



Tidsskriftet
DEN NORSKE LEGEFORENING

Palliative treatment and care for dying nursing home patients with COVID-19

KLINISK OVERSIKT

SIREN ERIKSEN

E-mail: siren.eriksen@aldringoghelse.no

Norwegian National Advisory Unit on Ageing and Health
Vestfold Hospital Trust

She has contributed to the concept, literature review, design, drafting and revision of the manuscript and approval of the submitted manuscript version.

Siren Eriksen, nurse and professor.

The author has completed the ICMJE form and declares no conflicts of interest.

ELLEN KARINE GROV

Faculty of Health Sciences
Oslo Metropolitan University

She has contributed to the literature review, design, drafting and revision of the manuscript and approval of the submitted manuscript version.

Ellen Karine Grov, nurse and professor.

The author has completed the ICMJE form and declares no conflicts of interest.

BJØRN LICHTWARCK

The Research Centre for Age-related Functional Decline and Disease
Innlandet Hospital Trust

He has contributed to the design, drafting of the manuscript and approval of the submitted manuscript version.

Bjørn Lichtwarck, PhD, specialist in general practice and senior consultant.

The author has completed the ICMJE form and declares no conflicts of interest.

INGUNN HOLMEFOSS

Solberglia nursing home
Drammen municipality

She has contributed to the design, drafting of the manuscript and approval of the submitted manuscript version.

Ingunn Holmefoss, nursing home doctor.

The author has completed the ICMJE form and declares no conflicts of interest.

KJELL BØHN

Jevnaker Care and Rehabilitation Centre
Ringerike municipality

He has contributed to the design, drafting of the manuscript and approval of the submitted manuscript version.

Kjell Bøhn, doctor.

The author has completed the ICMJE form and declares no conflicts of interest.

CHRISTIAN MYRSTAD

Norwegian National Advisory Unit on Ageing and Health

Vestfold Hospital Trust

He has contributed to the design, drafting of the manuscript and approval of the submitted manuscript version.

Christian Myrstad, specialist in geriatric medicine and PhD scholar.

The author has completed the ICMJE form and declares no conflicts of interest.

GEIR SELBÆK

Norwegian National Advisory Unit on Ageing and Health

Vestfold Hospital Trust

and

Institute of Clinical Medicine

University of Oslo

He has contributed to the idea, literature review, design, drafting of the manuscript and approval of the submitted manuscript version

Geir Selbæk, specialist in psychiatry, professor and research director.

The author has completed the ICMJE form and declares no conflicts of interest.

BETTINA HUSEBØ

Department of Global Public Health and Primary Care

University of Bergen

She has contributed to the idea, design, drafting of the manuscript and approval of the submitted manuscript version.

Bettina Husebø, specialist in anaesthesiology and professor.

The author has completed the ICMJE form and declares no conflicts of interest.

Frail elderly patients with multimorbidity are at high risk of serious illness and death in cases of corona virus infection. Unlike 'normal deaths' in nursing homes with time to prepare, the condition can change rapidly and cause organ failure. In this article we describe palliative non-invasive and invasive interventions for frail elderly patients in nursing homes who are dying due to COVID-19.

COVID-19 (SARS-CoV-2) is communicable and may cause infections in all age groups of the population, but frail, elderly and multimorbid patients are vulnerable and at high risk of serious illness and death (1-3). Data from Norway show that the average age of those who die from the disease is 84 years (Norwegian Institute of Public Health, 14 April 2020). Wang and colleagues highlight that in people over 70 years of age, the course of illness develops faster than in other age groups (3). However, most of the older people in whom a coronavirus infection is detected recover. For people over 80 years of age, figures from Italy indicate a mortality rate of 20.2 %, and from China 21.9 % (3, 4). Among people over 90 years of age, a mortality rate of 22.7 % has been observed in Italy (5). A study from the United States found that 33.7 % of nursing home residents infected with COVID-19 died from the disease (2).

