NU-09 Spinal injury, paralysis and the long-term patient

HEALING after the FALL, research library, NU-09

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

1. Findings by section

This report covers the person who survives the first weeks of a spinal cord injury and must then be kept alive for years by a household. The acute injury, moving the patient and the first week belong to WO-07. Pressure-sore nursing in general and the carer's rota belong to NU-01, and the wheelchair and cushion to NU-05. This report covers the bladder, the bowel, numb skin, autonomic dysreflexia, the family's day, and the record of survival with and without such a regime.

The short answer. Before 1944 most people with a complete traumatic paraplegia died within weeks to three years, of urinary sepsis, kidney failure and pressure sores. The "80 per cent mortality" everyone quotes is a soldier's estimate from the First World War. From 1944, Guttmann's two-hourly turning and no-touch intermittent catheterisation let most survive and work. From 1972, Lapides let patients catheterise themselves with a catheter washed in soap and water. Without such a regime, three-quarters or more died within a year or two in Botswana before 2011, in Sri Lanka in 1997 and in Zimbabwe in the 1960s. With a small unit that teaches families and supplies catheters, nobody may die in the first two years after discharge, yet a quarter are dead within ten, mostly at home and mostly of pressure sores. After the Fall a household can keep a paraplegic alive with a catheter, soap, a bed, a cushion, a schedule and a rota. A high tetraplegic takes a household's whole labour, and one who cannot breathe cannot be kept.

1.1 Before Guttmann: what paraplegics died of, how fast, and where "80 per cent" comes from

Record shows. In 1917 Guttmann was an orderly at the coal-miners' accident hospital in Königshütte. There he watched a miner with a thoraco-lumbar fracture-dislocation, manipulated and put in plaster, die four weeks later of sepsis from urinary infection and multiple pressure sores (Guttmann 1976, p4). His historical chapter is the source most later writers use. In 1898 Wagner and Stolper called keeping complete lesions alive "the physician's forlorn task". Mortality in the Balkan wars exceeded 95 per cent. Cushing found that 80 per cent of the American Army's cord injuries in the First World War died within two weeks, and that "only those cases survived in which the spinal lesion was a partial one". In the British Army, early mortality was 47 to 65 per cent (Vellacott and Webb-Johnson 1919, via Guttmann). Overall mortality after three years was "estimated at 80 per cent (Thompson-Walker, 1937)". Life expectancy was "as a rule 2-3 years to the utmost" (Guttmann 1976, pp4 to 6). At the Star and Garter Home men were kept on morphia, atropine and hyoscine for their spasms (Gowland, via Guttmann).

Silver adds that 75 per cent of Boer War cases died within a few weeks, and that 160 of 339 admitted to King George V Hospital in the First World War died of urinary infection. Thomson-Walker called bladder management "the surgical failure of the War" (Silver 2012).

What killed them, and how fast. Urinary sepsis came first, rising from an overdistended or permanently catheterised bladder to the kidneys. Then came pressure sores that deepened, became infected and reached bone.

Complete cervical and high thoracic lesions died within a fortnight. Paraplegics who survived the first weeks died within months to three years. The long survivors were mostly incomplete lesions (Cushing, via Guttmann 1976).

Where the 80 per cent comes from. The WHO world report says "the prevailing 80% mortality rate of SCI began to decline" with turning and bladder care, but gives no period, denominator or population (WHO and ISCoS 2013). In Guttmann the figure is Thompson-Walker's 1937 estimate of three-year mortality among British soldiers. Cushing's 80 per cent is a different number, deaths within two weeks. The book can say that before 1944 most complete lesions died within weeks to three years. It should not attach "80 per cent" to civilians, to a fixed interval, or to Guttmann's own patients.

1.2 The Stoke Mandeville regime and what it achieved

The National Spinal Injuries Centre opened on 1 February 1944 with one patient and 26 beds. The staff were one sister, one auxiliary nurse and 8 Army orderlies (Guttmann 1976, p9). Other accounts give 28 beds [VERIFY].

Skin. "In 1944 I introduced ... immobilization on pillow-packs combined with 2-hourly turning of the paralysed patient, day and night" (p125). Orderlies turned patients in one piece. Sores were taught as preventable, which made a sore a failure of nursing rather than a fate.

Bladder. Suprapubic cystotomy, the standard of the day, gave way to a "non-touch technique of intermittent catheterization carried out in the acute stages by the medical attendant himself" (p10). A newly paralysed bladder could be left without a catheter for at least 24 hours if fluid was restricted (p126). Guttmann and Frankel reported 476 traumatic patients over 11 years, all admitted within 14 days of injury. Of these, 370 arrived with sterile urine, and 81 of the 106 infected on arrival had been given Foley catheters elsewhere (Guttmann and Frankel 1966, abstract via search summary). Hydronephrosis developed in 35 (7.4 per cent), and women did worse (Guttmann 1976, p353) [VERIFY: imperfect OCR].

Purpose. The first six paraplegics were working in a factory by the end of 1944 (p10).

Results. Of the first 3,000 patients, admitted from 1944 to May 1963, 496 had died (16.5 per cent). After removing deaths unrelated to the injury the figure was 343 (11.4 per cent) (pp627 to 631). The cohorts show what late arrival cost. First World War veterans, admitted decades after injury, had 58.2 per cent crude mortality, and Second World War veterans 26.7 per cent. Civilians, mostly admitted early, had 12.5 per cent crude and 9.0 per cent corrected. From 1957 to 1963, 30 of 396 early admissions (7.6 per cent) died in the early phase, mostly people over 40 with cervical injuries (p126). These are cumulative deaths over up to 19 years, not annual rates, and the OCR is imperfect [VERIFY].

Inference. The regime cost labour, not drugs. Penicillin arrived in the same years and cannot be cleanly separated out, but turning needs no drug, and the 1966 paper credits sterile urine to the technique.

