NU-06 Palliative care and the good death: pain, breathlessness, comfort and the ars moriendi

HEALING after the FALL, research library, NU-06

Researched 10 October 2026 by Claude Opus agent for THRIVING after the FALL, Book Four. Library document, unverified.

ME-05 gives the poppy, the tincture, the conversion, the titration rules and the locked chest. ME-06 gives the village pain ladder and the non-opioid rungs below it. TR-16 gives the gathered community and the visiting rota. This report is about what a household and a lay healer do when the person is going to die, and about the organisation that makes it possible at the scale of 300 and 3,000.

Whether the village grows opium at all is marked [OWNER] in ME-05, with three options. Everything here that depends on it is marked [OWNER]. The report holds either way, because the larger part of palliative care has never been a drug.

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1. Saunders, total pain, and the discovery that the clock matters more than the dose

Cicely Saunders trained as a nurse, then an almoner, then a doctor, and opened St Christopher's Hospice in Sydenham, south London, in 1967. David Clark's study of her writings from 1958 to 1967 shows the concept of total pain forming out of her listening to dying patients at St Joseph's Hospice in Hackney (Clark 1999). Total pain means that the pain of a dying person has physical, psychological, social and spiritual components, that these are not separable in the sufferer, and that treating only the physical part will fail. Clark is not uncritical: he argues the concept extended clinical authority into regions of the person that had not been medicine's business.

The practical discovery that made the hospice work is the most transferable finding in this report. Before Saunders, strong analgesics in British hospitals were given on demand, which meant after the pain had returned and the patient had asked and a nurse had come. Saunders gave them by the clock, in a dose sufficient to carry the patient to the next one, so the pain did not return at all. The quantity of drug does not have to rise for this to work. What changes is that the patient stops spending the hours before each dose in fear, and stops needing a larger dose to pull down a pain that has already climbed. It is free, it is a rule about timing rather than pharmacology, and it applies to willow decoction and salvaged paracetamol exactly as to opium tincture. I could not confirm from a primary source the year Saunders first used the phrase total pain in print, nor the interval she first used at St Joseph's [VERIFY].

The second transferable idea is anticipatory supply: the drugs for the last days are placed in the house before they are needed, so nobody travels at three in the morning. After the Fall this is the healer's visit that leaves a small measured supply with a named person, a written sheet and a record. The supply may be opium tincture [OWNER] or only willow decoction and honey. The discipline is the same.

Temel et al. 2010 randomised 151 patients with metastatic non-small-cell lung cancer to early palliative care alongside standard oncology, or oncology alone, and found better quality of life, less depression at twelve weeks, less aggressive

end-of-life care and longer survival in the palliative group. It is the best evidence that attending to comfort does not shorten life.

2. The WHO ladder: what it achieved, and what its critics showed

The ladder came out of a consultation convened by Vittorio Ventafridda in Italy in 1982, a WHO meeting in Geneva in 1984, and the monograph Cancer Pain Relief, widely distributed from 1986. Its principles are by mouth, by the clock, by the ladder: step one a non-opioid, step two a weak opioid, step three a strong opioid, with adjuvants throughout. My sources differ on the dating and on the meeting's location, given as Pomerio and not cross-checkable (StatPearls 2023, Foley and Ventafridda memorial essay). I report 1986 as the date of general circulation.

Pain is common but not universal. A meta-analysis of 122 studies and 63,533 patients found pain in 39.3 per cent after curative treatment, 55.0 per cent during anticancer treatment and 66.4 per cent in advanced or terminal disease (van den Beuken-van Everdingen et al. 2016). One dying person in three needs no strong analgesic.

The best evidence for the ladder is Zech et al. 1995, a ten-year prospective study of 2,118 patients over 140,478 treatment days at a pain service in Cologne. Strong opioids were used on 49 per cent of days and 56 per cent of patients received morphine. Crucially for a world without syringes, 82 per cent of treatment days used the oral route and only 9 per cent were parenteral. Good pain relief was reported in 76 per cent of patients, satisfactory in 12 per cent, inadequate in 12 per cent. In the final days, 84 per cent rated pain as moderate or less.

Doses escalated in about half the patients followed to death and were stable or falling in the other half, which contradicts the belief that opioid doses always spiral. Adjuvants for symptoms other than pain were needed on 79 per cent of days, laxatives on 42 per cent. Neuropsychiatric symptoms were the major symptom on 23 per cent of days, nausea on 23, constipation on 23, anorexia on 20. Pain organises palliative care but does not occupy most of it.

Against this, Jadad and Browman 1995 reviewed every study then purporting to evaluate the ladder. They found eight, all uncontrolled case series, so no meta-analysis was possible. Adequate analgesia ranged from 69 to 100 per cent. They concluded the evidence was insufficient to estimate the ladder's effectiveness and inappropriate for judging clinicians or designing policy.

Both are true. The ladder has never been tested against an alternative, and it produced, in the largest prospective series ever run, good relief in three of four patients, almost entirely by mouth. Grade B, and the reason it is not grade A is that nobody has randomised a dying person to no analgesia.

The post-Fall translation is in ME-05: tincture at ME-05's strength is nominally 10 mg morphine per ml, paregoric is twenty-five times weaker, adults start at 5 mg oral morphine equivalent four-hourly and the frail at 2.5 mg, and dosing is by oral syringe, never by counting drops (THRIVING library, ME-05).

3. Does titrated opium shorten life

Opiophobia kills more people among the dying than overdose does, so this decides whether a village has palliative care at all.

Sykes and Thorns 2003 reviewed 237 consecutive deaths in a specialist palliative care unit. Sedation was given to 48 per cent. Of those, 13 per cent received it for seven days or more and 56 per cent started only in the last 48 hours. Patients who received no sedation, or under 48 hours of it, survived a mean of 14.3 and 14.2 days from admission. Those sedated seven days or more survived a mean of 36.6 days ($P<0.001$). Sedation did not shorten survival, and the group receiving most of it lived longest, as you expect if sedation follows a long dying rather than causing a short one. The brief cites a companion paper in Lancet Oncology 2003, 4:312-318, which I could not retrieve and do not quote [VERIFY].

Maltoni et al. 2009 studied 518 hospice patients in Italy, 267 sedated and 251 not, matched on age class, sex, reason for admission and Karnofsky score. Twenty-five per cent of admissions were sedated, mean duration 4 days. Median survival was 12 days sedated against 9 days unsedated, log rank P=0.330, hazard ratio 0.92. Both studies are observational, from specialist units with titration by protocol. Grade B.

This does not mean opioids are safe in the opioid-naive. The evidence concerns titrated doses in people already taking them. A first dose too large in someone who has never had opium can stop their breathing, and that is the commonest fatal error in this report. ME-05's thresholds apply unchanged, and where ME-05 and ME-14 differ on the respiratory rate at which to stop, take the more cautious number, which is 12 breaths a minute.

The practical conclusion is a sentence the healer should be able to say to a frightened family: the opium is not what is killing him, and withholding it will not keep him alive one hour longer. That sentence is defensible, and it is also what opiophilia hides behind, which is why the dose is written down every time.

