

National care pathway for lung attack with hospital admission

Better care for patients with COPD

PATIENT FOCUSED





National care pathway for lung attack with hospital admission

Better care for patients with COPD

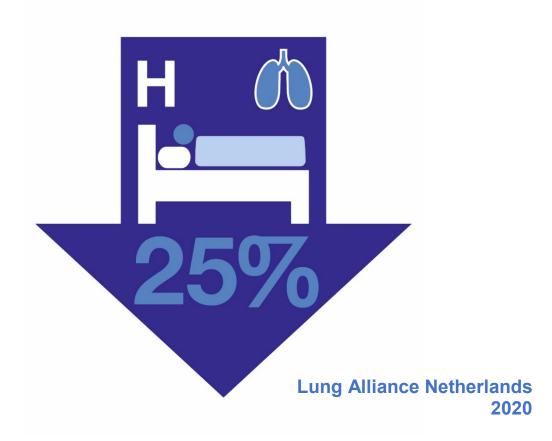


Table of contents

Schematic representation of lung attack care pathway 8 Reading guide 10 Specific contact moments 11 Element 1. Integral health status 18 Monitoring quality of life 20 Identify reason for hospitalisation 21 Global inventory of integral health status 22 Indication for multidisciplinary lung rehabilitation 21 Inventory of integral health status 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations sometry after hospitalisation 30 Coordinating Advance Care Planning expectations in a dation plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking ceassation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Hothif y smoking habit and quitting motivation shortly after hospitalisation 52	Summary	4
Specific contact moments 11 Element 1. Integral health status 18 Monitoring quality of life 20 Identify reason for hospitalisation 21 Global inventory of integral health status 22 Indication for multidisciplinary lung rehabilitation 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations 29 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 36 Draw up and discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan 36 Update the Individual Care Plan and Lung Attack Action Plan 36 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation 52 Check	Schematic representation of lung attack care pathway	8
Specific contact moments 11 Element 1. Integral health status 18 Monitoring quality of life 20 Identify reason for hospitalisation 21 Global inventory of integral health status 22 Indication for multidisciplinary lung rehabilitation 23 Inventory of integral health status 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globably discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan 36 Lement 4. Broking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 52 Check and discuss medication, inhalation technique and therapy compliance 52 Check and discus med	Reading guide	10
Element 1. Integral health status 18 Monitoring quality of life 21 Identify reason for hospitalisation 21 Global inventory of integral health status 22 Indication for multidisciplinary lung rehabilitation 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 36 Globally discurss Lung Attack Action Plan in combination with the Individual Care Plan. 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking status and quitting motivation shortly after hospitalisation 45 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance 52 Check discuss medication, inhalation technique, provide instruction 5		
Monitoring quality of life 20 Identify reason for hospitalisation 21 Global inventory of integral health status 22 Indication for multidisciplinary lung rehabilitation 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 35 Globally discuss Lung Attack Action Plan in combination with the Individual Care Plan. 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan. 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 43 Identify smoking habit and quitting motivation 43 Discuss moking status and quitting motivation 47 Evaluation of smoking status and quitting motivation 47 Evaluation of smoking status and		
Global inventory of integral health status 22 Indication for multidisciplinary lung rehabilitation 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations and action plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss moking cessation if necessary 45 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, and therapy compliance 50 Adjust medication and therapy compliance 50 Adjust medication and therapy compliance 50 Adjust medication and therapy compliance 50 Check add discuss medication, inhalation technique and therapy compliance <	Monitoring quality of life	20
Indication for multidisciplinary lung rehabilitation 23 Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 28 Discuss and coordinate expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking status and quitting motivation 47 Evaluation of smoking status and quitting motivation 47 Evaluation of smoking status and quitting motivation 50 Adjust medication and therapy compliance 50 Adjust medication and importance of therapy compliance 52 Check asirability of oxygen at home 53 Check and discuss medication, inhalation technique and		
Inventory of integral health status 24 Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Inventory of medication and therapy compliance and oxygen 48 Inventory of medication and importance of therapy compliance 52 Check desirability of oxygen at home 52 Check desirability of oxygen at home 52 <t< td=""><td>Global inventory of integral health status</td><td> 22</td></t<>	Global inventory of integral health status	22
Reassessment of integral health status 25 Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 28 Discuss and coordinate expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan in combination with the Individual Care Plan and Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 43 Discuss smoking cessation 41 Identify smoking habit and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation shortly after hospitalisation 47 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 52 Check asirability of oxygen at home 53 Check asirability of oxygen at home 54 Check and discuss medication, inhalation	Indication for multidisciplinary lung rehabilitation	23
Element 2. Advance Care Planning and Palliative Care 26 Manage wishes and expectations 28 Discuss and coordinate expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 36 Draw up and discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 50 Adjust medication and therapy compliance 50 Adjust medication and therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation t		
Manage wishes and expectations 28 Discuss and coordinate expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 36 Discuss smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance 50 Adjust medication and importance of therapy compliance 52 Check asirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance		
Discuss and coordinate expectations 29 Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 38 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance 50 Adjust medication and therapy compliance 52 Check desirability of oxygen at home 52 Check and discuss medication, inhalation technique, provide instruction 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy c		
Coordinating Advance Care Planning expectations shortly after hospitalisation 30 Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59	Manage wisnes and expectations	28
Coordinating Advance Care Planning expectations 32 Element 3. Individual Care Plan and Lung Attack Action Plan 33 Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise <td< td=""><td>Coordinating Advance Care Planning expectations shortly after bespitalisation</td><td> 29</td></td<>	Coordinating Advance Care Planning expectations shortly after bespitalisation	29
Element 3. Individual Care Plan and Lung Attack Action Plan33 33 Inventory of person-oriented lung attack recognition and action plan36 35 Globally discuss Lung Attack Action Plan in combination with the Individual Care Plan37 36 Update the Individual Care Plan and Lung Attack Action Plan37 37 Update the Individual Care Plan and Lung Attack Action Plan37 37 Update the Individual Care Plan and Lung Attack Action Plan37 31 Identify smoking habit and quitting motivation43 31 Discuss smoking cessation if necessary45 41 Identify smoking status and quitting motivation shortly after hospitalisation46 43 Discuss for Smoking status and quitting motivation47 45 Evaluation of smoking status and quitting motivation47 46 Inventory of medication and therapy compliance and oxygen		
Inventory of person-oriented lung attack recognition and action plan 35 Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 56 Check and discuss medication, inhalation technique and therapy compliance 56 Check and discuss medication, inhalation technique and therapy compliance 56 Check and discuss medication, inhalation technique and therapy compliance 56 <		
Globally discuss Lung Attack Action Plan 36 Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan37 Update the Individual Care Plan and Lung Attack Action Plan39 Element 4. Smoking cessation43 36 Identify smoking habit and quitting motivation43 43 Discuss smoking cessation if necessary45 43 Evaluation of smoking status and quitting motivation shortly after hospitalisation46 46 Evaluation of smoking status and quitting motivation shortly after hospitalisation47 47 Element 5. Medication, therapy compliance and oxygen48 48 Inventory of medication and therapy compliance50 50 Adjust medication and importance of therapy compliance52 52 Check and discuss medication, inhalation technique and therapy compliance53 54 Check and discuss medication, inhalation technique and therapy compliance53 55 Check and discuss medication, inhalation technique and therapy compliance59 57 Element 6. Mobility and exercise59 59 Inventory of exercise possibilities and energy distribution61 60 Drawing up care plan		
Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan 37 Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance and oxygen 48 Native medication and check inhalation technique, provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 65 Inventory and optim	Globally discuss Lung Attack Action Plan	36
Update the Individual Care Plan and Lung Attack Action Plan 39 Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance and oxygen 50 Adjust medication and therapy compliance 50 Adjust medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63		
Element 4. Smoking cessation 41 Identify smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 63 Inventory and optimisation of nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 <		
Identity smoking habit and quitting motivation 43 Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 54 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 63 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 67 Element 8. Comorbidity		
Discuss smoking cessation if necessary 45 Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and check inhalation technique, provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional interventi	Identify smoking habit and guitting motivation	43
Evaluation of smoking status and quitting motivation shortly after hospitalisation 46 Evaluation of smoking status and quitting motivation 47 Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and check inhalation technique, provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity <t< td=""><td></td><td>4 -</td></t<>		4 -
Element 5. Medication, therapy compliance and oxygen 48 Inventory of medication and therapy compliance 50 Adjust medication and check inhalation technique, provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Lement 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		46
Inventory of medication and therapy compliance 50 Adjust medication and check inhalation technique, provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 63 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71	Evaluation of smoking status and quitting motivation	47
Inventory of medication and therapy compliance 50 Adjust medication and check inhalation technique, provide instruction 51 Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 63 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71	Element 5. Medication, therapy compliance and oxygen	48
Discuss medication and importance of therapy compliance 52 Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Check desirability of oxygen at home 53 Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Check and discuss medication, inhalation technique and therapy compliance 54 Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Check oxygen consumption 55 Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Check and discuss medication, inhalation technique and therapy compliance 56 Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Element 6. Mobility and exercise 57 Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Engage physiotherapy and start therapy 59 Inventory of exercise possibilities and energy distribution 60 Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Inventory of exercise possibilities and energy distribution 60 Drawing up care plan61 Mobility and exercise evaluation62 Element 7. Nutritional status63 Inventory and optimisation of nutritional status65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation67 Element 8. Comorbidity68 Identify current comorbidity70 Comorbidity diagnostic and treatment plan71		
Drawing up care plan 61 Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Mobility and exercise evaluation 62 Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Element 7. Nutritional status 63 Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Inventory and optimisation of nutritional status 65 Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Assessment of nutritional status and nutritional intervention shortly after hospitalisation 66 Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71	Inventory and optimisation of nutritional status	6 5
Assessment of nutritional status and nutritional intervention 67 Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Element 8. Comorbidity 68 Identify current comorbidity 70 Comorbidity diagnostic and treatment plan 71		
Identify current comorbidity		
Comorbidity diagnostic and treatment plan 71	Identify current comorbidity	

Fewer hospital admission days for lung attacks necessary and feasible

Summary

Necessity

There are more than 600,000 people with COPD in the Netherlands, and this number is increasing. Every year, 30,000 people in the Netherlands are hospitalised for a lung attack. It concerns a total of approximately 200,000 hospital admission days, half of which are readmissions; 20% of these patients are even readmitted three or more times a year for a lung attack.

In the Netherlands, we attempt to not use the general medical term 'exacerbation' and have reframed to use the words lung attacks, to facilitate communication with patients and their beloved. It also serves to stress to both patients and caregivers that two year mortality after a lung attack (COPD) is higher than after a heart attack.

Lung attacks cause a lot of suffering to patients and their environment by greatly, and often permanently, increasing the burden of disease and care. More than 10,000 people die of COPD every year, largely as a result of lung attacks.

The health care costs of COPD will triple until 2032. More than 50% of all COPD-related health care costs are attributable to admissions as a result of lung attacks.

COPD care pathway success factors

The national care pathway for a lung attack with hospital admission has shown in a large-scale pilot that the number of admission days is substantially reduced with better job satisfaction for care providers, and at least an equal quality of life and patient satisfaction.

The success factors of the care pathway can be divided into three categories:

1) Increased problem awareness

Regions are more aware of the fact that there are many hospital admissions for lung attacks and that a relatively small group of patients cause a lot of readmissions. There is greater awareness that many (re)admissions can be prevented by tracing the underlying causes of the severity of the lung attack and acting accordingly.

2) Care organisational improvements

Without a structured approach and organised cooperation, the variation in practice between institutions, between care providers, and between the actual times of admission (morning, afternoon, working days, weekends, etc.) is enormous. Working with the care pathway provides structure, for example by appointing a monitor/care coordinator, as well as by organising a transmural collaboration/transfer between second and first line work settings, geriatric rehabilitation and intensive collaboration with home care providers. Structure and good organisation, both during and after admission, contribute to a decrease in the number and duration of (re)admissions.

3) Substantive health care improvements

Working according to the national care pathway has shown that COPD patient care is improved and the number of admission days is reduced. Interventions that have a significant association with fewer days of admission are:

- initiation of contact moment in the first week after discharge;
- non-pharmacological as well as pharmacological smoke control in the year following hospitalisation;
- discussion of the Lung Attack Action Plan (LAAP) in the year after hospitalisation;
- check on inhalation medication technique in the year after hospitalisation.

For more detailed information, see Appendix 1



Content of COPD care pathway

Continuum, patient central, identification and implementation

The care pathway for COPD attack with hospitalisation describes the structured care provided during admission and after discharge, to patients with COPD who are admitted for a lung attack. Continuity of care, listening to the needs of the patient and good interdisciplinary collaboration are requirements.

Readmissions are prevented by giving the patient more insight into the cause of the admission, the recognition of, and early action in the event of an exacerbation of symptoms. In addition, patients are given the opportunity to become coordinators of their own care plan.

During hospitalisation: identifying problems and opportunities, implementation after hospitalisation

One of the most important tasks concerning the treatment of the patient during admission is to identify and raise the issue of problems and opportunities, most of which will be discussed and dealt with together with the patient after the admission.

To this end, the care pathway during admission describes some crucial moments of contact between patient, informal carer and care provider.

1) The day-2 interview

The purpose of the day-2 interview is to find out at an early stage what the underlying reason for the admission is; this can serve as a starting point for drawing up the care plan. In addition, the different expectations of the patient, the informal carer and the care providers regarding admission and recovery will be streamlined. This involves looking forward to see what is required for a successful journey back home. Specifying the target discharge date is a fixed part of this.

2) The discharge meeting

The purpose of the discharge meeting is to find out whether the patient (and his/her (in)formal carer) have sufficient confidence in the discharge and can take the necessary actions in the event of increasing complaints. In addition, the essential activities of the first few weeks will be discussed. This includes checking whether the patient knows who the first point of contact will be in the coming period.

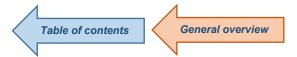
Some other topics that are discussed during admission are the early mobilisation of the patient, checking the inhalation technique, therapy compliance, and identification of smoking habits and quitting motivation. Also, in case of a positive quitting motivation, smoking cessation counselling should be started immediately. In addition, an admission is a good time to check whether a patient is eligible for Advance Care Planning meetings after admission, i.e. proactive care planning.

After admission: prevent relapse and support care plan

Additional efforts to prevent readmissions are necessary, as about half of hospitalisations for COPD are readmissions. These readmissions usually take place in the first few weeks after admission. For this purpose, several contact moments are planned with the patient, (in)formal carer and care provider.

3) Week 1 contact

Within one week after admission, the patient is contacted to check how the patient is doing and whether all the agreements made are clear. In this way, it is estimated whether or not things are in order and it is ascertained whether the patient is lapsing back into old habits. Regions attribute evident added value to home visits and/or eHealth applications, especially for patients who are admitted repeatedly. During a home visit, discussed matters can be discussed (again) in one's own familiar environment, including the actions to be taken in the event of a worsening of complaints and/or a relapse into a certain lifestyle. It also provides an overall impression of the patient's habits and behaviour.



4) Short term: drawing up care plan

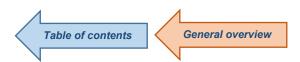
After about two weeks, the recovery from the lung attack is central and a first step is made to draw up an Individual Care Plan together with the patient. The patient's personal targets form the guideline for this care plan. Together with the patient, short-term/long-term objectives are formulated and the patient is supported in achieving this goal. If specific actions and/or health care professionals are required, these will be engaged. Specific components that may be focussed on include lifestyle factors such as smoking, exercise and nutrition, the proper inhalation of medication, dealing with any fear of suffocation and/or discussing any wishes (in due course) for a dignified end to life.

5) Long term: evaluation and adjustment

Over time (and ultimately at least annually), follow-up appointments are made, in which the central issue is the patient's integral health status and the personal targets of the patient are worked on. Objectives are evaluated and adjusted.

Schematic view of care pathway for lung attacks with hospitalisation

The care pathway is shown schematically on page 8. The horizontal axis shows the contact moments plotted in time. The vertical axis points at the different interventions per topic. The various topics, referred to as elements, are: Integral Health Status, Advance Care Planning, Individual Care Plan and Lung Attack Action Plan, Smoking cessation, Medication, Therapy compliance and oxygen, Mobility and exercise, Nutritional status and Comorbidity.



Lessons from the 2015-2018 pilot period

The national care pathway for a lung attack with hospitalisation has been tested in eight regions. Eleven hospitals, eleven care groups and six home care institutions were closely involved in the study. In the cohort study, at least 600 patients admitted for a lung attack were followed during one year. From a total of 752 patients, there was enough data for the analysis of success factors.

During the pilot, it became clear that implementing the care pathway is a process of trial and error. Do not underestimate the implementation phase and proceed systematically. The care pathway describes which activities are carried out and, where possible, indicates how this can be done well or even in the best possible way. At the national level, there is no definition of *who* should carry out the intervention, as the options vary greatly from region to region. Who does what, should be determined regionally.

The national care pathway should be seen as a template and requires regional implementations, in which all parties concerned (general practitioner, pulmonologist, nurses, paramedics, health insurer and possibly also social and welfare organisations) are involved at an early stage.

Process-based work directs the steps that need to be taken to develop, implement, evaluate and continuously monitor a care pathway. The seven-phase model of the Clinical Paths Network has been applied here.

In addition to process-based work and providing it with it time and manpower, it is important not to work on too many topics at the same time. Make a choice and choose a maximum of three topics that will be focused on first. Interventions that make the most significant contribution to the reduction of admission days are preferred. In addition, regional factors such as the current situation, the expected improvement potential and whether there is sufficient support from all parties involved (patient, health care providers and health insurer) should be taken into account.

During the pilot, many lessons were learnt that were recorded and bundled in a guide for regions that want to implement the care pathway (<u>Appendix 2</u>).

Future

The LAN asks all health care organisations, health care providers, health insurers, government authorities and other parties involved in COPD care to start implementing the care pathway in order to systematically reduce the number of admission days with COPD. This prevents suffering in COPD patients, increases the job satisfaction of health care providers and contributes to keeping health care expenditure under control.

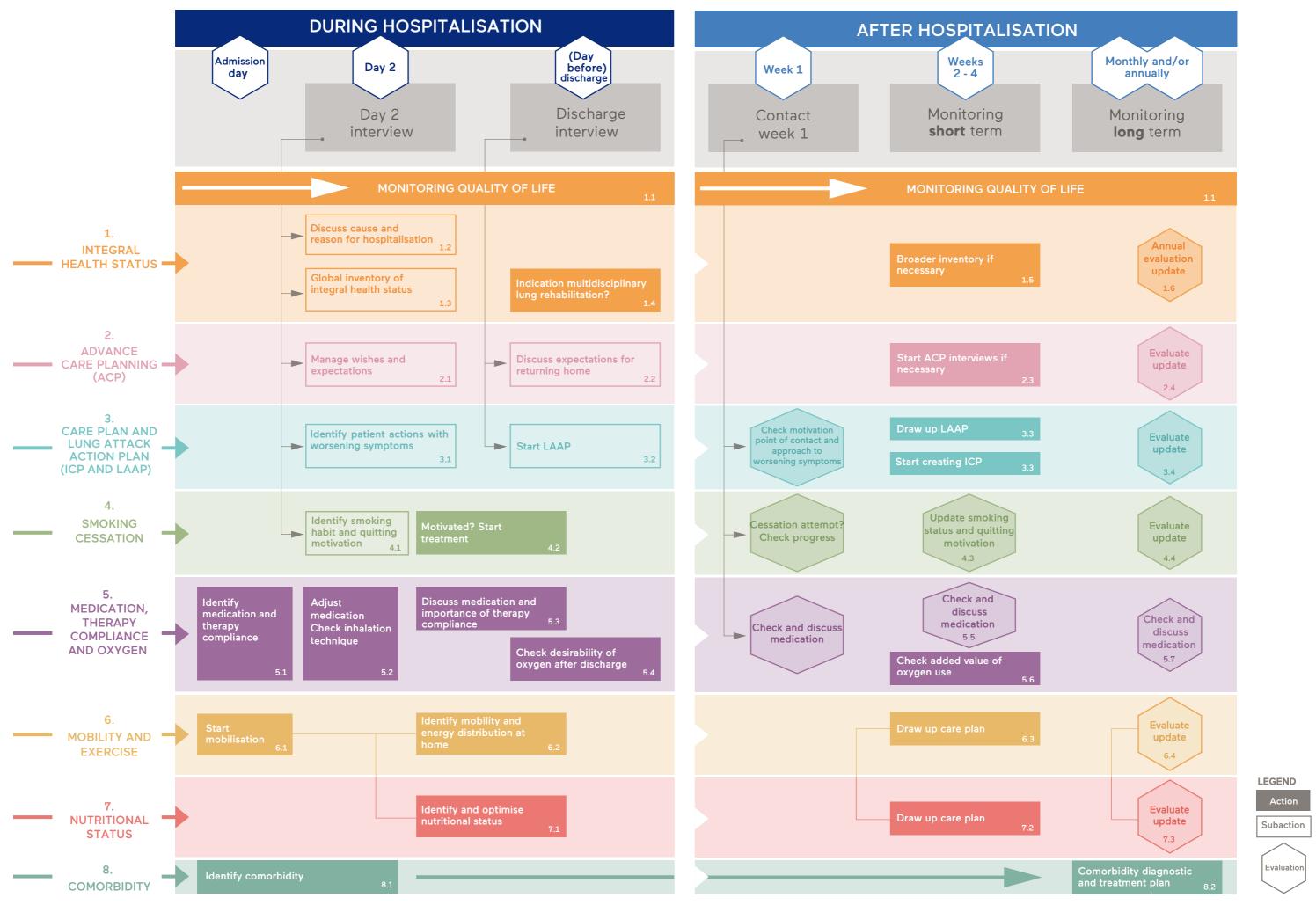
Because of the positive effects of working with the care pathway, we expect that lung patients and patients' associations, health care providers, health insurers, governments and inspectorates throughout the Netherlands will eventually emphatically request that systematic efforts be made to reduce the number of admission days for COPD. This is in the interest of COPD patients and the quality, accessibility and affordability of care.

With the support of the Ministry of Health, Welfare and Sport and *Innovatiefonds Zorgverzekeraars*, the Lung Alliance Netherlands (LAN) will continue to support working with the care pathway for a lung attack with hospitalisation in the coming years. All materials developed in the process will be made available to regions that are working on reducing hospitalisation days due to lung attacks. Furthermore, the care pathway will be integrated into guidelines, quality and care standards and purchasing conditions. More information can be found at <u>www.longalliantie.nl/zorgpad</u>.

The LAN wishes all patients, health care providers, health insurers and governments much success and satisfaction with the systematic reduction of lung attacks with hospitalisations.







Reading guide

The care pathway for a lung attack with hospitalisation describes consecutive interventions that will improve overall care for patients with COPD and reduce the number of hospitalisation days. These interventions are represented over time and divided into eight topics (elements). The continuity of care is central to the entire care pathway. That is why good interdisciplinary collaboration is a prerequisite for success.

Schematic representation of care pathway

The care pathway is shown schematically on page 8. This figure shows an overview of all interventions and contact moments.

The horizontal axis shows the contact moments plotted in time. These contact moments are described in the <u>Specific contact moments with the patient</u> chapter.



The interventions of the care pathway are divided into eight topics (elements). These elements can be found on the vertical axis of the Time Task Matrix and each has its own colour and number.



Intervention structure

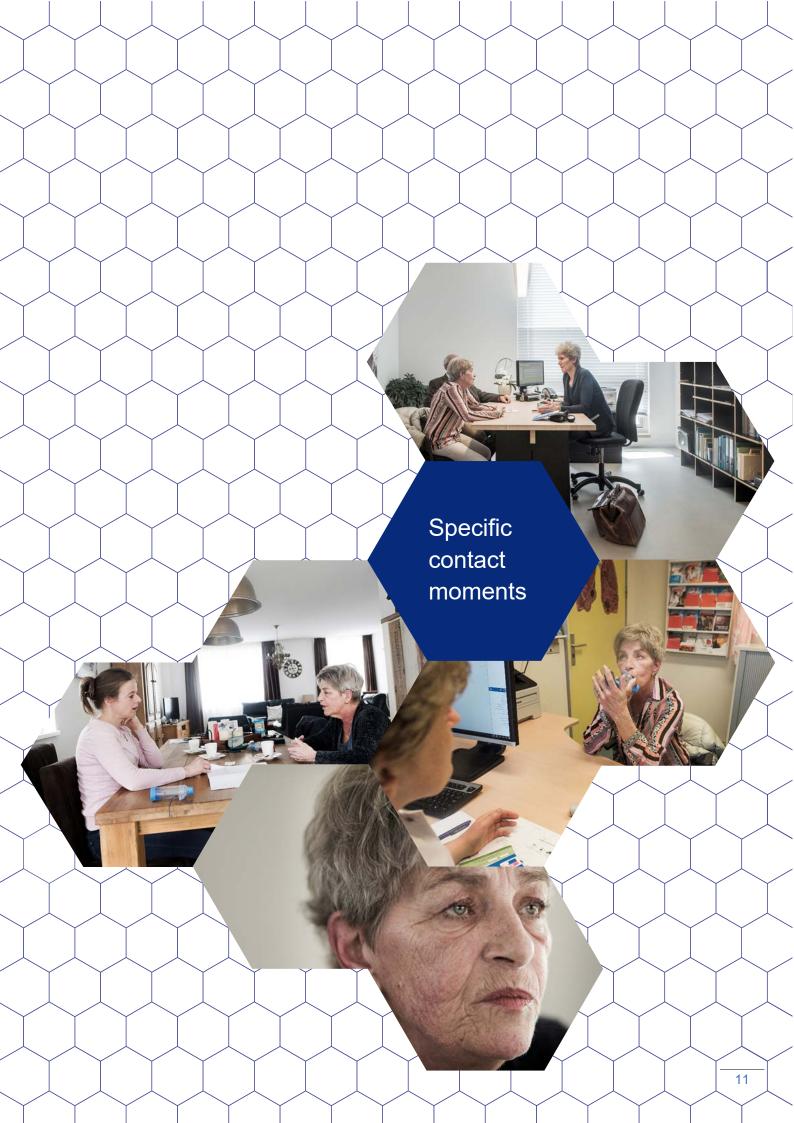
Each intervention has a similar structure and comprises the following components:

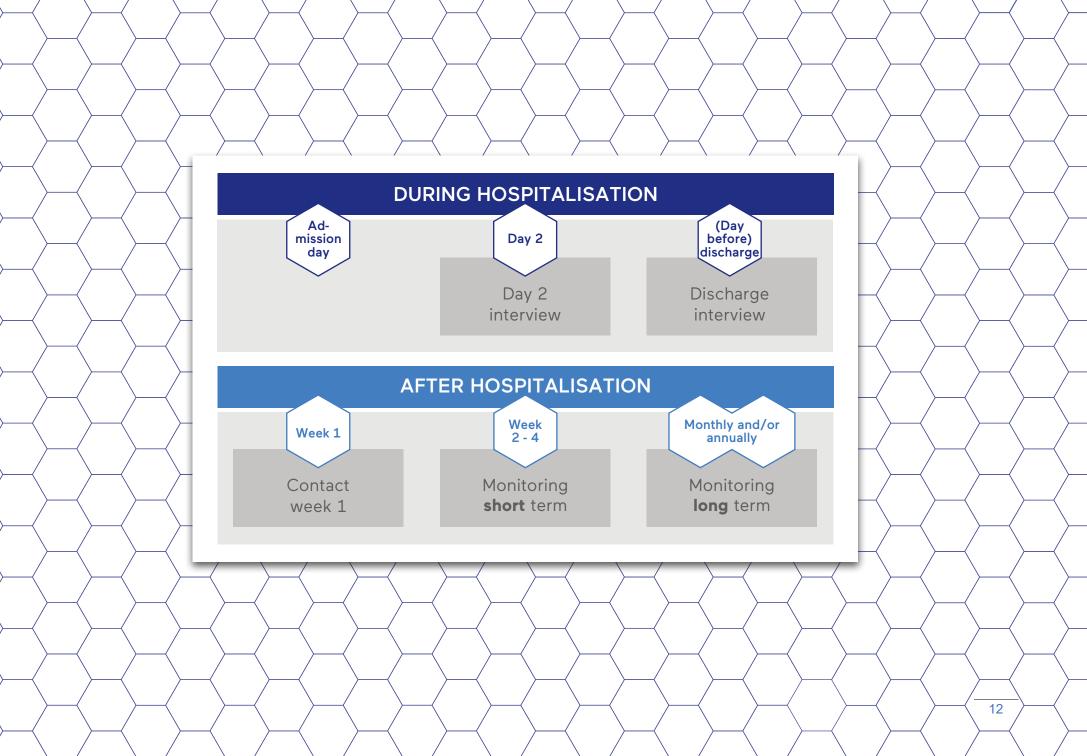
- 1. Concept description; indicates briefly what the intervention means.
- 2. Practical tools; indicates the minimum of activities that fall within the scope of this intervention.
- 3. Instruments; an overview of tools that can help with execution.

