STARVING FOR MEANING:
THE SEARCH FOR A PROACTIVE HALAKHA AND ETHICS ON ISSUES OF NUTRITION FOR PEOPLE WHO ARE ILL

Courtney L. M. Berman

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Hebrew Union College – Jewish Institute of Religion
School of Rabbinic Studies, Los Angeles, California

Advisor: Rabbi Dr. Rachel Adler
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Chapter 1:
Introduction: Food as Source of Life, Food as Source of Death

To say that food plays a major role in our lives is an understatement. Food, and the act of eating, plays such a huge role in our lives that it is hard to imagine an existence without it. On the most basic of levels, nourishment is necessary for the sustaining of life. When we eat, we are rewarded with a feeling of satiety. The opposite of satiety, hunger, is an undesirable state. Hunger is an empty, painful sensation that animals instinctively try to avoid. The act of eating leads to the rewarding feeling of transitioning from the state of hunger to the state of feeling sated. This positive reinforcement helps to ensure that animals continue to eat.

Beyond being a basic physiological need, food provides us with other benefits. The act of eating is pleasurable. We get to enjoy different tastes on our taste buds and different textures in our mouths. There is something satisfying about using our teeth to chew and coordinating all of the muscles necessary for the act of swallowing. Furthermore, food serves a number of social and emotional functions. Families and groups of friends often spend time socializing over meals. Since eating is an activity we have to do every day, the act of eating together can provide an excuse for people with hectic lives to pause and connect with one another for at least a short time. As humans, we also have certain feelings associated with food. For instance, we use the term “comfort food” when referring to certain foods that help us feel better when we have had a bad day. What a person defines as “comfort food” will depend on his or her background, but those foods tend to help the eater recall a time when he or she was happy, safe, and protected from the pressures of the world. If a person had a happy childhood, “comfort food” might be some of the foods that the person enjoyed eating as a child. Just as some foods can be associated with pleasant memories, it is also common for people to have certain food aversions. Some food

aversions are based on memories of bad experiences, not just a dislike for a specific taste or texture.

Seeing as food plays such a major role in our social and emotional lives, it should come as no surprise that food plays a strong role in defining cultures. The foods we eat, and the foods we avoid, help us to order our world in terms of who is part of our group and who is not part of our group. Being raised in the Deep South, I grew up with many foods that were specific to the culture of my area. Grits, gumbo, po'boys, king cakes, beignets, and dobache are just a few of the food traditions that I associate with being from Louisiana. Meeting other people who grew up with those foods – or even know what those foods are – provides a simple yet powerful sense of connection.

The same roles that foods play in forming cultures can also be applied to religion, especially seeing as religions consist of clusters of different cultures. Many aspects of Judaism can be viewed from the perspective of food practices. For some Jews, the question of who is "in" and who is "out" may be answered by whether one observes the laws of *kashrut*. Even within the more observant Jewish communities, the particular *heksher* that a person or family identifies as being authoritative can serve as a way of unifying a group of Jews, while Jews who find a different *heksher* to be authoritative are linked by their choice of *heksher*. Then there are Jews who do not keep kosher, yet even those Jews are linked by the sharing of food customs. Among Ashkenazi Jews, secular and strict Jews alike share certain food customs, such as the Jewish comfort foods that can be found at Jewish delis. Matzah ball soup, corned beef sandwiches, rugelach, and knishes are just a few of the comfort foods that bond these Jews together as a people. While cultural food customs, like my example above of Louisiana foods, link people together in a certain way, religious food customs are, arguably, more complex. *Halakhic* issues

such as *kashrut* and secular food customs such as corned beef sandwiches get woven together into a web of food practices that help to define what it is to be a Jew. Even Jews who do not keep kosher can bond over practices such as suffering through a week of eating *matzah* during *Pesach*. Such a practice is a religious command, yet the cultural aspect blends together with the component of religious obligation.

