When to Recommend a PEG Tube

A Decision Tree for Clinicians from a Catholic Perspective

The Ad-Hoc PEG Tube Study Group

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Abstract

The question of tube feeding often presents great challenges for the physician. Catholic moral teaching can be of great help to all people of good will in meeting this challenge. The Church teaches that tube feeding is, in principle, ordinary care and hence morally obligatory. How should clinicians go about deciding when to recommend tube feeding in a manner that serves the best interests of the patient and is in harmony with the Church's teaching? A PEG tube should be recommended when a patient is not eating or drinking adequately, has more than a short-term need, is not imminently dying, and has no

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contraindication to a PEG. This article presents a step-by-step discussion of the decision-making process to assist physicians and other health-care professionals. A decision tree is included that is clinically focused, practical, and straightforward. The authors represent a broad range of Catholic clinical experience. Practical suggestions are offered regarding how to go about discussing this difficult subject with patients and their families. The issues of patient refusal, advance directives, and physician recusal from care are addressed. A chronological reading list on the subject of PEG tubes is provided.

Introduction

The decision to place a percutaneous endoscopic gastrostomy tube (PEG tube) often presents as one of the more difficult decisions in clinical medicine. The potential life and death consequences engender great debate and emotion. First introduced in 1979, PEG tube feeding quickly became the most common method of providing long-term nutritional support for patients unable to eat or drink.[1] However, placing a PEG tube can raise ethical dilemmas such as the following: Will a PEG tube prolong a patient's suffering? Is a PEG tube an aspect of ordinary care and hence morally obligatory? Or is it rather a part of extraordinary care and thus optional?

Over thirty years ago, as PEG tubes came into widespread use, the Catholic Church began a process of deep ethical reflection over the use of assisted nutrition and hydration. The Church has concluded that in principle assisted nutrition and hydration (ANH) via PEG tube is ordinary care and hence morally obligatory. In contrast, the wider medical community commonly rejects the use of PEG tubes for many patients who are considered to have a poor quality of life and little hope of recovery. It is the experience of the authors that there is now considerable cultural bias against the use of feeding tubes in this country.[2]

The present article hopes to guide health-care providers as they walk through the process of advising patients and family about the use of PEG tubes. While this analysis is based upon Catholic moral teaching, it should be of help to all clinicians who are seeking to provide the best possible care for their patients. The present article should also be of help to physicians unfamiliar with Catholic teaching who are caring for Catholic patients.

While many patients benefit from a PEG tube, it is not the answer for every patient. The complications and limitations of PEG tubes must be recognized. Yet the physician must also avoid exaggeration of risks and minimization of the basic obligation to provide patients with food and water. The clinician should be prepared to answer questions and respond to objections. Many patients in need of a PEG tube are not mentally competent as a result of dementia, coma, or other impairments to cognition.

Often the decision about PEG feeding falls to the family. Ideally, a health-care proxy has been selected. If not and there is disagreement, decision making can become difficult and require considerable diplomacy. Furthermore, to be done well, the clinician's job requires prayer and wisdom. Throughout the process the needs of the patient should be kept at the forefront, especially his or her basic need for food and water.

This article hopes to offer practical, straightforward, and widely applicable guidance through this often challenging process. To be practical, we have crystallized the subject into a decision tree (fig. 1), designed