Hyperlinks in the document

In the digital version, there are several hyperlinks which allow you to jump directly to the relevant element/component. These hyperlinks can be found under the coloured blocks at the top right of each page and/or in the summary. Hyperlinks are also included in the schematic overview. The arrows at the bottom of each page bring you back to either the table of contents, the schematic overview or the summary.







Specific contact moments

COPD care pathway contact moments

Continuity of care and listening to the needs of the patient are focal points in the care for patients with COPD. That is why the care pathway specifies some crucial contact moments, which are central to the implementation of the care pathway:

- 1. the day-2 interview;
- 2. the Discharge Meeting;
- 3. contact moment week 1 after hospitalisation;
- 4. short-term appointments;
- 5. long-term appointments.

Signalling function during hospitalisation, to be addressed after hospitalisation

One of the most important tasks in the treatment of the patient during hospitalisation is to identify any problems and opportunities, and put them on the agenda. After hospitalisation, these are then picked up and addressed. The day-2 interview, the discharge meeting and the appointment of a care coordinator will certainly help to carry out this signalling function in a positive way.

Care coordinator:

- acts as the first point of contact for the patient;
- is the care provider who coordinates all tasks, agreements and actions between care providers within a multidisciplinary partnership;
- explicitly contributes to the communication between the care providers and the patient during the entire care process, especially during transfer moments;
- takes responsibility when things don't go as planned and calls people to account.

Care coordinator conditions:

- The care coordinator always acts in the interest and the care needs of the patient, is aware of the home situation and knows the social map of the region. Although it is formally possible, it is not usually the person ultimately responsible for the treatment of a patient (the primary practitioner). Preferably, there should be one coordinator throughout the entire process. Suitable persons for this task might be a specialised nurse from the hospital, home care or Assistant Practitioner.
- The importance of a care coordinator must be supported by all the professionals and facilitated in matters of cooperation, time and money.

Contact moments during hospitalisation

1. The day-2 interview

On day two of the hospitalisation, a conversation day-2 interview will take place with the patient, carer(s), nurse, doctor and preferably the care coordinator, following a standard format. The purpose of this meeting is to find out at an early stage what the real reason is for the hospitalisation, and this conversation may serve as a starting point for the care plan. In addition, the various expectations regarding hospitalisation and recovery are brought into line, and a start is made in thinking about what preparations can be made to ensure a successful return home.

Having a fixed moment in the early stages of the hospitalisation has added value; it gives structure to the daily activities and provides support to the patient and family.



Points for discussion with patient

- Find underlying reason for hospitalisation (<u>KI 1.2</u>);
- Inventory of wishes and expectations regarding admission AND recovery of the patient, informal carer(s) and care provider (<u>KI 2.1</u>);
 - The day-2 interview is an excellent moment to clarify that the patient will certainly not feel fully recovered when discharged, but, on balance, will be better off at home than in hospital;
 - Specifying the expected discharge date. By discussing this date, the discharge does not come as a surprise to the patient/informal carer and there will be time to prepare for a successful return home. In this way, additional care providers may also be introduced in time.
- Global inventory of integral health status, including psychosocial and philosophical issues (KI 1.3);
- Find out what the patient does in case of an exacerbation of symptoms (KI 3.1);
- Identify smoking habit and quitting motivation (KI 4.1);
- Agree who will be the first point of contact during hospitalisation.

Record the conversation in the patient file, so that, combined with the inventory of medication, exercise, nutrition and comorbidity, this can be used as input for

- a) the multidisciplinary consultation;
- b) the discharge meeting with the patient;
- c) the transfer after discharge.

2. The Discharge Meeting, preparing for discharge

On (the day before) discharge, a meeting takes place with the patient, informal carer(s) and care provider(s) following a standard format. The purpose of the conversation is to find out whether the patient (and his/her carers) have sufficient confidence in the discharge and can take the necessary actions in the event of increasing complaints. In addition, the essential activities of the first weeks are discussed, such as home visits, rehabilitation, etc.). Lastly, enquiries may be made as to what extent expectations regarding the admission and discharge have been met.

Points for discussion with patient

- Check whether patient/informal carer has confidence in discharge (KI 2.2);
- Check again what the patient thinks they need to successfully make the transition home and, if necessary, call in appropriate aid workers;
- Repeat which actions the patient/informal carer should take in case of increasing complaints (<u>KI</u> <u>3.2</u>);
- Provide written name and contact details of *first person to contact* after discharge and in case of emergency;
- Summarize the activities that are initiated immediately after admission;
- Has the patient indicated the intention to *quit smoking* immediately? In that case, the support that was started in the hospital must be continued immediately (<u>KI 4.2</u>);
- Briefly *state* the provisionally drawn up *care plan* and indicate that it will be *adjusted* to the personal needs of the patient *in the coming period* in close consultation with the patient (<u>KI 3.2</u>);
- Ask permission to send the discharge letter to the relevant care provider(s).

Preparation for discharge and discharge letter

Formalise agreements with first and second line workers about the follow-up process, including respective responsibilities. To do so, send a **transfer message** (or provisional discharge message) to general practitioner, care coordinator, and other relevant care provider(s) **within 24 hours**. An updated medication overview must be sent to the patient's pharmacy. Use a format for the transfer message that is tailored to each of the recipient's needs and, in addition to the content, make it clear which follow-up actions you expect from each party. The discharge letter with more detailed information may follow at a later date.



<u>Transfer message content (within 24 hrs)</u>: The day-2 interview and the discharge meeting can provide important input for both the transfer message and the discharge letter:

- Reason for hospitalisation;
- Abnormal findings during hospitalisation, including subsequent actions;
- Discharge date and reference to:
 - CCQ, all domains (if possible disease burden);
 - Smoking cessation intervention started?
 - Medication on discharge, including agreements in the event of worsening complaints;
 - Oxygen therapy?
 - Have wishes with regard to No resuscitation/No artificial respiration or No readmission been discussed, resulting in any advice on sending in?
 - LAAP discussed? (Long Attack Action Plan)
 - Advance Care Planning actions.
- Actions or advice for first line workers after discharge;
- Who will seek contact after approx. 1 week?
- Care coordinator/ first person of contact for patient;
- Contact details pulmonologist/responsible respiratory nurse (not a trainee);
- Involvement of partner/informal carer in agreements.

An *empathetic transfer* from hospital to (involved) external care provider can turn out to be extremely beneficial for good care:

- in the case of specific agreements in the context of Advance Care Planning/palliative care;
- in the case of ensuring continuity if the patient also had regular contact with various health care providers before hospitalisation;
- in the case of specific treatment goals having been formulated during hospitalisation for which contact with the patient is required shortly after discharge.

Providing information to the patient

Upon discharge, the patient/informal carer will receive useful information, such as:

- actions to be taken in the event of worsening complaints, including first person of contact (KI 3.2);
- dates and actions for follow-up appointments;
- <u>www.inhalatorgebruik.nl;</u>
- information material, including the patient version of the COPD care pathway, 'discharge' information sheet (<u>Appendix 4</u>) and the animated videos.

Examples of 1st line documents:

- Transfer message within 24 hours (Appendix 5b);
- Discharge letter (<u>Appendix 5c</u>).

3. Contact moment week 1 after hospitalisation

After discharge from the hospital, the patients (usually) return to their familiar home situation. This can be a pitfall for regression into old habits which may have been (at least in part) the cause of the lung attack. This has to be taken into account. Moreover, many patients are not back at their previous health level yet. Some additional support, where positive reinforcement is paramount, can make all the difference.

Points for discussion with patient

- How the patient has been doing since discharge and are there any questions;
- Are the agreements made quite clear to the patient, informal carer and care coordinator;
- Check familiarity with the care coordinator as the first person of contact,
- Motivation and progress of agreements already made;
- Recap *pitfalls/success factors* if necessary;
- Use of medication;
- What to do in case of worsening complaints;



- Always respond to a *smoking cessation* attempt.

The importance of a contact moment in the first two weeks after discharge for reducing hospitalisation days has been demonstrated in the pilot. Regions attribute clear added value to a home visit and/or an eHealth application, especially for patients who are admitted repeatedly. During a home visit, matters can be discussed (again) in one's own familiar environment, including the actions to be taken in the event of a worsening of complaints and/or a relapse of a certain lifestyle. It also provides a good overall impression of the patient's habits and behaviour. For more information and tips from the pilot regions, see <u>Appendix 3</u>.

4. Short-term monitoring

After approximately two weeks, there is a follow-up appointment between patient, informal carer(s), and care provider, in which the recovery from the lung attack is the central issue. If possible, the care coordinator, if he/she is not the care provider, will also be present at this meeting.

Points for discussion with patient:

Re-evaluate the integral health status and consider all elements relevant to the patient.

- Identify and *bundle the new insights*;
- Discuss the full Lung Attack Action Plan (KI 3.3);
- Together with the patient, make a start on drawing up an *Individual Care Plan*, in which realistic short-term objectives are central (<u>KI 3.3</u>);
- Make an inventory of what is needed for current *personal targets* and, if necessary, engage relevant case workers;
- If not yet done, agree on who will be *the first person of contact* in the follow-up process. Ideally, this should be the same person as during the hospitalisation.

Use the Individual Care Plan as a guideline throughout the conversation. This way, it becomes a living document and patients are given the opportunity to play an active role in their own care plan.

5. Long-term monitoring

After approximately two months (and ultimately at least annually), there is a follow-up appointment with the patient, informal carer(s), and care provider, in which the *integral health status* of the patient is the central issue (KI 1.6) and the patient's *personal targets* (KI 3.4) are reviewed.

Points for discussion

- Evaluate the general expectations, the effect of the treatment and/or the achievement of targets;
- Identify and bundle new insights;
- Together with the patient and informal carer(s), set realistic short-term and long-term goals and, if necessary, engage relevant professionals;
- Think of the benefits of iterative discussions on ACP (Advance Care Planning), smoke cessation motivation, integral health status, inhalation technique and compliance. Also include these in the Individual Care Plan.

Assistance for the contact moments

<u>Appendix 5</u> provides examples of:

- a guideline to a day-2 interview;
- a transfer message that can be sent to the 1st line care providers on the day of discharge;
- a discharge letter to the 1st line care providers;
- a written memo from week 1 (home visit);
- a Lung Attack Action Plan;
- an Individual Care Plan (week 2/4 and after approx. 3 months).



Patient version and animated videos for COPD care pathway

A version of the COPD care pathway has been developed for patients. It describes, in words and pictures, what the patient is to expect from the moment of hospitalisation due to a lung attack, as well as his or her own role in the process. And not just inside the hospital, but also outside.



It also contains information on important aspects about the prevention of lung attacks. The patient version is digital and freely available and can be adapted to the interpretation and planning of the own local/regional care pathway. An explanation of the patient version, indicating how this patient version can best be used, including references to the files, can be found in Appendix 4.

There are also <u>Animated videos</u>, which depict a number of topics in the patient care pathway into images. In addition to explaining various subjects, attention is also paid to the patient's own role, so that they can actively contribute to the treatment.

The topics of the animated videos are:

- How do I recognise a lung attack?
- Setting goals
- Informal carer
- Discuss Advance Care Planning

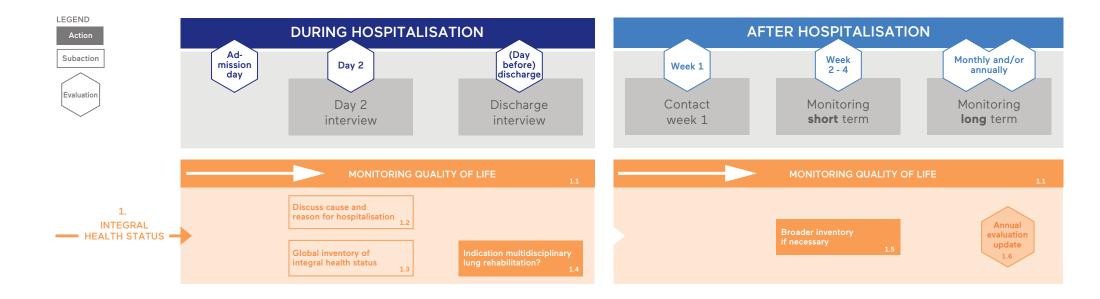
www.longfonds.nl/animatievideos-over-longaanval





N. Zist Control







Monitoring quality of life

When: from beginning to end of care pathway

Concept definition

The quality of life is measured on a regular basis, so that the care provider and the patient get a good idea of the (changes in the) experienced disease burden of the patient. Use a validated questionnaire that measures the integral health status (complaints, functional status, mental status) with respiratory complaints due to COPD.

Practical tools

The CCQ (or other instrument) is completed by the patient at least before the end of the hospitalisation period. The care provider interprets the CCQ and compares it with previous outcomes. Subsequently, the results and the resulting action points are discussed with the patient.

Depending on the results in the various domains, a personal action plan is drawn up in ICP (see element 3).

Assessment:

- 0-1 no problem;
- 1-2 consider action;
- >2 action necessary (insofar as there are treatment options);
- A stable condition in the CCQ outcome will also be weighed in the assessment.

Instruments

Measuring instruments:

- <u>Clinical COPD Questionnaire</u>(CCQ) (see <u>Appendix 7b</u>);
- The <u>Assessment of Burden of COPD (ABC)-Tool</u> gives the care provider and the patient insight into the patient's experienced disease burden. The Assessment of Burden of COPD (ABC)-Tool is a measuring instrument with which disease burden can be assessed in a simple, user-friendly and practical way, thereby providing a point of departure for a good, personalised conversation with the patient;
- The Nijmegen Clinical Screening Instrument (<u>NCSI</u>) is a tool for identifying and analysing problems in the integral health status.

Example of monitoring of COPD patients

Lucii; remote monitoring using eHealth. Patients with COPD complete a digital CCQ questionnaire every two weeks. Using an algorithm, conspicuous/needy patients are filtered out and connected to the home care help desk. Direct visual contact between patient and care provider is possible.

Sensire, Slingeland Hospital, Menzis



Key intervention 1.2 Identify reason for hospitalisation When: day 2

Concept definition

During the day-2 interview, the cause of a lung attack is identified. In addition to physiological causes, a broader view is needed of the deeper cause and/or reason for hospitalisation. If necessary, adjust the care plan to this knowledge, both during and after hospitalisation.

Practical tools

Example opening sentence: "if I'm hearing you right, you have been short of breath all year: what made it so different this time that you couldn't manage at home?"

Possible other questions that might be helpful:

- What do you think is the main reason you couldn't manage at home?
- Were there any infections or special exposures in your surroundings?
- What was different, besides more shortness of breath/coughing/sputum:
 - lost informal care;
 - home situation;
 - loneliness;
 - recent loss;
 - other conditions;
 - medication problems (availability, image(s) of medication);
 - reduced appetite or food intake?
- Are these changes acute/not acute and of a temporary or sporadic nature?
- Does the patient know why he/she has been admitted?
- Does the patient or informal carer suffer from anxiety or panic?

Instruments

Patient material:

- Animated video "What is a lung attack? and "How do I recognise a lung attack?;
- COPD care pathway, information sheets 'What is COPD' and 'What is a lung attack' (Appendix 4).



Key intervention 1.3 Global inventory of integral health status When: day 2

Concept definition

During the day-2 interview, a global impression of the integral health status is formed. Specific attention needs to be paid to the way the patient deals with the disease (coping and adaptation) and whether there are anxiety and/or mood problems. If necessary, an extensive inventory is made after hospitalisation and follow-up appointments are made.

Practical tools

The integral health status comprises:

- physiological functioning;
- experienced symptoms/complaints;
- functional limitations in daily life (including comorbidity);
- quality of life.

Possible questions that may be helpful with regard to coping and mood:

- How do you feel you are dealing with your complaints?
- How does your environment feel you are dealing with your complaints?
- How is your mood?
- Do you ever panic or get anxious?
- What rating would you currently give your life? Can you explain that?
- Do you have sufficient support?
- Do you call for help if you need it?
- Do you need additional help or information?

In addition to the generic and disease-specific anamnesis and the physiological spirometry values, 'measuring instruments' can also be used: CCQ (included in Assessment of Burden of COPD (ABC) tool), MRC and BMI (relevant weight loss). Screening questionnaires, such as the Distress screener, can also be helpful.

If there are sufficient indications of anxiety and/or mood problems in the patient, a further inventory is planned <u>after hospitalisation</u>.

See <u>Appendix 7a</u> for more information.

- Use a validated questionnaire, e.g. the CCQ, Assessment of Burden of COPD (ABC) tool or the Well-being meter (geriatrics);
- Distress screener (see Appendix 7);
- Hospital Anxiety and Depression Scale (HADS);
- Patient material:
 - Patient version of COPD care pathway, information sheet 'Fear, sadness and gloominess' (<u>Appendix 4</u>);
 - Information film 'understanding lung disease' and 'accepting your lung disease'.

Indication for multidisciplinary lung rehabilitation

When: (day before) discharge

Concept definition

Assess whether referral to a 2nd or 3rd line lung rehabilitation programme is necessary and, if so, take the corresponding actions.

Practical tools

In many patients who are hospitalised for a lung attack, there is an indication for multidisciplinary rehabilitation. This concerns a level A evidence intervention with, among other things, a reduction of further hospitalisation days as a result. Measurement of the integral health status (see $\frac{Kl}{1.3}$) can help to choose and refer to a 2nd or 3rd line multidisciplinary lung rehabilitation programme.

Directives are:

- degree of disease burden;
- use of health care:
 - frequent lung attacks with problematic self-management;
 - One or more hospitalisations in the year before the last hospitalisation;
- difficulty coping and adapting/presence of extraordinarily increased emotional burden such as anxiety and depressive complaints;
- low physical capacity and/or medical instability;
- presence of comorbidity;
- recent initiation of oxygen therapy;
- added value to initiating support by multiple disciplines;
- the seriousness of the problems experienced should determine referral to either 2nd or 3rd line.

Patients should be well informed about the possibilities of lung rehabilitation in order to promote motivation to participate in a lung rehabilitation programme.

- <u>Clinical COPD Questionnaire</u> (CCQ);
- Nijmegen Clinical Screening Instrument (NCSI);
- <u>Assessment of Burden of COPD (ABC)-Tool.</u>

Concept definition

A global inventory of the integral state of health should be comprehensible for all patients (see <u>KI 1.3</u>). For some patients, this global inventory does not suffice and a more detailed inventory is necessary. The desirability/necessity for this may have come to light during the hospitalisation_and must be picked up in the home situation in months to come after discharge.

Practical tools

Comprehensive inventory and treatment during hospitalisation is not preferred due to insufficient opportunity.

Advice:

- Plan a conversation with patient and informal carer, take your time for this;
- Before the conversation, let the patient know that you:
 - want to gain more insight into how the patient deals with the disease in daily practice, and
 - want to pay attention to certain emotions, such as stress, fear and gloominess. This gives the patient the opportunity to prepare for the conversation.
- Identify the improvement potential after the consultation with the patient and their informal carer(s);
- Draw up a care plan with points for improvement. Make sure that any other care providers are aware of these agreements;
- Check whether any previously planned referrals have been realised;
- If necessary, refer to a specialist care provider.

- <u>Clinical COPD Questionnaire (CCQ)</u>, distress screener and if necessary 4-DKL;
- Assessment of Burden of COPD (ABC)-Tool;
- Nijmegen Clinical Screening Instrument (NCSI);
- Hospital Anxiety and Depression Scale) (HADS);
- Consultation other disciplines (spiritual care/social work/psychologist/ etc.)

Reassessment of integral health status

When: periodically, depending on disease burden

Concept definition

Determine and record the integral health status annually in consultation with the patient and their informal carer(s).

Practical tools

Reassess the patient's integral health status, covering all topics relevant to this patient.

Basic assessment and frequency of monitoring:

The frequency of monitoring is determined by the severity of the disease burden and whether or not the patient has had a lung attack resulting in hospitalisation. All patients should receive a basic annual assessment as stated in care standard COPD 2016, §5.5 monitoring.

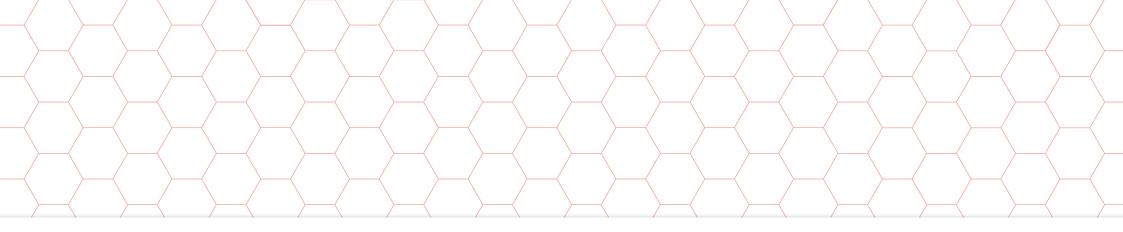
As a guideline for the frequency of monitoring, the following overview should be taken into account:

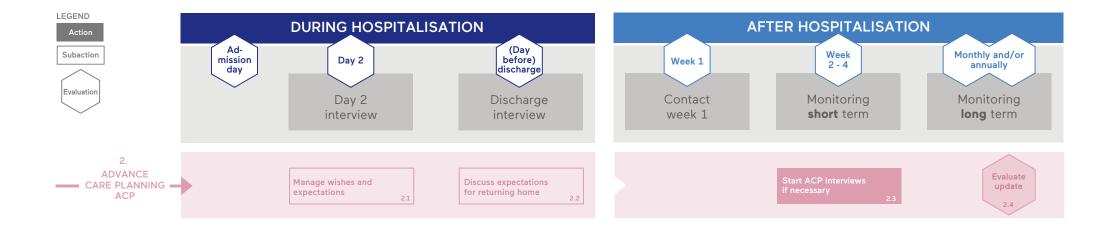
Patients	Check-up frequency	Spirometry frequency
Mild condition: patients without complaints and who do not smoke (any longer)	Yearly	None
Mild symptoms; patients with symptoms or who smoke	At least yearly	Once every three years
Moderate and serious illness	At least twice a year	Yearly, for patients managing their condition adequately and have stopped smoking and without relevant co-morbidity such as asthma, this can be done every three years
Limited life expectancy	Symptomatic care	Not recommended
Exacerbation	Extra after treatment of exacerbation	Not necessary

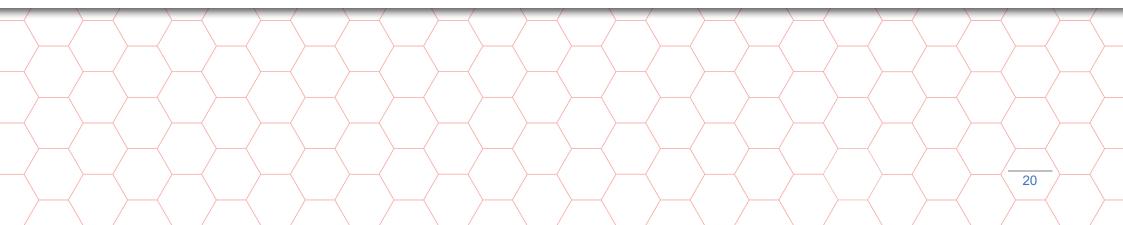
Monitoring and frequency based on disease burden (Source: LAN care standard COPD 2016 and NHG standard COPD 2015)

- COPD care standard, §5.5 Monitoring;
- NCSI/mMRC;
- <u>Clinical COPD Questionnaire</u> (CCQ) and if necessary <u>HADS;</u>
- Assessment of Burden of COPD (ABC)-Tool.









Manage wishes and expectations

When: day 2

Concept definition

During the day-2 interview, the expectations of the patient, informal carer(s) and care providers with regard to the current hospitalisation, including the target discharge date, are identified and brought into line.

Practical tools

- Discuss the expectations of both the patient and the care provider regarding:
 - the hospitalisation
 - the course of the disease;
 - the health status to be attained before discharge.
 - Discuss the expected day of discharge (date);
- Discuss the patient's specific wishes during hospitalisation (e.g. CPR yes/no, IC, mechanical ventilation, etc.);
- Who speaks on behalf of the patient when they cannot?
- Attention to psychosocial context, spiritual needs;
- Consider:
 - discussing existence/possibilities of palliative medication: benzodiazepines, opioids;
 - discussing when oxygen is or is not useful;
 - its potential place in palliative phase: optimise other medication.

Instruments

Patient material:

- Animated video 'Advance Care Planning';
- COPD care pathway, information sheets 'Day 2&3, what can I do myself' (Appendix 4);
- Patient version of COPD Palliative care guideline.

Discuss and coordinate expectations

When: (day before) discharge

Concept definition

At the start of the hospitalisation, the patient, informal carer(s) and care providers discussed expectations and wishes and, where possible, brought into line. One of the objectives now is to determine whether these expectations have been met sufficiently and whether steps need to be taken within the framework of Advance Care Planning (ACP, also known as proactive care planning) on palliative care outside of the hospital. If, after discharge, there are going to follow discussions with the patient about ACP, the patient will be asked to schedule a meeting about this shortly after hospitalisation.

Practical tools

During each patient's discharge meeting, check the following:

- whether his/her wishes and expectations regarding the course of the admission correspond to the current situation. Also indicate whether your expectations correspond to this;
- what the patient's expectations are about the first few weeks after discharge and adjust these expectations if, according to you, they are unrealistic;
- whether, after the hospitalisation, the patient is prepared to talk about wishes and expectations in light of the COPD disease process:
 - Example sentence: "Do you mind if we talk about your wishes and expectations at your first check-up after your hospitalisation?"
 - Bring up the subject in an accessible way; it doesn't have to be about the last stage of life at all yet. It is important for each patient to talk at a quiet moment with his/her care provider about the mutual expectations about (the course of) the disease.
- Record what's discussed, and possible follow-up actions, in the ICP and ensure a clear transfer to the rest of the chain (1st line carers and other participants).

A lung attack with hospitalisation justifies starting Advance Care Planning (ACP).

Instruments

Patient material:

- Animated video 'Advance Care Planning' and 'informal carer';
- COPD care pathway, information sheets 'Day 2&3, what can I do on my own' (Appendix 4);
- Patient version of COPD Palliative care guideline;

A scientific study is currently being conducted into the implementation of a step-by-step plan for Advance Care Planning in COPD patients admitted for a lung attack. The results of this study are expected in 2020. See <u>Appendix 8a</u>.





Coordinating Advance Care Planning expectations shortly after hospitalisation

When: weeks 2 to 4

Concept definition

Together with the patient and informal carer, the wishes and expectations regarding (the course of) the COPD disease are discussed. If necessary, the specific wishes, goals and preferences for care now, and around the end of life, are discussed in more detail.

Practical tools

A lung attack with hospitalisation justifies starting Advance Care Planning (ACP). After all, mortality in the first two years after admission is 30-50%, which is higher than after a heart attack. A discussion about the (immediate) future is also helpful for patients who are not yet in the last phase of their lives.

If the patient is - in all probability – in the last phase of their life (the palliative phase), a conscious effort should be made to engage in iterative discussions regarding ACP.

Shortly after hospitalisation, which also includes a reflection on what the hospitalisation has meant for the patient and informal carer, may be a good time to start. If previous agreements had already been made with the patient, these will be evaluated.