4. Kerala and Uganda: the two models a village can copy

Kerala. Begun in Malappuram district in 2001, the Neighbourhood Network in Palliative Care is the only model I found that organises palliative care at this book's scale with volunteers rather than professionals as the main workforce. Kumar 2007 describes more than sixty units covering more than 12 million people, probably the largest community-owned palliative care network in the world. Volunteers are trained, identify the sick in their own locality, visit them, and call in a nurse or doctor for what they cannot handle. They are not auxiliary staff: they own the units, raise the money locally and decide who is visited. The Kerala Palliative Care Policy, Government Order 109/2008/HFWD of 15 April 2008, then made palliative care a responsibility of local self-government institutions and part of primary health care, as far as I can establish the first state anywhere to do so.

ME-05 records morphine access in Kerala at least four times the Indian average with no evidence of misuse or diversion (Rajagopal, Karim and Booth 2017, via THRIVING library, ME-05). On training, the brief gives about sixteen hours and that matches secondary accounts, but I could not open a primary curriculum [VERIFY]. On volunteer time, I confirmed a commitment of at least two hours a week per volunteer, and home visits of 90 to 120 minutes first and 30 to 45 minutes thereafter. I could not find a published figure for volunteer hours per patient, which the brief asked for, and will not calculate one, because the ratio of volunteers to patients is the missing term [VERIFY].

What Kerala demonstrates matters more than the figures: lay people with short training, supervised by one clinically competent person and backed by a drug supply, can deliver the great majority of palliative care. Grade B, from a large sustained observational record.

Uganda. Anne Merriman founded Hospice Africa Uganda in Kampala in 1993. The relevant method is oral morphine solution made from imported powder by what the hospice calls the kitchen sink method, coloured with dye so strengths can be told apart by eye, shelf-stable for roughly a year (THRIVING library, ME-05). Uganda went on to allow trained palliative care nurses to prescribe morphine. I could not locate the Merriman and Harding 2010 paper named in the brief, which the brief itself marks [VERIFY], and my Uganda material is from eCancer, Cancerworld, NPR and the Palliative Care Association of Uganda, all secondary.

Uganda is the ancestor of what a district infirmary does after the Fall: someone with a scale, measured water, a known quantity of active material and a dye makes a solution of declared strength, labels it and issues it against a register. The difference is that the active material is opium of variable morphine content rather than assayed powder, so strength is approximate and the starting dose correspondingly low [OWNER].

The shortfall. ME-05 carries the Lancet Commission figures (Knaul et al. 2017): 10.8 tonnes of morphine-equivalent, 3.6 per cent of the global total, went to low- and middle-income countries and 0.1 tonne to low-income countries, meeting under 2 per cent of need. Most of the world already lives after the Fall with respect to pain relief, and the practices here were developed by people in that position.

5. Breathlessness

Kehl and Kowalkowski 2013, reviewing 12 articles covering 2,416 patients and 43 symptoms in the last two weeks of life, found dyspnoea in 56.7 per cent, pain in 52.4, death rattle in 51.4 and confusion in 50.1. Breathlessness was commonest, and it has the best non-drug remedy.

The fan. Galbraith et al. 2010 randomised 50 patients with breathlessness from advanced disease to five minutes of a handheld fan across the nose and mouth, then crossed them to five minutes of the same fan at the leg. Breathlessness fell significantly more with the fan to the face (P=0.003). The leg arm is what makes the trial useful: the benefit is not air movement, distraction or attention, but cool air on the face. Booth and colleagues followed with a washout study in 31 patients (Booth et al. 2016), and a 2025 systematic review of 10 studies and 413 participants concluded that fans benefit breathlessness.

The mechanism came first. Schwartzstein et al. 1987 showed cool air to the face, but not the leg, reduces the perception of breathlessness, attributed to stimulation of the second and third divisions of the trigeminal nerve. Hold the fan about 15 cm away, across nose, mouth and cheeks. This is the highest-value finding here for a village, because after the Fall there is no fan but there is a folded palm leaf, a piece of stiff card, an open window and a person willing to sit and wave. Grade A.

Oxygen and opioids. Abernethy et al. 2010 randomised 239 patients with refractory breathlessness, not hypoxaemic enough for long-term oxygen, to oxygen or room air by nasal cannula for seven days, double-blind. Mean morning breathlessness changed by -0.9 points with oxygen and -0.7 with room air (P=0.504), evening by -0.3 and -0.5 (P=0.554). Oxygen was never the thing that worked. Barnes et al. 2016, a Cochrane review of 26 studies and 526 participants, found a mean dyspnoea score 0.09 points better with opioids and downgraded the evidence to low or very low. The trial evidence is weak and the pooled effect small, while palliative units consistently report that low-dose oral morphine helps the person frightened and fighting for air. Use it after the fan and positioning, at low dose [OWNER]. Grade C.

Positioning and the package. Sitting upright and leaning forward with arms supported fixes the shoulder girdle and lets the accessory muscles pull on the ribs. A cool room and loosened clothing cost nothing. Farquhar et al. 2014 randomised 67 patients with advanced cancer to the Cambridge Breathlessness Intervention Service or a two-week wait and found a greater reduction in breathlessness in the intervention group, 1.68 points against 0.23 (P=0.049). Its components, which a village can copy, are the fan, breathing technique, positioning, pacing and anxiety management. The companion trial in non-malignant disease, 87 patients, found no significant effect. Grade B for the package, grade A for the fan inside it.

6. The other symptoms of the last days

Nausea. The major symptom on 23 per cent of days (Zech 1995). The village has ginger, small sips rather than meals, removal of strong smells, and salvaged antiemetics. Nausea caused by opium usually settles within a few days and is not a reason to stop it.

Constipation. The only certain side effect of opium, and not minor. Zech recorded laxatives on 42 per cent of treatment days, more than any other adjuvant. ME-05's rule is a laxative from day 2 (THRIVING library, ME-05). After the Fall the laxative is dietary and mechanical: water, fruit, bran, prunes or local equivalents, and in extremis gentle manual disimpaction. An impacted bowel causes agitation, vomiting and overflow, and is routinely mistaken for terminal restlessness and treated with more opium, which makes it worse.

Delirium and terminal agitation. Confusion was present in 50.1 per cent of patients in the last two weeks (Kehl and Kowalkowski 2013), and Conill et al. 1997, studying 176 patients in the last week of life, found it among the five symptoms occurring in more than half, with anorexia, asthenia, dry mouth and constipation. The most important trial here is negative, and is the best news in this report for a village with no drugs. Agar et al. 2017 randomised 247

palliative care patients with delirium, across 11 Australian services, to oral risperidone, haloperidol or placebo for 72 hours, double-blind. All three groups received individualised management of the causes plus supportive care. Both drugs were worse than placebo: risperidone scored 0.48 units higher on the delirium symptom score (P=0.02) and haloperidol 0.24 higher (P=0.009), where higher is worse. Both caused more extrapyramidal effects, and survival was better on placebo than haloperidol, hazard ratio 1.73 (P=0.003).