1.3 Survival now where care is thin

Botswana before and after. Before the specialist unit opened, local physicians estimated in 2010 that about 85 per cent died within a year of discharge, of pressure ulcers and urinary infection. Patients went home with indwelling catheters or colostomies. Mothers became the carers. Donated wheelchairs were the wrong size, cushions were rare and bowel care was done in bed (Löfvenmark 2016). After the unit opened, 50 consecutive patients were followed. Ten (20 per cent) died in hospital, a mean of 28 days after injury (range 2 to 50), and 9 of the 10 had cervical injuries. One was a ventilator-dependent C3 patient, the first in Botswana given a portable ventilator. Median stay was five months. Nobody died within two years of discharge. Yet at yearly follow-up 41 per cent had urinary infection and 48 per cent had pressure ulcers. Catheters were single-use in the unit but reused at home for want of supply, which the author suggests may explain the rise in infection.

Ten years on. Of the 39 alive at two years, 10 (26 per cent) were dead by ten years. Four died of pressure ulcers (two of them also had HIV), two of collapse, one of autonomic dysreflexia, one of HIV, one in a road accident and one of unknown cause. Mean age at death was 42.5 years, 5.4 years after injury, and eight died at home (Löfvenmark, Mogome and Sekakela 2024). The authors credit survival to free rehabilitation, family education, aids and consumables, a wound clinic and follow-up.

Sri Lanka and Zimbabwe. In Sri Lanka in 1997, 75 per cent of admissions died within 18 to 24 months, and training with proper chairs and cushions cut sores by 71 per cent (THRIVING library, NU-05, citing WHO 2008). In Zimbabwe 90 per cent died within a year in the 1960s (THRIVING library, WO-07, citing Oderud 2014).

The world. People with spinal cord injury are 2 to 5 times more likely to die prematurely. Standardised mortality ratios run from 1.9 in Norway to 5.0 in Estonia, higher for tetraplegia than paraplegia. In-hospital mortality is 6.1 per cent in the United States and nearly 35 per cent in Nigeria, where being carried crouched raised the odds of death 23.5-fold (WHO and ISCoS 2013). It is about three times higher in poor countries than rich ones (WHO 2024). Southern African first-year mortality is 25 to 61 per cent (Löfvenmark 2016).

Causes of death. Where care is good, the leading causes have moved from urosepsis and renal failure to pneumonia. Australian cause-specific SMRs are 17.1 for pneumonia and influenza, 6.8 for urinary disease and 4.4 for suicide (WHO and ISCoS 2013). In Denmark, among 888 people injured from 1953 to 1990, SMRs were highest for septicaemia, uraemia and pneumonia. They fell over time for all causes except pneumonia, suicide and heart disease (Hartkopp 1998a, abstract). In low-income countries the urinary tract and the pressure sore still lead (WHO and ISCoS 2013).

Inference. Survival changes with a household that has been taught and has catheters and a cushion, more than with the hospital. Over ten years it is the skin that kills.

1.4 The bladder

What happens. In spinal shock the bladder is flaccid (THRIVING library, WO-07). Werner tells families that injuries above the second lumbar vertebra often develop an automatic bladder that empties by reflex, while lower injuries usually stay limp (Werner 1987, ch25). The reflex bladder often squeezes against a sphincter that does not relax in step, which pushes pressure back to the kidneys [VERIFY: general physiology]. Both kinds damage the kidneys if left alone, and both are best emptied regularly by catheter.

Lapides. In 1970 Lapides taught a 30-year-old woman with multiple sclerosis and recurrent infection to catheterise herself every 2 to 3 hours. She used a 14 F rubber catheter washed in soap and water, and after four weeks her urine was sterile without antibiotics (Banerjee 2022, describing Lapides 1972). His theory was that overdistension destroys the bladder's resistance to infection, so frequency matters more than sterility. Patients were told to catheterise on time even without soap and water. Of 60 patients started ten years earlier, 27 were still catheterising, 18 had stopped and 15 were lost. None of those still catheterising had worse kidney function (Diokno 1983, abstract). Guttmann's method needed a doctor. Lapides' needed only the patient, or a relative.

Clean against sterile, single-use against reused. A Cochrane review of 23 trials and 1,339 participants found no clear difference in symptomatic infection between aseptic and clean technique (RR 1.20, 0.54 to 2.66, one study of 36). It found none between single-use and multiple-use catheters either (RR 0.98, 0.55 to 1.74, two studies, 97 participants, low certainty). Hydrophilic catheters did not clearly reduce infection (RR 0.89, 0.69 to 1.14) (Prieto 2021, abstract). The essentials are education, a clean and gentle technique and keeping to the schedule (Wyndaele 2002, abstract).

Against the alternatives. Among 316 patients followed for a mean of 18.3 years, complications affected 27.2 per cent on intermittent catheterisation and 32.4 per cent voiding spontaneously. They affected 44.4 per cent with a suprapubic catheter and 53.5 per cent with an indwelling urethral catheter (Weld and Dmochowski 2000, abstract).

Among 2,825 Swiss patients, bladder stones formed in 2 per cent on intermittent catheterisation and 1.1 per cent on reflex voiding. They formed in 6.6 per cent with an indwelling urethral catheter, fastest at a mean of 31 months, and in 11 per cent with a suprapubic catheter (Bartel 2014, abstract).

Reuse for years. In Chiang Mai, 28 men reused each silicone catheter for a mean of 3 years (range 1 to 7). In the previous year 10 had had fever, 5 epididymitis and 3 urethral bleeding, but every creatinine was normal. Men who catheterised more often had fewer urethral abnormalities. After two years the catheters were encrusted and 20 per cent stiffer (Kovindha 2004, abstract).

Cleaning. Werner tells families to boil the catheter for 15 minutes if possible. Otherwise they should wash it well after each use and store it in a clean jar or towel. He also tells them to use a water-soluble lubricant, never oil or Vaseline (Werner 1987, ch25). In the laboratory, boiling, steaming and microwaving killed bacteria but damaged the surface of PVC catheters, and vinegar only slowed bacterial growth. A detergent wash followed by diluted Milton (0.6 per cent sodium hypochlorite) killed bacteria without damage (Wilks 2020, abstract). The two sources differ, and the right method depends on the catheter's material [VERIFY: heat tolerance of rubber and silicone not confirmed].

