

# End of Life Issues in Halacha: DNR, Feeding Tubes, and Palliative Care

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I approach this task with trepidation. What right do I have to don the mantle of spokesman? I, in fact, claim none and therefore let no one read into my words the language of *psak halacha* – a language reserved for the ears of the individual questioner on these complex and often intimately personal issues. These life and death medical decisions are highly fact-sensitive and Rabbinic authorities together with the physicians in each case, must make a careful evaluation of a multiplicity of factors.

There is no area of human concern which Judaism fails to address. The very word *halacha* is derived from the verb “*halach*”, meaning to walk. *Halacha* is the means of regulating man’s journey through life.

I find myself traveling in a world of secular medical ethics. Many in the secular world have continually told me that there is little role for the religious voice in medical ethics. We who represent a Faith-tradition guided by a Torah of instruction given to us by the Creator of the Universe have a responsibility to ignore such requests and be ambassadors for Torah truths. Indeed, foremost among the credentials of Judaism is the exclusive witnessing of the most momentous event in the history of mankind: Almighty God's revelation at Sinai. It was there established for all time that His Word is the only source for a moral universe. We were, after all, the originators, the pioneers of moral law. Whatever other Faiths – certainly Monotheistic Faiths – have to say, they have in one form or another derived from us, albeit often with grave distortion. The Torah is the source of absolute truth, which alone can serve to guide man and for the Torah-true Jew the resolution of medical ethics issues must be viewed through the lens of *halacha*, not through personal predilection as molded by contemporary culture.

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The Torah says that when *Hashem* finished creating the world, He examined His creation, realized that death was to be a feature in it, for so He had decided, and He declared that the creation was *tov me'od*, very good.<sup>1</sup> And yet, in our society, death is very often perceived as an evil which should be postponed for as long as possible, and our medical professionals work to defeat death. The Jewish attitude on death has often been described as “death-defying” because we emphasize the sanctity of life; the need to preserve life even when it entails violating religious prohibitions.

Although it is true that Judaism is somewhat death-defying, this is only partially true as can be illustrated by an interesting comment made by Rabbi Dovid Ibn Zimra.<sup>2</sup> He discusses the question as to how Adom could follow Chava's advice to sin after he had been treated so well by *Hashem*, and he gives a fascinating answer: When *Hashem* told Adom not to eat from the *eitz ha-da'at tov v'ra* – the Tree of Knowledge, good and evil, he threatened the punishment of death. This says, Radbaz, referred to an essential death, not a natural death. Adom realized that his natural death was inevitable for there was no reason for him to have thought himself immortal. He knew that there was an *eitz ha-chaim* in the garden but he did not know where it was. The snake's argument to Chava, which she conveyed to her husband, was that by eating of the *eitz ha-da'at* they could be like *Hashem*; eternal, understanding the difference between good and evil. Adom believed that if he ate from this tree he would gain the information as to where the *eitz ha-chaim* was. He could then eat from it and serve *Hashem* eternally like the angels. He reasoned that it would be satisfactory to transgress one sin and then repent, since in the final analysis, he would better be able to serve *Hashem* if he was immortal.

To seek immortality, as Adom did, may strike us as being a pious act, but it was rejected outright by *Hashem*. If He had wanted us to be deathless like the angels, He would have created us that way.

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<sup>1</sup> *Bereishit Rabbah*, 9:5.

<sup>2</sup> *Shut. Radbaz* 256.

Most of us would like to die a quiet, dignified death. Anyone who works in a hospital knows that this reasonable wish is almost never fulfilled. The last rites of respirators, dialysis machines, nasogastric and gastrostomy tubes along with cardiopulmonary resuscitation and the 'nth round of chemotherapy may have their place, but they have changed death into a mechanized spectacle in which no sane person would like to be the main actor.

The *halachic*/ethical difficulties surrounding these issues arise from the tension between the obligation to save life and avoid the prohibition of *retzicha*, murder, while simultaneously not allowing human suffering. As life's only certainty, death is never more than a heartbeat away. Decisions about the end of life, such as whether to pursue aggressive care or withhold or withdraw life-sustaining treatments, require consideration of clinical factors in the context of other values.

Within the *halachic* tradition, the statement of a defendant is given unqualified authority even when contrary to his self-interest. Judgment is rendered against a person who accepts liability even if his confession is contradicted by the testimony of unimpeachable witnesses. This is so, however, only in *dinei mamonot*, monetary matters. In criminal cases, the *halachic* laws of evidence say that not only can an accused not be forced to testify against himself, but even should he confess, his testimony is ignored. Rabbi Dovid Ibn Zimra<sup>3</sup> explains a fundamental principle of Torah ethics by explaining why in matters where corporal or capital punishment can be meted out one's testimony is ignored. In monetary matters there is no concern since a person may do with his money as he wishes. Self-incrimination that might lead to corporal or capital punishment is not allowed because "man's life is not his possession, but the possession of the Almighty". Since man lacks proprietary rights over his body he may not do anything to harm himself.