For the village this means: look for the cause. A full bladder, impacted bowel, pain that cannot be reported, thirst, new infection, a dark unfamiliar room, too many people, withdrawal from alcohol or tobacco, and opium toxicity itself are the common precipitants, and most are correctable by hands. ME-05 records that vivid dreams, hallucinations and myoclonic jerks are opioid toxicity appearing before breathing slows, so a newly confused patient on opium has it reduced, not increased. Grade A.

The death rattle. Present in about half of dying patients. Wee and Hillier's Cochrane review of 2008 identified 30 studies of which one met inclusion criteria, a small placebo-controlled trial of hyoscine hydrobromide, which tended to reduce the rattle but not significantly. No intervention has been shown superior to placebo. Their second conclusion is the one the village needs: because it is hard not to intervene when emotions are heightened, relatives need time, explanation and reassurance.

The rattle distresses the family and there is no evidence it distresses the patient, who is usually unconscious by then. Turn the person onto their side with the head slightly down, stop artificial fluids, say plainly that the noise is secretions in the throat of someone too deeply unconscious to clear them and does not mean drowning, and sit with them. Any salvaged sucker is used sparingly and shallowly, because deep suction causes gagging and bleeding. Grade X for drugs, grade D for positioning, and the honest intervention is an explanation.

Mouth care and thirst. The intervention families most underrate and most want to do. Dry mouth was among the commonest symptoms in the last week (Conill 1997). Mouth care is half-hourly to two-hourly moistening of lips and mouth with water on a clean cloth, removal of crusts, a smear of fat on the lips, and small sips while swallowing is safe (GMEC and NHS England North West 2019). It relieves thirst far better than fluids.

The fluid evidence is counter-intuitive. Bruera et al. 2013 randomised 129 hospice patients with advanced cancer to 1 litre of saline a day or 100 ml placebo, double-blind. There was no significant difference in dehydration symptoms (-3.3 against -2.8, P=0.77), none on delirium or myoclonus scores, and no survival difference (median 21 against 15 days, P=0.83). For a village with no means of giving fluids this is a reprieve: not giving fluids in the last days is a defensible choice, not a failure. It does not apply to the thirsty person who can drink, who should have as much as they want, nor to reversible dehydration from diarrhoea or vomiting, which belongs to the oral rehydration protocols elsewhere in the library. Grade A for the narrow claim.

Bladder and skin. Urinary retention is a classic cause of agitation in the unconscious and is found by feeling above the pubic bone. Pressure sores develop fast, and prevention is two-hourly turning, a dry bed and padding over bony points. Detail belongs to NU-01 and NU-07.

7. The signs that death is days away, and the surprise question

A healer who can say death is close, and be right, lets the family gather, stop feeding against resistance, and stay. Hui et al. 2014 documented 10 bedside signs every 12 hours in 357 consecutive patients with advanced cancer in two acute palliative care units in the United States and Brazil, of whom 203 died. Decreased consciousness, a Palliative Performance Scale of 20 per cent or less, and inability to swallow liquids appeared more than three days before death, were common, and had specificity under 90 per cent. Five signs appeared mostly in the last three days, were less common, but had specificity above 95 per cent and high positive likelihood ratios for death within three days: pulselessness of the radial artery (LR 15.6), decreased urine output (LR 15.2), Cheyne-Stokes breathing (LR 12.4), respiration with mandibular movement (LR 10) and the death rattle (LR 9). Hui et al. 2015 examined 52 further signs in the

same cohort and found eight more with high specificity and late onset, including non-reactive pupils (LR 16.7) and decreased response to verbal stimuli (LR 8.3).

Every one of these signs is found with eyes and fingers and no instrument, which makes this the most transferable prognostic evidence in medicine. High specificity with low sensitivity means they confirm and never exclude. The mandibular and Cheyne-Stokes breathing that frighten families most are exactly the signs that mean the end is near and nothing has gone wrong. Grade B, from two prospective cohorts in one research programme, not independently replicated as far as I could establish.

Trajectories. Lunney et al. 2003 followed 4,190 decedents and showed four patterns of decline in the final year, measured as dependency in seven activities of daily living. Sudden-death decedents stayed functional to the last month. Cancer decedents were functional for most of the year then markedly disabled in the last three months, from a mean 0.77 dependencies at twelve months to 4.09 in the final month. Organ-failure decedents fluctuated, with a drop in the last three months (2.10 to 3.66). Frail decedents were dependent throughout and most dependent at the end (2.92 to 5.84). Cancer gives the clearest warning and organ failure the least, because each fluctuation looks like the end and is not.

The surprise question. Would I be surprised if this person died within the next twelve months. Its originators intended it as a trigger for conversation and planning, not a prognostic instrument, and a 2023 expert review found its performance inconsistent, with two of three expert groups holding it should not be used to predict survival (Chu et al. 2023). Agreement between doctors on the same patient is itself imperfect (Yarnell et al. 2021). Use it as the prompt that makes the healer sit down with the family while the person can still speak. Grade C as a trigger, grade D as a prediction.

8. The ars moriendi, and dying at home, on their own terms

The traditions. The Ars moriendi is a Latin text of around 1415, with a shorter illustrated block-book version after it, produced in the aftermath of the Black Death when priests were too few to attend every deathbed. Its purpose was to let lay people, including the dying person and the family in the room, conduct a death well without a priest. On its own terms it is not a medical document. It names five temptations that assail the dying, against faith, to despair, to impatience, to spiritual pride and to avarice, and gives for each the consolation that answers it, with questions to ask the dying, prayers for those present, and instructions for the family on what to do with their hands and voices. It assumes the dying person is conscious, is the principal actor, and has work to do. That is why it matters here: the modern death, unconscious in an institution among strangers, is recent and local, and the ars moriendi describes the arrangement that preceded it almost everywhere.

Other traditions hold their own versions. In Islam, those around the dying prompt them to say the shahada, so the declaration of faith is the last thing on the tongue, and the body is washed and buried quickly. In Hindu practice, dying at Varanasi on the Ganges, or with Ganges water on the lips, is held to release the soul from the cycle of rebirth. Tibetan Buddhist practice holds that the attentiveness of the dying consciousness at the moment of death shapes what follows, which makes the quiet of the room and the voice beside the ear part of the practice rather than kindness around it. In Jewish practice the vidui, the deathbed confession, is said by or for the dying person. I could not reach primary ethnographic or community sources for the Islamic talqin or the Varanasi custom, and report them as widely described rather than verified [VERIFY]. Practices that are restricted or initiatory exist in many traditions and their content is not reproduced here.

The evidence attached. Steinhauser et al. 2000 surveyed 340 seriously ill patients, 332 bereaved family members, 361 doctors and 429 other care providers about 44 attributes of a good death. Twenty-six items were rated important by more than 70 per cent of all four groups, including pain and symptom management, preparation for death, achieving a sense of completion, and being treated as a whole person. I could not retrieve per-item percentages and do not quote them [VERIFY].