The vast majority of Norwegian nursing home residents are frail, vulnerable and multimorbid. More than 80 % of them have dementia (6). The coronavirus pandemic gives rise to major challenges for the healthcare system and healthcare personnel, as well as to a number of ethical issues and dilemmas (7). Norwegian health authorities recommend that nursing home residents who fall ill with COVID-19 be treated in the nursing home and not admitted to hospital unless there are 'strong reasons to believe that hospitalisation will clearly help prolong life and give improved quality of life' (8).

Furthermore, the Norwegian Directorate of Health underscores that persons with serious illness at the end of life must be provided with appropriate palliative treatment and care that maintain the dignity of the patients and their families (8). In this article we will describe non-invasive and invasive interventions for frail and elderly nursing home patients who are dying from COVID-19. The article is based on guidelines, clinical experience and research literature.

Is the patient dying?

Frail older patients can have vague, diffuse and atypical symptoms of coronavirus infection, such as diarrhoea and nausea, headache or fatigue (3), which make it difficult to diagnose. Atypical symptoms are not uncommon, and acute functional impairment in the form of loss of ADL function (activities of daily living), acute disorientation, falls or incontinence can represent symptoms of serious illness in older people (9). Common symptoms of COVID-19, such as cough, fever or dyspnoea (3), may also frequently occur without being caused by the coronavirus.

The condition of frail older patients, such as those who have severe forms of dementia, often fluctuates, and it may thus be difficult to determine when the person is dying (10). To be able to establish that death is imminent, all reversible causes must have been considered, and the patient must have been thoroughly examined to rule out all other causes of the condition (11). Signs indicating that the patient is dying are shown in Box 1. When a person has been infected with COVID-19, other signs such as dyspnoea and respiratory failure may also be prominent, and the condition may change quickly (15).

Box 1 Signs indicating that the patient is dying (11–14)

The patient has:

- significant weakening and is increasingly bedridden
- need for a lot of sleep and may have a varying level of consciousness
- lack of intake of food and drink, or can take only small sips of fluid
- irregular respiration or Cheyne-Stokes respiration
- reduced circulation with cold, bluish extremities, sometimes a cold nose
- reduced urine production
- agitation/delirium
- nausea/vomiting
- secretions in the upper respiratory tract
- a characteristic facial expression, pallor around the nose and mouth

Advance care planning and clarification of treatment level

For the patients, their families, the doctor and other healthcare personnel it is essential to consider treatment intensity before an acute situation arises, such as a coronavirus infection. For nursing home residents, the nursing home doctor is responsible for ensuring that the patient's values and wishes regarding life-prolonging treatment are made clear through advance care planning. For persons with dementia, it is recommended that the doctor responsible for treatment, preferably the patient's GP, undertake advance care planning at an early stage of the dementia, thereby allowing the person him-/herself to take an active role. Such advance care planning should be repeated if the patient's health situation changes. For persons with cognitive impairment, it will often be natural to include the next of kin (16, 17).

The *Decision-making processes in the limitation of life-prolonging treatment* manual from the Directorate of Health may help healthcare personnel make appropriate decisions that also respect the patient's rights. Patients with a moderate to severe degree of dementia may also participate in a discussion of treatment options. If the patient is not competent to give informed consent, the doctor's decision must be based on a medical assessment of the

patient's best interests and an assumption of what the patient would have wanted (18). Before limiting life-prolonging treatment for patients who are not competent to give informed consent, other qualified healthcare personnel must be consulted for quality-assurance of these difficult and discretionary assessments (18). Family members should also be consulted to elucidate what they assume that the patient would have wanted (19).

For various reasons, no advance care planning has yet been undertaken for some COVID-19 patients in nursing homes. Even though the discussion must now be undertaken by telephone or video call, it is essential that it be held.

Palliative interventions when the patient is dying

On the basis of international experience, we may assume that 20–30 % of all nursing home patients with COVID-19 will die from the disease (2, 5). When the patient is dying, the goal of all approaches is to ensure well-being, maintain the patient's dignity and provide relief. All inappropriate medication and interventions that cause the patient discomfort are to be discontinued. Comfortable positioning, regular mouth care and physical care to regulate the body temperature and alleviate discomfort are key interventions to prevent issues such as pain, respiratory problems, anxiety and respiratory secretions (11, 20).