There is also a complexity inherent in food relationships. Even excluding illness, food can be a source of life and healing, or a source of death and illness. Eating too little can cause illness or death, while eating too much can also cause illness, obesity, or death. We need nourishment to survive, yet as with many aspects of life, moderation and balance are key. When considering Judaism, keeping the commandments of *kashrut* is viewed as a source of blessing and life, whereas to ignore the commandments of *kashrut* is viewed as a source of curse and death.[1]

So what happens when the very substances needed to keep us alive do the opposite? That is to say, what happens when food, or the act of eating, could kill us? Unfortunately, I had to face this cruel contradiction. Whereas many people cannot imagine life without food, I lived without food or drink for several months at a time at two separate points in my 20s. During a complicated spinal surgery, I developed an esophageal perforation. During medical treatment, I went from early October until the end of January with nothing to eat or drink. I was nourished through a jejunostomy tube (J-tube).

My last meal in early October consisted of a few bites of a grilled cheese sandwich, a few bites of pumpkin pie, and a thickened juice drink. By the time the perforation was diagnosed, I had already been unable to swallow thin liquids for about a month, so anything I drank had to be

[1] See, for example, Deuteronomy 30:15-20

thickened with medical thickening agents. I did not know what an esophageal perforation was, so I did not know that choking on thin liquids was a symptom. And I certainly did not know that grilled cheese, pumpkin pie, and thickened juice were going to be the last foods I consumed for almost four months.

My first esophageal perforation was treated successfully, and I developed my second one when a piece of spinal hardware eroded through the first repair. During the second experience, I had to suffer *knowing* when I was eating my last meal until the completion of treatment. Oddly, the trauma of knowing means I have forgotten what my "last meal" was the second time. I remember the meal included some flourless chocolate cake I had been craving frequently at that time, but sadly I felt so nervous and sick that I did not finish the cake. It was a surreal experience to *know* I was eating the last food I would eat until complicated medical treatment was deemed successful, especially considering there was a chance I would die during treatment. There was also a chance I would live yet permanently be unable to swallow. During treatment for the second perforation, I was nourished with both a J-tube and a gastrostomy tube (G-tube), from mid-September until mid-November. The G-tube provided more of a feeling of satiation than the J-tube alone, and for this I was grateful. The fact that I could sometimes feel relief from the hunger during the second perforation changed my experience in a significant way, and I think details such as that matter in constructing well thought-out ethical responses.

When I was diagnosed with my first esophageal perforation and told I was not allowed to eat or drink anything for an indeterminate amount of time, I was unprepared for the level of isolation I would feel. My first month with nothing by mouth was spent in the hospital, and I felt safer in the hospital because I had my own small bubble of space where nothing was consumed by mouth. When I went back to my parents' house and had to live in a space with people who

had to eat, I was forced to encounter the full weight of my isolation. I was not emotionally strong enough to sit with my parents and my little brother while they ate dinner together. I was hungry because my body would not tolerate much nutrition through my J-tube. Also, I missed eating. I missed everything that goes with eating: the taste of the food in my mouth, the chewing and swallowing of food, and the rewarding feeling of not feeling hungry anymore. I did not want to sit and watch other people eat while I was suffering so miserably, obsessing about that which I could not have yet also trying to block the cravings that I could not even come close to fulfilling. That would have been a cruel type of torture, though I am not sure if my state of hungry isolation was much better. My family got into a pattern around dinnertime, even though we never explicitly decided to follow this pattern. I tried to spend time in the main living area, which was very close to the kitchen, earlier in the day. When my mom or dad started cooking, I retreated to my room to try to escape the tempting smells. My family ate dinner. Once they were finished, someone would come to let me know it was safe to leave my room. Then I sat with my family in the living area for a few hours before bedtime.