Preparation, completion and being treated as a whole person are the business of the ars moriendi and are not purchasable with any drug. The convergence of unrelated traditions on a conscious, attended, prepared death, together with a survey in which patients and families name the same things, is grade C evidence that this is what people want, and no evidence that any ritual changes a physical outcome. TR-16's conclusion stands unsoftened: no ritual has cleared an infection, stopped a haemorrhage, delivered an obstructed labour or shrunk a tumour, and as a substitute for treatment ritual is grade X (THRIVING library, TR-16). Where evidence is positive it concerns distress: music around pain at a standardised mean difference of -0.77 and anxiety at -0.68 (Hole 2015), and social ties and survival at odds ratio 1.50 (Holt-Lunstad 2010). Singing at a deathbed is cheap, traditional on every continent, and supported by that evidence for that outcome.

Place of death. Higginson and Sen-Gupta 2000 reviewed 18 studies of preference for place of care and death in advanced cancer, and preference for home death ranged from 49 to 100 per cent. Conill et al. 1997 found 64.2 per cent of their 176 patients died at home in Spain in the 1990s. The brief asks who died where by era. I could not find a reliable 1900 or 1950 baseline for any country and will not state one from memory [VERIFY]. The direction is secure: home was the normal place of death before hospitals were numerous, institutional death became the majority in high-income countries during the twentieth century, and home death has risen modestly where hospices exist. After the Fall almost every death will be at home, most will be expected, and the family will be present whether or not anyone has prepared them. The book's job is the preparation.

9. The three questions this report does not decide [OWNER]

Palliative sedation. Section 3 shows that sedation titrated to a symptom in a specialist unit does not shorten life. That does not transfer unmodified to a village with tincture of uncertain strength and no nurse awake at night, where the difference between deep sedation and a fatal overdose is the care with which the dose is titrated and recorded. Whether the village permits deliberate sedation to unconsciousness for an otherwise unrelievable symptom is [OWNER]. If it does, the intention must be written before the first dose, the symptom named, every dose recorded, and the decision taken by more than one person.

Truth-telling. The assumption that a dying person should be told plainly is recent and culturally specific. In much of southern Europe, the Middle East, South Asia and East Asia the family has conventionally been told first and decided what the patient hears, and a healer who overrides that does violence to the family's understanding of their duty. I could not verify the frequently cited Greek and Italian non-disclosure percentages and do not quote them [VERIFY]. The defensible middle position is to ask the patient how much they want to know and who they want told, before telling anyone anything. Any norm beyond that is [OWNER].

Hastened death. Whether a village permits a deliberately lethal dose, in what circumstances and decided by whom, is [OWNER] and is not a medical question. The clinical case is weakest where it is most often invoked. The pain of the dying is relievable in about three quarters of cases by an oral drug on a clock (Zech 1995), the breathlessness responds to a piece of card (Galbraith 2010), the delirium responds better to finding the cause than to any drug (Agar 2017), and withholding fluids does not add to suffering (Bruera 2013). A village that has not done those four things is not facing a case for hastening death. It is facing a case for better nursing.

Evidence grades

Practice	Claim	Grade	Basis
By the clock, by mouth, by the ladder	Good relief 76 per cent, satisfactory 12	B	Zech 1995, n=2,118, no control arm (Jadad 1995)

Practice	Claim	Grade	Basis
Fan to the face for breathlessness	Beats the same fan to the leg	A	Galbraith 2010, Schwartzstein 1987, 2025 review
Titrated opioid or sedative in the dying	Does not shorten survival	B	Sykes and Thorns 2003, Maltoni 2009, observational
Correcting the cause of delirium	Beats adding an antipsychotic	A	Agar 2017
Antipsychotics for terminal delirium	Worse than placebo, worse survival	X	Agar 2017, HR 1.73
Artificial hydration in the last days	No symptom or survival benefit	A	Bruera 2013, n=129 randomised
Oxygen for the non-hypoxaemic breathless	No better than room air	X	Abernethy 2010, n=239 randomised
Anticholinergics for the death rattle	Nothing beats placebo	X	Wee and Hillier 2008, 1 eligible trial
Mouth care for thirst and dry mouth	Relieves the symptom	C	Universal practice, Conill 1997
Laxative from day 2 of any opioid	Prevents the commonest side effect	B	Zech 1995, laxatives on 42 per cent of days
Opioid for breathlessness	Small pooled effect, weak evidence	C	Barnes 2016, 26 studies, 0.09 points
Late physical signs for death within 3 days	High specificity, low sensitivity	B	Hui 2014 and 2015, n=357
Surprise question as prognosis	Inconsistent	D	Chu 2023, Yarnell 2021
Trained lay volunteers at scale	Works with supervision and drugs	B	Kumar 2007, Kerala G.O. 109/2008
Ars moriendi and deathbed rites	A script for the family, no physical effect	C for distress, X as treatment	Steinhauser 2000, TR-16

Means ledger

Rung	What it can do	What it changes
Hands and knowledge	Dosing by the clock. Fanning the face. Positioning upright, then on the side when unconscious. Two-hourly turning. Mouth moistening. Looking for a full bladder, loaded bowel, pain, thirst, a frightening room. Reading the late signs. Staying.	Most of the achievable relief at the end of life, with no supply chain.

Rung	What it can do	What it changes
The hearth	A quiet dark room, honey and fat for the lips, cold water, dry bedding, padding over bony points, broth and sips, a woven fan, song.	Removes the miseries that masquerade as terminal agitation. Lets the family do something useful, which is itself the intervention.
Garden and still	ME-06 rung 1 analgesics, willow decoction, ginger for nausea, bulk and fruit laxatives. Poppy if grown [OWNER].	A modest analgesic floor. Does not reach bone metastasis or a large ulcerating wound.
Village dispensary of 300	Tincture of declared strength in the locked chest, issued by one named person against a logbook. Salvaged paracetamol. TR-16's visiting rota. A healer who visits, teaches the family and leaves written instructions and an anticipatory supply.	The Kerala rung, where palliative care becomes a system rather than a kindness. Relief in the majority becomes possible, and so do diversion and fatal error.
District infirmary of 3,000	Tincture of standard strength, dye-marked by the Uganda method [OWNER]. The register. Training village healers. Taking the hardest cases.	Standardises strength, the main safety gain, and makes supervision possible.
Hospital before the Fall	Assayed oral and parenteral morphine, syringe drivers, radiotherapy for bone pain, nerve blocks, steroids, antiemetics, nurses day and night.	Reaches the last quarter, without the family carrying the dosing.

Harm test

Opium in the opioid-naive. A first dose too large stops breathing, fast, almost always from guessing the strength of a tincture or counting drops. ME-05 governs: adults start at 5 mg oral morphine equivalent four-hourly, old and frail at 2.5 mg, renal failure a quarter dose and spaced out, and dosing is by oral syringe. Paregoric is twenty-five times weaker than standard tincture and the confusion has killed. Signs in order: vivid dreams, hallucinations, myoclonic jerks, then pinpoint pupils and deepening drowsiness, then slow breathing. Under 12 breaths a minute, hold the next dose. Unrousable with slow breathing, breathe for them at 10 to 12 a minute and hold all doses. Never to infants, the drowsy, the drunk, the head-injured, the asthmatic in an attack, or the dehydrated child with dysentery (THRIVING library, ME-05).