While it is certainly true that every moment of life is intrinsically valuable and that preservation of life, even for a moment, is important enough to violate all the mitzvot, save three, this not to say that life must be preserved in any and all circumstances.<sup>4</sup> Patients near the end of life who may be suffering intractable pain are entitled to refuse treatment that is clearly

<sup>3</sup> *Mishne Torah, Sanhedrin* 18:6.

<sup>4</sup> See *K'rainia D'Iggarta* p. 190.

medically futile or entails great suffering. Intractable pain without hope of recovery is far too burdensome to demand using modern medicine to prolong the dying process and may very well be beyond the Torah's license of *verapo yerape*.

While the physician is uniquely qualified to diagnose illness and to access the probable prognosis and avenues of treatment, the decision to treat or not to treat is a value judgment, not a medical decision and for observant Jews involves consultation with *halachic* experts.

Let me make some comments about palliative medicine, CPR vs. DNR and artificial nutrition and hydration.

The Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment ("SUPPORT"),<sup>5</sup> an empirical study conducted over a four-year period that involved 9,105 adult patients suffering from life-threatening illnesses and five university hospitals from around the country, determined that half of the study-patients who were conscious in their final days of life suffered severe pain. While palliation can and should always be an integral part of the entire spectrum of patient care, it stands alone as the care for the patient who has been diagnosed with an *irreversibly deteriorating or terminal* condition and for whom *curative treatment* is no longer the goal of care.

There are many misconceptions of the role that palliative care should play in a treatment plan. Because of its association with end-of-life care, palliative treatment is often viewed as just that. While many physicians have begun to recognize the need for the administration of palliative care throughout all stages of a painful medical condition, many are still of the belief that palliation is a recognition of failure – that it is an alternative, rather than a complement, to aggressive curative treatment.

The end stages of chronic, progressive diseases bring a host of difficult symptoms and causes of suffering. There are disease-mediated symptoms, such as pain, dyspnea, fatigue, and loss of mobility, and there are the accompanying emotional states, such as depression, anxiety, and a sense of uselessness. Of the many symptoms experienced by those at the end of life, pain is one of the most common and most feared. Pain is often under-treated, but

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<sup>5</sup> See 274 *JAMA* 1591 (1995).

with careful assessment and a comprehensive plan of care that addresses the various aspects of the patient's needs, pain can be controlled in the vast majority of cases.

All the members of a palliative care team play important roles in comprehensive pain management. Both physicians' and nurses' roles begin with assessment and continue throughout the development of a plan of care and its implementation. Clinical pharmacists, social workers, and chaplains can often provide important essentials in helping patients optimize their quality of life, heal relationships, complete unfinished business, and find peace as they approach death.

Pain management can be accomplished through a variety of adjuvant therapies including palliative radiotherapy, acupuncture, hypnosis, and, most commonly, through the giving of drugs; in cases that involve severe pain, the administration of opioids – pain medications, like morphine, derived from opium, or synthesized to behave like opium derivatives.

Pain can usually be defined as nociceptive or neuropathic. Patients in the terminal stage of an illness may often experience different mechanisms of pain operating simultaneously. It is important to differentiate among different types of pain because the type of treatment is largely dictated by the pain mechanism and its original source.<sup>6</sup> Nociceptive pain is typically the result of a musculoskeletal or visceral injury or disease and includes somatic and visceral mechanisms.<sup>7</sup> Neuropathic pain is caused by lesions or physiologic changes in the nervous system, and it is characterized by hypersensitivity either in the damaged area or in the surrounding normal tissue.<sup>8</sup>

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<sup>6</sup> In some conditions, pain appears to be caused by a complex mix of nociceptive and neuropathic factors. In these cases, an initial nervous system dysfunction or injury may trigger the neural release of inflammatory mediators and subsequent neurogenic inflammation.

<sup>7</sup> Primary afferent neurons receive nociceptive input from peripheral nociceptors. Nociceptors are activated in response to noxious stimuli, which can be thermal, chemical, or mechanical in character. Somatic pain is characterized by aching, throbbing, stabbing, and/or a sensation of pressure. Its source is skin, muscle, or bone. Visceral pain is characterized by gnawing, cramping, aching, sharp, and/or stabbing sensations, and its source is the internal organs. Nociceptive pain usually resolves when the initial tissue damage heals, and tends to respond well to treatment with anti-inflammatory agents and opioids.

<sup>8</sup> The pain is often triggered by an injury or disease, but there may not be demonstrable damage to the nervous system other than the subjectively reported

There is significant evidence that inadequate pain relief hastens death by increasing physiologic stress, potentially diminishing immunocompetence, reducing mobility, increasing proclivities toward pneumonia and thromboembolism, and increasing the work of breathing and myocardial oxygen requirements. Pain may lead to spiritual despondency and significant decrease in emotional well-being because the individual's quality of life is impaired.