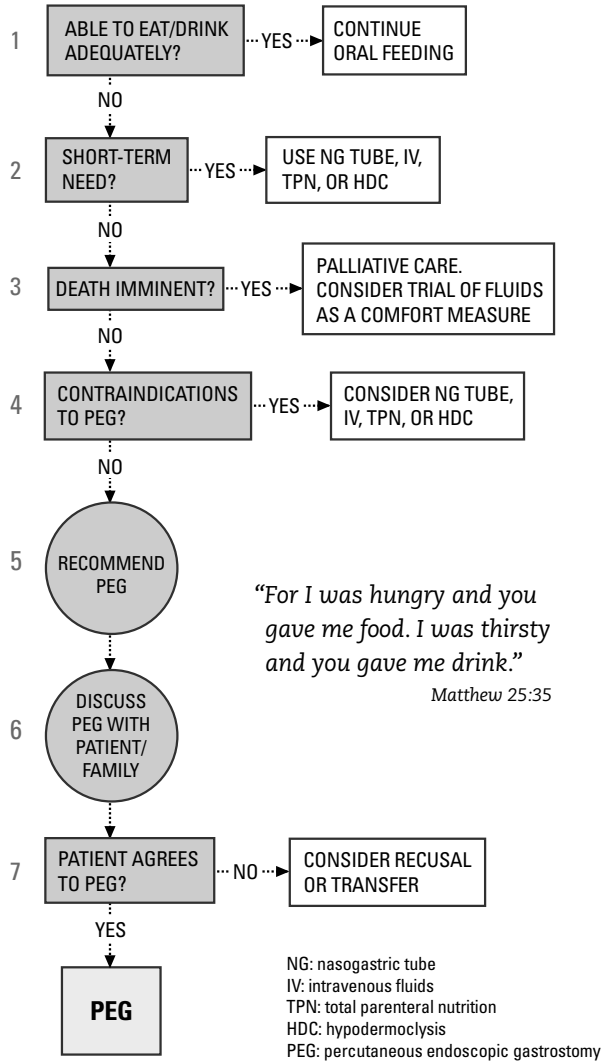

Figure 1. When to recommend a peg tube: A decision tree for clinicians from a Catholic perspective. In using this decision tree, please see the accompanying article for explanatory text.

to be a clinical tool that clinicians, hospitals, and other health-care facilities might find helpful. Much has been written on the subject of tube feeding from the perspective of moral theology (see "Further Reading" below). This article attempts to translate the moral theology into practical clinical guidelines. The accompanying text offers explanatory notes for each point of the decision tree.

To be straightforward, we focus on the use of PEG tubes and not the more general subject of assisted nutrition and hydration. The focus is on the role of PEG in nutrition and hydration, not cases in which PEG is being considered to prevent aspiration or to provide drainage of the gastrointestinal tract as in cases of advanced malignancy with obstruction. While straightforward, this process cannot be reduced to a simple "cookbook." While often helpful, decision trees have their limitations. There will often remain a degree of uncertainty that calls for prudence and wisdom.

To make sure that our teaching is widely applicable, we have gathered together an ad-hoc group representing a broad range of Catholic clinical experience: family physicians, general internists, hospitalists, nurses, hospital administrators, speech pathologists, gastroenterologists, neurologists, hematologists-oncologists, pulmonologists, critical-care physicians, geriatricians, and priests/hospital chaplains. We are honored also to have had the assistance of a bishop with wide experience in moral theology. The decision tree and these explanatory comments are written primarily for Catholic health-care professionals in the developed world. We have not attempted to deal with the special challenges in the developing world where PEG tubes are largely unavailable. Above all, this article and decision tree seek to be faithful to Christ and to his Church.

Essential Church documents relating to PEG tubes are listed at the end of the article. Of particular importance in the United States is directive 58 (as revised in 2009) of the U.S. Conference of Catholic Bishops' *Ethical and Religious Directives for Catholic Healthcare Services*.[3] When thinking about PEG tubes we should all find inspiration in the words of Christ, that in serving others we serve Him: "For I was hungry and you gave me food, I was thirsty and you gave me drink, a stranger and you welcomed me, naked and you clothed me, ill and you cared for me, in prison and you visited me" (Mt 25:35–36).

The PEG Tube Decision Tree

Step 1: Is the Patient Able to Eat and Drink Adequately?

A person completely unable to eat or drink is in a time of crisis. Unable to provide for essential bodily needs, the patient will soon die. Prompt action must be taken. But more often the problem is sub-acute. The patient's oral intake drops gradually, and he or she begins to lose

Table 1 Common indications for a PEG tube

• Stroke
• Coma and the minimally conscious state
• Advanced dementia
• Parkinson's disease
• Amyotrophic lateral sclerosis
• Other progressive neurodegenerative disorders
• Malignancy, especially for head/neck cancer
• Prolonged mechanical ventilation and recovery from critical illness

weight or manifest other signs of malnutrition or dehydration. A careful nutritional assessment should be done including the following: review of body mass index (BMI) over time, calorie counts, measurement of intake and output, and laboratory assessment (albumin, total lymphocyte count, iron studies, BUN/creatinine). Consultation with a nutritionist can be helpful in this process.