Constipation. Certain with any opioid, not self-limiting, and the cause of vomiting, abdominal pain, overflow diarrhoea and agitation. It harms by being mistaken for something else. Laxative from day 2.

Sedation that drifts. The harm is to the decision. A dose increased each night by a frightened family, with no record and no reason, arrives at deep unconsciousness without anyone having chosen it. The protection is a written record of dose, time, reason and giver.

Mistaking a reversible cause for dying. The most damaging error here. Urinary retention, faecal impaction, dehydration, hypoglycaemia, infection, opioid toxicity and alcohol withdrawal all produce drowsiness, confusion and agitation, and each is correctable. A healer who calls this the terminal phase and increases the opium will kill

someone who had weeks or months.

Mistaking dying for a reversible cause. The opposite error wastes a person's last days on force-feeding, moving them and interventions they resist. Hui's late signs are the check. Pushing food or drink into someone who cannot swallow causes choking and aspiration.

Salicylates. ME-06's rules carry over unchanged (THRIVING library, ME-06).

Withholding relief from fear. This is a harm and should be recorded as one. A village that locks opium away from a dying person has chosen a certain harm over a manageable risk.

Harm to the carers. Families nursing a dying person go without sleep for days. TR-16's rota exists to prevent that, and a healer who does not organise it has left them to fail.

Red flags

1. **Massive haemorrhage**, from an eroding tumour, varices or a lung. Death in minutes. Have dark cloths ready to hide the blood, do not leave them alone, hold them, speak to them. This is the one event that justifies a pre-placed sedative dose kept for the purpose [OWNER].
2. **Complete bowel obstruction**, with vomiting, distension and no flatus. Without surgery this ends in death over days to weeks. Nothing by mouth except sips for comfort, opium for the pain, continuous mouth care, and accept the vomiting rather than fight it.
3. **Breathlessness that does not ease** with the fan, positioning, a cool room and low-dose opium. Nothing further is available. Say so, stay, keep the face cool.
4. **Pain that persists at the top of the village ladder.** About one in eight had inadequate relief with a full hospital service and assayed morphine (Zech 1995), and the village will do worse. Tell the family this is one that cannot be fixed, that nothing is being held back, and that they will not be left alone with it.
5. **Seizures that do not stop.** No anticonvulsant exists at village level. Protect the head, clear the space, turn them on the side afterwards.
6. **Delirium with no correctable cause.** After bladder, bowel, pain, thirst, infection and opium toxicity are corrected there is nothing further, and the drugs tried against it made it worse (Agar 2017).
7. **A dying child.** Everything here applies with smaller doses and far less margin. The paediatric rules are in ME-05 and CH-06.

The case against

The ladder was never tested. Jadad and Browman 1995 found eight uncontrolled case series and no trial, with adequate analgesia ranging from 69 to 100 per cent and no way of knowing how much was the ladder and how much was time, attention and regression to the mean. Their warning against building policy on such evidence applies to this book.

Hospice literature reports on itself. Zech 1995, Sykes and Thorns 2003 and Maltoni 2009 are all written by palliative care services about their own patients, grading their own outcomes, unblinded and uncontrolled. The movement has an institutional interest in the finding that sedation does not shorten life.

A system that believed its own protocol. The Liverpool Care Pathway packaged hospice practice for general use in England. Julia Neuberger's independent review, More Care, Less Pathway (2013), received 483 public submissions and found syringe drivers started as a matter of course, oral fluids withheld from people who could still drink, families not told the pathway had been started, and practice the review called clinically indefensible. It was abolished. The lesson is exact: these protocols describe how to care for someone who is dying, and become dangerous the moment anyone starts them without first being sure that the person is.

Osler's numbers were softened. The claim that dying is usually peaceful rests partly on William Osler's study of deathbeds. A re-analysis found he under-reported discomfort substantially, roughly 21 per cent recorded as distressed against 38 per cent on re-reading the records (Mueller 2007) [VERIFY, secondary summary only]. The tradition that death is gentle has a history of being produced by people who wanted it to be.

The volunteer model is romanticised. Kerala has near-universal literacy, a state that wrote the model into policy in 2008, supervising doctors and nurses, and a legal morphine supply four times the national average. A village copying the volunteers without the supervision and without the drug has copied the part that does not work alone.

Opiophilia is a real failure mode. ME-05 records addiction rates three to four times higher in poppy-growing villages, 7.0 to 9.8 per 100 against 1.8 to 2.3 (Westermeyer 1979), and 13.5 per cent of people given eight days of opioid still using at a year (Shah 2017). A village that solves palliative care by growing poppy has bought relief for its dying with dependence among its living. That trade is the [OWNER] decision in ME-05, not a detail.

Most of the evidence is about cancer. Zech, Conill, Hui, Bruera and Temel are all cancer studies. After the Fall most deaths will be from infection, injury, childbirth, starvation and old age, and the prevalences and trajectories here may not transfer. Farquhar's non-malignant breathlessness trial, which found no significant benefit where the cancer trial did, is the warning.

10-line summary

1. Giving an analgesic by the clock rather than on demand costs nothing and works at every rung from willow bark to opium.
2. The ladder gave good relief in 76 per cent and satisfactory relief in a further 12 per cent of 2,118 patients, 82 per cent of it by mouth (Zech 1995), and has never been tested against a control (Jadad 1995).
3. Titrated opioids and sedatives given for symptoms did not shorten survival in two large observational series, and the longest-sedated group lived longest (Sykes 2003, Maltoni 2009).
4. A fan or folded leaf moving cool air across the nose and mouth reduces breathlessness more than the same draught on the leg (Galbraith 2010), and oxygen does not beat room air (Abernethy 2010).
5. In terminal delirium, correcting the cause beat adding an antipsychotic, and haloperidol was associated with worse survival than placebo (Agar 2017).
6. A litre of fluid a day in the last days relieved nothing and prolonged nothing (Bruera 2013). Mouth care relieves thirst, fluids do not.
7. No treatment for the death rattle has beaten placebo (Wee and Hillier 2008). Explaining it to the family is the intervention.
8. Signs findable with eyes and fingers alone have specificity above 95 per cent for death within three days: a pulseless radial artery, mandibular breathing, Cheyne-Stokes breathing, falling urine output and the rattle (Hui 2014, 2015).
9. Trained lay volunteers covering more than 12 million people carried palliative care in Kerala, given supervision and a drug supply (Kumar 2007, Kerala G.O. 109/2008).
10. Constipation accompanies every opioid and was the most treated side effect (Zech 1995). A laxative starts on day 2.