During my months of not eating or drinking, I felt so isolated that there were times when I ceased feeling human. The experience of eating and drinking is a natural activity, and to have such basic animal functions removed from my life meant I had to try to find a place for myself in a world where I was being forced to reassess what it means to be a human. I was still a breathing, walking, talking, thinking, loving person. I still brushed my teeth twice a day. I still had the same intellectual interests. I still found comfort in listening to music, cuddling comfort objects like my yellow blanket, and wearing soft clothes. I was still a daughter, a granddaughter, a sister, a wife, and a friend. I was still a Jew. And yet, I had become Other. I no longer fit the mold of what it means to be human. Some of me had leaked outside of that mold, and I felt lost, like as if I was

living an undefined existence that should not be possible. I could not satisfy my craving for food. At the very least, I wanted to satisfy my craving to feel connected to others in some way, and without eating or drinking around a table with them, without feasting with them in celebration, an important sensuous dimension of that connection could not be expressed. Similarly, an important way of expressing holiness becomes inaccessible when one cannot eat.

I wanted to feel connected to my Judaism. That is really when I started working on this project. I was not writing yet, but I was living the experiences that caused me to think deeply about the halakhic and ethical implications of the different ways of nourishing people who have illnesses or conditions that prevent them from eating normally. My thoughts and observations focused on the social and emotional experience of living with such drastic restrictions. And part of this exploration consisted of questions of how one could still live a full Jewish life while unable to eat or drink.

I identify as a Southern Reform Jew. When I was growing up, my parents always made sure I felt safe, supported and loved. They taught me the importance of Jewish values such as *v'ahavta l'rei'akha kamokha*, "love your fellow as yourself."[2] They taught me the importance of pursuing education, and they dragged me to religious school even though I protested. They sent me to the URJ camp in Utica, MS most summers, and I loved living my Judaism at camp so much that I celebrated my Bat Mitzvah there. My parents helped me form the strong Jewish identity I have today, though we did not keep kosher. We hardly ever went to services. We did not light the Shabbat candles at home often, either.

Even though I did not take part in many day-to-day Jewish rituals growing up with my family, when I was unable to eat or drink, I found myself looking for Jewish rituals I could

[2] Leviticus 19:18

observe. Somehow, when so many of my connections had been severed, I found myself grasping for any meaningful connection I could still feel. Yet there were so few. I felt disconnected from my loved ones already. And as I learned how little halakha has to say about a person in a state such as mine, I felt more and more disconnected from my Judaism as well. I wanted to say a blessing over my tube feedings, yet my Orthodox friend informed me that there is no blessing for tube feedings because Artificial Hydration and Nutrition (ANH) is not considered to be a form of eating. As a non-eater, I could not take part in *kiddush*. I could not take part in many of the practices associated with *Pesach*, though thankfully I never had to celebrate *Pesach* as a non-eater. And I could not take part in any of the other food customs associated with all of the Jewish holidays that occurred while I was a non-eater. The closest I may have gotten was my knowledge that other people fast on Yom Kippur. Yet, when I was a non-eater on Yom Kippur, I knew ANH is not considered fasting. So I was not eating, and I was not fasting. What *was* I doing? Where *did* I fit? Without meaning to – and certainly without wanting to – I found myself dwelling in a category that did not seem to exist in halakha, or at least not in a satisfactory way that takes into account most of the factors involved in a situation such as mine. I was on ANH, yet I was not necessarily going to die, and I was aware of what was happening throughout most of my treatment.

The M.D. Anderson Dysphagia Inventory (MDADI) takes into account the different aspects of life that can be impacted by swallowing difficulty.[3] The developers of the MDADI took statements that have been made by actual patients, and they wrote them into a questionnaire. Patients are meant to think about their own experiences with their swallowing difficulty and then rate each statement with one of five options, ranging from "Strongly Agree"

[3] Chen, Amy Y., et al. "The Development and Validation of a Dysphagia-Specific Quality-of-Life Questionnaire for Patients with Head and Neck Cancer: The M.D. Anderson Dysphagia Inventory." *JAMA Otolaryngology - Head and Neck Surgery* 127, no. 7 (July 2001): 870-876.