Step 2: Short-Term Need?

Once it is established that the patient is not eating or drinking adequately, it is important to do a thorough diagnostic evaluation. Is there a reversible cause such as depression, thyroid disease, or malabsorption? In patients with stroke, dementia, or other neurologic disorders, the primary problem is often a swallowing disorder with aspiration of oral contents. Consultation with a speech and language pathologist (SLP), a thorough swallowing evaluation, and swallowing therapy may help restore adequate oral intake for such patients.

Patients with an acute or short-term problem do not need a PEG tube, but perhaps intravenous fluids, intravenous hyperalimentation (peripheral or central), a nasogastric tube, or hypodermoclysis, in which fluids are infused under the skin with a butterfly needle.[4] Many patients can continue to eat and drink small amounts if hand-fed and encouraged by family or staff in accordance with a therapeutic feeding protocol established by the speech pathologist and attending physician. For such patients there should be no rush to begin tube feedings, but the patient's nutritional status should be monitored closely.

PEG tubes are intended for those unable to eat/drink for a more chronic period of time, at least a few weeks. Some patients with irreversible disease will need long-term tube feeding. Other patients will only need a PEG for a few months. For example, the patient with head and neck cancer will often need PEG tube placement and nutritional support during treatment with radiotherapy and/or chemotherapy.[5] Critically ill patients are often initially fed by nasogastric tube, but if they are likely to need nutritional support for more than a few weeks, PEG is often prefer-

able. This would include patients with multi-trauma injuries, patients with burns, and patients requiring prolonged mechanical ventilation.[6]

The timing of PEG tube insertion requires consideration of a variety of factors. Discussion about the possible need for PEG tube feeding should begin early and continue so that when placement becomes necessary to sustain life, the patient and family will have had ample time to accept the idea. When the patient demonstrates progressive signs of malnutrition or dehydration despite attempts to correct underlying causes, it is time to plan for PEG placement. If the problem is more acute and the patient has entirely stopped eating and drinking, a decision must be made promptly. IV fluids can be used as a bridge while a decision regarding a PEG tube is being considered.

Step 3: Is Death Imminent?

If death is not imminent a PEG tube should be considered. If the patient is terminal but not imminently dying, tube feeding can be an important part of compassionate palliative care enabling the provision of food, fluids, and also medication during the last months of life. Unfortunately, placement of a PEG tube is not a covered service for patients in hospice programs under Medicare regulations. Even worse, in the experience of the authors, some patients are placed in hospice care not because they are dying due to an underlying disease, but because a decision has been made to hasten death by denial of food and water.[7]

If death is imminent, where the end is expected in a matter of a day or two, insertion of a PEG tube would not be appropriate, and the patient should be given palliative care. Most imminently dying patients do not want to eat or drink.[8] Their bodily functions are shutting down. Yet, it is important to remember that some patients suffer greatly from dehydration at the end of life; and, for this reason, a trial of food and/or fluids as a comfort measure should always be considered.[9] Some patients who are still conscious may greatly enjoy taking small amounts of food or sips of liquids. Patients who are unconscious may benefit from measures to keep the mouth moist. Some patients may be comforted by provision of fluids via a small-bore nasogastric tube, the intravenous route, or hypodermoclysis.

Step 4: Contraindications to PEG?