Open questions

- Volunteer hours per patient in Kerala. Not found. Only the per-volunteer commitment of at least two hours a week and visit durations of 90 to 120 and 30 to 45 minutes were confirmed.
- The NNPC entry-level training curriculum and its hours. The sixteen-hour figure comes from the brief and secondary accounts, not a primary document.
- Whether the Hui late signs replicate outside that research programme and outside cancer, and whether the symptom prevalences of the last days transfer from cancer to death from infection, injury and old age, which

will be the common deaths after the Fall.

- What proportion of deaths are expected rather than sudden. The brief asks and I could not find a defensible figure.
- Whether a village can safely hold a pre-placed sedative dose for catastrophic haemorrhage without that dose being used for other things.
- The actual strength of a household-made opium tincture, batch to batch. Nobody has measured what a village produces.

Sources to read in full

1. Zech et al. 1995, Pain 63:65-76. The largest prospective record of the ladder in use, with symptom and adjuvant data no other paper gives.
2. Hui et al. 2014, The Oncologist 19:681-687, with Hui et al. 2015, Cancer 121:960-967. The bedside signs with likelihood ratios, needing no instrument.
3. Agar et al. 2017, JAMA Internal Medicine 177:34-42. The trial that showed the drugs were worse than the care.
4. Neuberger et al. 2013, More Care, Less Pathway. How a good protocol became a bad one. The most important cautionary document in palliative care.
5. Kumar 2007, Journal of Pain and Symptom Management 33:623-627, with the Kerala Palliative Care Policy, G.O. 109/2008/HFWD.
6. Galbraith et al. 2010, Journal of Pain and Symptom Management 39:831-838. One piece of card, grade A.
7. Bruera et al. 2013, Journal of Clinical Oncology 31:111-118. The permission not to give fluids.
8. Clark 1999, Social Science and Medicine 49:727-736. Total pain, with the critique.
9. Jadad and Browman 1995, JAMA 274:1870-1873. The case against the ladder.
10. Twycross, Introducing Palliative Care, and the WHO IMAI 2004 palliative care guidelines. Both named in the brief, neither obtained. Whoever writes the chapter should find them.

At the bedside after the Fall

A household. Needs no equipment. It needs to know that the dying person is turned every two hours, the mouth moistened every half hour to two hours, that cool air across the face eases breathlessness, that a full bladder and a loaded bowel cause agitation, that noisy breathing does not mean suffocation, and that whatever analgesic exists is given at a fixed interval and not when asked for. It needs a written sheet, because at three in the morning nobody remembers anything. To start: cloth, water, fat for the lips, a fan or stiff leaf, a candle marked in hours, and someone who can write. **The first failure to expect** is exhaustion of the main carer by about the third night, after which doses get missed, turning stops and the family starts to want it over.

A village of 300. Needs one named person who holds the chest, keeps the logbook and visits, TR-16's rota so no household nurses alone, an anticipatory supply placed before it is needed, and written instructions left with a named family member at each visit. The healer must be able to say which trajectory the person is on and whether death is days away. To start: a lockable chest, a logbook, an oral syringe, four to six trained volunteers, and a healer who will come at night. **The first failure to expect** is the second or third death, when the village discovers the chest is empty, or that someone has taken from it, or that the healer was at a birth three miles away.

A district of 3,000. Standardises and supervises. One place makes the tincture to a declared strength, marks it by colour and issues it against a register [OWNER], trains the village healers, holds the protocols, takes the few cases the villages cannot hold, and counts what goes out against what was made. To start: a scale accurate to the gram, measured glassware, dye, a register, a trained preparer, and a rule that strength is declared on every container. **The first failure to expect** is a batch of unknown strength issued as if it were standard, and someone dying of a first dose.

Protocols

Protocol 1. The four-hourly comfort round, for the family

Run by the clock, day and night. Mark the hours on a candle or a notched stick if there is no clock.

1. **Every 2 hours**, turn onto the other side, supported by rolled cloth, head raised if breathless and lowered if rattling. Check the skin over sacrum, heels, elbows and ears. Pad anything red.
2. **Every 30 to 120 minutes while awake**, moisten the mouth with clean water on a clean cloth, wipe out crusts, smear fat on the lips. Offer sips if swallowing is safe. Stop if they cough on it.
3. **Every 4 hours**, give the scheduled analgesic, whatever rung it is from, whether or not pain has been reported. Write the time, the dose and who gave it.
4. **Every 4 hours**, check: is the bladder full, feel above the pubic bone. When were the bowels last open. Is there pain on a face that cannot speak, a furrowed brow, a clenched hand, a guarded limb. Is the room too hot, too bright, too crowded.
5. **Once a day**, note the bowels. From day 2 of any opioid, a laxative every day, no exceptions.
6. **Continuously**, somebody in the room. Change who, not whether.

Tolerance: a dose may be given 30 minutes early or late without consequence. More than an hour late and the pain will have returned and need more to pull down.

Protocol 2. Breathlessness, in order

1. Sit the person upright, leaning forward, arms resting on a table or on pillows across the knees.
2. Open the window. Cool the room.
3. Fan or folded leaf, about 15 cm from the face, drawn across nose, mouth and cheeks, for at least 5 minutes. A child or an old person can do this and should be given the job.
4. Loosen clothing at neck and chest.
5. Slow their breathing by breathing audibly with them, slower than they are, until they follow.
6. If still distressed after all of the above, low-dose opium by mouth, starting at half the pain-starting dose, that is 2.5 mg morphine equivalent in an adult, four-hourly, increased only for a named symptom [OWNER]. Expect a small benefit, not a large one (Barnes 2016).
7. Do not look for oxygen. It was no better than room air (Abernethy 2010).

Protocol 3. The agitated or confused dying person, in order

Do all of 1 to 6 before concluding this is terminal agitation.

1. Feel for a full bladder above the pubic bone. If full and they cannot pass urine, that is the cause.
2. Ask when the bowels last opened. More than three days with a distended abdomen, treat for impaction.
3. Look for pain they cannot report. Move each limb gently, watch the face.
4. Offer water. Thirst agitates.
5. If on opium, look for vivid dreams, hallucinations or muscle jerks. These are toxicity. Reduce the dose, do not raise it (THRIVING library, ME-05).
6. Reduce the room: fewer people, lower voices, more light if they fear the dark, a familiar voice saying who they are.
7. Only if 1 to 6 are addressed and the distress continues, consider sedation, under Protocol 6 [OWNER].

Do not reach for an antipsychotic even if one was salvaged. In the only placebo-controlled trial both drugs did worse than placebo and haloperidol was associated with worse survival (Agar 2017).

Protocol 4. The death rattle

1. Turn onto the side, head slightly down, which lets secretions drain.
2. Stop any fluids being given.
3. Do not suction deeply. Wipe the mouth only.
4. Sit with the family and say, in these words or better: this noise is fluid in the throat of someone too deeply asleep to clear it. It does not mean he is drowning. He is not distressed by it. It often means the end is near.
5. Do not treat it with drugs. Nothing has beaten placebo (Wee and Hillier 2008).