In this group of patients, it must be absolutely clear who is the central case manager (care coordinator), agreements will be clearly stated in the ICP and there is a transparent transmission of wishes and follow-up actions to the rest of the care chain.

Topics that may be of interest for Advance Care Planning (ACP):

See also Appendix 8c for more information and example sentences.

- Wishes and expectations (near) future;
- Current experiences in the home situation;
- Psychosocial context, spiritual needs;
- Anxiety and depression;
- Wishes concerning possible readmission;
- Legal capability and trustees;
- Experiences and expectations of informal carer(s).

Consider:

- discuss medication: benzodiazepines, opioids;
- discuss what oxygen is and is not useful for;
- reconsider other medication;
- discuss possible role of physiotherapy at home in the context of palliation;
- cognitive behavioural therapy;
- identify pressure of care burden on informal carer (EDIZ questionnaire).

Point of attention:

In the context of Advance Care Planning, it may have been discussed with the patients that repeat hospitalisations are not a good solution any longer. Or the patient has explicitly indicated that he or she no longer wishes to be admitted. Identifying such a situation should, after consultation with the patient, lead to immediate consultation between first and second line care providers. After consensus, these directives must be explicitly mentioned in HIS

Table of contents

and ZIS and accessible to general practitioners in attendance and the ambulance services. The national exchange point may also have a role to play here. These wishes must also be expressed in the Individual Care Plan.

Instruments

- Instruments to determine whether a patient (with COPD) is in the palliative phase:
 - Propal COPD tool;
 - Surprise question ('Would I be surprised if this person were to die within 12 months? If the answer is no: start Advance Care Planning);
 - SPICT;
- Questionnaire that measures pressure of care burden on informal carer(s): Experienced Pressure by Informal Care (EDIZ), see <u>Appendix 8b</u>;
- Patient material: '
 - Animated video <u>'Advance Care Planning'</u> and '<u>informal carer'</u>;
 - COPD care pathway, information sheets 'Day 2&3, what can I do on my own' (<u>Appendix</u> <u>4</u>);
 - Patient version of COPD Palliative care guideline;
 - <u>Talk about your end of life in time</u>, ebook for patients (KNMG).

Literature suggestions:

- Focus areas for the ACP and palliative care (see Appendix 8c);
- The end of life interview, described in *Protocollaire Ouderenzorg* (www.protocollaireouderenzorg.nl);
- Bruntink, R., & Overman, M. (2018). End of life interviews: A whitepaper for health care providers. Hengelo: Bureau Morbidee;
- Talking about the end of life in time (KNMG doctor's guide);
- Guldemond, F., Ott, B en Wind, A. End of Life Advance Care Planning Toolkit (2017);
- Netherlands Integral Cancer Centre (IKNL), <u>Quality framework palliative care Netherlands</u>. Utrecht, the Netherlands; 2018;
- Lung Alliance Netherlands (LAN), <u>Palliative care guideline for people with COPD.</u> Amersfoort, the Netherlands; 2011;
- Concept vision document NVALT palliative care working group;
- Janssen et al <u>Advance care planning for patients with COPD: Past, present and future.</u> Patient EducCouns. 2011;
- Au D et al. <u>A randomized trial to improve communication about end-of-life care among patients</u> with COPD. Chest 2012;141:726-735.

Some examples of regions that have embedded ACP in their day-to-day operations:

- Quarterly home visits by respiratory nurses from the home care organisation to palliative patients with COPD, with access to the HIS and easy direct access to nursing specialists in the hospital.
 VGZ - Albert Schweitzer hospital - Home care organisations
- Outpatient supportive and palliative care for patients with COPD by lung specialist and palliative consultant. *Pilot region Groningen Ommelander hospital*
- Pilot of palliative care conversations with patient, pulmonologist and general practitioner together, at patient's home or via video conference. *Spaarne Gasthuis*

Coordinating Advance Care Planning expectations

When: periodically, depending on disease burden

Concept definition

Periodically, together with the patient/informal carer(s), identify the wishes, goals and preferences for care now and around the end of life, and bring them into line.

Practical tools

Points of attention:

- Keep in mind that wishes and expectations can change over time, for all parties involved;
- Regularly evaluate whether there are any changes;
- Periodically repeat what you think has been discussed and agreed;
- Evaluate which palliative phase the patient is in, and adjust policy if necessary. The four phases of palliative care are:
 - inventory phase;
 - consolidation phase;
 - last stage of life;
 - dying phase.
- For many patients, a recent hospitalisation for COPD will mean that the patient meets the criteria of the palliative phase.

Instruments

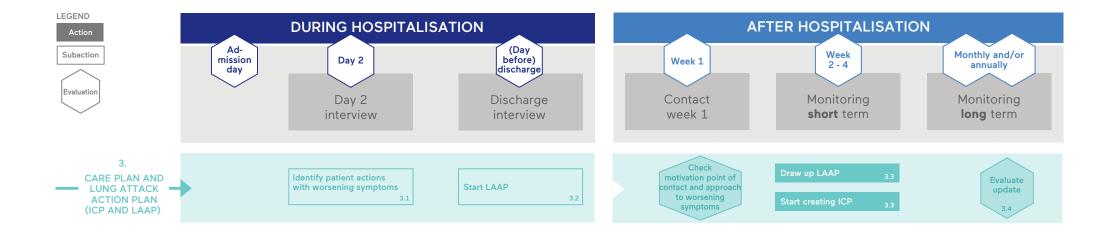
See <u>KI 2.3</u> for instruments, patient materials and literature suggestions.

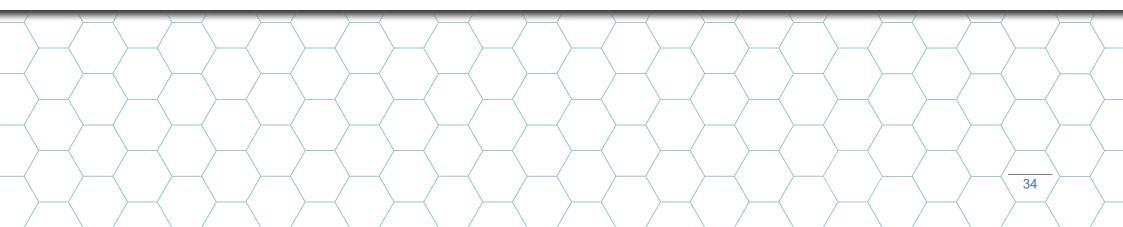


3. Individual Care Plan, Lung Attack Action Plan

No.







Inventory of person-oriented lung attack recognition and action plan

When: day 2

Concept definition

During the day-2 interview, it is examined how the person deals with complaints as a result of a lung attack.

Practical tools

The following will be verified and established in the meeting:

- Level of knowledge of patient and informal carer(s).
- Ability to recognise an increase in complaints.
- Which actions have been taken in the event of an increase in complaints, including:
 - increasing inhalation medication;
 - using prednisone and/or antibiotic in certain situations, as agreed;
 - which care provider will be brought in, and when?;
 - does the patient already have an Individual Care Plan or Lung Attack Action Plan (LAAP)? Develop and optimise these.

Planning and work

- The day-2 interview is exceptionally suitable as an inventory moment.
- Afterwards, a note should be drawn up that will serve as input for the advice to be given after discharge.

- Example DOPC Attack Action Plan (Appendix 5e) and Individual Care Plan (Appendix 5f).
- There are several action plans in circulation, including:
 - Lung Attack Action Plan (LAAP) (request from Dutch Lung Fund);
 - COPD Action plan (Medisch Spectrum Twente);
 - <u>REDUX recognition action plan</u>; reducing delay through education in COPD exacerbations: a project developed by CAHAG to identify and treat exacerbations at an earlier stage through training of care providers and education of patient.
- Patient material:
 - Animated video 'What is a lung attack' and 'How do I recognise a lung attack';
 - COPD care pathway, information sheets 'What is COPD' and 'What is a lung attack' (<u>Appendix 4</u>);
 - Information video (Dutch Lung Fund): <u>COPD and lung attacks: recognise the symptoms</u> and take action.

Globally discuss Lung Attack Action Plan

When: (day before) discharge

Concept definition

During the discharge meeting, the acute phases in the Lung Attack Action Plan are discussed, so that after discharge, the patient knows what to look out for if the symptoms worsen and what actions to take. Other points of the LAAP will be discussed after discharge.

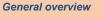
Practical tools

- During the day-2 interview, an inventory was made of how the patient deals with complaints as a result of a lung attack. This serves as input for the conversation with the patient and his/her informal carer(s).
- The following components will be discussed and elaborated during the conversation:
 - Contact person;
 - What to do in the event of worsening complaints;
 - Rescue medication.

This corresponds to the yellow block of the LAAP. Experiences from the pilot show that discussing the entire LAAP and Individual Care Plan before discharge is not feasible/useful. Moreover, the experience is that patient and informal carer cannot absorb more information adequately.

Instruments

For instruments such as a Lung Attack Action Plan and patient material, see KI 3.1.



Draw up and discuss Lung Attack Action Plan in combination with the Individual Care Plan

When: weeks 2 to 4

Concept description

- A. During this conversation, a complete Lung Attack Action Plan (LAAP) is developed and discussed with the patient and informal carer.
- B. The Individual Care Plan (ICP) should also be started in collaboration with the patient. The LAAP and the short-term objectives have priority here.

Practical tools

A. Lung Attack Action Plan (LAAP)

The aim of the action plan is to give the patient practical tips on how to deal with an exacerbation of symptoms that can lead to a lung attack.

The LAAP describes the individual patient's specific pattern of symptoms indicative of a lung attack, how they should act on which symptoms, and who the contact person is. A prerequisite for this is that the patient has the necessary knowledge about a lung attack and is able to recognise the associated pattern of symptoms.

The following matters will be discussed during the conversation:

- I. Education:
 - 1) What is, and how do you recognise, your own lung attack?
 - 2) What are the consequences of a lung attack?
 - 3) Effectiveness of medication, and a particular focus on extra medication that may be used.
- II. **Rescue medication** including prednisone and, if necessary, antibiotics can be prescribed to eligible patients. This rescue medication can be kept in stock at home, so that a timely start can be made. It should be clearly defined what specific complaints such rescue medication may be used for.
- III. Draw up and discuss LAAP with patient. The agreements made must be clearly expressed in the LAAP. In doing so, check whether the agreements made are described in a way that is clear to the patient.

Other components in the LAAP:

- Contact person;
- 24-hour accessibility of care workers including telephone numbers;
- 'When do I call who?'

B. Individual Care Plan (ICP)

Together with the patient, informal carer(s) and care provider, short-term (and possibly long-term) goals are discussed with the associated treatment and actions. These are laid down in the Individual Care Plan (ICP).

The following aspects have priority:

- Fully completed Lung Attack Action Plan;
- Short-term objectives, tailored to the specific needs of the patient;
- Rough outline of the long-term objectives.

Active role of patient, care provider as coach

- The aim is to make patients the owners of their own care plan (self-management). In order to be able to take on this active role, there needs to be a change in the relationship between care provider and patient. It must be clearly explained to the patient that he/she can play an active role in his/her treatment. The care provider uses his/her knowledge to support the patient's decisions and adjusts his/her approach accordingly. Training courses, including motivational interviewing and personalised care, can help with this;
- The LAAP and ICP support the patient in achieving his/her goals. That is why all care providers should use the ICP) as an aid in every conversation with the patient. In this way we can ensure the patient will also see it as an aid;
- In <u>Appendix 5f</u>, an ICP has been drawn up for a fictitious patient at the time of weeks 2-4 and about 3 months after hospitalisation.

- LAAP (see <u>KI 3.1</u> and <u>Appendix 5e</u>).
- ICP:
 - Fictional ICP during moments weeks 2/4 and month 3 (Appendix 5f).
 - See also:
 - Individual Care Plan COPD (Vilans sample format, very detailed);
 - ICP as used in a general practitioner's practice: there is a large number of individual care plans in circulation, both disease-specific and generic (see <u>www.zorgvoorbeter.nl</u>).
 Preference is given to a generic model, especially in view of the frequently present comorbidity;
 - Individual Care Plan File (NHG) and Individual Care Plan Pilot Reference Model (NHG);
 - <u>Report Plan of requirements for generic Individual Care Plan</u> (a project of NHG, NPCF and Vilans commissioned by the Quality Institute and financed by ZonMW), 2014.
- Patient material (see <u>KI 3.1</u>).

Update the Individual Care Plan and Lung Attack Action Plan

When: periodically, depending on disease burden

Concept definition

Patient, informal carer(s) and care provider discuss and update the short-term and long-term objectives and associated actions. Also consider the drawn up Lung Attack Action Plan (LAAP) here.

Practical tools

Shortly after discharge (see <u>KI 3.3</u>), the Lung Attack Action Plan has been drawn up and a start has been made with the Individual Care Plan. This ICP must now be completed with short-term and long-term objectives, so that the ICP can be used as a discussion guideline and support the patient with the specified objectives.

The following matters are included in the ICP:

- Lung Attack Action Plan;
- Current medication overview;
- Name and accessibility of care coordinator and first point of contact;
- Names of other care providers;
- Personal goals of the patient; short term, possibly long term;
- Relevant lifestyle advice;
- Health status monitoring;
- Agreements and wishes concerning readmissions, spiritual meaning, alleviation of suffering, end of life;
- Agreements on evaluation of the ICP.

Conversation with the patient (and his/her informal carer):

- Use the prepared Individual Care Plan as a conversation guideline and refer to it during every conversation;
- The aim is to make patients the principal owners of their own care plan. The care provider supports the patient in the objectives chosen by the patient. Training courses such as motivational interviewing and personalised care can help bring about this change in the relationship.

Discuss:

•

- Does the patient understand the information drawn up?
 - Are the different steps in the LAAP clear?
 - Can the patient recognise exacerbating symptoms?
- Frequency of lung attacks this period?
- What is the course and possible cause of the lung attack?
- What does the patient want to achieve in the coming period and set SMART goals, both in the short and long term.
- Target achieved in the short and/or long term?
 - If not, discuss obstacles and look for solutions together.
 - If so, does the patient have another (new) goal (which was not discussed before)?
- If necessary, adjust the LAAP and record agreements in the ICP.



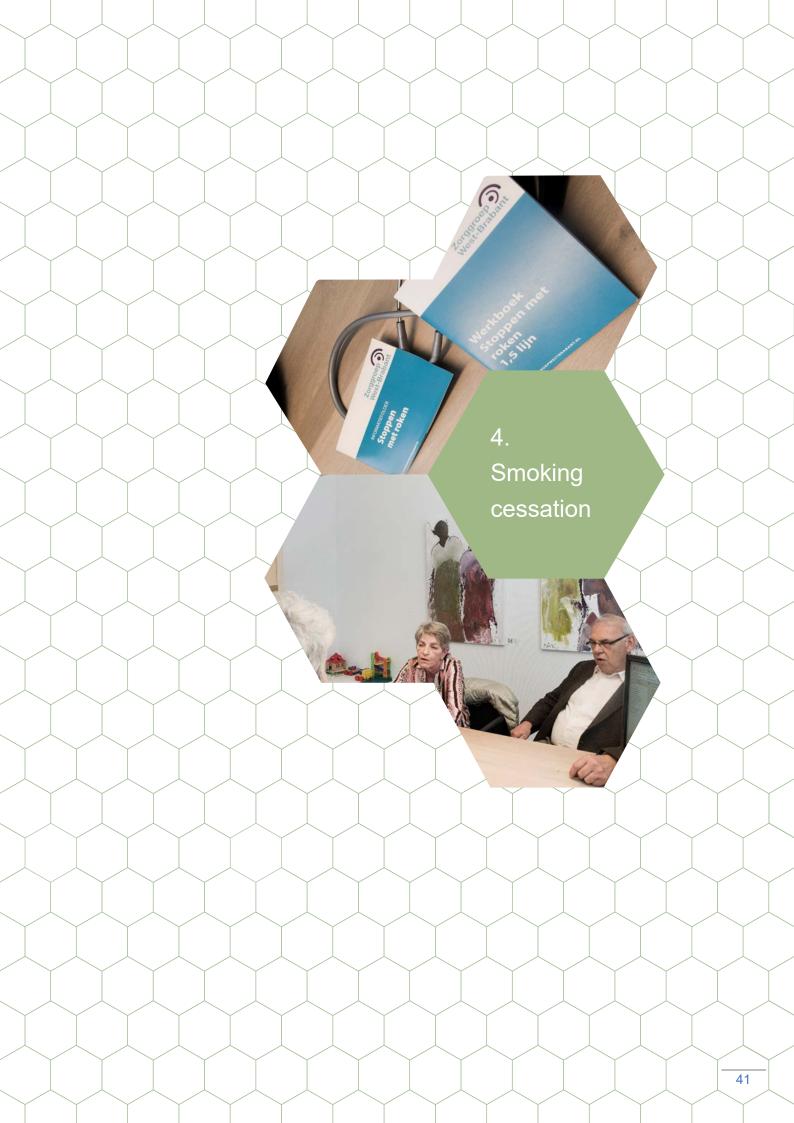
Instruments

- LAAP (see <u>KI 3.1</u> and <u>Appendix 5e</u>).
- ICP (see <u>KI 3.2</u> and <u>Appendix 5f</u>).
- Patient material (see <u>KI 3.1</u>).

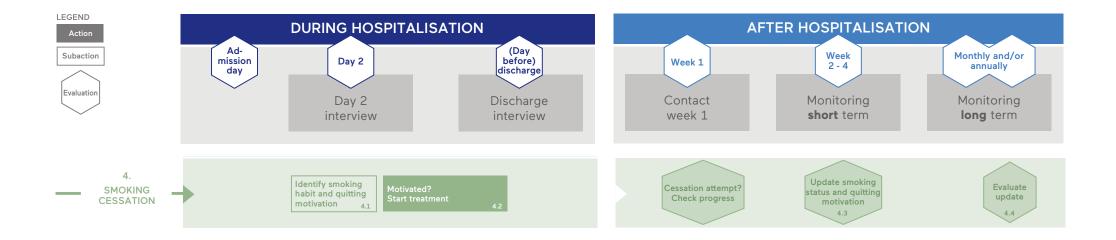
Some tips for drawing up an ICP:

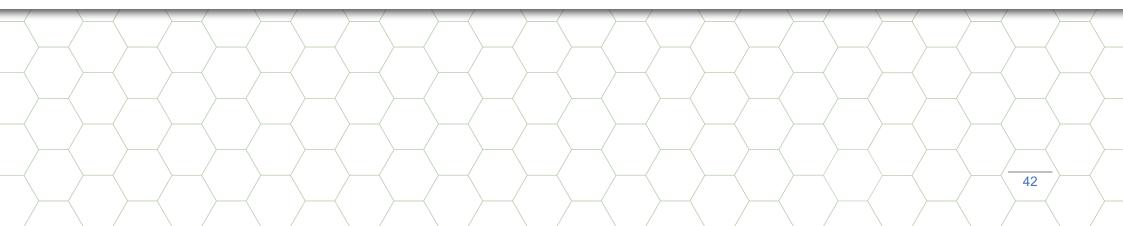
- (Fictional) example of ICP weeks 2/4 and month 3 (Appendix 5f);
- Ideally, there should only be one ICP for the chronically ill for reasons of clarity and feasibility. Unfortunately, this ICP is not yet available;
- Some tips for drawing up an ICP:
 - Do not make the ICP too long;
 - Use pictures and avoid the use of 'technical language';
 - Make the ICP personal by including all care providers involved;
 - A digital ICP has advantages, but this would be a project in itself;
 - A tear-off card with traffic light signals which, for instance, can be hung on the refrigerator, is considered useful.











Identify smoking habit and quitting motivation

When: day 2

Concept definition

During the day-2 interview, the smoking profile is drawn up. Is there a quitting motivation? If there is sufficient motivation, the smoking cessation treatment is **started immediately** and the coordination of the care process is ensured.

Practical tools

One to one conversation with patient in which the following is discussed:

- 1. Establish smoking status: smoker ex smoker never smoker:
- If smoker: determine pack years, ask about smoking behaviour and provide quitting advice;
- 2. Establish stop motivation: motivated considering not motivated.

Establish an action plan, taking into account the level of motivation:

A) Unmotivated/considering patient: engage in motivational boosting using the 5 Rs (see <u>Appendix 10a</u>):

Write down the minimum parameter set³:

- Smoking: smoker/ex-smoker/never-smoker;
- Date of quitting advice;
- Motivation after motivation boosting treatment: motivated/considering/unmotivated;
- Date of motivation boosting treatment;
- Follow-up appointments.
- B) Motivated patient: advice and direct supervision (behavioural and pharmacological support) using the 5 As (see <u>Appendix 10a</u>)

Write down the minimum parameter set in EPD:

- Start date of smoking cessation supervision;
- Pharmacological treatment: yes/no;
- If so, write down medication;
- Follow-up appointments;
- Quitting date.

Nicotine abuse should be discussed with anyone who has lung problems, including patients with advanced COPD. By not discussing smoking, the care provider is failing the patient. By discussing it properly (compassionately, see <u>Appendix 10a</u>), care providers show that smoking is not condemned as such, that sincere help can be offered and that the patient is worth the trouble. Moreover, the patient becomes an equal discussion partner instead of a listening ear to (sometimes unsolicited) advice. If it appears that the patient does not want to talk about it at the moment, then really do let it rest.



- Tests:
 - Fagerstrom test (degree of Nicotine dependence);
 - <u>Visual Analogue Scale</u> (VAS) "yardstick" 0-10: patient uses this to indicate quitting motivation.
- Guidelines and care modules:
 - Partnership Stop met Roken (2009), Smoking cessation care module;
 - Partnership Stop met Roken (2016), <u>Guideline for treatment of tobacco addiction and cessation of smoking support;</u>
 - NHG treatment guideline <u>guit smoking</u> (2017) and care module (2015).
- Further reading and literature suggestions:
 - How to bring up smoking cessation and underlying assumptions of the care provider, showing compassion (<u>Appendix 10a</u>);
 - Dekker P., <u>Tabaksverslaving: voorkomen is beter dan niet meer kunnen genezen...</u> (Bijblijven no. 5 2018);
 - Dekker P., de Kanter, W. Motiveren kun je leren (2010);
 - Smoking cessation toolkit (see <u>Appendix 10b</u>).
- Patient material:
 - COPD care pathway, information sheet 'quit smoking' (Appendix 4);
 - <u>www.rokeninfo.nl;</u>
 - patient version of smoking cessation care module;
 - Dekker P., de Kanter, W. Nederland stopt! met roken (2008).
- An example of a smoking cessation clinic that pays a lot of attention to trained staff and intensive supervision is the Red Cross hospital smoking cessation clinic in Beverwijk. After a year, 50% of people have still successfully stopped smoking (<u>www.rkz.nl/rookstoppoli</u>).

Discuss smoking cessation if necessary

When: during hospitalisation

Concept definition

The quitting motivation and the current status of non-smoking are discussed with the patient, and they are prepared for discharge and the maintenance of non-smoking after discharge.

Practical tools

In case of insufficient quitting motivation, repeat motivation-enhancing strategies using the 5 Rs (see <u>Appendix 10a</u>).

For patients who are actively working with a cessation plan:

Assist: help him/her to make attempt to quit

- Discuss the 'cessation plan' with the smoker again;
- Provide practical support;
- Try to arrange support from others;
- Sufficient effect of pharmacological support? Discuss any side effects;
- Prepare for discharge: obstacles/pitfalls.

Arrange: ensure follow-up as a form of relapse prevention

- Determine dates for follow-up contact, physically or by phone;
- During follow-up contact: evaluate how the cessation is going (successes, slip-ups, difficult moments) and the use of pharmacotherapy. If necessary, provide tools/aids.

Write down minimum parameter set

- Smoking status;
- Motivation: motivated/considering/unmotivated;
- Quitting date;
- Pharmacological treatment: yes/no;
- If yes, write down medication;
- Agree where and when smoke cessation supervision will be provided and make follow-up appointments.

Instruments

See <u>KI 4.1</u> for literature suggestions, tests, guidelines and patient materials.



Evaluation of smoking status and quitting motivation shortly after hospitalisation

When: weeks 2 to 4

Concept definition

Evaluate smoking status and quitting motivation during each contact moment. If there has been an attempt to quit, evaluate very regularly and, if necessary, adjust the plan of action.

Practical tools

Focus areas:

- Check smoking status and quitting motivation;
- How is the smoking cessation going? (successes, slip-ups, difficult moments);
- Adjust plan/action if necessary;
- Relapse prevention;
- Make follow-up appointments according to the patient's needs;
- Note the minimum parameter set described under <u>KI 4.2</u>.

Nicotine abuse should be discussed with anyone who has lung problems, including patients with advanced COPD. By not discussing smoking, the care provider is failing the patient. By discussing it properly (compassionately, see <u>Appendix 10a</u>), care providers show that smoking is not condemned as such, that sincere help can be offered and that the patient is worth the trouble. Moreover, the patient becomes an equal discussion partner instead of a listening ear to (sometimes unsolicited) advice. If it appears that the patient does not want to talk about it at the moment, then really do let it rest.

Instruments

See <u>KI 4.1</u> for literature suggestions, tests, guidelines and patient materials.



Evaluation of smoking status and quitting motivation

When: periodically, depending on disease burden

Concept definition

During follow-up appointments, relapse prevention is central. Treatment for smoking cessation stops after the last follow-up appointment and when the patient's last required details have been recorded. Inquiring about non-smoking remains part of the ongoing moments of contact between care provider and patient.

If the patient has started smoking again or still smokes: discuss reasons for relapse and ask what it will take to quit (again). Then restart the conversation and start the quit-smoking intervention (see $\frac{K14.1}{1}$).

Practical tools

- Check smoking status and quitting motivation;
- Adjust plan/action if necessary;
- When to stop pharmacological support?
- Relapse prevention;
- Note the minimum parameter set described under KI 4.2.

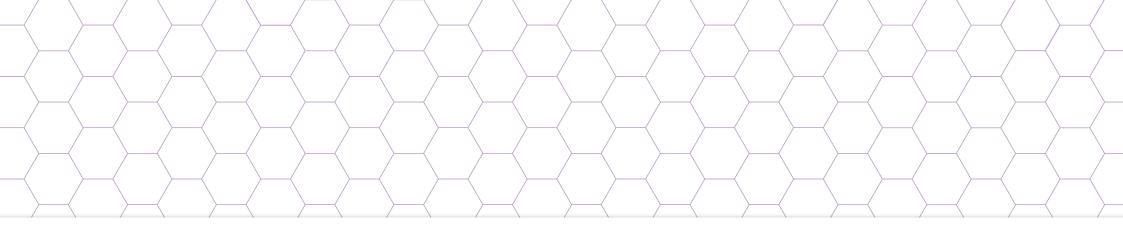
Instruments

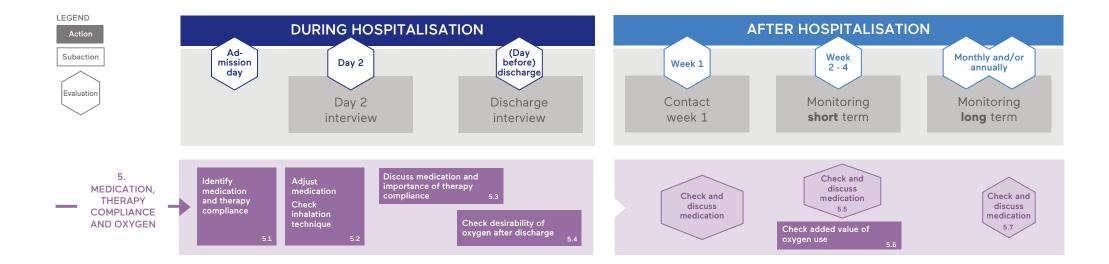
See <u>KI 4.1</u> for literature suggestions, tests, guidelines and patient materials.