to "Strongly Disagree." Patients' answers can help their treatment teams gauge the severity of the patients' dysphagia, after which fitting, informed, and ethical treatment decisions can be made. The following are a few of the items in the MDADI:

> "I do not go out because of my swallowing problem."
>
> "My swallowing problems limit my social and personal life."
>
> "I have low self-esteem because of my swallowing problems."
>
> "I feel excluded because of my eating habits."[4]

As can be seen from the statements cited, the MDADI takes into account the psychosocial impacts of dysphagia, not just the physical impacts. The MDADI is meant to help health professionals measure the patient's quality of life (QOL), and according to the conclusion of the article, their research and efforts have been successful: "The MDADI is the first validated and reliable self-administered questionnaire designed specifically for evaluating the impact of dysphagia on the QOL of patients with head and neck cancer."[5] The writers of this study note that caution is necessary when generalizing their findings to other groups of people with dysphagia due to the particular population they used for their research,[6] yet I am not using their research to make complicated decisions about a patient's treatment. I am merely noting that there are sectors of the medical community that are quite aware of the fact that swallowing difficulty impacts multiple areas of a person's life. When one has difficulty swallowing, one's problems extend far beyond the physical realm. The more severe the swallowing problem, the more severe the physical and psychosocial impacts to the patient will be.

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[4] Ibid. 872.
[5] Ibid. 870.
[6] Ibid. 876.

What I see when I look at the MDADI is a medical text that indicates the medical community is looking for a compassionate and ethical response to the situation of having patients that are suffering with swallowing problems. What I would like to see alongside this medical text is a Jewish text. Yet I have not found such a text. I have found plenty of Jewish responses to nutrition concerns at the end of life.[7] Jewish medical ethicists have interpreted halakhic sources quite skillfully, enabling families to make difficult decisions to remove ANH when ANH only prolongs the process of suffering that will surely still lead to death.

My intention is not to contradict such scholarship. I am dealing with a different category altogether. I am arguing that halakha has neglected the category of those who go through a period of time living on ANH with the expectation that they will survive. Halakha is based on interpreting law in light of different categories. Based on my research so far, I do not see enough work being done on the categories of those who have a chance at survival, or those who suffer from long-term conditions that lead to death eventually yet result in patients who struggle with swallowing problems when they still have life to live.

A concern I had when starting this project is that such an exploration might not matter. Perhaps I am wasting my time since, during my years on this earth so far, I have not encountered others asking the same questions I am asking. Then I realized we have an ethical duty to be asking such questions, so that we can respond in a more compassionate way to all those affected by swallowing problems, which includes the ones with the swallowing problems as well as their loved ones. Since I have not found that other Jews are responding to these issues in an informed and compassionate way, it is my responsibility to engage in this study.

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[7] See, for example: Dorff, Elliot N. *Matters of Life and Death: A Jewish Approach to Modern Medical Ethics.* Philadelphia: JPS, 2003: 208-217.

It is my responsibility to engage in this project precisely because issues of nutrition arise from a number of medical problems. Those who suffer from strokes can experience problems swallowing – or even a complete inability to swallow – after the stroke. And just as it is possible to recover from a stroke, it is also possible to regain one's ability to swallow normally after a stroke. Conditions such as Alzheimer's and ALS lead to an inability for patients to nourish themselves. Both of these conditions result in death, eventually, yet the process of reaching death can be slow, meaning those who suffer from these horrible conditions go through a period of time when they are painfully aware of what is happening to them. One woman produced a dysphagia cookbook because her partner was diagnosed with ALS, and she wanted her partner to be able to enjoy food for as long as possible and in as full a way as possible.[8] As for Alzheimer's, Rabbi Dr. Rachel Adler writes,

