, enter 11 in box 2, and so on, (see example of below)

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Rank	Statement Number
1.	5
2.	11

- To make this easier, you may like to cut out your 10 statement strips from the enclosed copy of the worksheet on page 7-8 of this questionnaire, discarding the rest, and arrange and rearrange these until you are happy that the order most correctly matches your view of their relative importance to your idea of recovery. Then simply copy the statement numbers in order into the boxes at the end of the questionnaire. Editing this copy is enabled, unlike the rest of the questionnaire.
- If you are unable to find 10 relevant statements, please place in rank order a minimum of 3 statements that are relevant to you, entering their numbers in the respective boxes.

	<b>Solution</b>
1.	The importance of medication management in end-of-life care should be formalized in institutional policies.
2.	A medication review should be an integral part of the care for patients at the end of life.
3.	Palliative care specialists should be available for consultation regarding medication management for patients at the end of life.
4.	Health care professionals should be acquainted with the local possibilities for consultation of palliative care specialists for medication management at the end of life.
5.	The importance of medication management in end-of-life care should be advocated for by health care professional organizations and discussed at national professional conferences
6.	Creation of policies or guidelines about medication management at the end of life should be sponsored or endorsed by internationally respected palliative care organizations (such as IAHP) in collaboration with other national and international guideline-creating groups (such as USPSTF in the USA, NICE guidelines in the UK, etc.).
7.	Education in medication management at the end of life should be organized for health care professionals.
8.	Physicians should be educated in the (patho)physiological changes at the end of life.
9.	Health care professionals should be trained in the pharmacological treatment of symptoms at the end of life.
10.	Health care professionals should be trained to denominate (mark) the end of life to patients and/or their family.
11.	Health care professionals should be trained in communicating with patients and/or their family about decision-making on medication management at the end of life.
12.	Pharmacist should be an integral part of educating other health care professionals about medication management at the end of life.

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13.	Education in medication management at the end of life should be incorporated in all medical training (nursing school, medical students, residencies and fellowships).
14.	Medical officers working in the field of palliative care need to undergo formalized training and pass this successfully before being allowed to operate at a consultant level.
15.	The pharmacological treatment of symptoms at the end of life should be more evidence based.
16.	Discontinuing medication at the end of life should be more evidence based.
17.	Alternative administration of drugs for patients unable to swallow at the end of life should be investigated.
18.	A list of drugs with a high risk of inappropriateness at the end of life should be developed.
19.	Studies investigating the effect of discontinuing medication should be done.
20.	At the end of life each drug should be revised for its potential congruence with the clinical aims of the specific situation in a specific patient.
21.	Patient or proxy based assessment tools (e.g. ESAS, EORTC, symptom diary, PPS, PPI) should be used to aid symptom assessment and treatment at the end of life.
22.	Physicians should discuss the end of life with the patient in a timely manner.
23.	Physicians should discuss the wishes, treatment goals and priorities regarding medication management at the end of life with the patient in a timely manner.
24.	Nurses should contribute to medication management at the end of life by monitoring and signaling.
25.	The primary treating physician should coordinate the medication management at the end of life.
26.	The primary treating physician should monitor the implementation of the end-of-life care plan.
27.	The primary treating physician should ensure that the information about the medication management is passed on in case of a transfer at the end of life.
28.	Other physicians should keep the primary treating physician informed in a timely manner about changes in the clinical condition or the medication of the patient.
29.	The primary care physician should help with end of life medication management long before the end of life, preparing the patient and family for likely changes to the medications that will occur when the patient is at the end of life.
30.	The role of the nurse in medication management at the end of life should depend on the level of education of the nurse.
31.	The role of the pharmacist in medication management at the end of life depends on the complexity of the patient, the expertise of the treating physician, the clinical setting and availability of a pharmacist.
32.	A medication review at the end of life should take place on admission.
33.	Medication management should be part of each multidisciplinary team meeting for patients at the end of life.
34.	The substitute of the primary treating physician should have access to the medication management plan at the end of life.
35.	In communicating about medication management at the end of life nurses and physicians should take into account the norms and values of the patient and/or family.

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36.	It should be discussed with the patient which role he/she would like to have in decision making regarding medication management at the end of life.
37.	It should be discussed with the patient and/or family that the goal of medication management at the end of life is improving/maintaining the quality of life.
38.	The indication and (dis)advantages of the medication should be discussed with the patient and/or family at the end of life.
39.	It should be discussed with the patient and/or family how the medication can be adjusted at the end of life and what can be expected of these changes.
40.	Changes in the medication management plan at the end of life and the motivation should be recorded in the (electronic) medical record.
41.	Both reasons for discontinuing and continuing of medication at the end of life should be recorded.
42.	Both reasons for discontinuing and continuing of medication at the end of life should be passed on at a transfer.
43.	Medication management at the end of life should be individualized, based on the patient's clinical situation.