Before a PEG tube is recommended the clinician should consider possible contraindications and adverse effects (see table 2). Placement of a tube should be deferred in acutely ill patients with high surgical risk until their condition can be stabilized.[10] If the patient's primary problem is aspiration, it should be recognized that tube feeding might not benefit the patient. PEG will not prevent aspiration of oropharyngeal or gastric contents.[11] Percutaneous endoscopic jejunostomy (PEJ) is no more effective than gastrostomy (PEG) for prevention of aspiration.[12]

Table 2 Contraindications and adverse effects of PEG tubes

Absolute Contraindications:
- Inability to perform an esophagogastroduodenoscopy (EGD)
- Bowel obstruction
- Peritonitis
- Uncorrected bleeding disorder
- Severe and untreatable fluid overload

Relative Contraindications:
- Acutely ill patients with high surgical risk
- Massive ascites
- Large gastric varices
- Previous abdominal surgery
- Morbid obesity
- Gastric wall neoplasm
- Intra-abdominal malignancy with peritoneal involvement
- Abdominal wall infection
- Intestinal malabsorption
- Cognitive impairment with "busy hands" and a likelihood that the patient would require restraints
- Severe psychological fear of tube feeding

Adverse Effects
- Aspiration pneumonia
- Infection
- Bleeding at the insertion site
- Leakage
- Diarrhea, nausea, vomiting
- Dislodgement/removal of the tube

As in step 3, when a PEG is contraindicated, alternatives should be considered, including the use of a small-bore nasogastric tube, intravenous therapy, total parenteral nutrition, or hypodermoclysis.

Step 5: Recommend PEG

A PEG tube should be recommended if the patient is not eating or drinking adequately, the problem is expected to last more than a few weeks, death is not imminent, and there is no contraindication to a PEG. If PEG feeding can assist in the nutrition and hydration of the patient, that is sufficient benefit to warrant recommending PEG.[13] Some would deny the possibility of benefit from PEG for patients with advanced dementia,[14] terminal illness,[15] or other conditions. One should resist the temptation to accept such blanket judgments. The medical literature on PEG tubes must be read critically because it is often biased against tube feeding and often overlooks the simple fact that without nutrition and hydration the patient will die. A recent analysis of the

literature regarding tube feeding in patients with dementia illustrates this problem.[16]

Step 6: Discuss PEG with Patient/Family

Recommending a PEG tube will almost always result in the need for considerable discussion between the patient and/or family and the physician, other health-care professionals, and clergy. Patients or families may ask practical questions such as the following: What is it like to have a PEG tube inserted? How are feedings given through the tube? What difficulties can we expect? Will it hurt? What if the tube gets pulled out? Can the patient still eat? Can the tube ever be removed or feedings stopped? Nurse educators, speech pathologists, and nutritionists can be very helpful in answering such questions. One simple and very effective teaching tool is to give patients and families an actual PEG tube for them to examine. To pick up a PEG, look at it, and touch it often diffuses much of the fear regarding the subject.

Health-care providers should be prepared to charitably respond to questions and objections. When a PEG is recommended, the patient and/or family may initially reject the idea. Many have misconceptions or deep-seated fears about tube feeding. In our society tube feeding is not seen as a moral obligation, but as something unnatural that prolongs suffering and death. Patients who are unable to eat or drink may be in pain and afraid of death. They may have financial worries or be saddened by their disability, loss of independence, and the impact of their illness on their family and friends. Patients may fear that with a PEG tube they will be a greater burden on others. The physician and all the members of the health-care team must listen to the patient and his or her family members so that they understand and are able to respond with compassion. While tube feeding may be initially rejected, in time it may be welcomed and even seen as a blessing. For example, the patient with amyotrophic lateral sclerosis (ALS) initially may reject a feeding tube, but as he or she has more and more trouble eating may have a change of heart. After placement of the PEG, such patients may be profoundly grateful because with the tube so much less time and effort are required to eat and drink.

In discussing PEG with patients and/or families, a careful spiritual and cultural assessment can be very helpful; and one should request the help of pastoral care, the hospital chaplain, or the patient's minister or priest, if any.[17] The approach will be different for a devout Catholic patient (as opposed to a nominal Catholic), a patient who is Protestant, a member of another faith, or a person of no faith. The physician and health-care team should recognize that differing religious beliefs entail differing attitudes towards illness, death, and PEG feeding in particular. Cultural traditions can strongly influence a patient's views for or against tube feeding and other end-of-life care choices.[18] It might be that in the

patient's culture, a person would never be allowed to die of hunger or thirst. Only once we understand the concerns and fears of the patient and/or family will we have an opportunity to help them to see the wisdom of tube feeding. As Catholic health-care professionals, we are fortunate to have the Holy Spirit and the teachings of the Church as guides, yet we must still listen first and talk second.