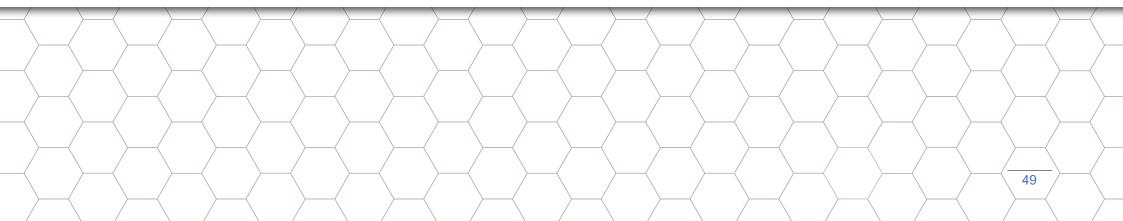


5. Medication, therapy compliance and oxygen

ravis 2







Inventory of medication and therapy compliance

When: day of admission

Concept definition

The medication used by the patient (both lung specific and co-medication) is identified. In addition, the current therapy compliance is discussed with the patient and, if necessary, with the informal carer.

Practical tools

- Ask about the daily use of maintenance medication or why this medication is not used continuously. Also ask about any recent extra use in connection with complaints the patient is experiencing;
- Check and compare the medication overview used at home;
- Use this information to create the medication overview so that recent medication and any
 problems in their use are clear to all care providers. Record agreements and progress in EPD and
 Individual Care Plan;
- Maintain the current home medication as much as possible.

Instruments

Patient material:

- www.inhalatorgebruik.nl;
- COPD care pathway, information sheet 'medication' (Appendix 4);

Adjust medication and check inhalation technique, provide instruction

When: 2nd day after hospital admission until discharge

Concept definition

Adjust the medication where necessary while preserving as much as possible of the devices already in use and check the patient's inhalation technique. If necessary, provide instructions so that the patient can optimally use (inhale) the medication with optimal results. Patient has good inhalation skills and knowledge of the maintenance of the specific inhalers upon discharge.

Practical tools

Adjust medication:

- Medication is adjusted on the basis of the severity of the complaints, (experiences with) home medication and new prescriptions.
 - Maintain the current home medication as much as possible;
 - Consider (connecting to) regional formulary for inhalation medication.
- If the patient receives medication via a nebuliser upon admission, the day on which the nebulisation stops and the patient switches to full home medication will be agreed upon.

Check inhalation technique:

- The inhalation technique is checked on day two and, where necessary, instructions are given to the patient. On day three, the inhalation technique will be checked again and, if necessary, instruction will be given again. On subsequent days, this instruction will be repeated if indicated.
- Instruction complies with the following:
 - In order to ensure uniformity and correctness of instruction, the care protocols, instructional videos and instruction manuals developed by LAN are used;
 - Instruction is given by a care provider trained according to criteria established by the LAN;
 - Attention is paid to the maintenance and cleaning of the inhalers.
- If the inhalation technique remains unsatisfactory, reconsider the choice of inhaler;
- Record agreements and progress in EPD and Individual Care Plan.

- Instructional material (www.inhalatorgebruik.nl):
 - LAN protocols inhalation instruction;
 - Good Usage of Inhalation Medication Report, 2018;
 - Practical explanation manual for inhalation protocols.
 - National framework of regional formulary for inhalation medication March 2018;
- Patient material:
 - <u>www.inhalatorgebruik.nl (LAN user manuals and instructional videos);</u>
 - COPD care pathway, information sheet 'medication' (Appendix 4);



Discuss medication and importance of therapy compliance *When: during hospitalisation*

Concept definition

Discuss the home medication and the importance of therapy compliance with the patient and informal carer(s). The purpose is that the patient has knowledge of how and in what dosage the medication should be used. The patient should also understand that use as prescribed is a condition for the intended result of the treatment.

The patient's local pharmacy manages the medication file.

Practical tools

- Patient has knowledge of the complete medication, both for continuous and occasional use;
- There is extra attention when symptoms worsen (see element 3 Lung Attack Action Plan);
- The patient receives an explanation of the importance of therapy compliance, in which specific attention is paid to the various groups of medications (continuous/occasional);
- The local pharmacy is aware of the complete set of medication at the time of discharge, and makes it clear which medication is intended for continuous use, which is optional, and which is for exacerbations.

- Give the patient an overview of the home medication, including instructions (<u>www.inhalatorgebruik.nl</u>);
- Send the complete medication overview to the local pharmacy upon discharge (by fax, e-mail or via EPD if possible);
- For the sake of the medical overview, it is preferable to indicate, on the prescription, which medication has been stopped when new medication is prescribed. The medication overview is also adjusted in the Individual Care Plan;
- See <u>KI 5.2</u> for patient material.

Check desirability of oxygen at home

When: (day before) discharge

Concept definition

Make an inventory of whether there are indications for oxygen therapy in the home situation and, if necessary, take the appropriate actions.

Practical tools

Many patients attach importance to the availability of oxygen at home, especially if they were given oxygen during the hospitalisation. Oxygen therapy at home is scientifically substantiated only under strict stage criteria. Because of the risks, be cautious with oxygen therapy at home.

Focus areas:

- If possible, assess blood gas values without oxygen if the patient is using oxygen on the day before discharge;
- Consider oxygen therapy when:
 - PaO2 < 7.3 kPa with or without hypercapnia, measured during 15 min breathing of room air in a stable phase;
 - PaO2 7.3-8.0 kPa, combined with indications of pulmonary hypertension, peripheral oedema or hematocrit > 0.55.
- For extra oxygen administration, the aim is to achieve a PaO2 > 8.0 kPa or O2 saturation measured with pulse oximetry > 90%;
- If necessary, request oxygen for home use at an early stage;
- Discuss the risks, expectations, and proper use of oxygen with the patient and include the use in the Individual Care Plan;
- Make a note for checking blood gas values, especially because of the possibility of further improvement shortly after hospitalisation.

- Guideline on Diagnostics and Treatment of a lung attack in the hospital (<u>https://richtlijnendatabase.nl/</u>);
- Nationally uniform oxygen forms:
 - <u>Request oxygen therapy;</u>
 - Oxygen Therapy Amendment/Termination Form;
 - Feedback form.
- Information material <u>Oxygen and COPD</u> (Lung Foundation).

Check and discuss medication, inhalation technique and therapy compliance

When: weeks 2 to 4

Concept definition

Discuss the complete set of medication and check that the patient is using the correct inhalation skills, including knowledge of maintenance.

The purpose of the instruction is to allow the patient to inhale the medication with optimal results. To this end, the patient has the knowledge of how, and in what dosage, the medication should be used and understands that use according to this prescription is a prerequisite for the intended result of the treatment.

Practical tools

Check and discuss complete set of medication:

- Check medication satisfaction and effect, with specific attention to side effects. Adjust if necessary (including new inhalation instruction);
- Check the patient's knowledge of the complete set of medication, which is to be used continuously, occasionally or if necessary. The patient also knows the importance of therapy compliance, even in a period of few complaints.

Inhalation technique:

The inhalation technique is checked after weeks 2-4 and instructions are repeated if necessary. Instruction complies with the following:

- In order to ensure uniformity and correctness of instruction, the care protocols, instructional videos and instruction manuals developed by LAN are used;
- Instruction is given by a care provider trained according to criteria established by the LAN;
- Attention is paid to the maintenance and cleaning of the inhalers.

If the inhalation technique remains unsatisfactory, reconsider the choice of inhaler.

Monitor all medication and inhalation technique:

- Monitor medication use in continuously in order to detect insufficient therapy compliance and, subsequently, to start an intervention in time to improve compliance;
- Write down agreements and progress in EPD and Individual Care Plan, in which cooperation and coordination between prescriber, coach and pharmacy are important;
- For the sake of the medical overview, it is preferable to indicate, on the prescription, which medication has been stopped when new medication is prescribed. The medication overview is also adjusted in the Individual Care Plan.

- See KI 5.2 for instructional and patient materials;
- MEMO method (Healthbase) to promote therapy compliance.



Check oxygen consumption

When: weeks 2 to 4

Concept definition

If the patient receives oxygen therapy at home, it will be evaluated whether this therapy can be phased out.

Practical tools

Oxygen therapy at home is scientifically substantiated only under strict stage criteria. Because of the risks, be cautious with oxygen therapy at home. Check the blood gas values. If oxygen is necessary, make a follow-up appointment to check the necessity again.

Considerations and other focus areas concerning oxygen use, see KI 5.4.

Instruments

See <u>KI 5.4</u> for guidelines, oxygen request forms and information material.



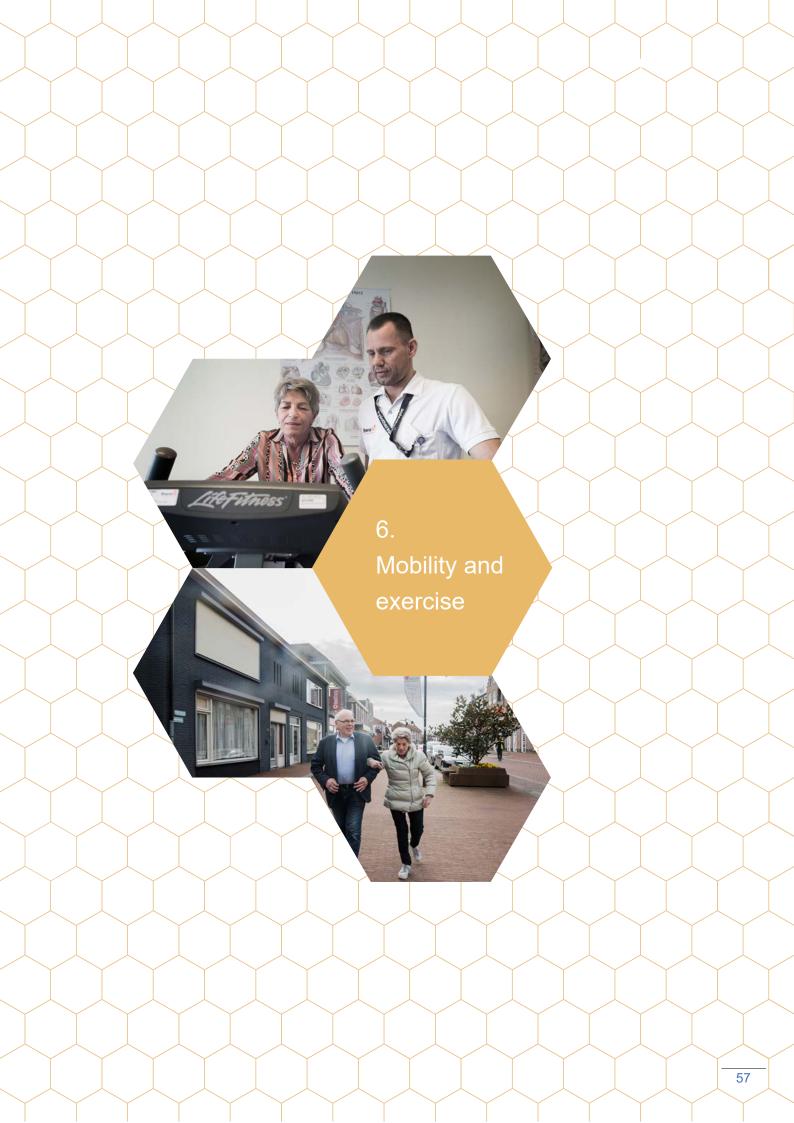
Check and discuss medication, inhalation technique and therapy compliance When: periodically, depending on disease burden

Concept definition See <u>KI 5.5</u>.

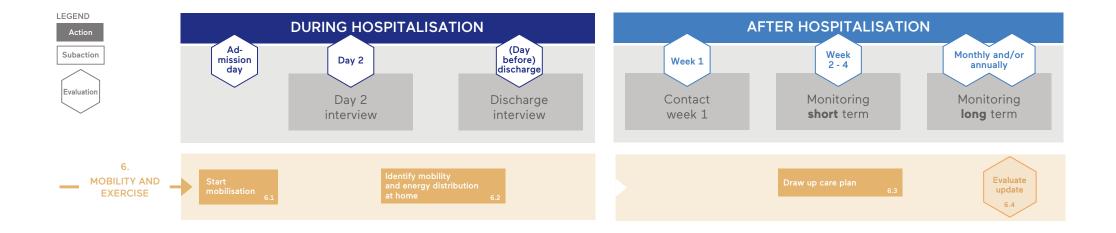
Practical tools See for instructions <u>KI 5.5</u>.

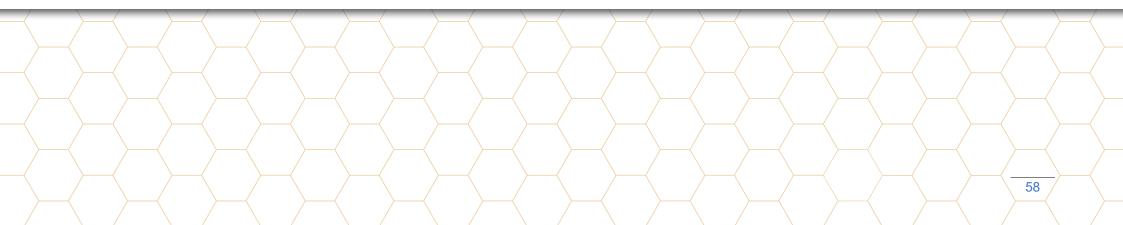
Instruments See <u>KI 5.5</u>.











Engage physiotherapy and start therapy

When: day of admission

Concept definition

Maintaining and possibly improving mobility during and after hospitalisation and, if necessary, help with symptom management.

Practical tools

Make a plan of action and start implementation:

- If necessary, call in a physiotherapist: indications may include: early mobilisation, improved breathing technique, sputum clearance;
- Take physiotherapeutic anamnesis;
- Set treatment targets.

(See Appendix 11 for more detailed description).

- Guidelines:
 - KNGF guideline;
 - <u>COPD Care Standard</u>.
- Patient material:
 - COPD care pathway, information sheet 'exercise' and 'good use of energy' (<u>Appendix 4</u>).

Inventory of exercise possibilities and energy distribution

When: during hospitalisation

Concept definition

Reassess the patient's mobility, load and load-bearing capacity and make an inventory of the possibilities at home. Record the inventory in the transfer document so that the treatment plan can be started after dismissal.

Practical tools

Inventory

- Inventory exercise behaviour;
- Identify the degree of balance between load and load-bearing capacity of the patient in the home situation;
- Identify whether the patient applies energy management adequately;
- Write the findings and the provisional care plan in the patient file and the transfer document.

Preparation of treatment plan 'shortly after discharge'

- Start reactivation in the first week after discharge and take the appropriate steps to do this;
- Advise the patient on these short-term objectives during the discharge meeting;
- For considerations, see multidisciplinary rehabilitation (KI 1.4);
- Assess whether a physiotherapist/occupational therapist should be involved in the home situation and ensure a good transfer.

Instruments

- Guidelines:
 - KNGF guideline;
 - Occupational Therapy Guideline for COPD; www.ergotherapie.nl;
 - NHG care module Exercise Lifestyle.
- Patient material:
 - COPD care pathway, information sheet 'exercise' and 'good use of energy' (Appendix 4);
 - Information video (Dutch Lung Fund): <u>COPD and exercise</u> and <u>Dealing with energy</u>.

Tips:

- Create a regional overview of the physiotherapists/occupational therapists with lung expertise;
- Provide structural consultation between paramedics in 1st and 2nd line settings;
- Create an overview of exercise initiatives in the neighbourhood (social map). There are several (free) sports clubs and/or health centres that offer things like walking under the supervision of a physiotherapist and/or general practitioner;
- Since January 2019, reimbursement of physiotherapy and exercise therapy from the 1st treatment under the basic health insurance, depends on the severity of the disorder. See the <u>website of KNGF</u> for further explanation.

Examples of regional cooperation:

Example for Arnhem region: Following the start of the COPD care pathway, a COPD network of physiotherapists in Arnhem and surroundings was formed. To join, criteria have been formulated to ensure sufficient quality. The objective of this network is: improving the quality of physiotherapy for COPD patients, improving care for this patient category and optimising the communication between care providers. Meetings will involve interdisciplinary consultation, intervision and case reports.



Drawing up care plan

When: weeks 2 to 4

Concept definition

If necessary, patient, informal carer(s) and care provider draw up a care plan, subdivided into short-term and long-term objectives.

Practical tools

In the transfer document (see <u>KI 6.2</u>), an inventory was made of the patient's exercise behaviour and load-bearing capacity and an initial design was made for the care plan. Together with the findings from the first weeks after discharge (including a possible reactivation and/or rehabilitation process), a care plan that matches the patient's targets is drawn up together with the patient. A distinction is made between short-term and long-term objectives.

Objective achieved?

- If not, discuss obstacles and look for solutions together;
- If yes, formulate new goal and corresponding action(s).

If a physiotherapist/occupational therapist is involved, it is checked whether they have been approached yet and that the care providers ensure an accurate exchange of information.

Record the agreements in the patient's Individual Care Plan.

Instruments

See <u>KI 6.2</u> guidelines and patient materials.

Tips:

- During an inventory among 1st line physiotherapists working in the pilot region of West Brabant, it appeared that 21 out of 51 physiotherapists were sporadically or never involved in sputum evacuation techniques during the treatment of COPD patients. Not so much because there would be no indication for this, but rather because less attention was paid to it. Since sputum retention can be a contributory factor in the onset or persistence of a lung attack, it is recommended that this be a recurring part of the therapy. This can make a positive contribution to the prevention of (re)admission to hospital;
- Ensure good cooperation between physiotherapist and dietician. Achieving a good result in COPD patients with a high disease burden depends on the right training combined with the right nutrition/intake. If this is not properly coordinated, the chances of success are slim.



Mobility and exercise evaluation

When: periodically, depending on disease burden

Concept definition

Patient, informal carer(s) and care provider discuss and update the short-term and long-term objectives and associated activities. These can be adjusted if necessary.

Practical tools

- Evaluate the set (short-term and long-term) objectives and associated activities. Objective achieved?
 - If not, discuss obstacles and look for solutions together;
 - If yes, formulate new goal and corresponding action(s).
- Record the agreements in the patient's care plan;
- The various care providers ensure an accurate exchange of information.

Instruments

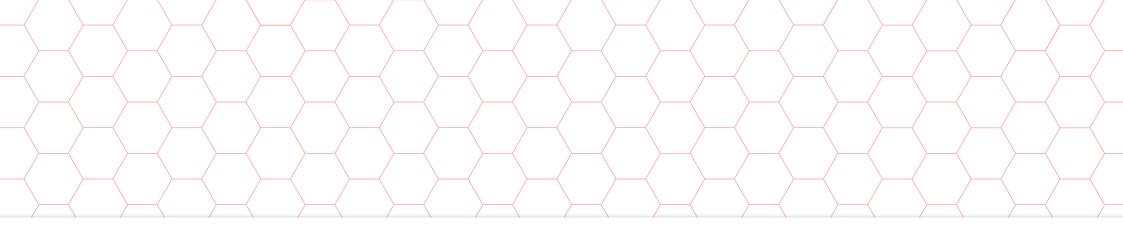
Table of contents

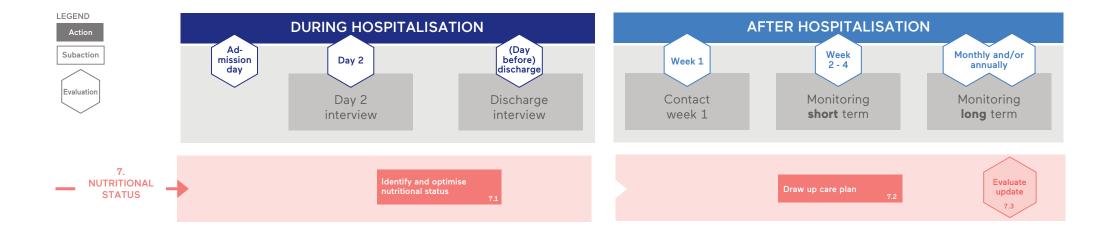
See KI 6.2 guidelines and patient materials.

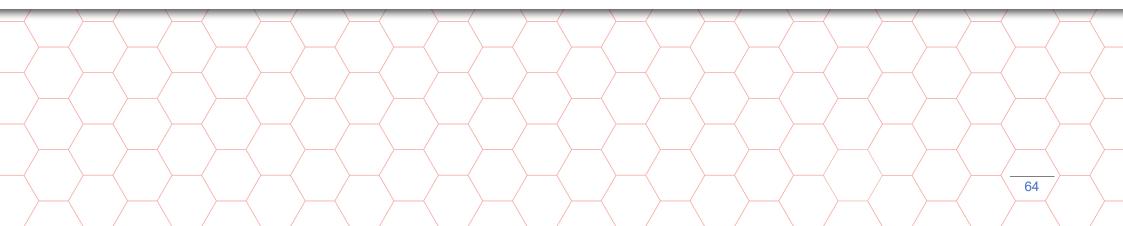
Summary

7. Nutritional status

9 .. 0







Inventory and optimisation of nutritional status

When: during hospitalisation

Concept definition

Inventory and, if necessary, optimisation of the nutritional status takes place during hospitalisation.

Practical tools

Within 24 hours after admission:

- Screen nutritional status by means of validated screening instrument;
- Determine the BMI if necessary.

During hospitalisation (end of hospitalisation):

- Determine the FFMI if necessary.

Consult dietician if:

- SNAQ =3, MUST =2;
- BMI <21;
- FFMI men <17, women <15.

Focus areas during hospitalisation:

- Discuss nutritional advice following discharge;
- Determine and discuss whether dietary intervention/supervision by a dietician is necessary in the home situation and include in the transfer message, if necessary. Record the following information in the transfer: request for help, FFMI;
- Nutritional intervention is only useful in combination with an exercise intervention/physiotherapeutic coaching, adjust the nutritional advice accordingly;
- Observe possible swallowing problems/dysfunction of the patient, bring in speech therapy if necessary;
- Identify overweight BMI >30 or BMI >25 with comorbidity and, if necessary, record agreements in ICP and fine-tune with the care coordinator.

Instruments

- Use <u>SNAQ</u> or <u>MUST</u> in hospital to screen for undesirable weight loss;
- Bio-Impedance Meter;
- TOAD transfer note of the NVD (www.stuurgroepondervoeding.nl).

Patient material:

- Patient version of COPD care pathway, information sheet 'mind your food)' (Appendix 4).

Tips/Examples:

- Provide an overview of dieticians in the region who are well able to supervise patients with COPD and arrange consultations with them;
- Together with physiotherapy, all tests (including the FFMI) are repeated twice a year, so that changes in body composition can be detected quickly (Tiel region);
- If the FFMI cannot be measured during the actual admission, see if it can possibly be determined in the lung function department during an outpatient visit.





Assessment of nutritional status and nutritional intervention shortly after hospitalisation

When: weeks 2 to 4

Concept definition

An evaluation of the nutritional status is carried out, and, if necessary, a nutritional intervention is started or continued.

Practical tools

- Check whether there has been any unwanted weight loss since discharge from the hospital;
- Check for undesirable weight gain, especially any weight increase between leaving the hospital and 2-4 weeks after discharge;
- If necessary, determine FFMI if this was not done during hospitalisation;
- With the patient and any informal carer(s), evaluate the plan of action to maintain or obtain optimal nutritional conditions and adjust if necessary.

Consult dietician if necessary:

- SNAQ (65+)= 3, MUST= 2;
- BMI <21;
- FFMI men <17, women <15;
- BMI >30 or BMI >25 with comorbidity.

Focus areas:

- Comorbidity;
- Smoking cessation;
- Use of systemic corticosteroids;
- Nutritional intervention is only useful in combination with an exercise intervention/physiotherapeutic coaching. Focus on the nutritional advice here;
- Record agreements in ICP and coordinate with care coordinator.

Instruments

- Validated screening instrument for the home situation and rehabilitation: SNAQ, SNAQ 65+ and 65-, SNAQ + BMI, SNAQ RC or MUST;
- Score list: e.g. Dutch questionnaire for eating behaviour (NVE).

Patient material:

- Patient version of COPD care pathway, information sheet 'exercise' and 'good use of energy' (<u>Appendix 4</u>).



Assessment of nutritional status and nutritional intervention

When: periodically, depending on disease burden

Concept definition

A periodic evaluation of nutritional status and intervention takes place.

Practical tools

2 to 12 months after discharge:

- Screen nutritional status by means of validated screening instrument, if >3 months ago. At least once per year;
- Ask about undesirable weight gain;
- Repeat the FFMI measurement if necessary;
- With the patient and any informal carer(s), evaluate the plan of action to maintain or obtain optimal nutritional status and adjust if necessary.

See <u>KI 7.2</u> for indications about:

- consult dietician if necessary:
- focus areas during the consultation.

> 12 months after discharge:

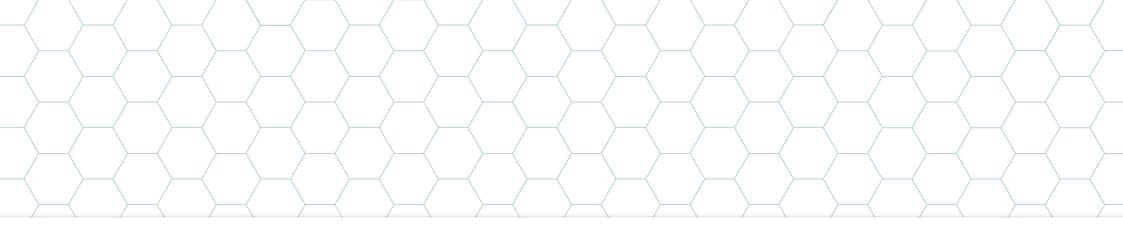
In case of weight loss and in case of doubt about muscle mass, the FFMI is determined.

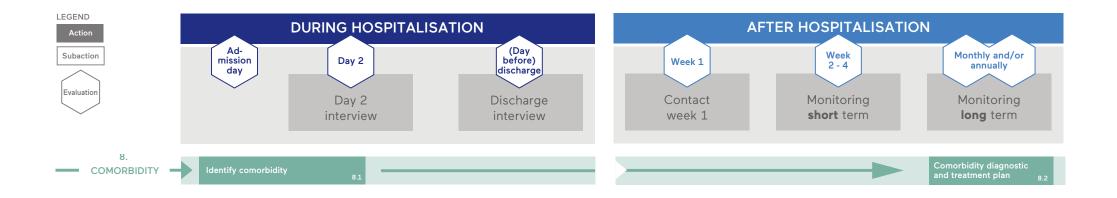
Instruments

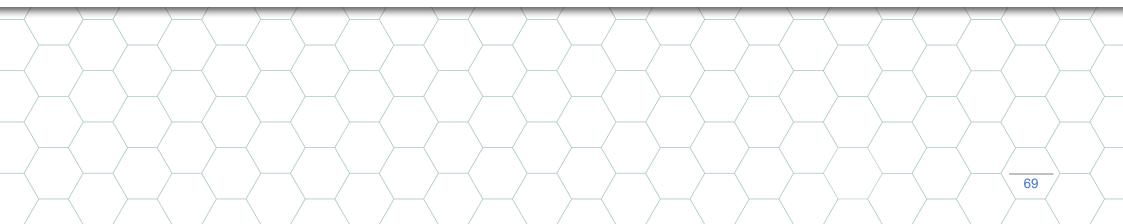
See KI 7.2 guidelines and patient materials.











Identify current comorbidity

When: day of admission

Concept definition

Identify one or more concomitant diseases that can influence the primary condition COPD and partly determine the burden of disease.

Practical tools

- Identify and document comorbidity;
- Co-medication is assessed and adjusted in the case of adverse interactions or contraindications for use with COPD etc.;
- Treat COPD as if there were no comorbidity as much as possible, and treat the comorbidity as if there were no COPD.

Instruments

- List of common comorbidities and potential complications (Appendix 12).

Literature suggestions:

Table of contents

- <u>Global Initiative for Chronic Obstructive Lung Disease</u> (GOLD Chapter 6);
- Lung Alliance Netherlands 2017, <u>http://www.longalliantie.nl/hartfalen-en-copd/</u> practical examples of good cooperation in diagnosing and treating people with COPD and heart failure.

Summary

Comorbidity diagnostic and treatment plan

When: periodically, depending on disease burden

Concept definition

Identifying a new as yet unknown undiagnosed disorder.