Schedule. The European nursing guideline advises catheterising 4 to 6 times a day to keep each volume under 500 ml, with one catheterisation last thing before sleep (EAU Nurses, via search summary). Alberta's spinal service also keeps volumes under 500 ml and never lets urine stand more than 6 hours. The next catheterisation is in 6 hours if the last volume was 400 ml or less, in 4 hours if it was 401 to 500 ml, and in 3 hours if it was over 500 (Alberta Health Services, via search summary). WO-07 allows 6 to 8 hours after the first week. I prefer a 6-hour limit for life. Lapides' mechanism is overdistension, and the death described in 1.6 followed missed night catheterisations.

Credé and straining. Credé's manoeuvre (pressing the bladder through the belly) forces urine against a closed sphincter. Seventy-four paraplegics from the 1976 Tangshan earthquake had used it for over 20 years. Residual urine exceeded 100 ml in 93.2 per cent, hydronephrosis was found in 35.1 per cent, stones in 31.3 per cent and kidney damage in 16.2 per cent (Chang 2000, abstract). The WHO report discourages manual emptying as the sole long-term method. It calls clean intermittent catheterisation "safe, efficient and cost-effective" in poor settings (WHO and ISCoS 2013). Werner's gentle press on the lower belly while the catheter is in is a different thing, because the outlet is open.

What families actually do. In the United States only 20 per cent of those discharged on intermittent catheterisation still used it 30 years later, while 71.1 per cent of those discharged with an indwelling catheter still had one (Cameron 2010, abstract). In Botswana a quarter of the chronic group had indwelling catheters (Löfvenmark 2016). The drift is towards the method that costs the carer least time and the patient most.

Infection without antibiotics. A catheterised person almost always has bacteria in the urine, and on their own they need no treatment. Fever, shaking chills, new leaking, foul urine with malaise, loin pain, new spasms or new dysreflexia mean infection. Pyelonephritis is the infection that kills. IN-14 gives the doses and grades cranberry X for the neurogenic bladder (THRIVING library, IN-14). Without antibiotics the household's tools are the schedule, fluid and a clean catheter, which is Lapides' whole theory. I found no series of intermittent catheterisation without antibiotics in reserve.

1.5 The bowel

The paralysed bowel is one of two kinds. After a lesion above the conus it is reflex: the anal sphincter is tight and the bowel empties when the rectum is stimulated. After a low lesion it is limp: the sphincter is slack, it leaks, and it must be emptied by hand. Werner sets out the programme (Werner 1987, ch25). Do it at the same hour every day or every other day, after a meal or a hot drink, sitting on a pot if possible, otherwise lying on the left side. For a reflex bowel, an optional suppository goes 2 cm in against the bowel wall, followed by a wait of 5 to 10 minutes. Then a gloved, oiled finger goes 2 cm inside and moves in gentle circles for about a minute until stool comes. Repeat 3 or 4 times. For a limp bowel, remove stool by finger after each meal or at least daily, and favour foods that firm the

stool. Avoid regular enemas and strong laxatives. Liquid leakage may be overflow around an impaction, so never give anti-diarrhoeal medicine. Bright red blood means be gentler, and black tarry stool needs medical advice.

The evidence is thin. A scoping review found only 33 studies of digital rectal stimulation. Most were cross-sectional, and most tested it alongside suppositories or enemas (Wincentak 2021, abstract). In Botswana's chronic group, 39 per cent had bowel care in bed and 20 per cent had colostomies (Löfvenmark 2016). Impaction is the second commonest trigger of dysreflexia, and examining the rectum can itself trigger it, which is why the guideline puts anaesthetic jelly in first (Consortium 2020). NU-01 Protocol 5 gives the enema, and WO-07 the first enema after injury. For the long term I side with Werner: the finger, the hour and the diet, with enemas kept for failure.

1.6 Autonomic dysreflexia

What it is. In injuries at T6 or above, a stimulus below the injury, most often a full bladder, sets off reflex narrowing of the blood vessels below the lesion. The brain cannot damp it down. The guideline defines dysreflexia as a rise in systolic pressure of more than 20 mmHg above baseline in adults, or more than 15 in children. Baseline systolic pressure in these patients is often 90 to 110, so a reading of 140 can be a crisis. Systolic pressure can reach 300 mmHg. Untreated, dysreflexia causes brain haemorrhage, retinal detachment, seizures, heart rhythm disturbance and death (Consortium 2020). Werner gives readings of up to 240/150 and calls it "a medical emergency" (Werner 1987, ch23).

Signs. Sudden pounding headache, flushing and sweating of the face and neck, goose pimples, a stuffy nose, blurred vision and a slow pulse (Consortium 2020, Werner 1987).

How often. On 24-hour monitoring, 26 of 28 patients injured above T6 (92.8 per cent) had episodes, a mean of 5.8 a day, and 42.9 per cent had silent episodes without symptoms (Lee and Joo 2017). Lifetime estimates of 19 to 70 per cent come from a review I saw only through a search summary (Blackmer 2003) [VERIFY]. In one survey, 41 per cent of people at high risk had never heard of the condition (McGillivray 2009, via Consortium 2020).

Why it is missed. Headache is "commonly seen in other conditions" (Consortium 2020), so the tetraplegic with a headache is given a painkiller and laid flat, which raises the pressure further.

What to do. The guideline and Werner agree on the order. 1. Sit the person up with the legs down. 2. Loosen clothing, belts, binders and leg-bag straps. 3. Check pressure and pulse every 1 to 2 minutes if a cuff exists. 4. Bladder first. Straighten a kinked catheter. Flush a blocked one with 10 ml of sterile saline or cooled boiled water, or replace it. If there is no catheter, pass one with lidocaine jelly. 5. Then the rectum, with lidocaine jelly, stopping if the signs worsen. 6. Then other triggers: tight clothes or shoes, pressure, an ingrowing toenail, a burn, labour (Consortium 2020, recommendations 2.6 to 2.27, Werner 1987, ch23).

When infection is suspected, Werner adds 10 ml of 1 per cent lidocaine in 20 ml of boiled water, put into the bladder through the catheter and clamped for 20 minutes. He advises any community with tetraplegics to keep lidocaine.