It is important to remind patients and families that all persons have essential needs for air to breath, food and water, shelter from the cold, and love and affection. A feeding tube is a tool to help us meet a basic human need. The insertion of a PEG tube is a minor surgical procedure, not a major operation. Use of a PEG tube is not intrinsically "heroic" or extraordinary but a part of the ordinary care to which all persons are entitled. Patients and families often find it helpful to know that a PEG tube can be a simple way to assure that food, water, and medication can be administered without the need for an intravenous catheter. It is also helpful to point out that many patients with a PEG can still eat small amounts of "comfort foods" such as ice cream. Many non-professionals incorrectly think that once a person has a PEG tube he or she can never eat normally again.

Frequently the patient or family will reject PEG outright because of the mistaken notion that tube feeding would be burdensome or because the overall situation is so burdensome. This requires patience and compassion on the part of the physician and health-care team. An attempt should be made to gently explain the rationale for the recommendation for PEG. It is essential to help the patient and/or family distinguish the perceived burden of the overall situation from the burden posed by the PEG tube itself. For example, the patient with advanced dementia may be wrongly perceived as a burden upon his or her family and society, but that is not a valid reason to deny the patient a PEG. Considerations about the "quality of life" cannot be used to justify the denial of basic care to the patient.[19] If the patient has an exceptional psychological fear of tube feeding or if it is likely to cause significant physical discomfort, then it is morally licit to refuse a PEG tube. With such a patient other alternatives should be considered, as discussed above at step 3.

Family members are often grieving the loss of an active, interpersonal relationship with a once-vibrant parent, sibling, or spouse. They will sometimes reject tube feeding because, in a sense, their loved one is already "gone." Pastoral counseling can be very helpful in enabling the family to establish a new type of relationship with the patient. If they can be helped to understand that the role of caregiver provides many opportunities for real interaction and a true relationship (although one much different from the one they had before), then they can more easily understand the obligation to provide food and fluids.

Advanced directives for health care can pose special problems. What if the patient signed an advanced directive stating that he or she

did not want a feeding tube? Most secular physicians would consider the matter settled. Yet in Catholic moral teaching, personal autonomy is not the paramount consideration. Just because a patient has expressed a wish not to have a feeding tube does not mean that the physician must be silent and acquiesce. While the patient cannot be forced to accept a PEG tube, neither should we automatically honor a living will that prohibits tube feeding. Furthermore, patients rarely write an advanced directive with all the information they need to make a fully informed decision. Can we really be so sure that we would never want a feeding tube years in the future at a time and in circumstances we can scarcely imagine? Prudent judgments cannot be made in advance regarding such issues.

The attending physician is primarily responsible for discussing the recommendation for PEG feeding with the patient and/or family, but after the doctor has left the room, the patient and/or family will often turn to the nurse or other caregivers for advice. All health-care providers must be prepared to respond to such requests. Caregivers who have had personal experience with PEG tubes can be especially helpful.

Some patients and families may reject PEG feeding because they want to hasten death. Indeed, some in our culture advocate the refusal of food and water as an alternative to euthanasia or physician-assisted suicide.[20] The physician should attempt to help the patient to see that life is a gift and we are not masters of life and death, but stewards. To refuse food and fluids in an attempt to hasten death, even if motivated by compassion, is a form of euthanasia. Patients who seek to hasten death "should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so that they can live with dignity until the time of natural death."[21] Spiritual counseling and pastoral care can sometimes help such patients and families turn the situation around and find redemptive purpose in the midst of suffering. When there is a major disagreement between the physician and the patient or family regarding a PEG, it can be helpful to request an ethics consult or the assistance of the hospital ethics committee.

There is a time to let go, to be at peace, to welcome death and rest in God's loving embrace. Those who would "do everything" lack wisdom. The Church does not insist that we pursue care that is lacking in benefit, but the Church does teach us that life is precious and is to be respected. As stewards of the life that God has given us, all persons have a moral obligation to use ordinary means to preserve our health and life.[22] PEG feeding is ordinary and obligatory when it is able to nourish and/or hydrate the patient and not excessively burdensome to the patient.[23] All persons regardless of their perceived quality of life are endowed with inherent human dignity and entitled to respect and basic care, which includes food and fluids, good hygiene, avoidance of pressure points, physical warmth, and human companionship and affection.