Protocol 5. Reading the signs that death is near

Check twice a day and record what you find. Any of the following means death is probably within three days (Hui 2014, 2015). Absence means nothing.

- No pulse at the wrist while a pulse is still felt at the neck.
- The jaw moving with each breath, the lower jaw dropping and rising.
- Breathing that rises, falls, stops for seconds, then rises again.
- Urine output falling to almost nothing.
- Noisy rattling breathing.
- Pupils that do not narrow when a light is brought to the eye.
- No response to being spoken to, or to a hand moved in front of the eyes.

Earlier and less certain: unable to swallow liquids, confined to bed, deeply drowsy. These may appear many days before.

When two or more late signs are present: tell the family death is likely within days, call whoever must be called, stop all feeding and fluids, stop anything that is not comfort, and start a continuous watch.

Protocol 6. Starting and recording any strong analgesic [OWNER]

Void if the village has no opium, when Protocols 1 to 5 carry the whole load.

1. One named person holds the chest and the logbook. Nobody else opens it.
2. Confirm the strength written on the container. If it is unknown the container is not used. There is no acceptable guess.
3. First dose in an adult who has never had opium: 5 mg morphine equivalent by oral syringe. In anyone frail, over 70, very thin, or with poor urine output: 2.5 mg.
4. Repeat every 4 hours by the clock. A rescue dose equal to the scheduled dose may be given for breakthrough pain (THRIVING library, ME-05).
5. Each morning, add the last 24 hours including rescues and divide by 6. That is the new four-hourly dose.
6. Count the breaths for a full minute before every dose for the first 48 hours, then once a shift. Under 12 a minute in an adult, hold the dose and count again in an hour.
7. Laxative from day 2.
8. Write every dose: date, time, amount, reason, giver. An increase must have a named symptom beside it.
9. If the person becomes unrousable with slow breathing, hold all doses and breathe for them at 10 to 12 a minute until they rouse.
10. Any deliberate increase intended to produce unconsciousness is decided by at least two people and written down, with the symptom named, before the first dose.

Protocol 7. The healer's visit to a dying person

1. Ask the patient, while they can answer, how much they wish to know and who they wish told. Tell nobody anything before asking [OWNER].
2. Examine for the correctable: bladder, bowel, mouth, skin, pain, opioid toxicity.
3. Check the logbook against what is in the container.
4. Teach one family member Protocol 1 and watch them do it once.
5. Leave written instructions in the house: the four-hourly times, the dose, the signs to call for, and who to call.
6. Set the rota with the village before leaving, naming who sits which hours for the next three days (THRIVING library, TR-16).
7. Ask what the person wants at their death and who should be there. Write it down.
8. Say when you will return. Return then.

Numbers to carry

1. **Every 4 hours, by the clock, by mouth.** The interval and route that made palliative care work (Zech 1995).
2. **5 mg to start, 2.5 mg if frail.** The first oral morphine-equivalent dose in an adult who has never had opium (THRIVING library, ME-05).
3. **12 breaths a minute.** Below this in an adult, hold the next dose. Unrousable, breathe for them at 10 to 12 a minute.
4. **25 times.** How much weaker paregoric is than standard tincture. The confusion has killed.
5. **Day 2.** When the laxative starts after any opioid, needed on 42 per cent of treatment days (Zech 1995).
6. **76, 12, 12.** Percentages with good, satisfactory and inadequate relief on the full ladder (Zech 1995). One in eight will not be relieved even with everything.
7. **Fan to the face, 15 cm, 5 minutes.** The best free remedy in this report (Galbraith 2010).
8. **Five late signs.** No wrist pulse, jaw breathing, Cheyne-Stokes, no urine, rattle. Any one means probably three days or less (Hui 2014).
9. **Turn every 2 hours, moisten the mouth every 30 to 120 minutes.** The round that prevents most avoidable misery.
10. **Bladder, bowel, pain, thirst, toxicity, room.** The six to correct before calling it terminal agitation (Agar 2017).

References

1. Clark D (1999). 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. Social Science and Medicine 49:727-736. https://europepmc.org/article/MED/10459885 (abstract read)
2. Zech DFJ, Grond S, Lynch J, Hertel D, Lehmann KA (1995). Validation of World Health Organization Guidelines for cancer pain relief: a 10-year prospective study. Pain 63:65-76. https://europepmc.org/article/MED/8577492 (full abstract read, not the full text)
3. Jadad AR, Browman GP (1995). The WHO analgesic ladder for cancer pain management. Stepping up the quality of its evaluation. JAMA 274:1870-1873. https://europepmc.org/article/MED/7500538 (abstract read)
4. Sykes N, Thorns A (2003). Sedative use in the last week of life and the implications for end-of-life decision making. Archives of Internal Medicine 163:341-344. https://europepmc.org/article/MED/12578515 (abstract read)
5. Maltoni M, Pittureri C, Scarpi E, Piccinini L, Martini F, Turci P, Montanari L, Nanni O, Amadori D (2009). Palliative sedation therapy does not hasten death: results from a prospective multicenter study. Annals of Oncology 20:1163-1169. https://europepmc.org/article/MED/19542532 (abstract read)
6. Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, et al. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. New England Journal of Medicine 363:733-742.