Drugs. The guideline advises a drug if systolic pressure stays at or above 150 in an adult. The threshold is 120 under age 5, 130 at 6 to 12 and 140 in adolescents. The drug should act fast and briefly (Consortium 2020, Appendix 2): - 2 per cent nitroglycerin ointment, 0.5 to 2 inches (1.25 to 5 cm) on the chest or back. It acts in 15 to 30 minutes, lasts about 7 hours, and is wiped off when the pressure falls. Never use it within 24 hours of sildenafil or vardenafil, or within 48 hours of tadalafil. - Nifedipine, immediate release, 10 mg by mouth. It acts in about 20 minutes and lasts about 8 hours. Biting it under the tongue is not recommended, because absorption that way is unpredictable. - Captopril 25 mg under the tongue. It acts within 15 minutes. Never use it in pregnancy. - Hydralazine 10 to 20 mg, or clonidine 0.1 to 0.2 mg, by mouth.

After any drug, check every 2 to 5 minutes for low pressure. Overdose gives faintness, pressure below baseline and a fast pulse, and the person should then lie flat with the legs raised. A review agrees that the first steps rest on consensus and the drugs on small trials (Krassioukov 2009, abstract). The doses come from one guideline, and the only second source is a case report using nifedipine 10 mg (Vaidyanathan 2018).

Deaths. A 36-year-old tetraplegic's carers missed his night catheterisations, then one catheterisation failed. At 192/109 he was given one dose of nifedipine 10 mg. He waited 40 minutes for help and died of a brain haemorrhage. The coroner found that emergency protocols had not been followed (Vaidyanathan 2018). A 62-year-old died the same way forty years after injury (Dolinak and Balraj 2007, abstract). One of Botswana's ten deaths was from dysreflexia.

Other autonomic traps. A fall in pressure of 20 mmHg or more on sitting up is silent in 41.1 per cent of cases. Fever without infection occurs in about 1 in 20 to 25 acute injuries, but no fever should be assumed to be that (Consortium 2020).

1.7 Skin, burns, bone infection and flaps

NU-01 covers staging, turning intervals and surfaces, and NU-05 the cushion and chair. Five points belong here.

Size of the problem. Pressure ulcers affect 32.4 per cent of people with spinal cord injury worldwide, and 41.2 per cent in Africa (Shiferaw 2020, abstract). Across 35 studies, incidence has fallen only from 33.9 per cent before 2005 to 27.1 per cent since 2016, and of 1,836 ulcers, 28.8 per cent were over the sacrum and coccyx, 12.9 per cent over the sitting bones and 12.3 per cent on the heels (Xu 2025, abstract). Under a pressure injury, the bone is infected in 43 per cent of cases (Jangholi 2024, abstract).

Turning. Guttmann turned every two hours, day and night, on pillow packs (Guttmann 1976, p125). Werner turns every 2 to 3 hours. He holds that lying on the belly is best, starting at 10 minutes once the spine has healed (Werner 1987, ch23). NU-01 reports no difference between two-hourly and four-hourly turning on a good surface (THRIVING library, NU-01, citing Gillespie 2020). But those trials were mostly in older people who can feel. A person who cannot feel gives no warning, so I keep to 2 to 3 hours on an ordinary bed [VERIFY: my inference]. NU-05 gives a lift or lean every 15 to 30 minutes in the chair (THRIVING library, NU-05).

Disagreement in the library. WO-07 recommends tyre-tube rings around bony points in the first week. NU-01 says never to use a hard inflated ring, because it makes a ring of ischaemia (Delano and Strong 1918, via NU-01). Guttmann's pillow packs and Werner's pads bridge a bony point by supporting the flesh on either side. I side with NU-01.

Burns. Guttmann's unit found hot-water bottles the main cause of burns and banned them even with a cover. Patients wore woollen bed socks instead. Other burns came from bath taps, hot drinks in the lap, an open fire and car floors (Guttmann 1976, p485). After the Fall, add the hearth, hot stones and a sun-heated seat [VERIFY: my inference].

Flaps. A deep sore that reaches bone needs debridement, removal of infected bone and a muscle flap. Even then, non-sensate flaps recurred in 34 per cent of 1,794 reconstructions over several years. Flaps that restored feeling recurred in 1 per cent of 75, on very weak evidence (Zwanenburg 2021, abstract). This is district or pre-Fall surgery, so a village must prevent the sore. Where neglect ran its course, Soeharso in Indonesia advised amputating both legs above the knee for fixed deformities (Guttmann 1976, pp39 to 42).

1.8 Pain, spasm, mood, suicide, sex and pregnancy

Pain. Neuropathic pain affects 57 per cent, whatever the age, sex, level, completeness or time since injury (Salehian 2025, abstract). NU-08 covers non-drug relief.

Spasm and contracture. Before Guttmann, spasms were managed with morphia, atropine and hyoscine (Gowland, via Guttmann 1976). A new rise in spasm usually means trouble below the injury: a full bladder, an infection, a sore or an impaction [VERIFY: clinical teaching, not from a source read]. Werner begins gentle range-of-motion exercises of the feet, hands and arms as early as possible, without moving the back until it heals (Werner 1987, ch23). I found no prevalence figure for spasticity or contracture in a source I could read.

Mood and suicide. Depression affects 20 to 30 per cent, and post-traumatic stress 7 to 27 per cent (WHO and ISCoS 2013). In Denmark, 23 of 236 deaths among 888 people were suicides, nearly five times the expected rate. The rate was higher in women, and it doubled between the 1953 to 1971 cohort and the later one. It was nearly twice as high in the marginally disabled as in complete tetraplegics (Hartkopp 1998b, abstract). In the United States the suicide SMR fell from 5.2 among people injured from 1973 to 1979, to 3.7, and then to 3.0 for 1990 to 1999 (Cao 2014, abstract). The brief's figure of 3 to 5 times holds. But the risk is highest in women and the walking wounded, not in the most paralysed. MI-04 covers depression.

Sexuality. Sexual activity can trigger dysreflexia. The guideline gives prophylaxis, such as prazosin 1 mg one to three hours before. It warns that nitrates must never be combined with erection drugs (Consortium 2020). I read nothing on male fertility after injury.