The Talmud<sup>9</sup> cites the verse “*And he shall surely cause him to be healed*” as the authority establishing permission to engage in the practice of medicine. Rambam basing himself on the interpretation of the Sifrei,<sup>10</sup> quotes “and you shall restore it to him” as the source of this permission and obligation. Ramban<sup>11</sup> says that in addition to treating illness, the obligation of the physician to treat a suffering patient is part of the mitzvah of “and you shall love your neighbor as yourself”. Rabbi Dovid ibn Zimra<sup>12</sup> writes that one is obligated to come to the assistance of an individual in distress due to being weighed down by a burden because of the obligation to restore “the loss of his body” as well as the commandment “you shall not stand idly by the blood of your fellow”. Relief of pain and suffering is thus mandated not only by the commandment to restore that which has been lost but also by the admonition not to “stand idly by the blood of your fellow”.

Given the above, there exists an affirmative obligation to utilize opioid analgesics and other necessary medication in an attempt to relieve a patient's pain and suffering. Judaism believes that everything in creation was designed for a purpose. There is every reason to accept that these types of drugs were given to mankind for the specific purpose of controlling pain and discomfort.

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sensory disturbance of pain. The pain frequently has qualities of burning, numbness, tingling, touch sensitivity, sharp and shooting sensations (lancinating pain), or electric shocks. Persistent allodynia, which is pain resulting from a nonpainful stimulus, such as a light touch, is a common characteristic of neuropathic pain. Neuropathic pain tends to persist long after the initiating event has resolved. Neural inflammation can change the actual structure of neural organization so that stimuli that were once interpreted as touch become perceived as painful. Typical examples include painful diabetic neuropathy, HIV/AIDS neuropathy, postherpetic neuralgia, and cancer-induced as well as post-treatment cancer pain syndromes, such as postmastectomy syndrome and radiation and chemotherapy neuropathies.

<sup>9</sup> *Bava Kama* 85a.

<sup>10</sup> Commentary on Mishna, *Nedraim* 4:4; *Mishneh Torah*, *Nedarim* 6:8.

<sup>11</sup> *Torat ha-Adam* in *Kol Kitvei* 2:48.

<sup>12</sup> *Shut. Radbaz* 2:628.

Since *halacha* is concerned about the danger of actively hastening a person's death, many ethically-minded physicians are worried that using opioid analgesics may do just that. But the medical literature has demonstrated that patients receiving chronic opioid therapy for the relief of pain develop tolerance to the respiratory depressant effects of these medications within a few days of initiating therapy.<sup>13</sup> Furthermore, studies demonstrate that when patients are on chronic opioid analgesics for pain, dosage increases of 50% or more are needed to treat breathlessness, another common symptom near the end of life. Additionally, such patients, when given opioids to treat their breathlessness, have improvement in symptoms and do not experience respiratory compromise or arrest.<sup>14</sup> Increasing the dose of morphine in the last week of life because of increased pain does not shorten patient survival.<sup>15</sup>

Failings in physician education have led to a phenomenon known as opiophobia – excessive concern about the addictive potential and side effects of narcotics. From early in their medical training, physicians are taught that narcotics cause respiratory depression, cardiovascular collapse and depressed levels of consciousness. This is completely accurate. However, it is necessary to differentiate those who turn to morphine for pain relief from those who do so for recreational purposes. The likelihood of these side effects occurring when morphine is used for the relief of pain is low,<sup>16</sup> and when these side effects do manifest, they are often easy to control. In contrast to pain-free morphine users, a patient with cancer pain can tolerate enormous doses of morphine without a

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<sup>13</sup> Hanks G, Chernys N, "Opioid analgesic therapy". In: Doyle D, Hanks G, McDonald N (eds), *Oxford Textbook of Palliative Medicine*, 2<sup>nd</sup> ed. New York: Oxford University Press, 2001, pp. 331–355.

<sup>14</sup> Weinreb NJ, Kinzbrunner BM, Clark M, "Pain management", In: Kinzbrunner BM, Weinreb NJ, Policzer J (eds), *Twenty Common Problems in End-of-life Care*. New York: McGraw Hill, 2001, pp. 91–145; Bruera E, MacEachern T, Ripamoni C, Hanson J, "Subcutaneous morphine for dyspnea in cancer patients", *Ann Intern Med* 1993;119:906–907; Bruera E, Macmillan K, Pither J, MacDonald RN, "Effects of morphine on the dyspnea of terminally ill cancer patients", *J Pain Symptom Manage* 1990;5:341–344.

<sup>15</sup> Bedell SE, Delbanco TL, Cook EF, Epstein FH, "Survival after cardiopulmonary resuscitation in the hospital", *N Engl J Med* 1983;309:569–576; Murphy DJ, Murray AM, Robinson BE, Campion EW, "Outcomes of cardiopulmonary resuscitation in the elderly", *Ann Intern Med* 1989;111:199–205.