**Now please place the numbers of the 10 solutions most relevant to your idea to formulate guidelines for medication management in the last phase of life in order with the MOST RELEVANT in box no 1, the second most relevant in box 2 and so on.**

Rank	Statement Number
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	

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Finally, we present the list of remaining solutions (with less than average agreement). Please state which solutions you think are crucial for guidelines about medication management in the last phase of life and should not be rejected, by ticking the boxes.

Not to be rejected	Solution
<input type="checkbox"/>	Physicians lacking experience with medication management at the end of life should consult a palliative care specialist.
<input type="checkbox"/>	Marking of the end of life should be part of education for health care professionals.
<input type="checkbox"/>	Health care professionals should be trained in using tools to aid marking of the end of life.
<input type="checkbox"/>	Physicians should be trained in pharmacokinetics at the end of life.
<input type="checkbox"/>	Validity and reliability of tools to mark the end of life should be improved.
<input type="checkbox"/>	The effect of discontinuing medication at the end of life should be more evidence based.
<input type="checkbox"/>	The pharmacological treatment of chronic diseases at the end of life should be more evidence based.
<input type="checkbox"/>	In current treatment guidelines (e.g. for hypertension, heart failure, diabetes etc.) recommendations for medication management at the end of life should be incorporated.
<input type="checkbox"/>	A list of drugs that could be tapered off or discontinued at the end of life under certain conditions should be developed (e.g. anticoagulant, antihypertensive, blood glucose lowering, antibiotic, antipsychotic, antidepressant or anticonvulsive drugs).
<input type="checkbox"/>	Available tools (e.g. the Prognosis in Palliative care Study (PIPS) predictor or the surprise question) should be used to aid marking the end of life.
<input type="checkbox"/>	Pharmacists should be actively involved in medication management decision-making at the end of life.
<input type="checkbox"/>	Pharmacists should be informed about the clinical condition of the patient to be able to give his/her expertise in medication management at the end of life.
<input type="checkbox"/>	Nurses should signal the end of life and discuss this with the physician.
<input type="checkbox"/>	Nurses should discuss the wishes, treatment goals and priorities regarding medication management at the end of life with the patient in a timely manner.
<input type="checkbox"/>	Nurses should contribute to medication management at the end of life by providing information, explanation and advice to the patient and/or family.
<input type="checkbox"/>	In the end-of-life care plan the primary treating physician should be registered.
<input type="checkbox"/>	The primary treating physician should formulate an end-of-life care plan with the patient and/or family.
<input type="checkbox"/>	The general practitioner is the primary treating physician when the patient resides at home.

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<input type="checkbox"/>	The primary treating physician is responsible for recording the medication management at the end of life.
<input type="checkbox"/>	The primary treating physician should inform the other care providers involved about the medication management at the end of life.
<input type="checkbox"/>	The primary treating physician should ensure the availability of a care provider who can be reached 24/7 by the patient for medication management at the end of life.
<input type="checkbox"/>	A medication review at the end of life should take place weekly at the grand rounds.
<input type="checkbox"/>	Discontinuation of disease-oriented treatment at the end of life should be followed by a medication review.
<input type="checkbox"/>	In primary care the general practitioner should review the medication at every contact with a patient at the end of life.
<input type="checkbox"/>	A substitute of the treating physician should review the medication in accordance with the primary treating physician at every contact with a patient at the end of life.
<input type="checkbox"/>	It should be discussed with the patient and family which role the family has in decision making regarding medication management at the end of life.
<input type="checkbox"/>	It should be discussed with the patient and/or family how medication changes at the end of life will be monitored.

**This is the end of this questionnaire.**

**Thank you for completing it.**

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**Supplement 1: Extra copy of worksheet for own use**

	<b>Solution</b>
1.	The importance of medication management in end-of-life care should be formalized in institutional policies.
2.	A medication review should be an integral part of the care for patients at the end of life.
3.	Palliative care specialists should be available for consultation regarding medication management for patients at the end of life.
4.	Health care professionals should be acquainted with the local possibilities for consultation of palliative care specialists for medication management at the end of life.
5.	The importance of medication management in end-of-life care should be advocated for by health care professional organizations and discussed at national professional conferences
6.	Creation of policies or guidelines about medication management at the end of life should be sponsored or endorsed by internationally respected palliative care organizations (such as IAHP) in collaboration with other national and international guideline-creating groups (such as USPSTF in the USA, NICE guidelines in the UK, etc.).
7.	Education in medication management at the end of life should be organized for health care professionals.
8.	Physicians should be educated in the (patho)physiological changes at the end of life.
9.	Health care professionals should be trained in the pharmacological treatment of symptoms at the end of life.
10.	Health care professionals should be trained to denominate (mark) the end of life to patients and/or their family.
11.	Health care professionals should be trained in communicating with patients and/or their family about decision-making on medication management at the end of life.
12.	Pharmacist should be an integral part of educating other health care professionals about medication management at the end of life.
13.	Education in medication management at the end of life should be incorporated in all medical training (nursing school, medical students, residencies and fellowships).
14.	Medical officers working in the field of palliative care need to undergo formalized training and pass this successfully before being allowed to operate at a consultant level.
15.	The pharmacological treatment of symptoms at the end of life should be more evidence based.
16.	Discontinuing medication at the end of life should be more evidence based.
17.	Alternative administration of drugs for patients unable to swallow at the end of life should be investigated.
18.	A list of drugs with a high risk of inappropriateness at the end of life should be developed.
19.	Studies investigating the effect of discontinuing medication should be done.
20.	At the end of life each drug should be revised for its potential congruence with the clinical aims of the specific situation in a specific patient.
21.	Patient or proxy based assessment tools (e.g. ESAS, EORTC, symptom diary, PPS, PPI) should be used to aid symptom assessment and treatment at the end of life.
22.	Physicians should discuss the end of life with the patient in a timely manner.