Pregnancy. Women injured at T6 or above are at risk of severe dysreflexia in pregnancy, labour and breastfeeding. It must be told apart from pre-eclampsia, and in labour it rises and falls with the contractions. Labour may go unfelt at T10 or above. The guideline therefore advises weekly cervical checks from 28 weeks, and spinal or epidural anaesthesia in labour (Consortium 2020, section 5). Breastfeeding triggered dysreflexia in 38.9 per cent of women with high injuries (Holmgren 2018, via Consortium 2020). In a small American cohort, 3 of 6 pregnant women with spinal cord injury had urinary infections against none of 12 controls, and their babies were smaller (McLain 2023, abstract).

1.9 Other long paralysis: polio, Guillain-Barré, hemiplegia and the ventilated patient

Copenhagen 1952. About 3,000 polio patients came to Blegdam Hospital from August to December 1952. About 1,250 were paralysed and 345 had bulbar polio. In the first three weeks, 27 of 31 bulbar patients died, 19 of them within three days. The hospital had one tank respirator and six cuirass respirators. After a meeting on 25 August, tracheostomy and hand ventilation with a bag were adopted. Up to 70 patients were bagged at once by about 1,500 students. They worked 6 to 8 hour shifts, 4 to 5 students per patient, about 165,000 hours in all, some for weeks. Mortality was "said to have dropped from ~90% to ~25%" (West 2005). I could not confirm the figure of 40 per cent sometimes quoted [VERIFY], and I could not read Lassen's 1953 paper.

Guillain-Barré. In Australia and New Zealand, a third of 711 patients in intensive care were ventilated. Hospital mortality was 6.9 per cent overall and 14.3 per cent among the ventilated, who stayed almost 40 days (Ancona 2018, abstract). In India, untreated patients did as well in hospital as those given immunoglobulin, with 2 against 2.6 per cent deaths, though ventilators were still available (Kalita 2022, abstract). I found no figure for mortality without ventilation. Bulbar polio before Copenhagen suggests that most patients whose breathing fails would die [VERIFY: inference].

Hemiplegia. Stroke belongs to NU-04 (THRIVING library, NU-04). The bladder, bowel and skin rules here apply to a bedbound hemiplegic. Dysreflexia does not.

The ventilated tetraplegic. The phrenic nerve arises from C3 to C5. A complete injury at C3 or above stops the diaphragm, and one at C4 often weakens it. Botswana's C3 patient with a portable ventilator died before discharge (Löfvenmark 2016). Copenhagen shows that hand ventilation can keep people alive for weeks, at 4 to 5 trained people per patient around the clock. But those patients mostly recovered their breathing. A person with a complete high cervical lesion does not.

1.10 Prognosis by level and the family's hours

Care needed. The Consortium's outcome guideline gives the expected hours of help a day one year after a complete injury (Consortium 1999):

Level	Help per day	Notes
C1 to C3	24 hours	Ventilator. Range 12 to 24
C4	24 hours	Range 16 to 24
C5	16 hours (10 personal, 6 home)	Median reported 23
C6	10 hours (6 personal, 4 home)	Median reported 17
C7 to C8	8 hours (6 personal, 2 home)	Median reported 12
T1 to T9	3 hours home help	Independent in self-care
T10 to L1	2 hours home help	Independent in self-care
L2 to S5	0 to 1 hour	Independent

The 24-hour figures include safety watching. Care needs rise with age.

Who pays the hours. In Botswana, mothers became the carers (Löfvenmark 2016). Among partners of seriously disabled people, 24.8 per cent reported a high caregiver burden (WHO and ISCoS 2013). Strained family carers have 63 per cent higher four-year mortality, and no one should nurse alone for more than 7 days (THRIVING library, NU-01, citing Schulz and Beach 1999). Golding in Jamaica held that a complete cervical lesion not improving by 3 weeks "is best sent home". Indonesia built a home for paraplegics "who otherwise would not survive in their village homes" (Guttmann 1976, pp39 to 42).

The honest prognosis for a tetraplegic after the Fall. In rich countries a person injured at C1 to C4 at the age of 25 can expect about 70 per cent of a normal lifespan (WHO and ISCoS 2013). After the Fall, my inference by level is as follows [VERIFY: inference from the figures above]: - **C3 and above, complete.** Death within hours to days unless someone breathes for the person. Hand ventilation for years is beyond any village. - **C4.** Breathes weakly, needs all care and constant watching. Pneumonia and sores probably end life within months to a few years. - **C5 to C6.** Needs 10 to 16 hours of help a day. Years of life if the family keeps a rota, catheterises on time and knows dysreflexia, months if not. - **C7 to C8.** Much self-care with adapted hands, prospects close to a high paraplegic. - **Paraplegic.** Independent within a year with a chair, cushion and self-catheterisation, and able to work. On the Botswana figures most will be alive at ten years, and the sore is the main threat.

2. Evidence grades

Practice	Tradition says	Record shows	Grade
Regular turning of the insensate	Guttmann's law	Survival transformed from 1944, no trial	B
A two-hour interval specifically	Guttmann's law	No trial in spinal injury, 2 = 4 hours in others (NU-01)	C
Intermittent over indwelling catheter	Guttmann, Lapides	Complications 27 against 54 per cent, stones 2 against 7 to 11	B
Clean over sterile technique	Lapides	RR 1.20, one small trial	B
Reusing a cleaned catheter	Household practice	RR 0.98, low certainty, Chiang Mai kidneys normal	C
Boiling a PVC catheter	Werner, 15 minutes	Kills bacteria, damages surface, in vitro	C

Practice	Tradition says	Record shows	Grade
Detergent then dilute hypochlorite	Milton method	Kills bacteria without damage, in vitro	C
Volumes under 500 ml	Lapides' theory	Guidelines agree, no trial	C
Credé's manoeuvre long term	Village default	Hydronephrosis 35 per cent over 20 years	X
Digital rectal stimulation	Werner, guidelines	33 weak studies	C
Sit up, loosen, empty bladder in dysreflexia	Guidelines	Consensus, deaths when missed	B
Nifedipine or nitrate for dysreflexia	Guidelines	Small studies, level 2	C
Hot-water bottle on numb skin	Comfort	Main cause of burns at Stoke Mandeville	X
Ring around a bony point	WO-07	Ring of ischaemia (NU-01)	X
Family training with consumables	Botswana, Sri Lanka	Before-and-after, 85 per cent to none	B