<sup>16</sup> See Pellegrino, "Emerging Ethical Issues in Palliative Care", 29 *JAMA* 1521 (1998).

negative effect on respiratory effort.<sup>17</sup> Therefore, there is no evidence that treating patients with the necessary therapeutic doses of opioid analgesic to relieve pain results in the hastening of death, and Jewish law fully supports appropriate treatment for the relief of pain without concern for respiratory compromise. Having been involved with this issue for many years and speaking with experts in palliative medicine, I have never heard of a single case of a death of a patient as a result of pain palliation – unless the death was intended or the medication not titrated properly.

The rule with regard to how much money a person must expend in order to avoid transgression is that a person is obligated to expend 20% of his net worth, but not more, in order to fulfill, or to avoid transgressing, a *Mitzvat Aseh* but is obligated to expend even *kol mamono* – his entire fortune in order to avoid transgressing a *Lo Ta'aseh*.<sup>18</sup> Many *Poskim* are of the opinion that a person is not obligated to use *kol mamono* – his entire fortune to preserve life.<sup>19</sup> A person in intractable pain would likely be willing to surrender his entire fortune in order to rid himself of pain. Since a person need not spend more than his entire fortune in order to preserve his life, he need not accept pain either. As recorded in Daniel, Nevuchadnetzar of Babylonia constructed a golden statue and gave Shadrach (Chananya), Maishach (Mishael) and Avaid (Azariah) an ultimatum: bow to it or be thrown into a fiery furnace. The Talmud<sup>20</sup> declares that had they been subjected to torture rather than immediate death, they would have succumbed. *Shita Mekubetzet* quotes an anonymous source who says that there is no obligation to sacrifice more than one's life and since sustained torture (and intractable pain) represents a sacrifice greater than martyrdom, no requirement exists to do so.

It is fundamental to our understanding of the role of mankind that we utilize the “laws of medicine” (*refu'ah beduka u'menusa*) for

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<sup>17</sup> See Hugh McIntosh, "Cancer Pain Management Receives Increased Attention", 83 *J. Nat'l Cancer Inst.* pp. 748-749 (1991) (“Respiratory depression, even with chronic morphine use, is a rare problem.”); Henry McQuay, "Opioids in Pain Management", 353 *Lancet* 2229, 2229 (1999) (“respiratory depression is kept to a minimum when appropriate regular doses of opioid are given to patients with chronic pain”). One explanation for this is that pain stimulates the respiratory center, thereby serving to counterbalance the respiratory depressant potential of the opioid.

<sup>18</sup> Rema *O.C.* 656:1; Rema *Y.D.* 157:1.

<sup>19</sup> e.g., *Chiddushei Rabbe Akiva Eger Y.D.* 157:1; *Shut. Chavat Yair* 134.

<sup>20</sup> *Ketubot* 33b.



the benefit of mankind.<sup>21</sup> (This is true on Shabbat as well where *pikuach nefesh*, life-threatening situations allow and mandate overriding otherwise prohibited activities. Such permission exists only with regard to known therapeutic efficacy based on “natural law” not the supernatural or the miraculous).<sup>22</sup> Intractable pain without hope of cure is a reason for non-treatment even when treatment is easily available. The benefits to be achieved are not worth the risk since the price to be paid is an unacceptable pain-filled life. As Rabbi Moshe Sternbuch<sup>23</sup> succinctly says: “We do not find any obligation for a person in intractable pain to remain so even though there will be no improvement in his condition.” Of course, if a person chooses to continue a treatment that prolongs his pain, he is entitled the full support of the health-care providers taking care of him.<sup>24</sup>

Cardiopulmonary resuscitation, originally developed to help people who experience a cardiac arrest from heart attack, drowning or electrocution, has become the universal standard of practice.

There have been many developments in the understanding of CPR (Cardiopulmonary resuscitation) since it was first described as a beneficial and life-saving treatment for cardiac arrest more than 40 years ago. It is only in the last decade or so that the poor outcomes of CPR in certain patient populations have been recognized. This has resulted in the acceptance of the DNR order, which, as an advance directive, allows patients or families to forgo future attempts at CPR. This process is now embedded in the concept of respecting patient autonomy by allowing competent individuals or their surrogates to refuse the potentially lifesaving therapy of CPR.

Cardiopulmonary resuscitation, when successful, restores heart beat and breathing. It is assumed that by restoring cardiac and pulmonary function it may be possible to prevent what would otherwise be imminent death. The process assumes that the

<sup>21</sup> The obligation of *ve'chivsuha* as well as *l'ovda u-leshomra*.

<sup>22</sup> See *Shut. Maharsham* 3:225 (end); *Shut. U'Bacharta B'Chaim* 87; *Shut. Tuv Taam V'Da'at* 239; *Rambam, Yoma* 8:6, *Shabbat* 6:10; *Shut. Radbaz* 1436; *Ibid. Leshonot HaRambam* 1526; *Birkei Yosef O.C.* 301:6.

<sup>23</sup> *Teshuvot V'Hanhagot* 859.