Step 7: Patient Agrees to PEG

Ideally, this should be the ordinary outcome. The patient cannot eat or drink and is provided sustenance via PEG. The patient and family members realize this is not a burden but a blessing. As health-care providers we are doing our job: to care for the patient.

If the patient refuses a PEG, the physician must consider recusal from care or transfer of care. The physician should always seek to avoid arriving at this point, the point at which a patient or family refuses an appropriate recommendation for PEG feeding. For example, consider a patient in prolonged coma or a minimally conscious state whose family members have insisted that tube feedings be discontinued in order to hasten death, cases such as the late Terri Schiavo. Can the physician in good conscience write an order to stop feeding such a patient? To do so would be to cooperate with an act of euthanasia, to formally cooperate with evil. In such a situation where the patient or family clearly intends to refuse PEG feedings in order to cause or hasten death, the physician has a moral obligation to continue feeding the patient and if pressed may need to recuse himself or herself from the case. In such a situation a Catholic hospital would be morally obligated to allow for transfer of the patient to another facility that is able to defer to the patient's wishes.

However, the physician should not be too quick to recuse from the care of a patient. As noted earlier, many patients and/or families will initially refuse PEG, but in "God's time" they will change their minds. They must have time to understand and freedom to come to a proper choice. The best option may be to say to the patient or family, "Let's give it a few days and talk again."

The question of recusal is always a difficult decision for the health-care provider and should be approached prayerfully. When recusal is being considered, a chaplain or priest can be helpful to the clinician as he or she thinks through the situation and tries to come to a decision. The clinical situation is not always clear-cut. The need to avoid cooperation with evil must be weighed against the need to care for and not abandon the patient. Catholic health-care professionals working in non-Catholic settings can face special challenges. Recusal from care could result in the health-care professional suffering ostracism, being disciplined, or being fired from employment. The extent of cooperation with evil in such situations is less for non-physician members of the health-care team. The Catholic hospital, which is bound to follow Catholic moral teaching, and the Catholic physician, especially the primary-care or attending physician, bear the principle responsibility to avoid cooperating with evil in these matters.

We should all pray and work for a world in which recusal from care would never need to occur, a world in which the care and dignity of all patients is respected and honored.

Conclusion

We have presented and described the use of a decision tree to aid Catholic health-care professionals in making decisions and in offering guidance for patients regarding the use of PEG tube feeding. It is our hope that the decision tree will be of practical help to Catholic and also non-Catholic health-care professionals, especially those with a reverence for the sanctity of life. Indeed, the ethical principles, upon which the decision tree is based, apply to all persons, for we all have a common Creator and are ultimately governed by a common standard of ethical conduct.

The question of PEG tubes is in principle very simple, but in practice can be very difficult and challenging. The physician may find the process daunting. Yet the question of PEG feeding also presents a great opportunity for all of us, physicians and patients, to draw closer to the Lord, to seek His guidance. It is a time when we may be given the privilege to share the love and compassion of Christ in a profound way with our patients and their families. This decision-making process can offer a unique moment to bear witness to the sanctity and dignity of human life. It is for such challenges and opportunities that we are here, serving in Christ's name. "For I was hungry and you gave me food, I was thirsty and you gave me drink" (Mt 25:35).

Further Reading

Foundational Reading:

U.S. Conference of Catholic Bishops. *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. Washington, D.C.: USCCB, 2009. http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf. Especially relevant are directives 23, 32, and 58. Directive 58, which directly addresses assisted nutrition and hydration, was recently revised (December 2009) and is quoted here in full: "In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the 'persistent vegetative state') who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or (would) cause significant physical discomfort, for example, resulting from complications in the use of the means employed.' For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort."

Catechism of the Catholic Church, 2nd ed. Washington, D.C.: USCCB, 1994. Particularly relevant are the following sections: "In the Image of

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Notes

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