3. Means ledger

Rung	What it can do	What it changes
Hands and knowledge	Turning, prone lying, skin checks, sitting up in dysreflexia, finger bowel care, joint exercises, a rota	Most of the skin and bowel effect, and the first steps of dysreflexia
Hearth	Boiled water, soap, a pot for catheters, clean jars and cloths, oil for the bowel, fluid, woollen socks	Clean catheterisation and the burn rules
Garden and still	Pillow packs, sheepskin or chaff pallet, transfer board, commode, wooden chair and cushion (NU-05)	Mobility and the sitting skin
Village dispensary (300)	Catheters, lubricant, lidocaine jelly, a cuff, nitrate or nifedipine, a trained visitor	Makes the regime a standard, catches sores and dysreflexia early
District infirmary (3,000)	Antibiotics, debridement, removal of infected bone, beds for failed families	Saves the infected kidney and the deep sore
Hospital before the Fall	Ventilators, flaps, urodynamics, bladder surgery, epidural in labour	The ventilated tetraplegic and the reconstructed sore, little for the daily regime

As with nursing generally (NU-01), most of the effect sits on the lowest rungs. The high cervical lesion and the deep infected sore are the exceptions.

4. Harm test

Catheter trauma. Caused by forcing the catheter, a dry catheter, too large a size, or a stiff, encrusted old catheter. Signs: bleeding, pain or dysreflexia during insertion, a stricture that makes passing hard, epididymitis (Kovindha

2004). What to do: lubricate generously, twist gently and never force. Use 12 to 14 F for adults [VERIFY: Lapides used 14 F, Werner gives 14 to 16 F for a large child]. Replace a catheter that has turned stiff or rough.

Overdistension. Caused by missed catheterisations, at night or when a carer is absent. Signs: leaking between catheterisations, volumes over 500 ml, dysreflexia, infection. What to do: shorten the interval and never miss the bedtime one.

Dysreflexia missed or mistreated. Caused by a carer who has never heard of it, or who lays the person flat. What to do: Protocol 3. The opposite harm is giving a drug when a low baseline has been misread as a crisis, or giving a nitrate after an erection drug, which can cause collapse.

Burns. Caused by hot-water bottles, bath water, the hearth or a hot cup in the lap. Signs: a blister on numb skin at the evening check. What to do: Protocol 5.

Bowel injury. Caused by rough fingers, long nails, routine enemas or strong laxatives (Werner 1987). Signs: bright red blood, or dysreflexia during bowel care. What to do: short nails, plenty of oil or jelly, and lidocaine jelly for anyone prone to dysreflexia.

Credé and straining. Damage the kidneys over years (Chang 2000). Use a catheter instead.

The indwelling catheter as a convenience. It saves the carer time and costs the patient stones and infections (Bartel 2014, Weld and Dmochowski 2000). If one is used, change it every 2 weeks or sooner with infection, keep the bag below the bladder and avoid kinks (Werner 1987).

The family's collapse. Caused by one carer doing everything. Signs: missed catheterisations, new sores, the carer's illness, despair or anger. What to do: Protocol 6. The Botswana deaths at home show where neglect happens.

5. Red flags

1. **Sudden pounding headache, flushing or sweating in an injury at T6 or above.** Sit the person up and go through Protocol 3 now.
2. **No urine, or a catheter that will not pass.** Dysreflexia and kidney damage follow within hours.
3. **Fever with shaking, loin pain or confusion.** Probable pyelonephritis. Antibiotics as in IN-14.
4. **A black, deep or foul sore, or one with bone or a tunnel in it.** Probable bone infection. District help.
5. **Breathlessness, a weak cough or fever in a tetraplegic.** Pneumonia is the leading killer. Sit up, assisted cough, district help.
6. **A swollen, hot leg.** Clot, fracture of thin bone or infection [VERIFY: not from a source read].
7. **Talk of being better off dead, or hoarding pills.** Suicide risk (MI-04).
8. **The carer stops coming or falls ill.** The patient is at risk within a day. Protocol 6.

6. The case against

Guttmann's figures are repeated without a source. The 80 per cent is a 1937 estimate about soldiers. Stoke Mandeville's survival tables come from an OCR copy of a 1976 book, and its patients were selected. The WHO repeats the figure with no time frame. The pre-1944 record should be told as weeks to three years, not as a number.

Modern data come from well-resourced centres. The SMRs, the lifespans and the Cochrane trials all come from people with antibiotics, urologists and spare catheters. Even Botswana had a funded unit and a wound clinic. A household after the Fall will do worse.

Clean catheterisation may be less safe without antibiotics. Lapides' patients had antibiotics in reserve. Ten of Kovindha's 28 men had had a fever in the past year. Botswana's infections rose when catheters were reused at home. The claim that frequency matters more than sterility comes from settings where a bad infection can still be treated.

Reflex voiding has defenders. It caused the fewest stones in the Swiss series (Bartel 2014) and spares a lifetime of catheterisation. Take a tetraplegic without hand function in a household short of labour. A reflex bladder emptying into a condom sheath may be the realistic choice for him, despite the risk to the kidneys.

Reuse without boiling. Lapides told patients to catheterise on time even unwashed, and Cochrane finds no clear harm in reuse. Boiling every catheter may waste fuel and catheters, but the evidence is thin either way.

Dysreflexia mistaken for a headache, and the reverse. The guideline's steps are consensus, not trial results, and the drugs cause low blood pressure. A household without a cuff must work on signs alone, and will sometimes treat a migraine.

The family's burden is hidden. Outcome studies count the patient's sores and deaths, not the mother's back, sleep or marriage. A regime that keeps a C5 tetraplegic alive for twenty years may cost one woman her health. The book should say so.