Practical tools

- Remain alert to the occurrence of new comorbidity;
- Routine diagnostic path for detection/exclusion of other conditions;
- Prepare treatment plan for new diagnosis;
- New medication is adjusted if adverse interactions occur or in case of (relative) contraindication for use with COPD etc.;
- Treat COPD as if there were no comorbidity as much as possible, and treat the comorbidity as if there were no COPD.

- List of common comorbidities and potential complications (Appendix 12);
- See <u>KI 8.1</u> for literature suggestions.

Appendices

1. Results of care pathway for COPD lung attack	73
2. Guidance for regions starting with the COPD care pathway	80
3. Other considerations; funding incentives, information transfer, tMDO and home visits _	84
4. Explanation of Patient version Care pathway COPD lung attack with hospitalisation	87
5. Examples of meeting documents	89
5a. Day-2 interview format	
5b. Transfer letter format	90
5c. Discharge letter format	92
5d. Home visit report	94
5e. Lung Attack Action Plan	95
5f. Individual Care Plan	
6. Meeting checklists and action lists	100
6a. Day-2 interview	100
6b. Discharge meeting	_ 101
6c. Contact moment week 1	
6d. Monitoring phase short term	103
6e. Monitoring phase long term	104
7. Integral health status	105
7a. Additional information Integral health status	105
7b. CCQ questionnaire	107
8. Advance Care Planning	108
8a. Additional information Advance Care Planning	108
8b. EDIZ questionnaire	
8c. Advance Care Planning Focus Areas	_ 111
9. Individual Care Plan and Lung Attack Action Plan	_ 113
10. Smoking cessation	_ 114
10a. Additional information on smoking cessation	
10b. Smoking cessation toolkit	_ 116
11. Mobility and exercise	_ 119
11a. During hospitalisation	_ 119
11b. After hospitalisation	_ 120
12. Comorbidity with COPD	_ 121
13. Glossary	122
14. Literature	_ 125
15. Composition of working groups and pilot regions	129
16. Lung Alliance Netherlands	_ 131



Appendix 1 Results of lung attack care pathway in pilot regions (2014-2018)

Background

The national transmural care pathway for a lung attack with hospitalisation is a cohort study, in which 600 patients admitted for a lung attack were followed for one year. Eight hospitals, in regions across the country, participated. A hospital region was defined as a hospital surrounded by a local network of first-line care group(s). But because not all care groups around hospitals joined in, not all of the patients could be included in the cohort.

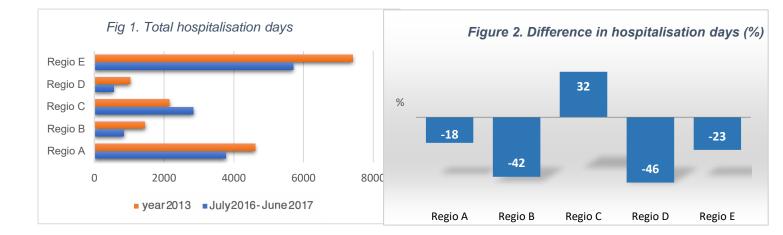
In consensus between many parties in the field, including patients, pulmonologists, general practitioners and respiratory nurses, a protocol was drawn up in which many ambitious elements of good care were formulated, as well as tools and insights that could contribute to achieving them. Deliberately, in order to respect autonomy and local possibilities, the protocol was therefore not a tight straitjacket, not in terms of method (e.g. which questionnaire to use, how to supervise smoking cessation) nor in terms of who should implement which component. The "what" was tightly specified; the "how" less tightly, and the "who" not at all.

Eight regions implemented the care pathway locally with different emphases, depending on the possibilities and priorities. In a large cohort, this breadth of variation allows examination of success factors: which of the many objectives (e.g. inhalation instruction, smoking cessation counselling, integrated health analysis, Individual Care Plan, contact moment soon after hospital admission, etc.) were achievable on the one hand and associated with better outcomes (fewer admission days in the first year) on the other.

Reduction in the number of hospitalisation days with lung attacks (DBC data)

The primary goal of the national care pathway was a reduction of hospitalisation days in the first year, whilst retaining equal, or improved, quality of life and patient satisfaction in 5 years time. To gain insight into the number of days, the participating hospitals were asked to compare the relevant DBC codes of transaction 1241 for the whole of 2013 with the period of July 2016 to June 2017. During this period, all pilot regions were implementing the care pathway. Data was available for five regions, which are shown in Table 1.

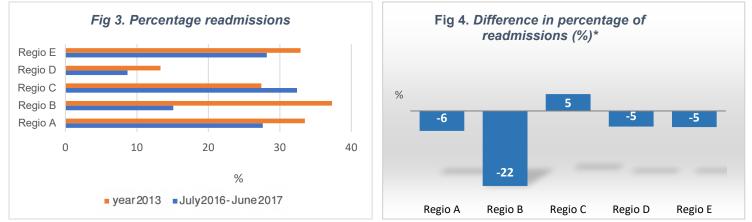
All regions show a decrease in the median duration of hospitalisation. Four out of five regions show a decrease in the number of hospitalisation days of between 18% and 46% (Fig. 2) and a decrease of the readmission rate of between 5% and 22% (Fig. 4).





	-				
	Region A	Region B	Region C	Region D	Regio E
Number of unique patients					
year 2013	450	94	246	111	618
July 2016-June 2017	471	107	302	84	546
Total hospitalisations					
year 2013	677	150	339	128	921
July 2016-June 2017	651	126	447	92	760
Total hospitalisation days					
year 2013	4607	1448	2149	1026	7409
July 2016-June 2017	3771	841	2840	550	5703
Average hospitalisation dura	tion (in day	s)			
year 2013	6.8	9.7	6.3	8.0	8.0
July 2016-June 2017	5.8	6.7	6.4	6.0	7.5
Median hospitalisation durati	on (in days)			
year 2013	6	8	6	7	7
July 2016-June 2017	5	6	5 or 6	5	6
% readmissions*					
year 2013	34%	37%	27%	13%	33%
July 2016-June 2017	28%	15%	32%	9%	28%

Table 1. Results hospitalisation days 2016/2017 per pilot region (DBC data)



Interpretation of region C

It is striking that region C shows an inverse picture compared to the other regions. Instead of a decrease in the number of hospitalisation days and readmissions, there was an increase of 32% in the number of hospitalisation days and 5% in the number of readmissions.

Before the start of the pilot, this region had already gone through a major improvement process, and started with the lowest hospitalisation duration. In addition, during the pilot period, this region was found to suffer badly from external factors that seriously disrupted the implementation of the care pathway. For example, there was a merger of the pulmonology ward with cardiology, internal medicine and oncology. As a result, the specifically trained workforce (in the field of pulmonary diseases) was widely deployed and had insufficient time to focus on patients with COPD. Furthermore, there was a structurally excessive workload due to a lack of staff.



Due to the many staff changes, the training of ward nurses was not feasible and the crucial interventions were not carried out according to protocol. After evaluation in the hospital with those responsible, considerable adjustments were made and a wing of the ward was made available again for patients with pulmonary disease only, so that the trained staff can be successfully deployed again. Unfortunately, these changes were only made after the pilot was completed and are therefore not reflected in the data. However, this example shows how fragile success can be and how important consolidation and continuous evaluation is.

Analysis of the decrease in the number of COPD hospitalisation days

The primary goal of the national care pathway was a reduction of hospitalisation days in the first year after an admission. Ideally, everyone admitted has 365 days of follow-up and the key parameter is simply the total number of hospitalisation days per person. However, in reality, people die, people withdraw from further participation, move house etc. and so there is missing data, and the follow-up period will turn out to be shorter. Conversely, in a number of regions, the care protocol and data input has continued, so that sometimes even more than 2 years of observations have been made. The primary parameter that was ultimately chosen was the percentage of hospitalisation: the ratio of the number of hospitalisation days (including the index admission at the beginning) divided by the length of the observation period, with a maximum of 1 year. Thus, 20 days of hospitalisation in one year weighs the same as 10 days in the first half year. This parameter is not normally distributed, which is why a presentation of medians has been chosen. The natural logarithm of this ratio is normally distributed and has been used for the regression equations.

Demography

For 752 patients, sufficient data was available to be included in the analysis of success factors; the demographic characteristics of these patients are shown in Table 2. The reasons for incomplete follow-up are shown in Table 3. As expected, there is a high mortality among this group: 13% died in the first year after hospitalisation.

The number of readmissions is described in Table 4.

Table 2. Demography

Number of patients	752
Age	69.6 (±10.0)
Women (%)	58.2
Smokers/ex-smokers (%)	35.2/52.4
GOLD stage 1 %	6
GOLD stage 2 %	33
GOLD stage 3 %	44
GOLD stage 4 %	18
Number of admissions pp py in year before participation	1.6

Table 3. Reason for shorter follow-up

Death	120
Moved	1
Stops further participation	3
Other	8

Hospital admission	Number of admissions	Admission duration (average)	Admission duration (median)
Initial admission	752	6.9	5.0
1st readmission	323	6.9	5.0
2nd readmission	135	6.7	6.0
3rd readmission	57	7.6	6.0
4th readmission	30	10.6	7.0
5th readmission	15	6.3	5.0
6th readmission	4	3.5	3.5
7th readmission	2	1.5	1.5
Total	1318	12.2	8.0

Table 4. Number of admissions and readmissions

Not all patients are equally at risk for many hospitalisation days. An example is the higher probability at a lower FEV₁. Before analysing which particular elements of the care pathway contributed to the reduction of the number of hospitalisation days, analysing which patient characteristics are predictive for a higher % of hospitalisation days at the start is key. The following patient characteristics were significantly associated and show that there are more hospitalisation days in more severe illness.

- Lung function expressed in FEV1%pred;
- Oxygen therapy before admission;
- Prednisolone as maintenance therapy before admission;
- Antibiotics as maintenance therapy before admission;
- The number of lung attacks 12 months before admission;
- The number of admissions for lung attacks 12 months before admission;

Table 5. Association of patient characteristics with % hospitalisation days

		Quant.	Beta	p-value
FEV1%pred		567	007	.000
Gender	Male	314	095	.135
-	Female	438		
Age	<60 years	145	.003	.326
	60-70 years	257		
-	70-80 years	231		
	>80 years	119		
Smoking status	Ex-smokers	394	.021	.889
-	Current smokers	265	092	.548
-	Never smokers or unknown	93	266	.147
Maintenance inhalation	No or unknown	236	038	.578
corticosteroids before adm.	Yes	516		
Maintenance oxygen therapy	No or unknown	626	.315	.000
before admission	Yes	126		
Maintenance prednisolone	No or unknown	654	.246	.007
before admission	Yes	98		
Maintenance antibiotics before	No or unknown	672	.241	.016
admission	Yes	80		
Exacerbations 12 months before	0	374	.084	.000
admission	1	185		
	2	102		
-	≥3	73		
Admissions 12 months before	0	500	.191	.000
admission	1	167		
-	2	52		
-	≥3	33		

The demographic elements have been corrected for the number of follow-up days

Table of contents

Factor	quantity no/yes	% of period hos (uncorrected) yes n		p-value
Contact moment within 1 week	336/416	3.2877	2.4255	.039
after discharge				
Home visit contact 1st week	189/227	2.4194	2.4316	.499
Home visit later in the year	576/176	2.5070	3.0137	.151
With smokers, non-	216/49	2.5084	2.0735	.718
pharmacological smoking				
cessation counselling initiated				
during hospitalisation				
With smokers, non-	243/22	2.5290	1.3699	.019
pharmacological smoking				
cessation counselling started later				
in the year				
Pharmacological smoking	219/46	2.1918	2.7397	.508
cessation supervision initiated				
during hospitalisation, with				
smokers				
Pharmacological smoking	253/12	2.4864	1.3952	.032
cessation supervision started later				
in the year, with smokers				
Lung Attack Action Plan discussed	316/436	2.2686	3.2787	.658
during hospitalisation				
Lung Attack Action Plan discussed	473/279	3.2877	2.1918	.036
during the year				
Inhalation technique checked	222/530	2.1918	3.0137	.013
during hospitalisation	100/0/-	0.50/5	0.1016	
Inhalation technique checked	433/319	3.5616	2.1918	.011
during the year				
Expectations of patient/family	558/194	2.7397	2.4658	.647
discussed during hospitalisation				
Discussion palliative care,	576/176	2.5576	3.0137	.105
advance care planning during				
hospitalisation	000/05	0.000	a =0.0 (
Discussion palliative care,	689/63	2.7397	2.7304	.995
advance care planning during the				
year				

Table 6. Analysis into (success) factors associated with reduction of hospitalisation days

If it was unknown whether an element had been carried out or not, it was decided in the analysis to consider it as not carried out.

Corrected in the analysis for significant patient characteristics as previously described in Table 4, and the number of days of follow-up.

Success factors

Regions have come up with what, according to care providers, has contributed most to improving care and the reduction of the number of hospitalisation days in their region. The answers can be divided into three categories:

1) Increased problem awareness

Regions are more aware of the fact that there are many hospital admissions for lung attacks and that a relatively small group of patients cause a lot of admissions. Upon admission, not only symptoms are treated, but the causes behind admission (such as anxiety and depression) are taken into account as well.

2) **Care organisational improvements** including the structured documented approach. Without a structured approach, the variation in practice is enormous: between institutions, between care providers, and between different admission times (morning, afternoon, working days, weekends,



etc.). Working with the care pathway provides structure, e.g. by setting up a monitor of structure/care coordinator, as well as transmural multidisciplinary cooperation/transfer between second and first line, geriatric rehabilitation and intensive collaboration with home care. Structure contributes to a reduction in the number of admissions and readmissions. The exact scope of this is difficult to quantify.

3) Health care improvements

For example, better inhalation instructions, home visits, use of lung attack Action Plan, smoking cessation and use of palliative care.

The increased awareness and protocol approach may be central to the success of the care pathway, but this cannot be analysed for their relative contribution to success as these factors apply to everyone in the care path cohort. The health care improvements under category 3 do lend themselves to analysis of success factors within the cohort due to existing variability. Moreover, there is a lot of work for the regions in the implementation of all the care elements mentioned under category 3 (the total list was even longer in the care pathway), so it is extremely useful to look at what actually contributes to success and what does not.

The following elements of the care pathway had a significant association with a lower % of hospitalisation days (see Table 6):

- Contact moment within 1 week after discharge (slightly later, up to 14 days accepted);
- Non-pharmacological smoking cessation support in the year following hospitalisation;
- Pharmacological smoking cessation support in the year following hospitalisation;
- Discussing Lung Attack Action plan in the year following hospitalisation;
- Check inhalation medication technique in year following hospitalisation.

One element was actually negatively associated, which was checking inhalation technique <u>during</u> hospitalisation.

Regional differences

Data was collected in eleven hospitals spread across eight regions; the distribution across the regions is shown in the table below. There is one region with a longer median hospitalisation duration. The other regions are within a close range.

Region	Quantity patients	Quantity admissions	Median 1st hospitalisation duration per admission	% of period hospitalised
1	90	133	6.0	2.74
2	99	220	5.0	2.56
3	98	180	5.0	2.19
4	57	104	6.0	2.47
5	102	148	5.0	1.96
6	98	179	7.0	6.32
7	111	201	5.0	2.33
8	97	153	6.0	3.14
Total	752	1318	5.0	2.74

Table 7. Hospital data by region

Table 8 shows the regional differences in the implementation of the elements. There are major differences between the regions in terms of which elements of the care pathway have actually been implemented (or at least quite often), and which have not. Initially, this does not seem to provide any other information than the scores in Table 6 (success factors).



Table 8. Regional differences in implementation of elements

Table 6. Regional anterences in implementation o	То		Regi	on 1	Regi	on 2	Regi	on 3	Regi	on 4	Regio	on 5	Regi	on 6	Regi	on 7	Regi	on 8
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
Total	752	100	90	12	99	13	98	13	57	8	102	14	98	13	111	15	97	13
Contact moment within 1 week after discharge	416	55	41	54	90	91	78	80	28	49	38	37	31	32	58	52	52	54
Home visit within 1 week after discharge	227	55	35	85	86	96	22	28	19	68	5	13	7	23	39	67	14	27
Home visit later in the year	176	23	34	38	15	15	12	12	1	2	11	11	0	0	32	29	71	73
Non-pharmacological smoking cessation support initiated during hospitalisation, with smokers	49	19	3	10	16	36	0	0	3	14	4	14	0	0	17	47	6	21
Non-pharmacological smoking cessation support during the year, with smokers	22	8	5	16	0	0	4	11	1	5	1	3	0	0	4	11	7	25
Pharmacological smoking cessation support initiated during hospitalisation, with smokers	46	18	0	0	10	22	11	29	6	29	0	0	6	17	2	6	11	39
Pharmacological smoking cessation support during the year, with smokers	12	5	5	16	2	4	0	0	4	19	0	0	0	0	1	3	0	0
Lung Attack Action Plan discussed during hospitalisation	436	58	86	96	84	85	39	40	0	0	9	9	82	84	77	69	59	61
Lung Attack Action Plan discussed during the year	279	37	47	52	73	74	14	14	8	14	3	3	3	3	59	53	72	74
Inhalation technique checked during hospitalisation	530	70	90	100	77	78	70	71	16	28	39	38	97	99	83	75	58	60
Inhalation technique checked during the year	319	42	30	33	48	49	39	40	45	79	8	8	2	2	71	64	76	78
Expectations of patient/family discussed during hospitalisation	194	26	40	44	22	22	55	56	15	26	42	41	2	2	5	5	13	13
Discussion palliative care, advance care planning during hospitalisation	176	23	39	43	34	34	17	17	18	32	39	38	3	3	6	5	20	21
Discussion palliative care, advance care planning during the year	63	8	1	1	24	24	15	15	6	11	0	0	1	1	11	10	5	5

Guide for regions starting with the COPD care pathway

The guide is subdivided into

Phase 1: focus areas prior to and at the start of the care pathway. Phase 2: focus areas that can be specified once the care pathway has been started.

Phase 1: Focus areas prior to and at the start of the care pathway

- 1. There is **support** in the region for reducing COPD hospitalisations.
 - This support exists within the hospital(s), care group(s) and home care institution(s);
 - This support is evidenced by the (written) commitment of the board and the employees responsible for the implementation of COPD care);
 - If other parties wish to be equally involved, they must also show their support and (written) commitment.
- 2. **Transmural care** is preferable. Therefore, the region in which **collaboration** between the hospital (pulmonology department), care group(s) and home care institution already exists has the advantage. This collaboration is preferably embedded in a regional structure:
 - Consultations are already taking place periodically;
 - The most important stakeholders know each other: pulmonologists, respiratory nurses, home care, care group/GPs/assistant practitioners;
 - There are contacts with adjoining disciplines: pharmacists, physiotherapists, dieticians, occupational therapists, social workers, etc.;
 - If this (structural) collaboration does not yet exist, setting it up is a priority. In addition, some interventions can be taken up internally without formal transmural collaboration. Think of collaboration between the outpatient/nursing department and operational interventions such as the day-2 interview or medication technique.
- 3. There is adequate **support for the collaboration**. Reducing the number of COPD hospitalisation days requires long-term commitment and patience. This requires a regional composition of:
 - A **project team** responsible for the implementation of the project. This team consists of at least:
 - a substantive ambassador involved in the primary process (e.g. a respiratory nurse);
 - a medical owner, responsible for medical decisions (doctor);
 - a line manager, responsible for allocation of tasks (e.g. team leader);
 - a project supervisor (e.g. policy advisor);

• expertise in Excel, HIS/KIS/ZIS and production figures is also available on demand. NOTE: lessons learned show that this project team should not be too large either. If necessary, a different composition for different goals may be required, but always will include at least the four team members mentioned above.

- A steering group in which all parties that have committed themselves (in writing) are represented. This steering group has the task of sketching the broad outlines, is in a position to implement decisions and ensures that decisions taken are also supported (financially or in terms of personnel). Involvement and/or cooperation of the management levels are therefore a requirement.
- A broad-based advisory group in which all parties involved in the care of the COPD patient are represented. This support group meets several times to be consulted and to ensure broad support throughout the region. In addition to care providers such as pulmonologists, respiratory nurses, paramedics and pharmacists, patients and informal carers are also represented. Social workers, municipalities and volunteer organisations may also be good additions to this team.

Table of contents

- This support is committed for at least two years. During this time, project members may leave the organisation, but it is important that there is an administrative commitment to ensure adequate succession in the project in those cases.
- 4. There is **support** from the preferential **health insurer(s)**, and this support has been translated into:
 - The health insurer's approval that the region in question will start work on the systematic reduction of hospitalisation days for lung attacks;
 - Preferably, the involvement of the health insurer in the allocation/release of funds for the regional support of the collaboration. Possibly translated into separate or regional (production) agreements on how to deal with the shift in demand for care: fewer and more intensive hospital admissions, more intensive aftercare provided by the home care organisation or GP/assistant practitioners.
- 5. The **input** from **patients** is adequately safeguarded, e.g. through involvement (in a sounding board group, etc.) of the local (Dutch Lung Fund) patients' association, 'Care Concern' or client councils.
- 6. There is a **clear picture of the production figures/numbers of patients** in the region and there is a willingness to share these figures with each other. This involves:
 - Numbers of COPD patients in primary care of hospital, care group and home care institution;
 - Number of hospitalisations for pulmonary diseases and number of readmissions;
 - Willingness to keep track of a limited number of indicators that (a) map one's own progress in implementation and (b) are needed (nationally) to compare regions with each other and with historical data.

7. Regional focus is present

The systematic and structural reduction of COPD hospitalisation days yields a lot: better quality of life for patients and their informal carers, more job satisfaction for care providers, freeing up capacity in the hospital, etc. Implementing the project requires a lot of dedication and time. It requires all those involved to focus their efforts on the proper implementation of this extensive and long-term project. This often means that only one or two projects of this kind can be run simultaneously per region.

8. Continuity is guaranteed

Ultimately it is necessary to continue the renewed approach sustainably in the region. A plan is needed for the continuity of the approach, so that the new care pathway naturally becomes the standard care in the region.



Phase 2: focus areas when working regionally with the care pathway

- 1. Use the **care pathway for a lung attack with hospitalisation** to give advice on the process and the interpretation of interventions.
- 2. Make use of the **national knowledge and expertise** regarding the LAN and other regions that have already gone through this process. If necessary, make use of buddy regions in your own area.
- Make use of the seven-phase model of the Belgian-Dutch clinical paths network and/or a comparable method as a guideline for the process to be followed and follow all steps closely. This instrument gives direction to the steps that need to be taken to develop, implement, evaluate and continuously monitor a care pathway.
- 4. Take a regional "picture" (phase 3): how far away are we from the **ideal situation** as described in the national care pathway? Which things are going well and which ones could go better? How many COPD patients are hospitalised on an annual basis? Use the sounding board group for a clear **overview of the perceived bottlenecks**.
- 5. Set content **priorities** (phase 4): The care path, with all its topics and interventions, is extensive; prioritisation is realistic. It requires a great deal of dedication from the various relevant parties, who (usually) suffer from a lack of sufficient time, manpower and financial resources. So it may be too challenging to implement all key interventions simultaneously.

Observe the following when prioritising:

- Experiences and/or analyses from the pilot show that a high degree of urgency was required for the interventions:
 - Day-2 interview;
 - Contact week 1;
 - Inhalation instruction;
 - Lung Attack Action Plan;
 - Smoke cessation supervision;
 - Continuity of care and collaboration within the region.
- Each region should make its own list of priorities. For example, first choose three topics and evaluate them continually.
- Some recommendations for making choices:
 - The initial situation in the region; Find out how far the region is from the ideal situation (phase 3 of the seven-phase model; diagnosis and objectification). It is important here that what is already going well does not need to be changed;
 - Is it to be expected that the greatest gains in the region can be made with regard to the chosen interventions in terms of improvement of care and a reduction in the number of admission days?
 - Is there enough enthusiasm to tackle a particular component in the region as well? If necessary, start on a small scale (e.g. three organisations) and expand when things go well (see phase 1, point 2);
 - Is it realistic to expect to obtain positive results in a fixed time period?
 - Take into account the expected effort/result ratio;
 - Find a good balance between the above points.
- Define a maximum of three SMART objectives per period (year). The 3-blackboard method, described in the 7-phase model, can help here.
- 6. Put together a **regional project team with a limited number of people**. In addition, set up a broader regional sounding board group, which will be informed and can come up with helpful ideas at certain times and which can also be involved in the (smaller) project team in due course when the number of interventions is increased. This way, the project team remains decisive, with broader support (see phase 1, point 3 for the composition of participants).



- 7. For the provision of good multidisciplinary transmural care, **information exchange** between care providers, but also with the patient, is essential. A good ICT system is desirable and secure e-mail exchange must be ensured.
- Consider the possibilities of involving (pharmaceutical) companies in support of the project/process. Several companies have developed instruments and strategies that could support regions. AstraZeneca, Boehringer-Ingelheim, Chiesi Pharmaceuticals, GSK and Novartis were particularly involved in the development of the national lung attack care pathway.
- 9. Pay attention to the process-based evaluation (steps 6 and 7). Experience shows that attention may slacken and/or other matters within the organisation gain more priority. The care pathway should also lose the status of project and be continued in current regular care. It is advisable to maintain the project team for this purpose, with the only adjustment being the removal of the team member project leader; after all, it is no longer a project, but current regular care. Also provide anchoring in the management structure by making it a fixed item on the agenda, e.g. in team meetings, and having it included in the team leader's monthly reports.
- 10. Spend a lot **attention to a good atmosphere** in the regional collaboration and celebrate successes. For instance, by checking at the patient level how much better patients are doing and how many new hospital admissions have been prevented. Organising a regional symposium may also be useful here.
- 11. **Communication** in a transmural care pathway requires a lot of attention and time, but pays off in the long run.

Other considerations; Funding incentives, transfer of information, tMDO and the added value of home visits

Funding incentives

When implementing the care pathway, it is important to pay explicit attention to a number of underlying issues in the health care sector that affect the willingness of the various target groups to implement the care pathway.

The most important issue in the health care sector is the cost of care. In short, the current method of health care funding does not make a stimulating contribution to reducing the number of hospitalisation days for lung attacks. Care is paid for on the basis of billing codes for procedures (admissions) and fewer admissions mean less income for (especially) hospitals. A larger role for the care of these patients by care groups and/or home care service providers means that a patient category with a high burden of disease and care is added to the already large chronic patient population. This results in an (even) higher work load and the question arises to what extent this care will be funded. The strategy of Lung Alliance Netherlands is to address the issue of funding by drawing the attention of the Ministry of Health, Welfare and Sport, the Dutch Health Care Authority (NZa) and health insurers to the problems experienced in the area of funding as much as possible. Well thought-out regional solutions to new ways of providing care (despite the incentive structure) will be disclosed to other regions.

Information exchange

For the provision of good multidisciplinary transmural care of people who are, or have been, hospitalised with a lung attack, information exchange between care providers, but also with the patient, is essential. This, too, is a bottleneck that affects the entire Dutch health care system and on which the LAN has insufficient influence.

Tips:

The problem of the funding structure and the exchange of information cannot be solved in an individual region. There are, however, a few tips on how to deal with this problem:

- Join regional and/or national developments if available. An example: on the initiative of VitaValley, the coalition Vitaal Thuis: Ziekenhuiszorg Thuis collaborates with 60 parties on the large-scale implementation of safe, reliable, usable and affordable hospital-care home applications, such as remote care for COPD patients. Among other things, the coalition is working on structural funding for this type of hospital care at home and has written a practical step-by-step plan to arrive at a contracting model. This step-by-step plan can be found on the VitaValley website;
- Discuss the problems with the care pathway improvement team and be frank about the problems and interests of each individual organisation. Openness creates understanding and can result in joint solutions;
- Involve the health insurer in the short term. In the health care funding system, there are possibilities to (partially) reimburse projects such as the care pathway. To apply for this, it is up to the care group, home care or hospital to contact a health insurer.