> Eighteen percent of American Jews are over sixty-five, making dementia a growing concern in the Jewish community. These diseases erase the personality. They destroy the ability to talk, walk, think logically, calculate, write, read, respond, and remember. Ultimately, those affected cannot swallow food or drink. Those at risk dread dementia, and sufferers are feared and shunned. Alive and breathing, they are being unmade before our eyes.[9]

Crohn's Disease is another condition that can lead to patients having difficulty getting the nourishment they need. As Jon Reiner points out in his book, Crohn's impacts a higher percentage of those with Ashkenazi Jewish ancestry, though this disease can impact anyone.[10] There are other conditions that lead to dysphagia as well, including mouth or esophageal cancer.

I have also been told stories of people who survived living on ANH for a period of time. One way people relate to someone going through something like what I went through is by

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[8] Achilles, Elaine. *The Dysphagia Cookbook: Great Tasting and Nutritious Recipes for People with Swallowing Diffculties.* Nashville: Cumberland House, 2004: xv.

[9] Adler, Rachel. "Those Who Turn Away Their Faces: Tzaraat and Stigma." In *Healing and the Jewish Imagination: Spiritual and Practical Perspectives on Judaism and Health*, edited by William Cutter, 142-159. Woodstock: Jewish Lights Publishing, 2007: 143.

[10] Reiner, Jon. *The Man Who Couldn't Eat.* New York: Gallery Books, 2011: 6.

telling stories of others they know who had to endure something similar. These stories helped me at that time specifically because the stories showed me I was not as isolated as I may have felt. The stories situated me within a group of people who had lived under similar circumstances before and survived all of it – the isolation, the different types of suffering associated with the conditions, and the undeniable physical danger that could all too easily lead to death but that is survivable in some cases. The stories I heard helped to give me courage to continue fighting to survive. And I still remember those stories: The temple president at my first student pulpit told me his son had to live on ANH for a while because part of his digestive system was burned in a fire. My weekend home health nurse told me he had been shot through part of his digestive system and had to live on ANH while his wound healed. And a long-time friend and teacher from my home congregation told me about a boy who has used ANH since he was young because he is unable to take in enough calories orally. These three people all used ANH and survived.

Now, looking back, these stories also provided me with additional reasons why this project is worthwhile. If the field of Medical Ethics can respond to the constant advances in the practice of medicine, surely Judaism should respond as well. I have seen that Jewish Medical Ethicists *have* responded to many important medical advances. Yet I see a lack of response in relation to this particular issue. I wish to fill that void. In the chapters to follow, I will begin that attempt. I undertake this project with the understanding that it will be incomplete. I hope to fill in other pieces, and I hope to strengthen what is not strong enough yet. For now, starting the project is a step in the right direction.

In Chapter 2, I will explore rabbinic interpretations of halakha surrounding the issues and questions of my thesis. The first question to consider is the rabbinic definition of what it means

to eat. There are several key terms I will consider carefully, including *ha'naat m'ayim* and *ha'naat garon*. Based on such research, I will consider issues such as when it is appropriate for a person being fed artificially to take part in food-based *mitzvot*. I will also start to try to move the halakhic discussion by trying to address the actual group of people I am considering in this thesis. Halakhic discourse on issues of ANH has focused primarily on those who are nearing death, or those who are hospitalized and unaware of what is happening to them due to something such as a comatose state. Because most of the halakhic discourse deals with those who are nearing death or in comas, the legal material is addressed to the loved ones of the person on ANH. When a person is on ANH for an extended period of time and is aware of what is happening, that person might benefit from having more personal agency in his or her own decisions and actions, including his or her Jewish decisions and actions. It is also relatively common for a person to live on a form of ANH for several days after certain medical procedures, and those cases are at least acknowledged by some halakhic responses, but it is a very different experience to live on ANH for a few days than it is to be dependent on ANH for months or even years. I want to try to get to the point of addressing those who must endure living their lives for an extended period of time on ANH such that it becomes part of the fabric of their lives, not just those who face ANH as a very fleeting effect because of a surgery or other medical procedure. Another area that I argue can be very important to serious halakhic inquiry regarding ANH has been, to the best of my knowledge, completely ignored in the existing resources. And that is the question of what type of ANH is being used. There are four broad types of ANH, with different mixes or subcategories possible[11], and the specific method of feeding being used has different