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23.	Physicians should discuss the wishes, treatment goals and priorities regarding medication management at the end of life with the patient in a timely manner.
24.	Nurses should contribute to medication management at the end of life by monitoring and signaling.
25.	The primary treating physician should coordinate the medication management at the end of life.
26.	The primary treating physician should monitor the implementation of the end-of-life care plan.
27.	The primary treating physician should ensure that the information about the medication management is passed on in case of a transfer at the end of life.
28.	Other physicians should keep the primary treating physician informed in a timely manner about changes in the clinical condition or the medication of the patient.
29.	The primary care physician should help with end of life medication management long before the end of life, preparing the patient and family for likely changes to the medications that will occur when the patient is at the end of life.
30.	The role of the nurse in medication management at the end of life should depend on the level of education of the nurse.
31.	The role of the pharmacist in medication management at the end of life depends on the complexity of the patient, the expertise of the treating physician, the clinical setting and availability of a pharmacist.
32.	A medication review at the end of life should take place on admission.
33.	Medication management should be part of each multidisciplinary team meeting for patients at the end of life.
34.	The substitute of the primary treating physician should have access to the medication management plan at the end of life.
35.	In communicating about medication management at the end of life nurses and physicians should take into account the norms and values of the patient and/or family.
36.	It should be discussed with the patient which role he/she would like to have in decision making regarding medication management at the end of life.
37.	It should be discussed with the patient and/or family that the goal of medication management at the end of life is improving/maintaining the quality of life.
38.	The indication and (dis)advantages of the medication should be discussed with the patient and/or family at the end of life.
39.	It should be discussed with the patient and/or family how the medication can be adjusted at the end of life and what can be expected of these changes.
40.	Changes in the medication management plan at the end of life and the motivation should be recorded in the (electronic) medical record.
41.	Both reasons for discontinuing and continuing of medication at the end of life should be recorded.
42.	Both reasons for discontinuing and continuing of medication at the end of life should be passed on at a transfer.
43.	Medication management at the end of life should be individualized, based on the patient's clinical situation.



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## Supplement 2: Adjusted and added solutions

The following solutions suggested by you as experts were added to the solutions presented in the first round or were adjusted. Presented in *italic* the words added and ~~striketrough~~ the words deleted.

### Awareness and organization

A medication review should be an integral part of the ~~daily~~ care for patients at the end of life.

The importance of medication management in end-of-life care should be advocated for by health care professional organizations and discussed at national professional conferences.

Creation of policies or guidelines about medication management at the end of life should be sponsored or endorsed by internationally respected palliative care organizations (such as IAHPCC) in collaboration with other national and international guideline-creating groups (such as USPSTF in the USA, NICE guidelines in the UK, etc.).

### Education

Physicians should be *educated* ~~trained~~ in the (patho)physiological changes at the end of life.

Health care professionals should be trained *to denominate (mark) in denominating* the end of life to patients and/or their family.

Pharmacist should be an integral part of educating other health care professionals about medication management at the end of life.

Education in medication management at the end of life should be incorporated in all medical training (nursing school, medical students, residencies and fellowships).

Medical officers working in the field of palliative care need to undergo formalized training and pass this successfully before being allowed to operate at a consultant level.

### Research and development

~~The effect of~~ discontinuing medication at the end of life should be more evidence based.

A list of drugs *with a high risk of inappropriateness that normally can be stopped* at the end of life should be developed.

Studies investigating the effect of discontinuing medication should be done.

At the end of life each drug should be revised for its potential congruence with the clinical aims of the specific situation in a specific patient.

### Tools

*Patient or proxy based assessment tools* ~~available tools~~ (e.g. ESAS, EORTC, symptom diary, PPS, PPI) should be used to aid symptom assessment and treatment at the end of life.

### Roles

The primary care physician should help with end of life medication management long before the end of life, preparing the patient and family for likely changes to the medications that will occur when the patient is at the end of life.

The role of the nurse in medication management at the end of life should depend on the level of education of the nurse.

The role of the pharmacist in medication management at the end of life depends on the complexity of the patient, the expertise of the treating physician, the clinical setting and availability of a pharmacist.

### Decisionmaking

The substitute of the *primary* treating physician should have access to the medication management plan at the end of life.

### Other

Medication management at the end of life should be individualized, based on the patient's clinical situation.

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