<sup>24</sup> *Shut. Iggerot Moshe C.M.* 2:74-2; *Shut. Tzitz Eliezer* 13:87; *Shut. Minchat Shlomo* 2:82; *Ibid.* 82-4; *Ateret Sholom* Vol. 7 p. 112.

underlying condition that precipitated the arrest is potentially reversible; otherwise the activity would be clinically futile. In the appropriate situation, in which the cardiac arrest itself is an aberration in cardiac electrophysiological function or part of a self-limiting condition (such as an acute myocardial infarction), CPR may return the heart to a self-sustainable rhythm and cardiac output, without irreversible damage to other vital organs.

In the geriatric long-term care population, the heart stoppage itself is often the final common pathway to death following the lethal deterioration of other organ systems. The heart rhythm and cardiac output is usually not capable of being permanently restored. In such situations, CPR serves no clinical purpose.

The success of CPR depends on the patient's overall medical condition. Age alone does not determine whether CPR will be successful, although illnesses and frailties that go along with age often make CPR less successful. When patients are seriously ill or terminally ill, CPR may not work or may only work partially, leaving the patient brain-damaged or in a worse medical state than before the heart stopped. The patient may be alive, but will be connected to a ventilator or be left with neurological damage as a result of the time that has lapsed without blood supply to the brain.

Many people have an exaggerated perception regarding the success of CPR. The medical literature suggests that, in general, CPR as a procedure is not very successful.<sup>25</sup> It is reported that only about 15% of all patients who receive CPR survive to hospital discharge, with the rate of survival varying by location, from a high of 39% for a selected group of cardiac patients who have sustained a witnessed arrest in a monitored setting, to a survival rate of less than 1% for patients who have an out-of-hospital and/or unwitnessed arrest.<sup>26</sup> Because chronically ill elderly patients who require CPR have a less than 5% chance of surviving to hospital discharge, one can infer an even lower success in terminally ill

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<sup>25</sup> Diem SJ, Lantos JD, Tulsy JA, "Cardiopulmonary resuscitation on television. Miracles and misinformation", *N Engl J Med*, 1996;344:1578-1582; Von Gunten CF, Weissman DE, "Discussing do-not-resuscitate orders in the hospital setting: Part 2", *J Palliat Med* 2002;5:417-418.

<sup>26</sup> Bedell SE, Delbanco TL, Cook EF, Epstein FH, "Survival after cardiopulmonary resuscitation in the hospital", *N Engl J Med* 1983;309:569-576; Murphy DJ, Murray AM, Robinson BE, Campion EW, "Outcomes of cardiopulmonary resuscitation in the elderly", *Ann Intern Med*, 1989;111:199-205.

patients, many of whom are in more advanced stages of the same chronic illnesses.

CPR is often harmful, increasing pain and suffering in the few terminally ill patients who might survive the procedure. Autopsy studies have demonstrated significant traumatic injury following CPR, including rib and sternal fractures, mediastinal hematomas, aspiration pneumonia, epicardial hemorrhage, and other injuries to various cardiac and respiratory structures in the chest. And as indicated above, patients who survive CPR often are left with severe and irreversible neurologic deficits as well.

Assessing all the evidence, CPR is not beneficial for patients who are near the end-of-life and may be harmful. From a *halachic* perspective therefore, CPR may be withheld from or refused by Jewish patients who are terminally ill or at the end of life where agreement exists that there is no clinical value to the procedure.

Feeding an incompetent, demented geriatric patient is a common challenge that raises complex questions on a daily basis. Since eating is such a basic component of life, losing the ability to do so is a major blow to one's integrity. The result of this inability is a combination of medical problems such as malnutrition and aspiration, as well as psychological problems. The decision to stop nutritional support is almost inconceivable. When deglutition is abnormal, one loses the ability to swallow, tube feeding is needed and several options exist: nasogastric tube is the simplest to insert, but may be uncomfortable for the patient; it is easily removed, but it may be associated with increased risk of aspiration. More invasive techniques include the insertion of a gastric or a jejunal feeding tube. The main advantage of these is the ease of use coupled with the relative comfort of the patient. With the introduction of percutaneous endoscopic gastrostomy (PEG), the insertion of a gastric tube without the need for a surgical procedure became a very attractive option to provide feeding when the oral route is no longer effective.

In *Cruzan vs. Director, Missouri Department of Health*,<sup>27</sup> the U.S. Supreme court ruled that nutrition and hydration were medical interventions and as such could be withdrawn. Jewish medical

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<sup>27</sup> 497 US 261 (1990).

ethics does not make distinctions between "natural" and "artificial". Rambam<sup>28</sup> writes that the Almighty provides for all the needs of mankind. He causes man to seek bread for food and in a similar manner He allows for the discovery of medicines and technology so as to benefit mankind. Hydration and nutritional support are thus ruled by most *Poskim* to be basic care rather than medical interventions. A *metzi'ut* question, however exists as it relates to end-of-life treatment. As opposed to stroke and PVS patients, hydration and nutritional support for patients near the end of life raises significant medical questions as to whether or not these forms of care are indeed beneficial and whether or not there is risk of harm. I would like to specifically mention the case of patients suffering dementia and Alzheimer's disease.<sup>29</sup>

Dementia is a fatal neurological disorder involving progressive loss of memory, judgment, language, and other aspects of cognition, and results in death within a decade of diagnosis. In its most advanced stage, the affected individual loses the capacity to communicate or to help with personal care and suffers from severe memory loss.