Some examples:

- Funding of a care coordinator for district nursing care, or for the broadly defined job description of the COPD case manager with direct and indirect care responsibilities, or to raise the production ceiling (pilot region Zaanstreek/Waterland). Zilveren Kruis Achmea Evean
- COPD visualised; funding monitoring of COPD patients in the home situation using e-Health.

Menzis – Sensire – Slingeland hospital

- Reorganisation of the financing of lung care across the partitions of various disciplines; 3-year contract based on the triple-aim principle. *Zilveren Kruis Achmea – De Nije Veste*

Table of contents

Summary

Transmural Multi Disciplinary Consultation (tMDO)

The aim of tMDO is to discuss and evaluate the specific demand or need for care with practitioners from both first-line and second-line work settings and medical, technical and psychosocial professionals.

Tips:

A well-functioning tMDO:

- is the result of everyone's commitment;
- is periodic (e.g. monthly);
- has a clear structure and agenda. This requires good preparation. Fixed components in the consultation are:
 - the patient's specific care needs;
 - the patient's medical as well as psychosocial status;
 - the activities required to meet this demand for care, including allocation of responsibilities (set up of plan of action);
 - evaluation of previously discussed patients, and if necessary, the transmural collaboration.
- all those involved are present (physically or virtually). The patient's general practitioner (or representative), the pulmonologist and the care coordinator form the core. In addition, care providers relevant to the demand for care are present, such as paramedics, but a social worker from the district team can also be helpful;
- above all has a good moderator, ideally the care coordinator.

Example:

An example of transmural care is the pilot region Zaanstreek/Waterland. In this region, a care coordinator from the home care services has been appointed (referred to here as the case manager) for patients who are hospitalised repeatedly. She is involved in tMDO during hospitalisation, contacts the patient within 2 days after discharge and visits the patient's home (usually within one week). Depending on the disease burden (often heavy), complexity and comorbidity, the patient is either included in the case management project, or referred back, with advice, to assistant practitioner/GP or respiratory nurse/pulmonologist. The case manager acts as the spider in the web of care providers that the patient sees. The case manager (performs care diagnostics) assesses care needs, implements the treatment plan (ICP) together with the core team (tMDO), evaluates it and makes adjustments. The core team consult each other by telephone once every 2 months.

Pilot region Zaanstreek/Waterland - Evean

Potential added value of home visit

In the pilot period, several regions opted for a home visit in the first weeks after hospitalisation, as this was regarded as added value, especially for patients with repeated admissions. A great advantage of a home visit is the opportunity to discuss/review matters again in one's own familiar environment, including:

- gaining an objective insight into the patient's home situation with potential barriers hindering recovery;
- checking whether integral health status is stable or still improving. Is there any relapse in one or more domains (CCQ);
- does the patient know who his/her first person of contact is (care coordinator)?
- have all aspects of the patient's care needs been addressed and are they known to the patient and informal carer (ICP)?
- have all contacts been established with the care providers for follow-up appointments (e.g. assistant practitioner, home care, dietician, physiotherapist, occupational therapy or social worker)?

Table of contents

Summary

General overview

Different implementation partners

Depending on the regional situation, various disciplines have taken on home visits, including:

- home visit by a care coordinator from home care (pilot region Zaanstreek/Waterland);
- home visit by a hospital respiratory nurse (pilot region Arnhem);
- home visit by a home care respiratory nurse (pilot region Amsterdam, Rotterdam, Brabant, Arnhem);
- home visit by the general practitioner (pilot region Maastricht). If this approach is adopted, it is advisable to start with a small group of sympathetic general practitioners and expand it over time. In addition, it is advisable to provide a brief summary of what is expected of the (general practice) GP practice. Good communication is key here.

Example of reporting

An example of a home visit report is shown in <u>Appendix 5d</u>. The content of this form may vary from patient to patient. The fixed format is divided into the SOAP categories (Subjective, Objective, Analysis and Plan).

Literature

- Holstege, M. et all (2016). Pilot study into the effectiveness of COPD case management by Evean on the reduction of the number of hospital readmissions.
- Van Eeden, A.E. et al. (2015). Effectiveness of case management in the reduction of COPD readmissions: results of a pilot study.



Appendix 4 Explanatory notes to the patient version of care pathway for a lung attack with

hospitalisation

Instructions for the use of patient information for lung attack care pathway

A patient version of the lung attack care pathway has been developed. The aim of the patient version is to give patients additional information about the treatment and to assist them during hospitalisation. Attention is given to what a patient will be facing in the coming period, and what they can do themselves. In addition, there is the possibility to provide additional information about, for example, medication or exercise. Separate sheets have been developed for this purpose. The information is based on input from patients. They have indicated what they consider to be important with regard to content and layout.

What is the content?

The total package comprises a general part and seven separate parts.

- General part (information about what to expect, what to do, returning home, COPD and a lung attack);
- Fear, sadness and gloominess;
- Exercise;
- Good use of energy;
- Nutrition;
- Medication;
- Smoking;
- Working after a lung attack.

Why separate parts?

The idea behind the separate parts is that as a care provider, you should not overload the patient with information. Too much information can cause the patient to absorb less of it. When a subject comes up for discussion, you can provide targeted information. Not all parts have to be discussed.

When do I give the patient the information?

Of course, as a care provider, you know this best. In general, the intention is that patients receive the general information on their first day. This way, the patient or his/her informal carer(s) can get a view of the information and read about what is going to happen in the time to come.

The separate parts can be provided when the subject comes up and the patient feels the need for them.

Where can I find this?

The patient version can be downloaded at www.longalliantie.nl/zorgpad.

Technical manual patient information lung attack care pathway – for communication

Medication;

Working after a lung attack.

Smoking;

The patient version consists of a general part and seven separate parts. The separate parts are:

- Fear, sadness and gloominess;
- Exercise:
- Good use of energy;
- Nutrition;

Three formats are available:

- Word;
- PDF;
- InDesign.

These can be downloaded at www.longalliantie.nl/zorgpad

The PDF format is ready to print. You can also add your organisation's logo and then print it. If you want to customise further or create your own layout, you can use the following options:

Word

With the Word document, you can use the texts and develop your own layout. If you feel that not all of the information applies, you can also use parts of the text.

PDF

In PDF format, you will find the entire document, but also the separate parts. You can make changes with Adobe Acrobat Pro. It is also possible to add the organisation's logo.

InDesign

This file provides you with the layout and texts. You have the possibility to edit everything. You will also find the fonts used. The organisation's logo can easily be added.

Good luck working with the patient version of the lung attack care pathway!



Appendix 5 **Examples of conversation documents**

Appendix 5a. Example of Day-2 interview format

Source of format: UMCG Pulmonary Diseases Department (dated 26-04-2015)

	Ι	
	Persons involved	Task division/Conversation topics in order
Preparation	Nurse by the bed	Announcement family meeting + date/time preference between 15:00 and 17:00)
(day of admission)		Brief explanation of purpose and content of the conversation (demarcation!)
		Brochure 'hospitalisation with COPD exacerbation'
	Patient	Arrange family for family meeting
Family meeting,	Doctor	1. Discuss increase in complaints and direct cause for hospitalisation
part 1 – 10 min. (day 2)		2. Explanation of COPD and exacerbation (general)
		3. Explanation of findings in patient (specific)
		4. Explanation of plan of action:
		 Goals and wishes hospitalisation
		Target discharge date
		Medication
		Possible additional assessment
		 Activate in ward + physiotherapy (mention)
		5. Check with pt: Ideas on the reason for the exacerbation. Could this have been prevented?
		6. Inventory of own questions patient/family: Which have been answered? Which should be answered by doctor?
	Nurse Patient + 1 to 2 family members	16. Keep minutes
		 and 5: Elaborate on cause and course of complaints Input of own questions
Family meeting, part 2 – 10 min. (day 2)	Nurse	 1. Inventory of additional policy: What is needed for discharge and long-lasting recovery? Map the home situation: What is needed for discharge? Screening of psychosocial problems Identify: Smoking status (+ possible quitting motivation) Weight (over time)/Nutritional status
		Check inhalation technique
		 Make an inventory and if possible answer patient/family questions Provide additional info or hand out additional brochure(s)
	Patient + 1 to 2 family	4. Bring in patient's questions
Additional -	members Nurse who	Reporting Family meeting part 1 and 2 in Poliplus
on indication (day 3)	attended the interview	Feedback with patient/family, discuss any other questions
	'Nurse by the bed'	If necessary: check that relevant disciplines are consulted

Table of contents

Summary

General overview

Appendix 5b. Format for a lung attack transfer letter (within 24 hrs to 1st line)

	F	Pulmonary diseases
	l	_ocation:
	F	Phone:
	F	Fax:
Dear Sir/Madam		
Mr/Ms, general practitioner		
Address	[Date:
		·
Subject: Name Patient , BSN: xxxxx patient number: xxxx	x, born: dd-mm-yyyy ,	residing at: xxx, in: xxxx ,
Dear colleague,		
The patient mentioned above was admitted t	to the pulmonology dep	partment.
ADMISSION	DATE	NOTES
Reason for admission		
Lung attack (exacerbation) based on		
Admission date		
Discharge date		
ACTIONS DURING HOSPITALISATION	IMPLEMENTED?	NOTES
Abnormal findings during hospitalisation:	Yes / No	
Results		
CCQ	Yes / No	
Interventions carried out		
SCC started?	Yes / No	
Oxygen therapy?	Yes / No	
Oxygen inerapy:	103/110	
Medication		I
Maintenance		
In case of worsening complaints		
(Re)admission policy		
NR/NA/wishes on readmission	Yes / No	
If so, what's been discussed		
Include any advice on (re)admission		
LAAP discussed?	Yes / No	
Advance Care Planning actions	N/A / Yes	
Advance care Flamming actions Alternative actions taken during	Yes / No	
hospitalisation:	165/100	
Involvement of partner/informal carer	Yes / No	

Table of contents

Summary

CONTACT	WHO?	CONTACT DETAILS
Care coordinator /1 st contact person for patient		
Responsible pulmonologist and/or respiratory nurse		
(FOLLOW-UP) ACTIONS 1 st LINE	WHO	EXPLANATION/REQUEST
Who contacts who in week 1 after admission		
Actions/Advice GP and Medical Centre		
Please report back on		
Discharge letter with more information wi	l Il follow as soon as poss	sible.



Appendix 5c. Format discharge letter lung attack

	Pulmonary diseases
Dear Sir/Madam Mr/Ms, general practitioner	Location: Phone: Fax:
Address	
	Date:
Subject: Name Patient , BSN: xxxxxx , born: dd-mm-yy patient number: xxxx	yy, residing at: xxx, in: xxxx ,
Admission: 00-00-00 Discharged: 00-00-00 Dear colleague,	
The patient mentioned above was admitted to the pulmonary de	partment.
Reason for admission COPD exacerbation based on	
Medical history	
Medication upon admission	
Medication allergies or intolerances	
Anamnesis	
Physical examination	
Additional examination	
Laboratory: Arterial blood gas:	
X-ray:	
ECG:	
Sputum culture: Lung function:	
Brief description of hospitalisation process	
Cause of exacerbation: Treatment medication:	
Mobility and physical activity mMRC score:	
Describe consultation/conclusion physiotherapy	
Indication physiotherapy in the 1st line: yes/no	
If so, has the patient been referred yet?	
Nutritional status BMI:	
Indication dietician 1st line: yes/no	
Supplementary nutrition: yes/no If so, state what supplementary nutrition and frequency	

Table of contents

Summary

General overview

Follow-up: Name Patient, dd-mm-yyyy, patno. xxxx

Integral health status

Consultation social work or psychologist during admission: yes/no *If yes, describe consultation advice* Indication follow-up in 1st line: yes/no Already known to psychologist in 1st line: yes/no *If yes, state diagnosis*

Co-morbidity

Relevant co-morbidity: Describe consultations with other specialisms during hospitalisation Describe whether additional outpatient assessment will be carried out/is advised

Smoking cessation

Current smoking status: never smoked/stopped/still smokes Pack years: Indication for smoking cessation support: yes, 1st line/yes, 2nd line/N(<u>/</u>)A

Advanced care planning and palliative care

NRNA/IC/NIV policy next admission: Indication oxygen at home: yes/no/temporary

Medication

Inhalation medication: Describe active substance, device and dosage frequency If inhalation steroids provide arguments If applicable, provide arguments for choice of device Emergency medication: Other pulmonary medication: Think of maintenance antibiotics, allergy tablets, oxygen at home Inhalation technique: adequate/needs attention

Other medication upon discharge

Discharge to: home/nursing home Home care requested: yes / N/A

Additional advice to general practitioner

Remember lab check Also state what actions you expect the GP's practice to take in response to the chosen care plan. Think of a home visit, smoking cessation support, social work consultation and reporting back to the 2^{nd} line.

Checkups:

dd-mm-yy at 00.00 with Respiratory Nurse dd-mm-yy at 00:00 with Dr X

Conclusion

- 1. COPD exacerbation caused by:
- 2. Referrals:
- 3. Primary practitioner:

Yours faithfully,

Table of contents

Summary

Framework:

- ✓ No smoking
- ✓ Sufficient exercise
- ✓ Healthy weight
- Medication compliance and technique
- ✓ Lung Attack Action Plan

Registration with home care respiratory nurse;

Mr X with COPD gold2, hospitalisation 10 -11 to 14-11-18 exacerbation COPD

Report home visit dated 20 Nov. 18;

PERSONAL GOAL OF THE PATIENT

Patient wants to be able to be active again and be less short of breath.

SUBJECTIVE

Lung problems (CCQ):

Patient felt short of breath again last night. He is now short of breath also during home visits. He is breathing 'high', which he often suffers from. No phlegm, coughs to the point of vomiting, wheezes, no fever. Patient is especially short of breath at night, which makes him anxious, and causes the onset of breathing superficially.

Smoking behaviour:

Used to smoke and quit 35 years ago

Nutrition; Fine, varied diet

Exercise;

- He thinks exercise is important;
- He attends physio 1xpw. I called them during a home visit to check/instruct breathing techniques with an eye on breathing control.

Miscellaneous:

Cognition: nothing in particular

Mental/social/ACP:

- COPD for 3-4 years. This upsets him and he is serious about complying with treatment. He's still full of life;
- Lives with his wife, who's healthy. Profession; house lettering and decoration, studied at the Rietveldacademie. Hobby; painting! Goes well, with window slightly open, no central heating;
- Is socially active. Cycles a lot, might purchase electric bicycle. Don't have a car. Referred to Wmo for supplementary public transport.

Sleep At present disturbed by shortness of breath. Normally good *Adjustments in and around the house:* N/A

Table of contents

Summary

ANALYSIS / CONCLUSION

Tightness/shortness of breath. Sleeps poorly due to anxiety and shortness of breath. High breathing/hyperventilation?

PLAN, GOALS AND (FOLLOW-UP) ACTIONS

- 2 puffs salbutamol and 1 puff ipratropium. This can now be used 6xpd. LAAP completed. Patient now knows what can do in the event of exacerbation;
- Call the pulmonologist concerning shortness of breath. Dr A. will prescribe a course of 1 wk prednisone because of complaints. Patient will start with this on 26 Nov. Inform general practitioner;
- Consultation with hospital pulmonology nurse, because the patient would like someone to come to his home at this moment. Couple knows I'm the care coordinator and know when to call me. Left my calling card;
- Please call patient next week to evaluate present complaints.

Appendix 5e.

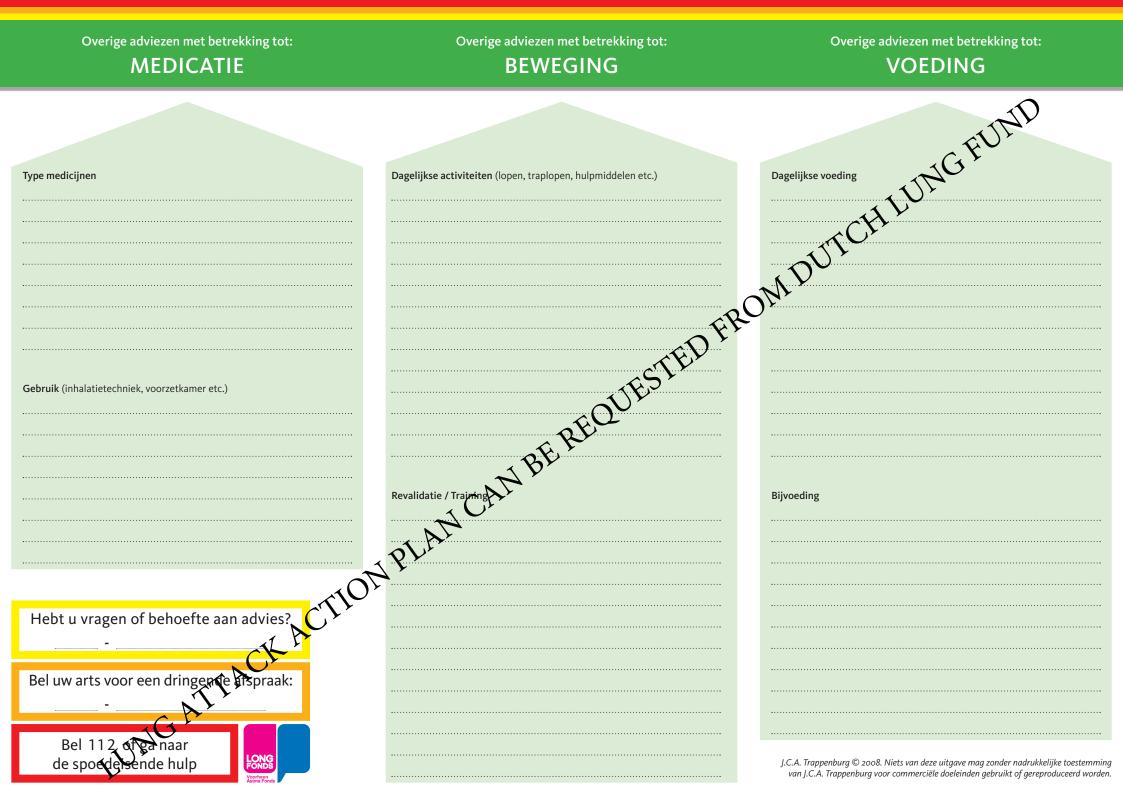
Lung Attack Action Plan

On the next page, you will find the Lung Attack Action Plan (LAAP). This format can be requested free of charge from the Dutch Lung Fund by both patients and health care providers (https://www.longfonds.nl/longaanval-actieplan-0).

The LAAP is a tool for recognising a lung attack. The care provider completes the LAAP together with the patient. The action plan states how the patient can recognise a lung attack and what they can do if the symptoms exacerbate. Taking more medication, for instance. This way, the patient will recover more quickly and hospitalisation may be avoided.



COPD Actieplan	Huisarts	Fysiotherape	eut	
Mile norm in	Longarts	Diëtist		
Mijn naam is:	Longverpleegkundige	Overige 1		LONG FONDS
Neem uw actieplan mee naar deze personen!	Praktijkondersteuner	Overige 2		Voorheen Astma Fonds
'Ik voel me goed'	Mijn medicatie		Beweging en voeding	Tim
Ik ben kortademig als ik:	Luchtwegverwijders:	per / dag per / dag	Probeer volde	ende te blijven bewegen drink voldoende'
Ik geef dagelijks slijm op: nee ja, kleur Het slijm is gemakkelijk op te hoesten	Luchtwegverwijders met	per / dag per / dag	Ga op timen	naar de fysiotherapie voor training
Ik hoest regelmatig: nee ja Ik kan mijn dagelijkse activiteiten uitvoeren	Slijmoplossers:	per / dag per / dag	Overige adviezen:	per / dag
Ik kan helder nadenken	Antibiotica / Prednison: Zuurstof:	er in rust liter by nomining		
'Het gaat iets minder'	Extra medicatie	TEN	Ademhalingstechniel	(zie ademhalingsbrochure)
 Ik ervaar een toename in <u>1 of meer</u> van de onderstaande symptomen: Kortademigheid Meer slijm of dikker / taaier slijm Grijzer / groener / bruiner slijm Piepende ademhaling Hoesten Vermoeid en niet in staat om normale dagelijkse activiteiten uit te voeren Hoofdpijn of duizelig bij het wakker worden Moeite met concentreren / vergeetachtig Meer dan 2 dagen in de gele zone of Bloederig slijm Koorts Helemaal niet in staat activiteiten uit te voeren 	Extra Extra Verdee of venergie en CHebt u vragen of b	per / dag per in rust itter by themning per / dag per / dag per / dag per / dag per / dag per / dag	Ophoesten van slijm huffen flutter houdingsdrainage	nhaling
'Na 2 dagen geen verbetering'			5 5	×
Meer dan 2 dagen in de gele zone of • Bloederig slijm • Koorts • Helemaal niet in staat activiteiten uit te voerte	Bel uw arts voor eer	n dringende afspraak:	Naam Geboortedatum	DODPAS
'De situatie is bedreigend'			Huisarts	
 Zeer kortademig, ook in rist Pijn op de borst Verward, een vergeetachtig, duizelig of gevoel flauw te vallen Moeilijn wekbaar 		of ga naar isende hulp	Longarts Medicatie	



Appendix 5f. Example Individual Care Plan

An example of an ICP is shown below. The initial document was drawn up, together with the patient, during an outpatient visit 2 to 4 weeks after hospitalisation and will be handed to the patient together with the Lung Attack Action Plan (LAAP). In this ICP, it is important to emphasise, in addition to the agreements with care providers, the exercises/agreements that the patient is expected to do by himself/herself. It was decided to draft the ICP in the first person, in order to underline the ownership of ICP by the patient. The second form is a continuation of the agreements made. The first ICP served as a practical guide during the meeting (approx. 3 months after hospitalisation). Together with the patient, the agreements in the ICP are evaluated and adjusted. This new ICP (approx. 3 months after hospitalisation) is shown in form 2.

		Form 1		
PERSONAL CARE PLAN (2-4 weeks after hospitalisation)				
	DATE			
	PATIENT			
PERSONAL GOAL OF THE PATIENT				
I want to be active again.				
GOAL IN COMING PERIOD				
I want to be able to walk so far that I can open the front door when	there are visitors.			
ACTIONS TO ACHIEVE GOAL				
 I'll work on my overall fitness. I am supervised by a physiotherapist and do the exercises we discussed every day; I will also pay more attention to how I distribute my energy throughout the day. To help me do this, an occupational therapist will visit me at home; Take medication as indicated on the traffic light card (LAAP). 				
EVALUATION OF PREVIOUS PERIOD				
A major cause of my hospitalisation was wanting to do too n the coming period, I'm going to work on improving my overa more evenly throughout the day.		•		
EVALUATION MOMENT FOR NEXT OBJECTIVE				
After three weeks at outpatient clinic				

Form 2

.

.

PERSONAL CARE PLAN

(approx. 3 months after hospitalisation)

DATE

PATIENT

PERSONAL GOAL OF THE PATIENT

I want to be active again. Six months from now, I would like to go on holiday to my bungalow in the Veluwe.

GOAL IN COMING PERIOD

Being able to go out and be among people more.

ACTIONS TO ACHIEVE GOAL

- Perform daily exercises of the physiotherapist and take more breaks during the day;
- Purchase walker;
- Optionally apply for a mobility scooter via Wmo (at the municipality);
- Take medication as indicated on the traffic light card (LAAP).

EVALUATION OF PREVIOUS PERIOD

My physical fitness has improved a lot. My physiotherapist's exercises help. The distribution of energy has improved somewhat, but remains a point of attention. Especially with holidays, it was difficult to take enough breaks. I also find that I would like to be among people a bit more.

In the coming period, I'm going to gradually expand activities and see how things go outside the house. During the conversation with the respiratory nurse, we discussed that it is especially important to pay attention moments of rest during extra activities. That's why, for longer distances, I will use a rollator, which I will apply for. I will also check with the municipality whether I qualify for a mobility scooter.

EVALUATION MOMENT FOR NEXT OBJECTIVE

After three months at outpatient clinic

Timing for discussion of checklists and action lists

Appendix 6a.

Day-2 interview with patient and informal carer(s)

On day two of the hospitalisation, a meeting takes place to find out, at an early stage, what the underlying reason is for the admission and this discussion can, among other things, serve as a starting point for the care plan to be drawn up. In addition, the different expectations regarding hospitalisation and recovery are brought into line, and we look ahead to see what preparations need to be made for a successful return home.

Action by the patient's care provider	v	What action is necessary?
Find underlying reason for hospitalisation		
Match the wishes and expectations regarding hospitalisation AND recovery of both patient, informal carer(s) and care provider		
Specify the expected discharge date		
Find out how the patient acts in the event of worsening complaints		
Global inventory of integral health status, including psychosocial and philosophical issues		
Identify smoking habit and quitting motivation		
Clarify who is the first point of contact during hospitalisation		



Appendix 6b.

Discharge meeting and preparation for discharge

On (day before discharge), a meeting takes place to verify whether the patient (and their informal carer) have sufficient confidence in the discharge and can take the necessary actions in the event of increasing complaints. In addition, the essential activities of the first weeks are discussed (e.g. home visits, rehabilitation, etc.). Finally, an assessment can be made of the extent to which expectations regarding the admission and discharge have been met.

Action by the patient's care provider	٢	What action is necessary?
Find out whether patient/informal carer has confidence in discharge		
Check what the patient feels they need to make the transition home successfully and, if necessary, call in relevant care workers		
Discuss which actions patient/informal carer should take in case of increasing complaints		
Provide name and contact details in writing of first person of contact after discharge and in case of emergency		
Go over the activities that are initiated immediately after admission		
Does patient want to quit smoking? Start support, including follow-up		
Briefly mention drawn up care plan and announce follow-up regarding draft ICP		
Ask permission for sending the discharge letter to the care provider(s) involved, including the care coordinator		



Appendix 6c. Contact moment week 1

After discharge from the hospital, the patients (usually) return to their familiar home situation. This can be a pitfall for regression into old habits that are (partly) the cause of the lung attack. This has to be taken into account. Moreover, many patients have not gotten back to their previous level yet. Some additional support, where positive reinforcement is paramount, can make all the difference.

Action by the patient's care provider	v	What action is necessary?
Check how the patient is doing and whether there are any queries		
Check whether agreements made are clear to the patient and informal carer		
Check whether care coordinator is known as first person of contact		
Check motivation and progress of agreements already made		
Discuss the pitfalls/success factors		
Use of medication		
Check what to do in case of worsening complaints		
Attempt to quit smoking		

Appendix 6d. Short-term monitoring phase

After approximately two weeks, there is a follow-up appointment between patient, informal carer(s), and care provider, in which the focus is on the recovery from the lung attack.

Action by the patient's care provider	٧	What action is necessary?
Identify and bundle new insights		
Discuss the full Lung Attack Action Plan		
Get started with the Individual Care Plan		
Identify personal targets and mobilise care workers if necessary		
Check whether it is clear who the first person of contact is		



Appendix 6e.

Long-term monitoring phase

After approximately two months (and ultimately at least annually), there is a follow-up appointment with the patient, informal carer(s), and care provider, in which the focus is on the integral health status of the patient.

Action by the patient's care provider	v	What action is necessary?
Evaluate the expectations, effect of the treatment and/or targets to be achieved		
Identify and bundle new insights		
Set realistic short-term and long-term goals and enlist care workers if necessary		
The Individual Care Plan and Lung Attack Action Plan have been updated		





Appendix 7a.

Additional information integral health status

Anxiety and depression: goal

To differentiate between anxiety and mood problems as a result of a normal reaction to an unpleasant situation versus anxiety and mood disorders (according to DSM-5).

Use of the Distress screener

The Distress screener is a tool to get a first impression of the degree of anxiety and mood problems and consists of three screening questions:

- 1. Have you been brooding in the past week?
- 2. Did you suffer from lethargy in the past week?
- 3. Have you been feeling tense in the past few weeks?

Score possibility: no=0, sometimes=1 and regularly/(very) often=2.

There is (moderate) distress with a total score of 4 or more. A more detailed evaluation is then required by means of a conversation supplemented by a HADS or 4-DKL questionnaire.