Symptoms and interventions must be based on each individual patient's disease course, underlying diseases, wishes and needs. Observations from the interdisciplinary team are crucial to clarify symptoms and afflictions in dying patients. Care interventions should always be attempted, but if these fail to provide relief, medications should be used (21). The Directorate of Health has developed recommendations for treatment of COVID-19 patients in nursing homes, and it is important to become familiar with these (8). Table 1 provides a summary of non-invasive and invasive interventions.

Table 1

Non-invasive and invasive interventions for dying patients (11, 13, 14, 22, 23)

Symptom	Non-invasive interventions	Invasive interventions
Upper respiratory secretions	<ul style="list-style-type: none"> • Frequent change of recumbent position • Side positioning with raised upper body, avoiding backwards tilt of the head • Placing cushions under both forearms • Ensuring fresh air • Informing that upper respiratory secretions, which may induce anxiety, are a well-known and treatable symptom 	<ul style="list-style-type: none"> • Treatment with anticholinergic drugs is recommended, despite known adverse effects such as mouth dryness, increased heart rate, delirium, increased tiredness/sleep, confusion and hallucinations
Anxiety, agitation, delirium	<ul style="list-style-type: none"> • Avoiding leaving the patient alone • Regulating the environment (light, noise and temperature) 	<ul style="list-style-type: none"> • Tranquillisers (benzodiazepines) are well tolerated by persons with dementia, have few adverse effects and are best administered subcutaneously. • Neuroleptics are effective in reducing anxiety, especially when the patient is also suffering from confusion or hallucinations. • When the anxiety is caused by pain or dyspnoea, these symptoms should be treated with opioids, and the patient should be given anxiety-reducing medication in addition as required.

Symptom	Non-invasive interventions	Invasive interventions
Pain	<ul style="list-style-type: none"> • Change positioning in the bed • Avoid specific positions that cause discomfort • Establish a sense of security and calm 	<ul style="list-style-type: none"> • Peripheral and/or central analgesics prior to nursing care, as a regular prescription, and as needed.
Dyspnoea	<ul style="list-style-type: none"> • Do not leave the patient alone • Use Fowler's position • Reduce fluid intake • Establish a sense of security (see above) 	<ul style="list-style-type: none"> • For dying patients with dyspnoea, the main treatment is morphine. • 1–2 l/min O₂ for dyspnoea and/or reduced SpO₂ (oxygen saturation). This procedure is discontinued if the desired palliative effect is not achieved.
Cough	<ul style="list-style-type: none"> • Use Fowler's position 	

The clinical picture of a COVID-19 patient can change quickly and be complicated by acute respiratory failure, heart failure, sepsis and possibly renal failure (8, 24). This differs significantly from 'normal deaths' in nursing homes, for which there is time to prepare (Box 1). Special attention needs to be paid to symptoms such as rapid exacerbation of dyspnoea or worsening general condition, respiratory rate ≥ 22 per minute, hypoxia, newly occurring confusion and reduced general condition (8).

Multiple concurrent symptoms, so-called symptom clusters, are common in these patients. The combination of fever, cough and shortness of breath is mentioned by many sources (3, 25–31). Respiratory problems may be especially challenging for frail, older people with weak muscles. Moreover, the combination of cough, increased mucus production, dyspnoea, fatigue and headache may cause major challenges regarding the positioning of the patient in bed and the need for attendance by personnel.

Shortness of breath, rapid breathing, high mucus production and cough may each cause anxiety in the patient. In combination, these symptoms may cause a real fear of not having a sufficient oxygen supply. The experience of being unable to breathe has been described for COPD patients in particular (32), but also among patients with pneumonia (33). Most studies published to date report that bilateral pneumonia, high respiratory rate and poor oxygen saturation frequently occur (2, 25–31).

Subcutaneously administered morphine is the main treatment for dyspnoea at the end of life. This relieves anxiety, helps economise on the respiratory effort, lowers pressure in the pulmonary circulatory system, reduces cough and helps the patients achieve deeper breathing, instead of shallow hyperventilation (22).