7. Ten-line summary

1. Before 1944, complete paraplegics died within weeks to three years, of kidney sepsis and pressure sores.
2. "80 per cent" is a 1937 estimate for First World War soldiers, not a measured civilian rate.
3. Guttmann's turning and no-touch catheterisation let most survive and work.
4. Lapides made catheterisation a household skill: clean, frequent, gentle, never overfilled.
5. Clean is as good as sterile, and reused as good as single-use, in the trials that exist.
6. Indwelling catheters and Credé's manoeuvre cause the most stones and kidney damage.
7. Dysreflexia above T6 kills, is missed as a headache, and is treated first by sitting up and emptying the bladder.
8. Pressure sores remain the main killer at home over ten years, and numb skin burns easily.
9. Suicide runs at 3 to 5 times the general rate, highest in women and the least disabled.
10. A household with a rota can keep a paraplegic. A high tetraplegic takes its whole labour. A ventilated one cannot be kept.

8. Open questions

1. How did intermittent catheterisation fare with no antibiotic in reserve? No such series was found.
2. Which catheter materials survive repeated boiling, and for how long? Wilks tested only PVC.
3. Can catheters be improvised from salvaged material, and what do they do to the urethra?
4. What is the mortality of Guillain-Barré and bulbar polio where no ventilator exists?
5. How common are spasticity and contracture in long-term injury in poor settings?
6. What happens to male erection and fertility, and what can be done without equipment?
7. What did the families in Botswana or Sri Lanka spend in hours, and what did it cost them?
8. Is reflex voiding into a sheath safer than an indwelling catheter for a tetraplegic in a small household?

9. Sources to read in full

1. Guttmann 1976, the historical, bladder and statistics chapters, in a clean copy rather than OCR.
2. Lapides et al. 1972, the original paper and its patient series.
3. Prieto et al. 2021, the full Cochrane review, for the reuse and cleaning trials.
4. The Consortium for Spinal Cord Medicine guidelines on bowel and on bladder management, which I did not read.
5. Werner 1987, Disabled Village Children, chapters 23 to 25 in full.
6. Löfvenmark 2015 in Spinal Cord, the primary Botswana paper, read here only through the thesis.
7. Lassen 1953 in the Lancet, the first account of Copenhagen.
8. Oderud 2014 on Zimbabwe, read here only through WO-07.

10. At the bedside after the Fall

The household. A paraplegic needs a firm bed reachable from both sides, pillow packs or a chaff pallet, a cushion and chair (NU-05), two or three catheters, a clean jar, soap, lubricant, a pot, woollen socks and a slate for the chart. Within months the person does his own catheterisation, bowel care and mirror skin checks, and the family turns him at night and keeps him from the fire. A tetraplegic needs all of it done by others. The first failure to expect is the missed night catheterisation, the second the sacral sore after a week of fever.

The village of 300. At any time it may hold one or two people with long-term paralysis from injury, polio, stroke or Guillain-Barré [VERIFY: my estimate]. It needs one trained person who teaches families Protocols 1 to 5, visits every paralysed person weekly, and holds the catheters, lidocaine jelly, a blood-pressure cuff and the dysreflexia drug. Every household with a person injured at T6 or above keeps the dysreflexia card on the wall.

The district of 3,000. Antibiotics for pyelonephritis, surgery for deep sores and infected bone, a few beds for people whose families have failed, and a school for new families in their first month. The failure to expect is the sore that comes back after discharge.

Decisions only the owner can make. - [OWNER] Whether the village must supply carers to a family that cannot cover the hours. - [OWNER] Whether a ventilator-dependent tetraplegic is hand-ventilated, by whom, for how long, and who decides to stop. - [OWNER] Whether catheters are held as a village stock, how many each patient may keep, and whether reuse after washing or boiling is the rule. - [OWNER] Who may hold and give nifedipine, nitrate ointment or captopril. - [OWNER] Whether an indwelling catheter is allowed for a tetraplegic whose family cannot catheterise six times a day.

11. Protocols

Protocol 1. The first year with a paraplegic: day and week

Each day 1. On waking: catheterise and record the volume. Check the skin from sacrum to heels, by mirror or a carer's eyes. 2. After breakfast: the bowel programme (Protocol 4), daily or every other day at the same hour. 3. Mid-morning: catheterise. Move every joint below the injury through its full range, 10 times each [VERIFY: repetitions not from a source read]. 4. In the chair: lift or lean every 15 to 30 minutes (NU-05). In the first weeks no more than 2 hours at a time, building up as the skin allows [VERIFY: my inference]. 5. Midday and mid-afternoon: catheterise. 6. Evening: catheterise. Check the skin again, and the feet for blisters, burns and ingrowing nails. 7. Bedtime: catheterise. Never miss this one. 8. Night: turn every 2 to 3 hours, or lie prone. Catheterise once in the night if the bedtime volume was over 400 ml. 9. Fluid: about 1.5 to 2.5 litres spread through the day, so that each catheterisation finds 300 to 500 ml [VERIFY: my arithmetic from 4 to 6 catheterisations under 500 ml]. Drink less in the evening. 10. From the second month: work, sport or a set task every day (Guttmann 1976).

Each week 1. A visit from the village's trained person to check the skin, the catheters, the chart and the person's mood. Ask about thoughts of death (MI-04). 2. Wash all catheters and the jar thoroughly, and boil or soak them by the village rule (Protocol 2). 3. Trim the nails on hands and feet. 4. Count missed catheterisations and volumes over 500 ml, and change the schedule if needed.

Tolerances. Every volume under 500 ml. No interval over 6 hours, day or night. A red patch that does not fade carries no weight until it does (NU-01 gives the blanch test).

Protocol 2. Clean intermittent catheterisation with a washed or boiled catheter

1. Wash hands with soap and water, the carer's as well as the patient's.
2. Wash the genitals with soap and water, retracting the foreskin, or front to back between the labia.
3. Lubricate the tip with water-soluble jelly, never oil or Vaseline (Werner 1987). Use lidocaine jelly if the person is prone to dysreflexia.