Several distinct factors conspire to create nutritional problems among demented patients. Those in the end stages of dementia are unable to eat for various reasons such as indifference to food, refusal of food, or failure to manage the food bolus properly once it is in the mouth. Demented patients who stop eating become malnourished rapidly. It is very common to see such individuals recommended for artificial nutrition and hydration. This is done with the justification that it improves nutrition, maintains skin integrity by enhanced protein intake, prevents aspiration pneumonia, minimizes suffering, improves functional status, and extends life. However, the literature does not support these

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<sup>28</sup> *Perush HaMishnayot, Pesachim 55a.*

<sup>29</sup> What I write here should not be confused with this issue as it relates to other patients. For example, in the now-famous case of Terri Schiavo who was in a Persistent Vegetative State (PVS), I was against removal of her feeding tube. All her bodily functions were essentially normal, but she lacked the ability to "meaningfully" interact with the outside world. Her impairment was cognitive and *halacha* does not recognize any less of a right to treatment for one who is cognitively impaired. It could very well be that the removal of her feeding tube constituted murder.

claims.<sup>30</sup> Indeed, mortality among hospitalized patients during the first month following PEG insertion is high, ranging from 20% to 60%.<sup>31</sup>

In a study reported in the *Journal of the Israel Medical Association*,<sup>32</sup> despite the vast clinical evidence that there is no benefit in performing PEG in demented older patients, most of the referring physicians in the study recommended PEG because they believed it would prevent aspiration and improve quality of life. The majority of gastroenterologists, however, did not believe this to be true.

Review of the medical literature examining the benefits of artificial nutritional support by feeding tube (either via a nasogastric tube or a gastrostomy tube) in patients with advanced dementia (who may or may not be terminally ill) has shown:

1. No reduction in risk of aspiration pneumonia.<sup>33</sup>
2. No improvement in clinical markers of nutrition.
3. No improvement in patient survival.

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<sup>30</sup> Finucane TE, Christmas C, Travis K, "Tube feedings in patients with dementia: A review of the evidence", *JAMA* 1999;282:1365-1370; Gillick M, "Sounding board: Rethinking the role of tube feeding in patients with advanced dementia", *N Engl J Med* 2000;342:206-210; Dharmarajan TS, Unnikrishnan D, Pitchumoni CS., "Percutaneous endoscopic gastrostomy and outcome in dementia", *Am J Gastroenterol* 2001;96:2556-63.

<sup>31</sup> Meier DE, Ahronheim JC, Morris J, Baskin-Lyons S, Morrison S., "High short-term mortality in hospitalized patients with advanced dementia: lack of benefit of tube feeding", *Arch Intern Med* 2001; 161:594-9; Abuksis G, Mor M, Segal N, et al., "Percutaneous endoscopic gastrostomy: high mortality rates in hospitalized patients", *Am J Gastroenterol* 2000;95:128-32; Lang A, Bardan E, Chowens Y, et al., "Risk factors for mortality in patients undergoing percutaneous endoscopic gastrostomy", *Endoscopy* 2004;36:522-6; Abuksis G, Mor M, Plaut S, Fraser G, Niv Y., "Outcome of percutaneous endoscopic gastrostomy (PEG): comparison of two policies in a 4-year experience", *Clin Nutr* 2004;23:341-6.

<sup>32</sup> *IMAJ* 2007; 9:839-842.

<sup>33</sup> One study (*J Am Geriatr Soc* 1990; 38:1195-8) involving 104 severely demented nursing home patients found that patients with feeding tubes experienced significantly more episodes of aspiration pneumonia (58%) than the patients without feeding tubes (17%). Investigators also compared the incidence of aspiration between patients with jejunostomy tubes and those with gastrostomy tubes. A meta-analysis (*Arch Phys Med Rehabil* 1990; 71:46-53) of 45 studies between 1978 and 1989 with a total of 2,976 gastric tubes and 386 jejunal tubes found that aspiration rates were highly variable across different patient populations and studies and that there were thus no data to demonstrate decreased risk of aspiration at one tube site compared with the other. The continued risk of aspiration despite feeding tube placement may result from continued reflux of gastric contents and aspiration of oropharyngeal secretions (See *Ann Intern Med* 1995; 122:179-86).