Additional interventions such as breathing guidance, tranquillisers, if needed, mouth care and O₂ treatment may also be initiated. The Directorate of Health recommends that the nursing homes administer oxygen for relief (8).

The Directorate of Health recommends four key drugs to provide relief for severe symptoms when the patient has a short expected lifespan: morphine, haloperidol, midazolam and glycopyrrolate. These drugs are administered as subcutaneous injections (8). The dosage of drugs must be clarified before the patient becomes poorly, and a plan for necessary increasing of the dosage should be in place. A doctor should be available by telephone for decision-making support.

The Coordination Reform emphasises interaction between health service levels and the need for seamless collaboration between the specialist and primary health services. Palliative teams, both in hospitals and in primary care palliative units, can be contacted for advice on symptom management (34).

Family members

Family members are often an important resource for people who are dying, and they are considered members of the patient's healthcare team (11). This point is also underscored by

the Directorate of Health, and the goal is for nobody to die alone (8). In the context of the coronavirus pandemic, however, all Norwegian nursing homes have introduced restrictions on visits, including by family members, to protect vulnerable residents against infection.

In some cases, exemptions from the restrictions will be called for, in order for family members to visit critically ill loved ones (8). The Norwegian Geriatrics Society has specified this (35). It is suggested that the exemption be applied to patients who are expected to die within a short time; patients with acute and very severe illness who therefore have a special need to socialise with family members; family members who have a serious psychosocial, psychiatric or somatic condition that gives rise to a special need; patients who have a condition for which visits by family members have a significant, positive effect on the prognosis, e.g. as a social intervention to replace drug-based sedation for delirium; and in cases where the presence of family members is considered to lend support to infection control, e.g. by helping a disoriented patient comply with infection control routines.

When exemptions are made, the nursing homes need to make a stringent assessment on a case-by-case basis of the value of the visit weighed against the risk of infection. Physical interaction must be assessed in light of alternative forms of interaction, such as a video call. The frequency of visits and the number of visitors must be kept to a minimum. It is recommended to use clinical ethics committees or establish visit committees, since this may make for more consistent practices and provide collegial support for decisions (35, 36). The clinical ethics committees can also be contacted for advice on other ethical dilemmas.

Family members also need support and consideration. When family members choose to visit their loved ones who are infected with COVID-19, they must wear a full set of personal protective equipment. Witnessing symptoms such as anxiety and respiratory failure in the patient can be very distressing for family members. The personnel must therefore seek to provide information, establish a sense of security and take care of family members, and offer them as much contact and follow-up as possible.

REFERENCES:

1. Wu C, Chen X, Cai Y et al. Risk factors associated with acute respiratory distress syndrome and death in patients with coronavirus disease 2019 pneumonia in Wuhan, China. *JAMA Intern Med* 2020; 180. doi: 10.1001/jamainternmed.2020.0994. [PubMed][CrossRef]
2. McMichael TM, Currie DW, Clark S et al. Epidemiology of Covid-19 in a long-term care facility in King County, Washington. *N Engl J Med* 2020; 382: NEJMoa2005412. [PubMed][CrossRef]
3. Wang L, Wang Y, Ye D et al. Review of the 2019 novel coronavirus (SARS-CoV-2) based on current evidence. *Int J Antimicrob Agents* 2020; 55: 105948. [PubMed][CrossRef]
4. Palmieri L, Andrianou X, Bella A et al. Characteristics of COVID-19 patients dying in Italy Report based on available data on March 20th, 2020. Istituto Superiore di Sanità Caratteristiche dei pazienti deceduti positive a COVID-19, Italia. https://www.epicentro.iss.it/coronavirus/bollettino/Report-COVID-2019_20_marzo_eng.pdf Accessed 14.4.2020.
5. Onder G, Rezza G, Brusaferro S. Case-fatality rate and characteristics of patients dying in relation to COVID-19 in Italy. *JAMA* 2020; 323. doi: 10.1001/jama.2020.4683. [PubMed][CrossRef]
6. Helvik AS, Engedal K, Benth JS et al. Prevalence and severity of dementia in nursing home residents. *Dement Geriatr Cogn Disord* 2015; 40: 166–77. [PubMed][CrossRef]
7. Curtis JR, Kross EK, Stapleton RD. The importance of addressing advance care planning and decisions about do-not-resuscitate orders during novel Coronavirus 2019 (COVID-19). *JAMA* 2020; 323. doi: 10.1001/jama.2020.4894. [PubMed][CrossRef]
8. Helsedirektoratet. Prioritering av helsehjelp i Norge under covid-19-pandemien. <https://www.helsedirektoratet.no/veiledere/koronavirus/kapasitet-i-helsetjenesten/prioritering-av-helsehjelp-i-norge-under-covid-19-pandemien/kommunal-helse-ogomsorgstjeneste/institusjon-sykehjem-omsorgsbolig-og-hjemmetjenester> Accessed 14.4.2020.