Additional meeting

During a conversation, the following aspects can be helpful in differentiating between 'normal' emotional reactions or extraordinary anxiety and mood problems:

- Duration of the complaints: are the anxiety and/or mood complaints present for more than 2 weeks?
- Intensity of the complaints: are the anxiety and/or mood complaints always so severe?
- In case of depressive complaints: are you gloomy all day?
- Can you still enjoy daily activities as you could before?

It is also important to distinguish whether the anxiety and mood complaints are disease-related or not.

Notes

Gloomy and anxious feelings are common in patients with COPD, and are usually but a normal reaction to being in an unpleasant situation. Anxiety disorders and depressive disorders are much less common.

In the case of a normal reaction to an unpleasant situation, that unpleasant situation may be the result of problems in the integral health status, but can also be the result of other non-disease-related psychosocial problems. Usually, inadequate adaptation to the disease and/or inadequate coping with psychosocial problems underlie these feelings. Treatment in such cases should therefore not primarily focus on the anxiety and mood problems themselves (e.g. medication), but on improving coping and adaptation behaviour.

Tools

If there are signs of an anxiety or mood disorder, specialist treatment by a psychologist or psychiatrist is indicated.

Consultation during hospitalisation:

- *Psychologist:* If the anxiety and/or mood problems interfere with the hospitalisation and/or the treatment during admission.
- *Psychiatrist:* Serious anxiety and/or mood disorders, where vital signs play a role requiring medication, or in case of suspected delirium. In this case, there should be a follow-up with a







psychiatrist as well. Where indicated, he or she will refer to a psychologist or mental health care institution (GGZ).

Referral after hospitalisation:

- Psychologist: Possible in all cases. They will involve a psychiatrist if indicated. In anxiety and/or mood problems as a normal reaction, but in which the underlying causes do not become clear. Or in anxiety and/or mood disorders, in which case a consultation for interdisciplinary analysis Dutch Lung Centres (LCN) may be considered.
- Psychiatrist:
 - In case of present psychiatric disorders. Including anxiety and/or mood disorder with vital signs, or if medication is indicated;
 - In case of interactions of medication that can have a detrimental effect on lung problems;
 - In case of medication with side effects such as gloominess.



Appendix 7b.

CCQ questionnaire

The CCQ questionnaire

The questions in the CCQ are divided into three domains:

- Symptoms; items 1, 2, 5 and 6;
- Functional status; items 7, 8, 9 and 10;
- Mental status; items 3 and 4.

The individual items are equally 'weighted' and the total score is calculated by adding up the scores and dividing by ten (number of questions). You can also calculate the scores per domain (via <u>www.ccq.nl</u>). The total score varies between 0 (good health) and 6 (bad health).

Clinically important difference

It is important to be able to assess whether a change in score is a significant improvement or deterioration, or whether it is a minor change. In the CCQ, an average score of 0.4 of the total score is of clinical relevance.

The COPD questionnaire can be downloaded in many different languages at <u>www.ccq.nl</u>.



Appendix 8 Advance Care Planning

Appendix 8a.

Additional information Advance Care Planning

The **palliative phase** is the stage of the disease when medical treatments no longer improve COPD. Whether a patient is in the palliative phase is determined by the (worsening in) clinical picture, having undergone intensive treatments without (lasting) effect, the subjective self-estimation and wishes of the patient, and the estimation of care providers. Due to the unpredictable course, it is difficult to predict how the palliative phase will progress and how long it will last.

4 phases of palliative care are:

- inventory phase;
- consolidation phase;
- last stage of life;
- dying stage.

Find out what stage of palliative care the patient is in and take the appropriate actions (see vision document NVALT for more information).

In the care pathway, it was decided to mark the hospital admission as the starting point of palliative care. After all, mortality in the first two years after admission is 30-50%, which is higher than after a heart attack. From that moment on, a conscious effort should be made to enter into discussions iteratively, in the context of proactive care planning (Advance Care Planning, ACP). Identification and timely scheduling can already be started up during hospitalisation, but the first moments of contact after hospitalisation, looking back at what the admission meant for patients and informal carers, can be a good time to start. Experience shows that the conversation about ACP upon readmission often has different characteristics, and a different approach, than with the first admission.

Tool for defining palliative phase:

Assistance for determining whether one can speak of a palliative phase (From LAN palliative care guideline):

- FEV1 <30% of predicted;
- Bad blood gases;
- 'Cor Pulmonare' (with pulmonary hypertension);
- MRC dyspnoea scale score of 5;
- Underweight (BMI <21 kg/m2) or muscle mass loss;
- Poor quality of life score (CCQ or SGRQ);
- Relevant co-morbidity (e.g. heart failure);
- Frequent hospital admissions for acute exacerbation, increasingly short intervals between these admissions and limited recovery after admissions.

For many patients, a recent admission for COPD will mean that they meet the criteria of the palliative phase.



Compassion:

The LAN is currently carrying out a project, with a subsidy from ZonMw, which aims to improve palliative care for people with COPD. In a scientific study, the Compassion study, the effect of palliative care and advance care planning is studied and determinants of successful implementation are identified. To do this, an online toolbox and a training course for health care providers have been developed.



The components are:

- Marking: recognising patients with COPD who benefit from palliative care and proactive advance care planning during hospitalisation using the Propal COPD tool;
- Multidimensional assessment: current and expected problems are mapped on all four dimensions: physical, psychological, social and spiritual (meaning);
- Proactive care planning: the goals, expectations and wishes of the patient and his/her nearest are discussed;
- Coordination and continuity: there is interdisciplinary consultation and the policy, objectives and agreements are laid down in an Individual Care Plan and are available to the care providers involved;
- Aftercare: after death, the care in the final phase is evaluated with the care providers and relatives involved.

The results of the study are expected in 2021.



Appendix 8b.

EDIZ questionnaire (overburdening of informal carer)

The care provider pays attention to the burden, the changing role and the experienced health of loved ones and informal carers. An inventory is made as to whether the relatives and informal carer are bearing up to the overload. The following questionnaire can be used for this purpose: <u>EDIZ</u> (Experienced Pressure on Informal Care), developed by Dr Anne Margriet Pot (1995).

Score guideline: A guideline for estimating the load on the informal carer is:

- EDIZ > 4: moderate load;
- EDIZ > 7: severe load.

The EDIZ comprises 9 items that together form a one-dimensional hierarchical scale, varying from less to more pressure. After completion, the scores are dichotomised, with the answer categories 'yes!', 'yes' and 'more or less' encoded in '1', which means that one experiences pressure. The answer categories 'no' and 'no!' are encoded in '0', which means no pressure is experienced. This results in a total score ranging from 0 to 9.

Interpretation: someone who does not feel heavily burdened will only (hesitantly) answer the first questions in the affirmative. Someone who answers questions 8 and 9 with 'yes' usually feels heavily burdened.

A moderately burdened and overburdened informal carer is asked: what can the team practically do for you to make your task easier? Think of things like the possibility of respite care. It can also be important for informal carers to consider the involvement of the local community while retaining control. To this end, an independent personal-strength coordinator can be brought in to make the connection between people's immediate environment and the system world of organisations and public authorities (see www.eigenkrachtcentrale.nl).



Appendix 8c.

Advance Care Planning Focus Areas

At the beginning of each interview, as described in element 2 Advance Care Planning (ACP), an opinion must be formed about the phase the patient is in, and whether he/she needs, or is ready for, proactive care planning. At the beginning of the hospitalisation, the wishes and expectations with regard to the admission should be discussed. Strictly speaking, such a conversation does not fall under ACP or palliative care.

Conducting these interviews is individually tailored and requires empathy for the patient and a good listening ear.

- Who conducts that interview?
- How do you do it (do you draw up a list of questions, open questions etc.? What do you do when there are ambiguities regarding diagnosis, questions about disease course, time schedule etc.)?

If there is severe COPD and/or severe comorbidity causing the patient to move towards the palliative phase, ACP is appropriate. It is not the prognosis, but the patient's needs that determine whether palliative care should be provided.

Example sentences:

- Day one: Opening sentence for discussion about advance care planning could be, for instance: "It must be difficult to think about getting any sicker. But it is very important for me to know from you what treatment you would want if things suddenly got worse".
- (Day before) discharge: A possible opening sentence for advance care planning in this phase could be, for instance: "I'm not discussing this subject because I'm worried things are getting worse just now. This is something I wish to talk about with all my patients to make sure I know their preferences."

When to have the conversation?

In time. At a time when there are reasons to think in the direction of the palliative phase: for instance, in the event of a new - soon after the previous lung attack - decline in load-bearing capacity, increasing weight of the burden of disease, at the start of a new treatment, at the start of oxygen therapy, the unavailability of new treatment options, and any other milestones.

Doctor and patient should take the time and space for such a conversation. Enquire beforehand who the patient wants to be present, as this also provides insight into their environment and relationships. Ideally, an informal carer will be present.

ACP requires several conversations, the first of which addresses the what and the why of ACP and a brief introduction will be given.

The second conversation is about emotions and anxieties, and in the third conversation, agreements are made. In subsequent conversations they will be discussed again. The clinical picture, the time prognosis and the wishes of the patient can change over time.

It remains important to emphasise that carrying out ACP requires training and maintenance; no matter how empathetic you are by nature.

Who conducts ACP interviews?

Preference is given to a regular care provider. Patients indicate that not knowing if the doctor they are talking to will be the same one that will take care of them afterwards, acts as a barrier to talking about ACP.

ACP requires some connection and continuity. The pulmonologist or the general practitioner could do this, or possibly a respiratory nurse, provided he or she is competent and trained to do so. The person conducting the ACP interviews must have skills and preferably be educated in ACP.



How do you do ACP?

Preferably as taught in a training course.

Specific communication skills are needed to deal with the interaction between giving prognostic information and maintaining hope. Also touching upon existential questions, searching together for a meaning of life despite its limitations. Support groups can also be helpful here.

Daisy Jansen (geriatric specialist at CIRO) specifies the following topics for ACP:

- Diagnosis and prognosis;
- Goals and expectations of the patient;
- Preferences with regard to resuscitation, ICU, invasive and non-invasive ventilation;
- Preferences for the care process surrounding the death;
- Dying and what may happen;
- Options for alleviating suffering;
- The issue of Meaning;
- Role of a legal representative;
- Concerns and questions.

And the following style requirements: a trainer can look at which style suits you best, but you need to master a certain repertoire in order to be able to connect with the patient.

- Honesty, openness;
- Empathetic;
- Personal;
- Explore emotions;
- Listen actively;
- Eye contact;
- Make the patient feel in control;
- Appropriate language, tailored to the patient;
- Use the words 'death' and 'dying';
- Balance between sensitivity and honesty.

Example sentences:

- Suppose I'm an old friend you meet again after years, how would you explain what's wrong with you, and then,
 - 'Would it be possible to make it clear to me what such a disease does to you and those around you?' (see also the short film <u>Agonizomai</u>);
 - Then, perhaps comments like: 'I'd be scared stiff to suffocate, do you feel like that?'
 - At difficult moments: 'What helped you move forward at difficult times in your life? Could that help you now when you're having a hard time with your COPD?'

How do you record the conversation?

The transfer of information from second to first line and vice versa, is extremely important. The Individual Care Plan (ICP) could be the right place for this, in which the patient is the key person. The ACP agreements in the ICP would then be the starting point for evaluation at subsequent contact moments.

If there is no ICP, a practical solution, such as a communication notebook containing agreements and important notifications, may be a handy tool.

Individual Care Plan and Lung Attack Action Plan

The Lung Attack Action Plan (LAAP) is a document (part of the Individual Care Plan) that describes how a patient can recognise an early-stage lung attack, what to do and who, in the case of poor results, to contact.

Specific questions Lung Attack Action Plan

- 1) 'I feel good'
 - a) What are normal complaints/symptoms?
 - b) What is the daily medication?
 - c) What are the normal/usual activities?
- 2) 'It's not going so well'
 - a) What are your complaints/symptoms?
 - b) What to do with medication?
 - c) What to do with physical activities, breathing techniques, shortness of breath and coughing up mucus?
- 3) 'Acute worsening of complaints or no improvement after 2 days'
 - a) What are your complaints/symptoms?
 - b) What to do?
- 4) 'The situation is threatening'
 - a) What are your complaints/symptoms?
 - b) What to do?

An example of the Dutch Lung Attack Action Plan can be found in Appendix 5e.

The **Individual Care plan (ICP)** is a tool to give patients more control over their own disease and to stimulate them to apply self-management with the help of the care provider(s). The ICP helps patients and care providers to enter into a conversation about the goals the patient wants to work towards. It can also help improve patient safety and quality of life. In addition, it promotes transparency between patient and care provider regarding, for instance, the agreements made.

An example of an Individual Care Plan (ICP), completed in weeks 2-4 and month 3 after admission, can be found in <u>Appendix 5f</u>.



Smoking cessation

Appendix 10a.

Additional information on smoking cessation

Objective

With COPD, smoking cessation is an important part of the treatment. If the admitted patient with COPD is a smoker, smoking cessation support is initiated during hospitalisation with the aim of having the patient quit smoking during and after the hospitalisation. The follow-up will prevent relapse if possible.

Quitting smoking can be a lengthy process and the attempt itself is not an end point in itself. After the cessation attempt, the patient often regresses into the old smoking habit, because the force of the addiction is powerful and there may be bothersome withdrawal symptoms.

Follow-up appointments increase the patient's chances of succeeding in not smoking. Therefore, and in order to monitor pharmacological treatment, it is important to offer follow-up appointments for a long period of time after the initial quitting moment. The frequency of follow-up appointments will depend on the individual needs and wishes of the patient.

Motivational interviewing:

- the 5 R's:

- 1. Relevance: Tell smoker importance of quitting, as personally as possible;
- 2. Risks: Ask about, and discuss, the risks of smoking;
- 3. Rewards: Ask about the (personal) advantages of not smoking;
- 4. Roadblocks: Ask what the barriers are for possible stopping;
- 5. Repetition: Repeat this strategy as long as the smoker is not motivated.

- the 5 A's:

- 1. Ask: Systematically ask (preferably annually) whether he/she smokes;
- 2. Advice: Advise him or her emphatically to quit smoking;
- 3. Assess: Assess the willingness to quit smoking;
- 4. Assist: Help him/her undertake the attempt to quit;
- 5. Arrange: Ensure follow-up as a form of relapse prevention.

How do you open the conversation?

Nicotine addiction should be discussed with anyone who has lung problems, no matter the disorder or the severity. This would include patients with advanced COPD. By not discussing smoking, the care provider is failing the patient. Which usually is on account of an unconscious prejudice on the part of the care provider.

Discussing nicotine addiction shows respect toward the patient. It makes them feel taken seriously. However, it needs to be done properly. Preferably through motivational interviewing (see article tobacco addiction, P. Dekker).

The question that needs to be asked is: "Do you smoke or have you smoked before?"

If someone smokes, the next question is: "May I talk to you about your smoking?" You can clarify it a bit more (for example): "I'm not asking just to say that it's wise to stop, because you undoubtedly know all about that. I'm asking because, if you'd like to quit but find it difficult, I can offer assistance"

Patients obviously have the option of saying they don't wish to talk about it. Then ask if it's okay to come back to it the next time, and make that note in the file. When someone doesn't want to talk about it at all (anymore), this must also be respected. Make a clear note of this in the file. Point out that the





patient may still broach the subject anything changes, so that smoking cessation support can then be initiated: always keep the door open.

By discussing it in this way, you show that you do not condemn it, that you sincerely can offer help and that you find someone worthwhile. Moreover, the patient becomes an equal discussion partner instead of a listener to (sometimes unsolicited) advice. It also helps the care professional and there will be less frustration. When someone doesn't want to talk about it, let it be.

Unconscious prejudice on the part of the care provider

First, some important facts and points of departure:

- (Almost) every smoker wants to quit;
- (Almost) every smoker feels guilty and/or ashamed;
- From the above, someone with COPD stands up for himself less: "never mind, it's my own fault", or "I have to suffer now because I did it to myself.";
- It always makes sense to discuss nicotine addiction;
- It always makes sense to quit;
- Advice to stop smoking is not the same as providing support .

Common unconscious prejudices on the part of the care provider are that it is no longer worthwhile/doesn't matter, or that they want to save someone the trouble (from discussing it or from going through the smoking cessation support process) or that smoking is the only thing left. Also, many care providers still think that psychiatric disorders can deteriorate by smoking cessation. This is incorrect and in fact, the opposite is true: symptoms frequently decrease and the patient feels calmer.

Discussing nicotine addiction shows proper respect to the patient. One will feel taken seriously. It can also help someone cope with the disorder (by discussing and/or fighting the cause of the misery together). It also makes sense with regard to physical complaints: less coughing and less sputum production (although sometimes temporarily a bit more at first). Furthermore, it is better for oxygen transport (lower COHb) and improves blood circulation in organs (and muscles). Conversely, not discussing smoking can be experienced as: 'I'm not worth it; the care provider thinks I can't do it anyway; it is apparently pointless by now'. It also creates insecurity and patients will wonder when it will come up: 'when will the care provider say something about it and start lecturing me?' This cannot be part of good communication and shared decision making and may even lead to resistance to consultation.

Discussing nicotine addiction can strengthen the therapeutic relationship. When done properly, the care provider beside the patient and the issue of smoking no longer stands between them.

P. Dekker. *Tobacco addiction: prevention is better than not being able to heal* (Bijblijven, edition 5/2018).

After describing the extent and consequences of tobacco addiction and smoking-related illnesses, behavioural tobacco addiction is discussed by means of thought twists. An interesting thought twister is that smoking helps against stress, whereas the said stress is caused by withdrawal symptoms. Through step-by-step motivational conversations, it is made clear how a patient can be motivated to quit smoking. The article concludes with some learning points. <u>https://mijn.bsl.nl/tabaksverslaving-voorkomen-is-beter-dan-niet-meer-kunnen-genezen/15730132</u>



Appendix 10b.

Smoking cessation toolkit

This document contains information about:

- 1. Courses on motivational interviewing;
- 2. <u>Scientific information from the Trimbos Institute on the effects of (the different) various interventions;</u>
- 3. <u>Smoking cessation tools;</u>
- 4. Other tools/alternative treatment methods;
- 5. First-line (guidance) supervision;
- 6. Second line (guidance) supervision;
- 7. Promising private initiatives;
- 8. Self-management;
- 9. Courses on smoking Cessation;
- 10. Useful addresses and links.

Both smokers and care providers know that quitting smoking is not easy. A good interviewing technique is essential for all care workers!

1. Motivational interviewing

An effective interviewing technique that can be applied in coaching. Courses on motivational interviewing can be found in the Smoking Cessation Quality Register via this link www.kwaliteitsregisterstopmetroken.nl/geaccrediteerde-

activiteiten/nascholing/?search=motiverende+conversation&search button=search+%E2%80%BA

2. Background information Trimbos Institute

Effect of advice/treatment on smoking cessation in the literature:

- A short smoking cessation advice from a doctor is effective: 1 in every 40 patients stops definitively as a result;
- Most pharmacological treatments double the number of stopped smokers from 7 10% to 17 22%;
- Without behavioural support, 11% of smokers quit; when there is support, this number rises to 14% (1 - 3 minutes face-to-face contact), 19% (4 - 30 minutes face-to-face contact) and 27% (31 -70 minutes face-to-face contact);
- E-cigarette: The electronic cigarette provides a similar quitting percentage as nicotine replacement medication (7 9% quit after 6 12 months). The long-term effects are not yet known;
- Physical exercise reduces the urge to have a cigarette, and also diminishes withdrawal symptoms such as depression, irritability, restlessness and concentration disorders;
- Most people need three to four attempts to quit smoking permanently.

3. Smoking cessation tools:

Smoking cessation tool proven to be effective increase the chances of success. The following tools have shown to increase the chance of success:

- Nicotine substitutes (chewing gum, mouth spray, plasters or tablets containing nicotine); in case of more than 10 cigarettes a day;
- Individual support: General practitioner, assistant practitioner, smoking cessation coach, outpatient smoking cessation at hospital;
- Phone support;
- Certain group training courses; see point 7;
- Support medication(<u>s</u>): varenicline, bupropion, nortriptyline, cytisine (be aware of possible side effects and contraindications);
- Certain self-help materials: books (e.g.: *Nederland stopt! met roken*, authors Dekker and de Kanter, *Stoppen met roken* (author Allen Carr), leaflets or online.

Table of contents

Summary

General overview



- Acupuncture; once-per-year cover by a number of health insurers. Effect has not been scientifically proven;
- Laser treatment; once-per-year cover by a number of health insurers. Effect has not been scientifically proven;
- E-cigarette, with or without nicotine. The long-term effects are not clear as yet. Disadvantages are that the e-cigarette is not registered as a medicine, the quality of the products is not sufficiently guaranteed and quitting attempts with an e-cigarette are generally not behaviourally supported. Young people also use e-cigarettes. It cannot be ruled out that e-cigarettes may act as a stepping stone to 'regular smoking', but there is no literature on this yet. With the e-cigarette, the nicotine addiction and smoking behaviour is maintained. Toxicity of the substances used has not been tested yet;
- E-health; Various supporting Apps: paid or for free. These include:
 - Quitty: A game where you shoot cigarettes away from you. Currently undergoing doctoral research. The version of this game for excessive alcohol consumption has proven to work;
 - Stopstone: Specifically for young people. Developed by the Trimbos Institute. Personal texts are chosen that motivate one to quit smoking and persevere;
 - Quit smoking buddy: Keeps track of exactly how long you've quit. Sharing on Facebook is a possibility;
 - Stop smoking Easy Quit free: English-language app;
 - For more apps: www.rokeninfo.nl/publiek/blog/post/?bericht=12.

5. First-line support:

- The GP practice can almost always support patients who want to quit smoking;
- Together with the patient, the general practitioner or assistant practitioner discusses the most appropriate care profile. A mental health practitioner or a first-line psychologist can also provide support;
- Intensive supervision with medical treatment and behavioural support is the most effective.

6. Second-line support:

- Smoking cessation outpatient departments of many hospitals;
- Support by an institute for addiction care, such as:
 - Brijderstichting (<u>www.brijder.nl</u>);
 - Jellinek kliniek (<u>www.jellinek.nl</u>);
 - Terwille Verslavingszorg (<u>www.terwille.nl</u>).

7. Promising private initiatives:

- 'Ik stop er mee' (<u>www.ikstopermee.nl</u>): 4 hours of group therapy, after which 59-81% of people quit smoking. Results after 1 year still good, phone aftercare. Study by Universiteit of Groningen;
- 'Pak je kans'. Group training. (<u>www.steunpuntstoppenmetroken.nl/aanbod/pakje-kans</u>).

8. Self-management

Help patients on their way who want to quit smoking on their own, and have sufficient skills to do so. Point out where to find adequate information and online_help programmes. If more than 10 cigarettes a day are smoked, offer a nicotine-containing drug or medication support.

At <u>www.thuisarts.nl</u>, advice can be found on quitting smoking, tailored to people who are motivated to quit, who are considering quitting or who have already quit. This information is based on the NHG Standard and the Smoking Cessation Care Module;

- At <u>www.rokeninfo.nl</u>, background information can be found about (quitting) smoking, kinds of support, local health care providers and reimbursements;
- <u>www.medipro.nl_and www.rokendebaas.nl</u> also provide information about (quitting) smoking;
- The effect of self-help materials is limited. Because of its effectiveness, intensive support is preferred; this is done in group programmes of the Municipal Health Centres (GGDs) and home care institutions, or via programmes with individual (telephone) coaching (<u>www.rokeninfo.nl</u>);

- Information about care providers in the area can be found at <u>www.rokeninfo.nl</u>. However, this website also refers to organisations and health care providers that, in addition to proven effective interventions, also offer, for instance, laser therapy and other unproven treatments;
- Social map for local help (<u>nearby</u>) (<u>www.ikstopnu.nl/hulp-in-de-buurt</u>).

9. Smoking cessation courses

Training courses recognised by the Smoking Cessation Quality Register can be found via the link: www.kwaliteitsregisterstopmetroken.nl/geaccrediteerde-activiteiten/opleidingen/?pagina=1.

10. Useful addresses and links

- If care providers offer proven effective interventions, they can sign up in the Quality Register (<u>www.kwaliteitsregisterstopmetroken.nl</u>).
- For scientific research on quitting smoking: (<u>www.trimbos.nl/themas/stoppen-met-roken1/stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen-stoppen</u>
- Clients/patients who want to find their own care provider: (www.ikstopnu.nl/hulp-in-de-buurt).
- Accredited motivational interviewing courses: (www.kwaliteitsregisterstopmetroken.nl/geaccrediteerdeactiviteiten/nascholing/?search=motiverende+gespreksvoering&searchbutton=zoeken+%E2%80% BA).

Footnote:

There are very many providers of smoking cessation interventions. A personal selection was made with the intention of creating a Smoking Cessation "Toolkit" that is clear and usable. This Toolkit has been put together in 2017 by Door Martijnse, member of the working group version 2.0, advisory general practitioner. Since then, new insights may have become available which have not been incorporated in the above-mentioned toolkit.



Mobility and exercise instructions

Appendix 11a.

During hospitalisation

The aim of clinical physiotherapy/occupational therapy is to improve or maintain the functional exercise capacity, to improve mucus clearance and to improve the activities of daily life. Modalities, such as resistance training, breathing exercises, exercise training and patient education, are used.

<u>Method</u>

Analysis:

- Take note of the patient's health problems;
- Determine whether there are sensations of shortness of breath at rest or during exercise;
- Determine whether there are signs of reduced exertion capacity or limitations in normal daily physical activities;
- Determine if there are any signs of impaired mucus transport;
- Take note of the natural course of symptoms and disorder;
- Determine if there are factors that affect symptoms and their progression;
- Determine the influence of COPD on well-being and daily life;
- Determine whether the patient has a need for information.

Treatment plan:

- Shortness of breath and difficulty with sputum clearance: start breathing techniques (active expiration; mucus clearance techniques; PLB; relaxation techniques using breathing);
- Start mobilisation (with or without a walking aid or oxygen supplementation) in which saturation, heart rate and clinical shortness of breath (borg dyspnoea score) will be monitored. The extent of de-saturation, and how, and in what time, the recovery occurs, are observed;
- In case of prolonged inactivity, (assisted) active movement/muscle strength exercises are started, optionally supported by electric muscle stimulation;
- Identify whether there is ineffective energy management, an imbalance between load and loadbearing capacity or an excessive action pace: Specify and discuss the consequences of this on the ADL.

Transfer:

On discharge, arrange a transfer in which the focus is on specific parameters, amenable to influence. For instance, think of:

- reduced functional exertion capacity;
- problems with mucus clearance;
- restrictions in activities due to dysfunctional breathing regulation;
- imbalance between load and load tolerance;
- high action pace;
- ineffective energy management.

Possible instruments:

- COPD Assessment Test;
- Breathlessness, Cough and Sputum Scale;
- Hand Dynamometer;
- Borg Dyspnoea scale.

Appendix 11b.

After hospitalisation

<u>Method</u>

Look for key issues in the transfer provided by the clinical physiotherapist. If there is no transfer, contact the clinical physiotherapist.

It is advised to work according to the KNGF Guideline COPD.

Analysis:

- Are there any COPD-related health problems?
- Which bodily functions and activities are restricted and which participation problems are experienced by the patient?
- What are the main objectives of the treatment?
- Which complaints, bodily functions and activities may be influenced by physiotherapy?
- Which factors could potentially support or undermine the treatment (motivation, confidence, comorbidity and psychosocial characteristics)?

Treatment plan:

The most common treatment objectives for physiotherapeutic interventions are:

- 1. reducing shortness of breath;
- 2. Improving exercise capacity and physical activity;
- 3. Improving mucus clearance;

4. Improving knowledge, self-management skills and the confidence to be able to carry out activities. (See KNGF guideline COPD for checklist/measuring instruments).

It is advised to be extremely attentive to the following factors:

- Impaired mucus transport/mucus retention;
- Influenceable behavioural factors, such as an imbalance between load and load-bearing capacity, dysfunctional energy management and an excessive action pace;
- Collaboration between physiotherapist and dietician in order to match the right training with the right nutrition/intake.

Comorbidity in COPD

A pulmonary comorbidity in COPD is lung cancer.

COPD is an independent risk factor for the development of lung cancer. The risk is two to six times greater than that of smokers without COPD.