4. No improvement in, or prevention of, decubitus ulcers.
5. No reduction in infection risk.
6. No improvement in functional status or slowing of decline.
7. No improvement in patient comfort.<sup>34</sup>

On a practical level – *halacha l'ma'aseh* – patients who are terminally ill should be provided food and fluid, but physicians have a responsibility to make sure that the food and fluid provided (or the method by which they are provided) do not cause the patient harm and/or discomfort. If a competent patient refuses nutrition or hydration after attempts have been made to convince him or her to accept the supportive care, the patient's wishes must be respected.<sup>35</sup> In situations where the physician believes that the food or fluid is of no benefit and/or harmful to a patient near the end of life, such as in those with dementia, the specific circumstances of the patient should be discussed with a Rabbi knowledgeable in this subject, because there may be situations where even the provision of artificial nutritional support and hydration can be avoided. The initiation of artificial hydration and nutrition should certainly not occur if it is determined that the patient is a *gosses*.

### Editor's note:

Unfortunately the literature quoted with respect to artificial feeding of the demented patient is, for the most part, far from conclusive and is often misleading. Let me make a few preliminary points:

1. No patient can live without nutrition or hydration, so that a decision not to feed a patient or to remove the only source of nutrition is a death sentence, with all of its consequences.
2. If it is possible to feed a patient orally, even with much investment of time and effort, this is preferable to tube or enteral feeding. And, as pointed out by my colleague Alan Jotkowitz,<sup>36</sup> such time and effort consuming feeding by a child of a patient is part of the requirement of *kibbud av va'em*.

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<sup>34</sup> See note 30 *supra*.

<sup>35</sup> *Shut. Iggerot Moshe, C.M. 2:74*.

<sup>36</sup> Jotkowitz A., Clarfield AM., Glick S., "The care of patients with dementia: a modern Jewish ethical perspective", *JAGS* 2005:53, pp. 881-884.

3. There has not to my knowledge ever been published a randomized control study in which patients who were candidates for possible tube feeding were divided into two groups, one tube fed and one not, comparing the two groups. Thus the generalizations repeated over and over again by individuals like Finucane and Gillick, decrying enteral feeding in terminal dementia, are not supported by adequate evidence. Criticism of their conclusions has been published by several authors, including myself.<sup>37,38,39,40</sup>

Since Finucane's articles, in which he reviewed the literature between 1996 and 1999, are quoted over and over again, and are regarded as definitive, I will analyze briefly his interpretation of some of the quoted data and indicate the serious errors:

Callahan<sup>41</sup> et al attempted to study 150 patients who had percutaneous endoscopic gastrostomy (PEG) feedings performed. They write that among patients surviving 60 days or more "at least 70% had no significant improvement in functional, nutritional, or subjective health status". Finucane wrote an editorial<sup>42</sup> commenting on the article, and he states "mortality rates were very high". But the high death rates were probably unrelated to the PEG, because a large percentage of the patients selected for PEG died even before they could be included in the study. These were very sick patients to begin with. Finucane writes further, "only a minority of patients showed any measurable improvement. Functional status, serum albumin, and weight were better at follow-up in very few patients" But the actual data in the paper showed that 30% had a significant improvement in serum albumin, and only 5% had a deterioration in serum albumin. Is 30% considered "very few"? But more important, PEG maintained nutritional and functional status in the overwhelming majority of the patients, in essence keeping them

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<sup>37</sup> Kunin J., "Withholding artificial feeding from the severely demented: merciful or immoral? Contrast between secular and Jewish perspectives", *J. Med Ethics* 2003:29, pp. 208-212.

<sup>38</sup> van Dijk Y Sonnenblick M, "Letter to the Editor", *IMAJ* 2006:8, pp. 894-895.

<sup>39</sup> Glick S., "More caution about tube feeding", *JAGS* 2001:49,1128.

<sup>40</sup> Glick S., "Appropriate use of artificial nutrition and hydration", *N Eng J Med* 2006:354, pp. 1320-1321.

<sup>41</sup> Callahan CM et al, "Outcomes of percutaneous endoscopic gastrostomy among older adults in a community setting", *JAGS* 2000:48, pp. 1048-1054.

<sup>42</sup> Finucane T.E., Christmas C. "More caution about tube feeding", *JAGS* 2000:48.1167-1168.

alive. The value of prolonging life itself is given very little attention in the discussion, in contrast to its major importance in the Jewish tradition. Were these patients not to have been fed at all they certainly would have progressed rapidly to their demise.

Finucane describes the "horrible mortality" of PEG tube feeding and comments pejoratively that a "surgical procedure with these mortality figures would probably not be done more than 100,00 times a year" He further suggests that families be told, "If the PEG is placed there is a very high chance that he/she will die soon". This, to my mind, is grossly misleading, because the population in whom these procedures were done were desperately ill before the PEG placement, and in all likelihood they did not die because of the PEG, but rather with a PEG, and perhaps in spite of a PEG.

There are several reports in the literature which clearly contradict the dire prospects described by Finucane and by Gillick. Lindemann from Germany<sup>43</sup> reports that more than half his demented patients in whom PEG had been placed lived longer than six months. He suggests that one should consider placing the PEG at an earlier stage in the dementia. Shapiro and Friedmann<sup>44</sup> describe their own experience with demented patients in several nursing homes in Jerusalem. They report that 43% of the patients were still alive after 2 years and 31% were alive 3 years after PEG insertion. Their experience coincides with the data reported by Peck et al,<sup>45</sup> that the terminal stage of dementia may be prolonged for months or even years if supportive care such as artificial nutrition is provided. Similarly van Dijk and Sonnenblick<sup>46</sup> tell of their extensive experience in which such patients survive for years.