9. Wyller TB. Geriatri – en medisinsk lærebok. Oslo: Gyldendal akademiske, 2015.
10. Sandvik RK, Selbaek G, Bergh S et al. Signs of imminent dying and change in symptom intensity during pharmacological treatment in dying nursing home patients: A prospective trajectory study. *J Am Med Dir Assoc* 2016; 17: 821–7. [PubMed][CrossRef]
11. Husebø B. Lindrende demensomsorg. I: Tretteteig S. Demensboka. Lærebok for helse- og omsorgspersonell. Tønsberg: Forlaget Aldring og helse, 2016.
12. Brandt HE, Deliens L, van der Steen JT et al. The last days of life of nursing home patients with and without dementia assessed with the palliative care outcome scale. *Palliat Med* 2005; 19: 334–42. [PubMed][CrossRef]
13. Brandt HE, Ooms ME, Deliens L et al. The last two days of life of nursing home patients—a nationwide study on causes of death and burdensome symptoms in The Netherlands. *Palliat Med* 2006; 20: 533–40. [PubMed][CrossRef]
14. Eriksen S. Lindrende behandling, omsorg og pleie til personer med demens. I: Rokstad AMM, Smebye KL. Personer med demens. Oslo: Cappelen Damm, 2020: 341–65.
15. Kunz R, Minder M. COVID-19 pandemic: palliative care for elderly and frail patients at home and in residential and nursing homes. *Swiss Med Wkly* 2020; 150: w20235. [PubMed][CrossRef]
16. Thoresen L, Ahlzén R, Solbrække KN. Advance Care Planning in Norwegian nursing homes—Who is it for? *J Aging Stud* 2016; 38: 16–26. [PubMed][CrossRef]
17. Flo E, Husebo BS, Bruusgaard P et al. A review of the implementation and research strategies of advance care planning in nursing homes. *BMC Geriatr* 2016; 16: 24. [PubMed][CrossRef]
18. Helsedirektoratet. Beslutningsprosesser ved begrensning av livsforlengende behandling. <https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/67/IS-2091-Beslutningsprosesser-ved-begrensning-av-livsforlengende-behandling.pdf> Accessed 1.4.2020.
19. LOV-1999-07-02-63. Lov om pasient- og brukerrettigheter (pasient- og brukerrettighetsloven). <https://lovdata.no/dokument/NL/lov/1999-07-02-63> Accessed 1.4.2020.
20. Davies N, Iliffe S. After the Liverpool Care Pathway Study. Rules of Thumb for End of Life Care for People with Dementia. London: Global University, 2016. <https://www.kcl.ac.uk/scwru/pubs/2016/reports/RuleOfThumb-Sept16-2nd.pdf> Accessed 14.4.2020.
21. Behandlingsalgoritmar for vanlege symptom hos døyande vaksne. Dei fire viktigaste medikamenta. Bergen: Haukeland universitetssjukehus, 2020. <https://helse-bergen.no/kompetansesenter-i-lindrande-behandling/palliasjon-verktoy-forhelsepersonell/behandlingsalgoritmar-for-vanlege-symptom-hos-doyande-vaksne-dei-fire-viktigaste-medikamenta> Accessed 14.4.2020.
22. Husebø BS, Husebø S. Sykehjemmene som arena for terminal omsorg—hvordan gjør vi det i praksis? *Tidsskr Nor Lægeforen* 2005; 125: 1352–4. [PubMed]
23. Eriksen S, red. Palliasjon og demens. Et e-læringskurs for leger. Forlaget Aldring og helse på oppdrag fra Helsedirektoratet.
24. Wang W, Tang J, Wei F. Updated understanding of the outbreak of 2019 novel coronavirus (2019-nCoV) in Wuhan, China. *J Med Virol* 2020; 92: 441–7. [PubMed][CrossRef]
25. Chen N, Zhou M, Dong X et al. Epidemiological and clinical characteristics of 99 cases of 2019 novel coronavirus pneumonia in Wuhan, China: a descriptive study. *Lancet* 2020; 395: 507–13. [PubMed][CrossRef]
26. Guan WJ, Ni ZY, Hu Y et al. Epidemiological and clinical characteristics of 99 cases of 2019 novel coronavirus pneumonia in Wuhan, China: a descriptive study. medRxiv 2020 doi: 10.1101/2020.02.06.20020974. [CrossRef]
27. Huang WH, Teng LC, Yeh TK et al. 2019 novel coronavirus disease (COVID-19) in Taiwan: Reports of two cases from Wuhan, China. *J Microbiol Immunol Infect* 2020; 53: S1684–1182(20)30037-2. [PubMed][CrossRef]
28. Huang C, Wang Y, Li X et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China. *Lancet* 2020; 395: 497–506. [PubMed][CrossRef]