The extra-pulmonary comorbidities in COPD, and their prevalence, are:

-	Osteoporosis/osteopenia	50-70%
-	Hypertension	40-60%
-	Gastro-oesophageal reflux disease (GERD)	30-60%
-	Skeletal muscle dysfunction	32%
-	Depression	25%
-	Ischemic heart disease	10-23%
-	Previous myocardial infection	4-22%
-	Anaemia	17%
-	Diabetes	12-13%
-	Previous stroke	10-14%
-	Cardiac arrhythmia	6-14%
-	Chronic kidney failure	6-11%
-	Congestive heart failure	5-7%
-	Obstructive sleep apnoea	1-4%

Common potential complications in COPD are:

- 1. <u>Somatic complications</u>
 - AECOPD;
 - Increased respiratory insufficiency;
 - Pneumonia and Bronchopneumonia;
 - Lung embolism;
 - Pneumothorax;
 - Lung haemorrhage;
 - Decompensatio cordis;
- 2. Emotional complications
 - Anxiety;
 - Depression;
- 3. <u>Psychosocial complications</u>
 - Problematic smoking addiction;
 - Decrease in cognitive functions;
- 4. Meaningfulness
 - Increased dependency;
 - Loss of self-worth;

- Side effects AB (diarrhoea, reduced appetite)
- Cachexia and unwanted weight loss;
- Loss of fitness;
- Fluid retention (oedema);
- Delirium;
- Fatigue.
- Sleeplessness (Insomnia);
- Problems with acceptance.
- Social deprivation;
- Load on informal carer
- Worry about surviving partner.

Glossary

Adaptation

Adaptation of behaviour to physical disorder.

Advance care planning (ACP)

Or proactive care planning: the process of thinking ahead, planning and organising. Guided by joint decision-making, proactive care planning is a continuous and dynamic process of discussing current and future life goals and choices, and what kind of care is appropriate now and in the future. This is therefore not a one-off good conversation, but an iterative process of coordination. Thoughts and choices that can change over time and, above all, evolve over time, are often part of this.

Care coordinator

Acts as the first point of contact for the patient. This care provider coordinates all agreements and actions between care providers within a multidisciplinary partnership. The care coordinator explicitly contributes to the communication between the care providers and the patient throughout the entire care process, especially during transfer moments. This coordinator also takes responsibility when things do not go as planned and holds people to their responsibilities.

Comorbidity

Any combination of two or more conditions in one person that relate to each other.

Complete medication overview

There should be a complete medication overview of both lung medication and co-medication.

Dysphoea Shortness of breath.

Exacerbation

Sudden aggravation of symptoms (lung attack). In the Netherlands, we attempt to not use the general medical term 'exacerbation' and have reframed to use the words lung attacks, to facilitate communication with patients and their beloved. It also serves to stress to both patients and caregivers that two year mortality after a lung attack (COPD) is higher than after a heart attack.

Individual Care Plan (ICP)

A dynamic set of agreements between the patient and the care provider(s) about care and selfmanagement. These agreements are based on the individual goals, needs and situation of the patient. They have come about through joint decision-making, which is the key to the process of individual care planning.

Integral health status

Traditionally, care for people with COPD has a medical focus: diagnostics and treatment are mainly focused on the physiological disorder, particularly on airway obstruction. Besides smoking cessation, treatment options include medication and improving cardiovascular fitness and muscle strength. However, a patient with COPD not only has a physiological disorder, but also experiences complaints, limitations in daily functioning and problems in the quality of life. These four domains (disorder, complaints, limitations, quality of life) together form the integral health status and consist of many more concrete subdomains that are relatively independent of each other. This means that each subdomain represents a unique aspect of the individual patient's integral health status. The main goal of all care efforts is to promote the integral health status.



Lung Attack

Sudden aggravation of symptoms (lung attack). In the Netherlands, we attempt to not use the general medical term 'exacerbation' and have reframed to use the words lung attacks, to facilitate communication with patients and their beloved. It also serves to stress to both patients and caregivers that two year mortality after a lung attack (COPD) is higher than after a heart attack.

Lung Attack Action Plan (LAAP)

A document (part of the Individual Care Plan) describing how the patient can recognise an incipient lung attack, what to do and, in case of unsatisfactory recovery, who to contact.

Motivational interviewing

A collaborative, goal-oriented conversation style with a special focus on the language of change. The method is designed to strengthen personal motivation and commitment to a particular goal, by eliciting and exploring one's own reasons for wanting change, in an atmosphere of acceptance and compassion. It is – in terms of motivational interviewing – a challenge for the care provider to enter into a CO-EXPERT relationship with the patient. This means that the patient, as an expert of his/her own life, is just as important as the doctor is as a medical expert: an equal relationship.

MUST

Malnutrition Universal Screening Tool, a checklist to determine the degree of malnutrition. The MUST consists of 3 questions about BMI, food intake and acute illness. Each question is scored on a three-point or two-point scale. Desired interventions are linked to the total score.

Nutritional status

The condition of the body as a result of the intake, absorption and utilisation of nutrition on the one hand and the influence of disease factors on the other. Nutritional status is determined by food intake but also by age, disease and medication.

A good nutritional state is a physical state in which there is a good biological function. Poor nutritional status therefore automatically implies reduced biological function, with reduced function of the immune system and increased morbidity and mortality.

Pack years

The number of years a person has smoked, times the number of packs per day. So 2 packs a day for 20 years = 40 pack years. So half a pack a day for 10 years = 5 pack years.

For smokers of shag tobacco, two and a half packets a week is roughly equivalent to one packet of cigarettes a day. For cigar smokers: one cigar equals three cigarettes.

Palliative care

Palliative care is defined by the WHO as an approach that seeks to improve the quality of life of patients and their informal carer, who are facing a life-threatening disease, by preventing and alleviating suffering, through the early identification and treatment of pain and other physical, psychosocial and spiritual problems.

Primary practitioner

The care provider who bears final responsibility for the content of the care process (diagnostics, treatment and continuity of care).

Proactive care planning

Or Advance Care Planning (ACP): the process of thinking ahead, planning and organising. Guided by joint decision-making, proactive care planning is a continuous and dynamic process of discussing current and future life goals and choices and what care is appropriate for them now and in the future. This is therefore not a one-off good conversation, but an iterative process of coordination. Thoughts and choices that change over time and, above all, evolve over time are often part of this.



Pulmonary rehabilitation

Pulmonary rehabilitation is an integral multidisciplinary treatment programme for patients with pulmonary disorders which, following a thorough assessment, has been individually designed. It sets out to optimize the patient's overall health status, participation and autonomy and the intensity of the programme may vary. Rehabilitation can be offered in outpatient setting or in a rehabilitation centre: the key principle is close multidisciplinary corroboration.

Self-management

Focusses on learning and consolidating new behaviours which enable people with COPD to make considered decisions in all areas of their daily lives. As a result, they take co-responsibility for their treatment.

SNAQ

The Short Nutritional Assessment Questionnaire (SNAQ) can be used to determine whether a patient is malnourished. The aim of the list is to improve the quality of nutritional care through early recognition and treatment of malnourished patients. In addition, there are several extensions to this instrument. With SNAQ 65+, the arm circumference is measured in addition to the questionnaire. With other SNAQ 65-, SNAQ+ BMI and SNAQ RC, the BMI is also determined.

Therapy compliance

The extent to which patients carry out their treatment as agreed with their practitioner. Therapy compliance improves the patient's health and reduces health care costs. Many patients consciously or unconsciously deviate from the treatment agreed with the care provider. There are several reasons for this. People forget, prefer not to use drugs, are not aware of using the drug in the wrong way or stop using it because of side effects. Promoting therapy compliance therefore requires tailoring.



References

- Au, D. H., Udris, E. M., Engelberg, R. A., Diehr, P. H., Bryson, C. L., Reinke, L. F., & Curtis, J. R. (2012). A Randomized Trial to Improve Communication About End-of-Life Care Among Patients With COPD. *Chest*, *141*(3), 726–735. https://doi.org/10.1378/chest.11-0362;
- Barnes, P. J., & Celli, B. R. (2009). Systemic manifestations and comorbidities of COPD. *European Respiratory Journal*, *33*(5), 1165–1185. https://doi.org/10.1183/09031936.00128008;
- Bruntink, R., & Overman, M. (2018). End of life interviews: A whitepaper for health care providers. Hengelo: Bureau Morbidee;
- CAHAG. (z.d.). REDUX, exacerbaties herkennen en behandelen. Consulted on 11 March 2019, at https://www.cahag.nl/scholingen/redux-exacerbaties-herkennen-en-behandelen;
- Dekker, P. (2018). Tabaksverslaving: voorkomen is beter dan niet meer kunnen genezen.... *Bijblijven*, *5*;
- Dekker, P., & De Kanter, W. (2008a). Nederland stopt! Met roken. Amsterdam: Thoeris, Publisher;
- Dekker, P., & De Kanter, W. (2008b). Nederland stopt! Met roken. Amsterdam: Thoeris, Publisher;
- Dekker, P., De Kanter, W., & Rueb, M. (2010). *Motiveren kun je leren: Gidsen naar gezond gedrag, het handboek voor hulpverleners*. Amsterdam: Thoeris, Publisher;
- Elia, M., Dutch version: Stuurgroep ondervoeding (2003) Malnutrition Universal Screening Tool. Consulted at http://www.meetinstrumentenzorg.nl/Home/SearchPost?meetinstrument=253;
- Evers, A. W. M., & Van Middendorp, H. (2017, 11 September). Distress screener. Consulted on 11 March 2019, at https://zelfzorgondersteund-instrumentenkiezer.nl/distress-screener-enpatientprofielkaart-screening/;
- Fagerstromtest. (z.d.). Consulted on 11 March 2019, at https://www.nhg.org/actueel/dossiers/dossier-individueel-zorgplan;
- GOLD. (2019). *Global Initiative for Chronic Obstructive Lung Disease*. Consulted at https://goldcopd.org/wp-content/uploads/2018/11/GOLD-2019-v1.7-FINAL-14Nov2018-WMS.pdf;
- Guldemond, F., Ott, B., & Wind, A. 2017: *Toolkit Advance Care Planning mbt het levenseinde.* Consulted at

https://www.nhg.org/sites/default/files/content/nhg_org/uploads/toolkit_acp_mbt_het_levenseindeokt _2017.pdf;

- Healthbase. (s.d.) MEMO. Consulted on 11 March 2019, at https://www.healthbase.nl/veelgesteldevragen/;
- Holstege, M. et all (2016). Pilot onderzoek naar de effectiviteit van casemanagement COPD bij Evean op de reductie van het aantal ziekenhuis heropnamen;
- IKNL, & Palliactief. 2017: Kwaliteitskader palliatieve zorg Nederland. Consulted at https://www.iknl.nl/docs/default-source/palliatieve-zorg/kwaliteitskader-palliatieve-zorg-nederland_iknlenpalliactief_14september2017.pdf?sfvrsn=0;
- Janssen, D. J., Engelberg, R. A., Wouters, E. F., & Curtis, J. R. (2012). Advance care planning for patients with COPD: Past, present and future. *Patient Education and Counseling*, *86*(1), 19–24. https://doi.org/10.1016/j.pec.2011.01.007;
- Kennisplein Zorg voor Beter. (z.d.). *Zorg voor Beter* [Video]. Consulted on 11 March 2019, at https://www.zorgvoorbeter.nl/;
- KNGF. 2017: *KNGF richtlijn COPD*. Consulted at https://www.kngf.nl/kennisplatform/richtlijnen/copd;
- KNMG. (2017, 13 September). Tijdig praten over het levenseinde, KNMG-handreiking voor artsen. Consulted on 11 March 2019, at https://www.knmg.nl/advies-richtlijnen/dossiers/praten-over-het-levenseinde-1.htm;
- KNMG. (2017, 13 September). Praat op tijd over uw levenseinde, ebook voor patiënten. Consulted on 11 March 2019, at https://www.knmg.nl/advies-richtlijnen/dossiers/praten-over-het-levenseinde-1.htm;



- Kruizenga, H.M., Seidell, J.C., et al. (2015) Short Nutritional Assessment Questionnaire (SNAQ), consulted at http://www.meetinstrumentenzorg.nl/Home/SearchPost?meetinstrument=255;
- Lung Alliance Netherlands. (z.d.-a). Inhalatorgebruik.nl. Cnsulted on 11 March 2019, at https://inhalatorgebruik.nl/nl/home;
- Lung Alliance Netherlands. (z.d.-b). Ziektelastmeter COPD. Consulted on 11 March 2019, at http://www.longalliantie.nl/ziektelastmeter-copd/;
- Lung Alliance Netherlands. (z.d.-c). Palliatieve zorg COPD, COMPASSION studie. Consulted on 11 March 2019, at http://longalliantie.nl/palliatieve-zorg/;
- Lung Alliance Netherlands. (z.d.-d). Landelijke uniforme zuurstofformulieren. Consulted on 11 March 2019, at http://www.longalliantie.nl/publicaties/;
- Lung Alliance Netherlands. (2011). *Richtlijn palliatieve zorg voor mensen met COPD*. Consulted at http://www.longalliantie.nl/files/9413/6752/1360/LAN_Richtlijn_Palliatieve_Zorg_COPD-4spread.pdf;
- Lung Alliance Netherlands. (2016). *Zorgstandaard COPD*. Consulted at http://www.longalliantie.nl/zorgstandaard-copd;
- Lung Alliance Netherlands. (2018a). *Goed Gebruik Inhalatiemedicatie*. Consulted at http://www.longalliantie.nl/files/6615/1851/8145/Rapport_Goed_Gebruik_Inhalatiemedicatie_2018_d efinitief.pdf;
- Lung Alliance Netherlands. (2018b). *Landelijk kader regionale formularia inhalatiemedicatie*. Consulted at

http://www.longalliantie.nl/files/1015/2283/4528/LAN_LandelijkKaderRegFormulariaInhal.medicatie_ 2-los.pdf;

- Lung Alliance Netherlands, & NVALT. (2018). *Richtlijn Diagnostiek en behandeling van een COPD longaanval in het ziekenhuis*. Consulted at https://richtlijnendatabase.nl/?query=Diagnostiek+en+behandeling+van+een+COPD+longaanval+& specialism=&sort=1;
- Lung Alliance.Netherlands 2017: Hartfalen en COPD. Consulted on 11 March 2019, at http://www.longalliantie.nl/hartfalen-en-copd/;
- Dutch Lung Fund. (z.d.-a). Patiëntenversie Richtlijn palliatieve zorg bij COPD. Consulted on 11 March 2019, at https://bestellen.longfonds.nl/product/patientenversie-palliatieve-zorg-copd/;
- Dutch Lung Fund. (z.d.-b). Longaanval Actieplan COPD. Consulted on 11 March 2019, at https://bestellen.longfonds.nl/product/longaanval-actieplan-copd/;
- Dutch Lung Fund. (2013, 21 November). *Longaanval en COPD: herken de symptomen en kom in actie* [Video]. Consulted on 11 March 2019, at https://www.youtube.com/watch?v=khOtdAnDHAM;
- Dutch Lung Fund. (2017a, 6 February). *Begrip bij een longziekte* [Video]. Consulted on 11 March 2019, at https://www.youtube.com/watch?v=PGntFiHTVYw;
- Dutch Lung Fund. (2017b, 6 February). *Accepteren van uw longziekte* [Video]. Consulted on 11 March 2019, at https://www.youtube.com/watch?v=MwOW7y_MXdA;
- Dutch Lung Fund. (2018, 6 September). Zuurstof en COPD. Consulted on 11 March 2019, at https://www.longfonds.nl/copd/behandeling-copd/zuurstof-en-copd;
- Dutch Lung Fund. (2019, 5 February). Animatievideo's over longaanval. Consulted on 11 March 2019, at https://www.longfonds.nl:443/animatievideos-over-longaanval;
- Dutch Lung Fund; Lung Alliance Netherlands. (z.d.). Patiëntenversie zorgpad COPD longaanval ziekenhuisopname. Consulted on 11 March 2019, at
- http://www.longalliantie.nl/zorgpad/patientenversie-landelijk-transmuraal-zorgpad-copd-versie-20/;;
 NHG. (z.d.-a). Dossier Individueel Zorgplan. Consulted on 11 March 2019, at
- https://www.nhg.org/actueel/dossiers/dossier-individueel-zorgplan
 NHG. (z.d.-b). Landelijke Eerstelijns Samenwerkings Afspraak COPD. Consulted on 11 March
- 2019, at https://www.nhg.org/themas/artikelen/lesa-copd;
- NHG. 2017: Richtlijn stoppen met roken. Consulted at https://www.nhg.org/sites/default/files/content/nhg_org/uploads/nhgbehandelrichtlijn_stoppen_met_roken_-_bronversie_010318.pdf;;



General overview

- NHG, NVKG, & OMS. (2012). *Multidisciplinaire richtlijn Polyfarmacie bij ouderen*. Consulted at https://www.nhg.org/sites/default/files/content/nhg_org/uploads/polyfarmacie_bij_ouderen.pdf;
- Partnership Stop met Roken. (2009). *Zorgmodule stoppen met roken*. Consulted at http://www.partnershipstopmetroken.nl/;
- Partnership Stop met Roken. (2011). *hulp nodig bij stoppen met roken?*. Consulted at http://www.partnershipstopmetroken.nl/wp-
- content/uploads/2013/01/FolderHulpnodigbijStoppenmetRoken_000.pdf;
 Partnership Stop met Roken. (2016). *Richtlijn behandeling van tabaksverslaving en stoppen met roken ondersteuning*. Consulted at http://www.partnershipstopmetroken.nl/richtlijn-2/;
- Patel, A. R., & Hurst, J. R. (2011). Extrapulmonary comorbidities in chronic obstructive pulmonary disease: state of the art. *Expert Review of Respiratory Medicine*, *5*(5), 647–662. https://doi.org/10.1586/ers.11.62;
- Pot, A.M., van Dyck, R., en D.J.H. Deeg (1995). Ervaren druk door informele zorg; constructie van een schaal. In: Tijdschrift voor Gerontologie en Geriatrie (1995) 26, p. 214-219. https://www.zorgvoorbeter.nl/mantelzorg/overbelasting-herkennen;
- Raeijmaekers, N. L. M., De Snoo-van Vuuren, C., & Schoof Groefsema, I. M.
 2017: Dieetbehandelingsrichtlijn COPD. Consulted at https://www.dieetbehandelingsrichtlijnen.nl/richtlijnen/12HK_chronische_obstructieve_longaandoeni ngen_1.html;
- Rigotti, N. A., Clair, C., Munafò, M. R., & Stead, L. F. (2012). Interventions for smoking cessation in hospitalised patients. *Cochrane Database of Systematic Reviews*, . https://doi.org/10.1002/14651858.cd001837.pub3;;
- Spruit, M. A., Singh, S. J., Garvey, C., ZuWallack, R., Nici, L., Rochester, C., . . . Wouters, E. F. M. (2013). An Official American Thoracic Society/European Respiratory Society Statement: Key Concepts and Advances in Pulmonary Rehabilitation. *American Journal of Respiratory and Critical Care Medicine*, *188*(8), 13–64. https://doi.org/10.1164/rccm.201309-1634st;
- Stuurman-Bieze, A. G. G. (2004). Interventions on the principle of Pulmonary Medication Profiles: A strategy in pharmaceutical care. Groningen: s.n.;
- Stuurgroep ondervoeding. (z.d.). TOAD overdrachtsformulier. Consulted on 11 March 2019, at http://www.stuurgroepondervoeding.nl/wp-content/uploads/2015/02/TOAD-overdrachtsformulier.pdf;
- Stuurgroep Ondervoeding. (2019). *Richtlijn ondervoeding*. Consulted at https://www.stuurgroepondervoeding.nl/wp-content/uploads/2019/02/SoV01-Richtlijn-Ondervoedinglosse-paginas-210x297februari-2019.pdf;
- Terluin, B. (1996). VierDimensionale KlachtenLijst. Consulted on 11 March 2019, at https://www.nhg.org/sites/default/files/content/nhg_org/uploads/4dkl_voor_nhg_2014.pdf;
- Turner, M. C., Chen, Y., Krewski, D., Calle, E. E., & Thun, M. J. (2007). Chronic Obstructive Pulmonary Disease Is Associated with Lung Cancer Mortality in a Prospective Study of Never Smokers. *American Journal of Respiratory and Critical Care Medicine*, *176*(3), 285–290. https://doi.org/10.1164/rccm.200612-1792oc;
- Van Berlo-van de Laar, I. R. F., Driessen, E., Merkx, M. M., & Jansman, F. G. A. (2012). Analysis of medication information exchange at discharge from a Dutch hospital. *International Journal of Clinical Pharmacy*, *34*(4), 524–528. https://doi.org/10.1007/s11096-012-9639-x;
- Van Eeden, A.E. et all (2015). Effectiveness of case management in the reduction of COPD readmissions: results of a pilot study.;
- Van der Kloot, W. A., & Vertommen, H. (1989). Visual Analoque Scale (VAS). Consulted on 11 March 2019, at http://www.meetinstrumentenzorg.nl/Home/SearchPost?meetinstrument=41;
- Van der Molen, T. (z.d.). Calculate the CCQ. Consulted on 11 March 2019, at http://ccq.nl/?page_id=391&lang=nl;
- Vercoulen, J. (z.d.). NCSI. Consulted on 11 March 2019, at http://psychologymedicine.nl/ncsi/;
- Vilans. (z.d.). *Individueel Zorgplan COPD*. Consulted at https://www.zorgvoorbeter.nl/zorgvoorbeter/media/documents/thema/zorgleefplan/individueelzorgplan-copd-nw-utrecht.pdf;



- Vilans. (2014). Plan van eisen generiek Individueel Zorgplan. Consulted at https://www.nhg.org/sites/default/files/content/nhg_org/uploads/rapport_pve_izp_eindversie_300114 .pdf;
- Zigmond, A. S., & Snaith, R. P., Dutch translation Pouwer, F., Snoek, F.J. & Van der Ploeg, H.M. (1997). Hospital Anxiety and Depression Scale. Consulted on 11 March 2019, at http://www.meetinstrumentenzorg.nl/Home/SearchPost?meetinstrument=438;
- Pot, A.M., van Dyck, R., en D.J.H. Deeg (1995). Ervaren druk door informele zorg; constructie van een schaal. In: Tijdschrift voor Gerontologie en Geriatrie (1995) 26, p.



Composition of working groups and pilot regions care pathway for a lung attack with hospitalisation 2015-2019

Chairs

Prof. Dr. Huib Kerstjens, pulmonologist (Dutch Association of Physicians for Lung Diseases and Tuberculosis);

Philippe Salomé, general practitioner (COPD & Asthma General Practitioners Advice Group).

Working group members version 1.0

Erik Bergkamp (Royal Dutch Society for Physiotherapy); Dr Bas Holverda (Dutch Lung Fund); Margot Klijnsma (doctoral student); Nynke Kuypers (COPD & Asthma General Practitioners Advice Group); Jacqueline Muilwijk-Kroes (Dutch Association of Lung Function Analysts); Renée van Snippenburg (Dutch Association of Physicians for Lung Diseases and Tuberculosis); Marleen Stegers (Dutch Dietitic Association); Dr Ada Stuurman-Bieze (Royal Dutch Society for the Advancement of Pharmacy); Dirk van Ranst (Dutch Lung Centers); Nelleke Torrenga (Respiratory Nurses Department of Nurses & Caretakers Netherlands); Dr Jan Vercoulen (Dutch Institute of Psychologists); Gertrud van Vulpen-Handels (Department of Practice Nurses & Assistant Practitioners of Nurses & Carers Netherlands).

Working group members version 2.0

Jacob van Dijke (general practitioner pilot region Arnhem); Els Fikkers (nurse specialist pilot region Arnhem); Dr Bas Holverda (Dutch Lung Fund); Kitty de Jong (Innovation advisor home care organisation pilot region Zaanstreek-Waterland); Door Martijnse (advisory general practitioner care group pilot region Zaanstreek-Waterland); Marleen Stegers (Dutch Dietitic Association);

Gertrud van Vulpen-Handels (Department of Practice Nurses Et Assistant Practitioners of Nurses Et Carers Netherlands);

Hans in 't Veen (pulmonologist pilot region Rotterdam).

Working group members version 3.0

José Brummelhuis (Nurse specialist home care organisation pilot region Zaanstreek-Waterland);

Jasmijn van Campen (pulmonologist pilot region The Hague);

Els Fikkers (nurse specialist pilot region Arnhem);

Dr Bas Holverda (Dutch Lung Fund);

Roland Riemersma (general practitioner pilot region Groningen);

Ronald van Rijsewijk (physiotherapist pilot region Brabant);

Marleen Stegers (Dutch Dietitic Association);

Dr Niels de Voogd (Dutch Institute of Psychologists);

Gertrud van Vulpen-Handels (Department of Practice Nurses Et Assistant Practitioners of Nurses Et Carers Netherlands).

Process adviser

Lidewij Sekhuis (project leader, Lung Alliance Netherlands).



Participating pilot regions 2015 - 2018



- * Amsterdam Slotervaart Hospital & ROHA
- * Arnhem Rijnstate Hospital & Care Group Arnhem
- * Den Haag Haaglanden Medical Center, Haga Hospital & ELZHA, Arts en Zorg, SHG
- * Maastricht-Heuvelland Maastricht UMC & Zorg In Ontwikkeling
- * Noord Groningen Ommelanden Hospital Group & St. EZA, GHC
- * Rotterdam Franciscus Gasthuis & IZER
- * West-Brabant Bravis hospital location Roosendaal and Bergen op Zoom & Care Group West-Brabant
- * Zaanstreek-Waterland
- Dijklander hospital location Purmerend, Zaans Medical Center & care group SEZ & home care organisation Evean

Overview of member organisations of Lung Alliance Netherlands

Lung Alliance Netherlands (LAN)

Lung Alliance Netherlands is the federative association in the field of prevention and care of chronic lung diseases. Within the LAN, parties from the pulmonary field, such as patient associations, professional associations, health insurers and companies join forces. Collaboration within the LAN ensures synergy.

The objectives of the LAN are:

- ✓ Reducing the number of people with chronic lung diseases;
- Reducing the severity of their illness and the number of deaths due to chronic lung diseases;
- ✓ Promoting the quality of life of people with chronic lung diseases.

The following organisations make up the LAN.

Members:

- Royal Dutch Society for Physiotherapy;
- Royal Dutch Society for the Advancement of Pharmacy
- Dutch Lung Centres;
- Lung Foundation Netherlands.
- Dutch Institute of Psychologists;
- Netherlands Respiratory Society;
- Netherlands Association of Physicians for Lung Diseases and Tuberculosis;
- Dutch Dietetic Association;
- Dutch Association of Lung Function Analysts;
- Dutch Association for Paediatrics;
- COPD Foundation and Asthma General Practitioners Advice Group and the National Association of General Practitioners;
- Inhalation Medication Instruction School Foundation;
- Nederland-Davos Association;
- Nurses & Carers Netherlands.

Company members:

- Alk-Abéllo;
- AstraZeneca;
- BENU Apotheek;
- Boehringer Ingelheim;
- Chiesi Pharmaceuticals;
- Focus Care Pharmaceuticals;
- GlaxoSmithKline;

- Medidis;
- Mediq / Tefa;
- Mundipharma Pharmaceuticals;
- Novartis;
- Sandoz;
- Sanofi Genzyme Netherlands;
- Teva Netherlands.

More information can be found on the website of the LAN: longalliantie.nl



COLOPHON This publication was developed by Lung Alliance Netherlands.

> ISBN 978-94-90789-09-1 © 2020: Lung Alliance Netherlands

> > TEXT Lung Alliance Netherlands

PHOTOGRAPHY and PHOTOGRAPHIC REPORT

Mona van den Berg Photography With many thanks to Mrs and Mr Hoogsteden and the Bravis hospital

DESIGN Chantal Baartmans, Vitamin Mix - concept I creation I communication Lidewij Sekhuis, Lung Alliance Netherlands

> COORDINATION Lidewij Sekhuis, Lung Alliance Netherlands