Of course PEG has complications, as does any procedure, and in each case there needs to be a careful evaluation of the potential benefits versus the problems of any course of therapy. But good ethics must be based on correct facts, and unfortunately the literature on the subject has been seriously biased, leading to

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<sup>43</sup> Lindemann B., Nikolaus Th. "Outcomes of percutaneous endoscopic gastrostomy in dementia patients", *JAGS* 2001;49,838-839.

<sup>44</sup> Shapiro D.S., Friedmann R., "To feed or not to feed: the terminal demented patient-is there any question?", *IMAJ* 2006;8, 507-508.

<sup>45</sup> Peck et al., "Long term enteral feeding of aged demented nursing home patients", *JAGS* 1990;38, 1195-1198.

<sup>46</sup> See note 38.



conclusions which are clinically as well as ethically unsound, certainly as evaluated from a *halachic* point of view.

Shimon Glick

**Author's rejoinder:**

I am honored and delighted that Professor Shimon Glick took the time to comment on an aspect of my article. Dr. Glick is an outstanding physician and one of the best spokesmen the Torah world has for our eternal values. He is a role model of what a Jewish physician ought to be – a *ben torah* of high caliber and one who throughout his long and illustrious career, made a daily *Kiddush Shem Shamayim*.

I must, however, take exception to his critique. As a Rabbi, I am fully aware that like all areas of *halacha*, life and death decisions of which I wrote are highly fact-sensitive and *Poskim* must make a careful evaluation. *Psak halacha* is to the Talmud what engineering is to mathematics. If the raw data is inaccurate, the bridge will collapse. If the raw data is accurate but the conclusions drawn are in error, then the greatest mathematician will have labored in vain, because the engineer has misinterpreted his instructions. I believe that the data I quoted is accurate and falls within the scope of *chochma ba-goyim ta'amin* – and can thus be relied upon in reaching a *halachic* ruling.

I reiterate again that there is little question that in almost all situations the *halacha* requires the use of artificial nutrition and hydration and the fact that society terms these modalities as “artificial” has no impact in Jewish thought or law. I also fully agree that removing nutrition/hydration would be looked upon as an act of *retzicha* (murder) under the *p'sik reisha v'lo yamut* rule. However, in the patient population of which I wrote – those suffering from end-stage Alzheimers and other dementias – I am convinced that initial placement of a PEG once they lose the ability to swallow is as medically contraindicated as the introduction of fluids in a patient for whom fluids may cause pulmonary edema without definite beneficial results. In order for there to be an obligation to provide nutrition via a PEG, the assumptions of benefit and minimal risk must be met. It is this point that I believe has been shown to be scientifically accurate both from my review of the literature, conversations with experts in both geriatrics and gastroenterology, as

well as personal observation of many years dealing with this subset of patients.

Aside from the sources I have already quoted let me note the following: "Tube feeding in the Demented Elderly with Severe Disabilities", *Israel Medical Association Journal*, 8:870-874 (2006); "To PEG or not to PEG? Feeding the Incompetent Patient", *Ibid.* 9:881-882 (2007); *Long Term Feeding Tube Placement in Elderly Patients* (Mitchell, Tetroe, O'Connor, Ottawa Hospital, 2008);

### **Editor's dialogue:**

Since my original comment on Rabbi Kaye's article there was published a Cochrane document about enteral feeding in advanced dementia.<sup>47</sup> They retrieved some 452 articles, but found not one single randomized controlled trial. They were unable to do a meta-analysis because of the poor quality of the reports. Ultimately they discussed only 7 papers, of which 6 discussed mortality, and only 3 used exclusively PEG. The numbers in most of the studies were quite small. Their conclusion was that "there is insufficient evidence to suggest that tube feeding is beneficial in patients with advanced dementia. Data are lacking on the adverse effects of this intervention". They are also critical even of each of the 7 papers included in their analysis, and indicate the need for "better designed studies" to "provide more robust evidence". The kind of studies needed are proposed in the following article by Professor Steinberg. Unfortunately what has occurred is that the poor data from patients with "advanced dementia" have not only been widely quoted, but then extended in many articles to patients with dementia in general. If one waits until the stage of severe deterioration the benefits of the procedure are indeed diminished and the side effects increased. One needs to make early diagnoses of declining intake and poor nutrition; in such situations PEG can have long-term life preserving effects.

Source: ASSIA – Jewish Medical Ethics,

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<sup>47</sup> Sampson E.L., Candy B., Jones L., "Enteral tube feeding for older people with advanced dementia", *Cochrane Database of Systematic Reviews* 2009, Issue 2. Art. No.:CD007209. DOI:10.1002/14651858.CD007209. pub2.