29. Liu YC, Liao CH, Chang CF et al. A locally transmitted case of SARS-CoV-2 infection in Taiwan. *N Engl J Med* 2020; 382: 1070–2. [PubMed][CrossRef]
30. Liu J, Liu Y, Xiang P et al. Neutrophil-to-lymphocyte ratio predicts severe illness patients with 2019 novel coronavirus in the early stage. *medRxiv* 2020 doi: 10.1101/2020.02.10.20021584. [CrossRef]
31. Yang Y, Lu Q, Liu M et al. Epidemiological and clinical features of the 2019 novel coronavirus outbreak in China. *medRxiv* 2020 doi: 10.1101/2020.02.10.20021675. [CrossRef]
32. Yohannes AM, Junkes-Cunha M, Smith J et al. Management of dyspnea and anxiety in chronic obstructive pulmonary disease: A critical review. *J Am Med Dir Assoc* 2017; 18: 1096.e1–17. [PubMed][CrossRef]
33. Alexandroaie B, Huțuleac L, Costin G et al. Diagnostic approach of pneumonia in an elderly patient with comorbidities—case report. *Rev Med Chir Soc Med Nat Iasi* 2011; 115: 781–7. [PubMed]
34. St. meld. Nr. 47 (2008–2009). Samhandlingsreformen. Rett behandling – på rett sted – til rett tid. Oslo: Helse- og omsorgsdepartementet, 2008.
<https://www.regjeringen.no/contentassets/d4foe16ad32e4bbd8d8ab5c21445a5dc/no/pdfs/stm20082009004700odddpdfs.pdf> Accessed 14.4.2020.
35. Norsk geriatrisk forening. Om pårørende og besøksforbud under koronaepidemien.
<https://www.legeforeningen.no/contentassets/3af24f518cf540ea804a699595242f52/om-paarorende-og-besoksforbud-under-koronapandemien.pdf> Accessed 14.4.2020.
36. Ethical considerations for decision making regarding allocation of mechanical ventilators during a severe influenza pandemic or other public health emergency. Ventilator Document Workgroup, Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention, 2011. https://www.cdc.gov/about/advisory/pdf/VentDocument_Release.pdf Accessed 14.4.2020.

Published: 6 May 2020. *Tidsskr Nor Legeforen*. DOI: 10.4045/tidsskr.20.0306

Received 3.4.2020, first revision submitted 10.4.2020, accepted 14.4.2020.

© The Journal of the Norwegian Medical Association 2020. Downloaded from tidsskriftet.no