[11] For example, there are both G-tubes and J-tubes. A person can have both simultaneously like I did during my second perforation. There is also a special tube that is both at once, called the GJ tube. In Chapter 3, when I provide a table of different feeding possibilities, I do not discuss the GJ tube since it is a mix of two existing methods. That is, however, an example of what I am talking about here.

consequences for the person. The differences should at least be considered in rendering accurate halakhic decisions in each case.

In Chapter 3, I will study *manna* with the goal of viewing ANH through a Jewish narrative lens. The *manna* that God provided to nourish the Israelites in the desert was a substance that had never been known before, just as ANH was unknown before medical advances made it possible to sustain a person unable to eat or drink in the natural manner. I will look at commentaries and *midrash* regarding *manna* as a way to explore the power of the human imagination when people are faced with deprivation. I will also explore what it means to be sustained, yet be upset or otherwise unsatisfied with the methods used in the sustaining of life.

Stated simply, the main goal of Chapters 2 and 3 is to acknowledge and discuss in the language of Jewish texts and traditions the subset of people in our Jewish communities who cannot take part in all of the *mitzvot* associated with food and eating, and are thus isolated from their day-to-day lives and from their Judaism. Then in Chapter 4, I will seek to come to some conclusions based on my research. I will try to answer the questions I laid out in this chapter. How can we include people in our communities that cannot eat in the traditional manner, or who have dysphagia? Is there a more ethical response to these problems, still rooted in halakha yet interpreted in light of this different category I have described? What might a proactive halakha look like in situations when someone has an illness that makes eating hard or impossible?

By seeking to answer such questions, I am trying to validate the experiences of an entire group of people that existing Jewish sources have, for the most part, ignored. Now that science has advanced far enough for people to live for extended periods of time on ANH, and some of those people are cognizant of what is happening to them and can take part in other areas of their lives, someone should be working on a valid Jewish response that does not diminish the

personhood of those who find themselves in such a situation. Those who cannot eat are unable to practice Judaism in all of the same ways that eaters can practice Judaism, just as those who cannot eat are unable to participate in society and their family groups in the same ways they can when able to eat. Yet this difference should not negate so many of their experiences as Jews. It should be possible for them to find a Jewish language of prayer and ritual for speaking to God about their situation. For those who are cognizant of what is happening to them and would like the resources to live as full a Jewish life as possible, I would like to try to make that possible. Part of the way this will be possible is through creative liturgy and readings, as well as through brainstorming rituals that substitute for the many food-based rituals within Judaism. For most people, I think it is safe to argue that living a life without food is living a life that has a gaping hole in it. It might be impossible to fill that gaping hole completely, because food and eating are such a basic and enjoyable part of being human. Even so, I think we can do better than we are doing. I think Judaism can respond to the medical advancements that have created this new group of Jews. And I will start to figure out how that might be possible.

Methodology

To do work like this, I am using a narrative feminist approach in the interpreting of halakha and in my exploration of the *mahn,* manna, narratives. Feminism is important to my project because one of the goals of feminism to is to see individuals for who they are as full human beings, as opposed to ignoring details that should be critical in rendering ethical decisions. When explaining a feminist approach to law, Dr. Adler writes: "In contrast to formalist legal approaches, this approach is implicitly historicist. It seeks out data about personal and social experience that abstract paradigms would exclude."[12] If I were using a formalist

[12] Adler, Rachel. "Innovation and Authority: A Feminist Reading of the 'Women's Minyan' Responsum." Edited by Walter Jacob and Moshe Zemer. *Gender Issues in Jewish Law: Essays and Responsa* (Berghahn Books), 2001: 6.