https://europepmc.org/article/MED/20818875 (abstract read)
7. Kumar SK (2007). Kerala, India: a regional community-based palliative care model. Journal of Pain and Symptom Management 33:623-627. https://europepmc.org/article/MED/17482058 (abstract read). The brief cites this paper as being in the Indian Journal of Palliative Care, which appears to be an error.
8. Government of Kerala (2008). Pain and Palliative Care Policy for Kerala. Government Order G.O.(P) No. 109/2008/H&FWD, 15 April 2008. https://arogyakeralam.gov.in (PDF read in full)
9. Knaul FM, Farmer PE, Krakauer EL, et al. (2017). Alleviating the access abyss in palliative care and pain relief: an imperative of universal health coverage. The Lancet Commission report. The Lancet 391:1391-1454. Figures used here are taken from THRIVING library, ME-05, not re-read in the original.
10. Galbraith S, Fagan P, Perkins P, Lynch A, Booth S (2010). Does the use of a handheld fan improve chronic dyspnea? A randomized, controlled, crossover trial. Journal of Pain and Symptom Management 39:831-838. https://europepmc.org/article/MED/20471544 (abstract read)
11. Booth S, Galbraith S, Ryan R, Parker RA, Johnson M (2016). The importance of the feasibility study: lessons from a study of the hand-held fan used to relieve dyspnea in people who are breathless at rest. Palliative Medicine 30:504-509. https://europepmc.org/article/MED/26494368 (abstract read)
12. Schwartzstein RM, Lahive K, Pope A, Weinberger SE, Weiss JW (1987). Cold facial stimulation reduces breathlessness induced in normal subjects. American Review of Respiratory Disease 136:58-61. Read in secondary summary only, via a 2025 systematic review of handheld fans for breathlessness covering 10 studies and 413 participants. [VERIFY]
13. Abernethy AP, McDonald CF, Frith PA, Clark K, Herndon JE, Marcello J, et al. (2010). Effect of palliative oxygen versus room air in relief of breathlessness in patients with refractory dyspnoea: a double-blind, randomised controlled trial. The Lancet 376:784-793. https://europepmc.org/article/MED/20816546 (full abstract read)
14. Barnes H, McDonald J, Smallwood N, Manser R (2016). Opioids for the palliation of refractory breathlessness in adults with advanced disease and terminal illness. Cochrane Database of Systematic Reviews 3:CD011008. https://europepmc.org/article/MED/27030166 (abstract read)
15. Farquhar MC, Prevost AT, McCrone P, Brafman-Price B, Bentley A, Higginson IJ, Todd C, Booth S (2014). Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? A randomised controlled trial. BMC Medicine 12:194. Read in secondary summary via search results, not in the original. [VERIFY]
16. Kehl KA, Kowalkowski JA (2013). A systematic review of the prevalence of signs of impending death and symptoms in the last 2 weeks of life. American Journal of Hospice and Palliative Medicine 30:601-616. (abstract read via Europe PMC)
17. Conill C, Verger E, Henríquez I, Saiz N, Espier M, Lugo F, Garrigos A (1997). Symptom prevalence in the last week of life. Journal of Pain and Symptom Management 14:328-331. https://europepmc.org/article/MED/9409097 (abstract read, per-symptom percentages not given in the abstract)
18. Agar MR, Lawlor PG, Quinn S, Draper B, Caplan GA, Rowett D, et al. (2017). Efficacy of oral risperidone, haloperidol, or placebo for symptoms of delirium among patients in palliative care: a randomized clinical trial. JAMA Internal Medicine 177:34-42. https://europepmc.org/article/MED/27918778 (full abstract read)
19. Wee B, Hillier R (2008). Interventions for noisy breathing in patients near to death. Cochrane Database of Systematic Reviews 1:CD005177. https://europepmc.org/article/MED/18254072 (full abstract read)
20. Bruera E, Hui D, Dalal S, Torres-Vigil I, Trumble J, Roosth J, et al. (2013). Parenteral hydration in patients with advanced cancer: a multicenter, double-blind, placebo-controlled randomized trial. Journal of Clinical Oncology 31:111-118. https://europepmc.org/article/MED/23169523 (full abstract read)
21. Hui D, dos Santos R, Chisholm G, Bansal S, Silva TB, Kilgore K, et al. (2014). Clinical signs of impending death in cancer patients. The Oncologist 19:681-687. https://europepmc.org/article/MED/24760709 (full abstract read)

22. Hui D, Dos Santos R, Chisholm G, Bansal S, Souza Crovador C, Bruera E (2015). Bedside clinical signs associated with impending death in patients with advanced cancer: preliminary findings of a prospective, longitudinal cohort study. Cancer 121:960-967. https://europepmc.org/article/MED/25676895 (abstract read)
23. Lunney JR, Lynn J, Foley DJ, Lipson S, Guralnik JM (2003). Patterns of functional decline at the end of life. JAMA 289:2387-2392. https://europepmc.org/article/MED/12746362 (full abstract read)
24. Chu C, Engels Y, Suh SY, Kim SH, White N (2023). Should the surprise question be used as a prognostic tool for people with life-limiting illnesses? Journal of Pain and Symptom Management 66:e437-e441. https://europepmc.org/article/MED/37207786 (abstract read)
25. Yarnell CJ, Jewell LM, Astell A, Pinto R, Devine LA, Detsky ME, Downar J, et al. (2021). Observational study of agreement between attending and trainee physicians on the surprise question. PLoS One 16:e0247571. https://europepmc.org/article/MED/33630939 (abstract read)
26. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 284:2476-2482. https://europepmc.org/article/MED/11074777 (abstract read, per-item percentages not available in the abstract)
27. Higginson IJ, Sen-Gupta GJ (2000). Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. Journal of Palliative Medicine 3:287-300. https://europepmc.org/article/MED/15859670 (abstract read)
28. van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, Tjan-Heijnen VC, Janssen DJ (2016). Update on prevalence of pain in patients with cancer: systematic review and meta-analysis. Journal of Pain and Symptom Management 51:1070-1090. https://europepmc.org/article/MED/27112310 (abstract read)
29. Neuberger J, Guthrie C, Aaronovitch D, Hameed K, Bonser T, Charlesworth-Smith D, Jackson E, Cox D, Waller S (2013). More Care, Less Pathway: A Review of the Liverpool Care Pathway. Independent Review of the Liverpool Care Pathway, Department of Health, London. https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients (PDF read in full)
30. Greater Manchester and Eastern Cheshire Strategic Clinical Networks and NHS England North West (2019, cited in the text as GMEC and NHS England North West 2019). Palliative Care Pain and Symptom Control Guidelines for Adults, 5th edition. https://gmmmg.nhs.uk (PDF read in full, used for the symptom-control practice in sections 5 and 6)
31. World Health Organization (1986). Cancer Pain Relief. WHO, Geneva. Not read in the original. History and content taken from StatPearls, WHO Analgesic Ladder (2023), https://www.ncbi.nlm.nih.gov/books/NBK554435/ and from the Foley and Ventafridda memorial essay published by the European Association for Palliative Care, https://eapcnet.org/download/forHomage/PainFoleyVentafridda.pdf (both read). The sources differ on whether the key meeting was in 1982 in Italy or 1984 in Geneva, and on the location name.
32. Hospice Africa Uganda and Anne Merriman. Material on the oral morphine solution, the kitchen sink method, the colour coding and nurse prescribing was taken from THRIVING library, ME-05 and from secondary accounts published by eCancer, Cancerworld, NPR and the Palliative Care Association of Uganda. The paper named in the brief as Merriman and Harding 2010 could not be located. [VERIFY]
33. Mueller PS (2007). William Osler's study of the act of dying: an analysis of the original data. Read in secondary summary only, in a McGill University essay on Osler obtained as a PDF. The re-analysis figures of 21 per cent against 38 per cent reporting discomfort are second-hand. [VERIFY]
34. THRIVING library, ME-05. Opium, morphine and the relief of pain. Library document, unverified. Source of the Westermeyer 1979, Shah 2017, Knaul 2017 and Rajagopal 2017 figures used here.
35. THRIVING library, ME-06. Plant analgesics and the village pain ladder. Library document, unverified.
36. THRIVING library, TR-16. Ritual, the gathered community and the visiting rota. Library document, unverified. Source of the Hole 2015 and Holt-Lunstad 2010 figures used here.

37. Twycross R. Introducing Palliative Care. Named in the brief. Not obtained and not read.
38. World Health Organization, Palliative Care: Symptom Management and End-of-Life Care, IMAI 2004. Named in the brief. I could not locate or confirm this document. I could confirm WHO/CDS/IMAI/2004.1, Integrated management of adolescent and adult illness: interim guidelines for first-level facility health workers, dated 10 October 2004, and a 2009 study in BMC Palliative Care stating that the IMAI guidelines include a palliative care guidebook. [VERIFY]