4. For men, hold the penis upward and slide the catheter in gently. At the sphincter, wait, twist gently, and never force it. For women, find the opening by touch or with a mirror.
5. Drain into a measured jar. Press gently on the lower belly at the end, only while the catheter is in. Withdraw it slowly.
6. Write the time and volume on the slate.
7. Wash the catheter inside and out with soap and clean water, rinse, shake it dry, and store it in a clean covered jar or towel.
8. By the village rule, boil rubber or silicone catheters for 15 minutes (Werner 1987). Wash PVC catheters with detergent, then soak them in diluted Milton, 0.6 per cent hypochlorite (Wilks 2020) [VERIFY: soak time not recorded], and rinse with boiled water.
9. Replace a catheter that is stiff, cracked, rough or discoloured.
10. The next catheterisation is in 6 hours if the volume was 400 ml or less, in 4 hours if it was 401 to 500 ml, and in 3 hours if it was over 500 (Alberta Health Services). Never wait longer than 6 hours.
11. Send for help if there is no urine, the catheter will not pass, bleeding does not stop, there is fever with shaking, or dysreflexia starts.

Protocol 3. The dysreflexia card (for injuries at T6 and above)

Signs. Sudden pounding headache. Red, sweating face and neck. Goose pimples. Stuffy nose. Blurred vision. Slow pulse. Pressure 20 mmHg or more above the person's usual figure, which is often only 90 to 110.

Do this now, in order. 1. Sit the person up with the legs hanging down. Do not lay the person flat. 2. Loosen everything: belt, trousers, binder, leg-bag straps, shoes, stockings. 3. Measure the pressure and pulse every 1 to 2 minutes, if a cuff exists. 4. Bladder. If a catheter is in, straighten any kinks and check the bag. If it is blocked, flush it with 10 ml of cooled boiled water or replace it. If there is no catheter, pass one now with lidocaine jelly. 5. If the signs persist, the bowel. Put lidocaine jelly on a gloved finger, wait 2 minutes, add more jelly, then feel for stool and remove it gently. If the headache worsens, stop, add jelly, wait 20 minutes and try again (Werner 1987). 6. If the signs persist, look for anything else: tight clothes or shoes, a sore, a burn, an ingrowing toenail, labour, a period. 7. If systolic pressure stays at or above 150, and the trained person holds a drug, give one of these: - Nitroglycerin 2 per cent ointment, 0.5 to 2 inches on the chest, wiped off when the pressure falls. Not within 24 hours of sildenafil. - Nifedipine 10 mg by mouth. - Captopril 25 mg under the tongue, never in pregnancy (Consortium 2020). 8. Afterwards, check every 2 to 5 minutes for low pressure. If the person turns faint, lay them flat and raise the legs. 9. Send for district help if the signs have not settled within about 30 minutes, or no cause is found [VERIFY: interval my inference]. 10. Write down the time, the cause, the readings and what worked.

Protocol 4. The bowel programme

1. Same hour every day or every other day, after breakfast or a hot drink (Werner 1987).
2. Sit on a commode or pot once the spine has healed. Otherwise lie on the left side on old cloth.
3. Reflex bowel. An optional suppository goes 2 cm in against the wall, then wait 5 to 10 minutes. A gloved, oiled finger goes 2 cm in and makes gentle circles for about 1 minute. Repeat 3 or 4 times, until no more stool is felt.
4. Limp bowel. Remove stool with a gloved, oiled finger after each meal, or at least once daily.
5. Put lidocaine jelly in first if the bowel pulls back or the person is prone to dysreflexia.
6. Clean the skin, check the skin around the anus, and wash hands.
7. Diet: water, bran, whole grain, beans, vegetables, fruit. Activity every day.
8. No routine enemas or strong laxatives. Never give anti-diarrhoeal medicine for leakage.
9. If there is no result for 3 days, check for impaction [VERIFY: threshold my inference]. NU-01 Protocol 5 gives the enema for failure.

Protocol 5. Skin and burns of a person who cannot feel

1. Look at the sacrum, sitting bones, hips, heels, ankles, knees and elbows morning and evening, by mirror or carer.
2. In bed, turn every 2 to 3 hours. Once the spine has healed, lie prone, starting at 10 minutes (Werner 1987).
3. Support the body on pillow packs that bridge a bony point. No rings.
4. In the chair, use a proper cushion and lift or lean every 15 to 30 minutes (NU-05).
5. Put no weight at all on a red patch until it fades.
6. Never use a hot-water bottle, even wrapped (Guttmann 1976). Use woollen socks for cold feet.
7. Test bath water with a hand that can feel. No hot drinks in the lap. Keep paralysed limbs away from the hearth.
8. Clean and dry the skin after every bowel action or leak.
9. Send a sore that is deep, black, foul, tunnelling or showing bone to the district.

Protocol 6. The carers' rota and the hours

1. Count the hours from the table in 1.10: 3 a day for a thoracic paraplegic, 8 at C7 to C8, 10 at C6, 16 at C5, 24 at C4 and above.
2. Never one carer alone. Name two carers and a reserve for every paralysed person. No one nurses alone for more than 7 days (NU-01).
3. For a tetraplegic, cover the night. The turns and the bedtime catheterisation are where carers fail.
4. Every carer learns Protocols 2 to 5, and the trained person checks them once before they work alone.
5. Each week, the trained person asks the main carer about their sleep, food and coping.
6. [OWNER] How many households share the rota for a tetraplegic, and what they receive in return.
7. If a carer falls ill, the reserve starts that day.

12. Numbers to carry

1. **T6.** Injuries at or above it can cause dysreflexia. Sit up, loosen, empty the bladder.
2. **20 mmHg.** A rise above the usual pressure, which is often only 90 to 110.
3. **500 ml and 6 hours.** The bladder ceiling and the longest interval.
4. **4 to 6.** Catheterisations a day.
5. **15 minutes.** Boiling time for a catheter whose material tolerates it.
6. **2 to 3 hours.** The turn for a person who cannot feel.
7. **Never.** A hot-water bottle on numb skin.
8. **27 against 54 per cent.** Long-term complications, intermittent against indwelling catheters.
9. **85 per cent, then none, then 26.** Botswana's one-year deaths before its unit, two-year deaths after, ten-year deaths after.
10. **3 to 5 times.** The suicide rate after spinal injury.
11. **24, 16, 10, 8, 3.** Hours of help a day at C4, C5, C6, C7 and thoracic levels.

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