approach to law in this project, my halakhic inquiry would be quite short and inadequate in dealing with the population I seek to address. A formalist approach, as I will discuss in Chapter 2, would be as simple as saying that a person on ANH is not eating and is thus not part of areas of Jewish life that involve food.[13] The impact of a formalist approach on actual lives is that it would deny full humanity and agency to those dependent on methods of ANH to continue living. A feminist approach, however, allows for a much fuller range of human experiences and, in fact, openly acknowledges that our society is full of various groups of people who do not conform to patriarchal boundaries.

The importance of narrative is one of the characteristics of a feminist approach, as mentioned above. It is worth noting explicitly the importance of narrative ethics to this thesis, though. The details of subjective or interpersonal impact that can be gained through narrative are important to my methodology. As Tod Chambers and Kathryn Montgomery point out, typically it is just the particular bodily malfunction that is the focus of medicine.[14] Chambers and Montgomery write: "This loss of individuality is part of the admirable, but sometimes appalling, egalitarian character of medicine. A bioethics case, by contrast, reintroduces character and motivation and thus thickens the plot."[15] Part of my methodology depends on the idea that not every person on ANH has the same experience. There are different types of ANH, and these have different impacts on the patient. Whether the patient ever feels satiated or not, and whether the patient has personal agency or not, should be factors in determining an ethical halakhic approach. Such details can only be found by examining narrative.

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[13] See, for example, *b.Ḥullin* 103b. See also CCAR Responsa Committee, "CCAR Responsum 5771.5, Reciting Blessings over Tube Feeding." *CCAR*. 2011. http://www.ccarnet.org/responsa/reciting-blessings-over-tube-feeding/ (accessed March 2015).

[14] Chambers, Tod, and Kathryn Montgomery. "Plot: Framing Contingency and Choice in Bioethics." In *Stories Matter: The Role of Narrative in Medical Ethics*, edited by Rita Charon and Matha Montello, 77-84. New York: Routledge, 2002: 81.

[15] Ibid. 81.

Also, as Dr. Adler does in her work, to engage in this project I need to differentiate between the traditional halakhic sources I am using and the liberal halakha I am seeking to construct using Jewish tradition. Based on the Hebrew root of the word halakha, which means to go or walk, Dr. Adler points out that halakha "is the act of going forward."[16] Part of going forward is responding in an ethical way to advances in medical technology, such as I am seeking to do in this thesis. My goal, therefore, is to build a proactive halakha surrounding issues of ANH. Such a halakha requires taking risks, because to create a proactive halakha one needs to be willing to define new halakhic categories and make unprecedented decisions based on those categories. This is precisely what I seek to do.

[16] Adler, Rachel. *Engendering Judaism: An Inclusive Theology and Ethics*. Boston: Beacon Press, 1998: 21.

Chapter 2:
Artificial Nutrition and Hydration in Halakha

A human is a type of animal. Animals need nourishment in order to live. They obtain nourishment by eating. When animals eat, they consume some type of food. These statements may seem self-evident, but a more critical look at some of the terminology is necessary when focusing on topics of nutrition.

Words like "eat" and "food" are terms we learn when we are very young. What does the word "eat" really mean, though? And what about the word "food"? What types of nourishment constitute "food"? Are there exclusions, meaning things that seem to fall into the category of "food" but are excluded for some reason? What ways of consuming nourishment can be defined as "eating," and are there exclusions in regard to this category? From the time we are very young, we begin to learn what we can define as food and what we do not want (or are not permitted) to put in our mouths. One of the first words we learn is our culture's equivalent of yuck/ick/feh/ichsa. When a conscious, thinking, feeling young adult or adult can no longer eat, the categories established as young children and reinforced throughout the years have to be reconsidered.

The fact that animals need food to survive means that, without intervention, an animal that can no longer eat will die. The intervention of Artificial Nutrition and Hydration (ANH) has enabled medical professionals to sustain the lives of some patients who are not able to nourish themselves. The term "Artificial Nutrition and Hydration" carries a couple of connotations. First of all, the word "artificial" tells us that this process of receiving nutrition is a human-made innovation, not a natural physical process. The terminology is also sterile, with the connotations that come with a medical setting.

Does the term "Artificial Nutrition and Hydration" lead us to make certain implications about the patients whose lives may be saved by this intervention? Though the form of nutrition is referred to as "artificial," the human being dependent on such a medical intervention is *not* an artificial being. The human being is still an animal, even though she cannot nourish herself through natural physical processes. That same human being will, ideally, be looking for whatever comfort can be found even in times of intense pain and suffering. One way we find comfort is through knowing what we can generally expect in life, and we form patterns based on those expectations. A natural expectation we have as people is that we eat, and even though we must eat in order to live, the act of eating goes far beyond sustaining our lives. Indeed, eating is a basic human function. Yet eating also serves many social, cultural, and religious functions. Because of this, food and the act of eating permeate many areas of our lives.

Unfortunately, even though it can be a life-saving measure, pain and suffering are often increased by ANH, partially because of the major role food and eating play in our lives and partially because being treated by ANH is painful and exceedingly hard. Most methods of ANH increase physical pain. In the case of feeding tubes inserted directly into the digestive system, for example, the tubes protrude from a hole in the body that was created by medical professionals. Our bodies know that these holes do not belong there, and neither does the tube protruding from that hole, so the body can respond to these tubes with reactions such as swelling, oozing, or even infection. It can also be quite difficult for a person to adjust to being nourished in a different way. With all forms of ANH, unpleasant side effects are possible and even common. With few physical comforts to be found, those on ANH need spiritual and emotional resources. As I have mentioned, one source of comfort is found in meaningful connections to others, but those connections are weakened when a person cannot eat precisely because of the strong link between

eating and socializing. And yet, even though a person cannot eat, like other human beings the person on ANH continues to have real feelings, including real needs for comfort and meaningful interactions with other people. None of these experiences are artificial.

Seeking to acknowledge the existence of real people in painful situations, I am going to explore some of the ways ANH has been thought about in halakhic sources so far. Then, I will try to provide more context so that I might be able to move the discussion further than the classical halakhic materials, including texts that target end-of-life concerns but not long-term disability concerns. I will start with the concept of אכילה, "eating." Interwoven with this discussion will be an exploration of different types of ANH. Different feeding methods involve different parts of a person's anatomy and have different implications for the patient. I believe that such distinctions should influence a serious interpretation of the halakhic issues involved, and I will explore some of the ways this may be possible.

Up to this point, the bulk of halakhic arguments have focused on ANH in patients who are at the end of their lives, or patients who are unconscious. There has also been some halakhic inquiry into what it is like to live on ANH as a temporary measure in a hospital setting. I seek to address a different group: those living on ANH who may survive, or those who may live on ANH for years with a terminal condition but are still living amongst their loved ones. The category of people I am addressing in this thesis are those who live on ANH as a way of life, either temporarily or while they slowly approach death due to conditions such as ALS. I am not focusing on those who are unconscious in a hospital, or those who are at the very end of their lives, or those who are on ANH for a couple of days or a week following a medical procedure. Brilliant scholars have addressed such groups already, and I enjoy reading their work. Their work gave me a starting point for my project. But those scholars and halakhic thinkers have

focused on a category much different than the category I am seeking to address. Therefore, my effort here is to begin to find a place for this relatively new category in Jewish law.

Legal Methodology

I approach this work keeping in mind scholarship by David Ellenson and Rachel Adler. Rabbi Ellenson stresses the importance of context in making legal decisions. Dr. Adler acknowledges the importance of context as well, and she also stresses the importance of narrative. The following are some of their ideas that are influencing my current work:

> Scholars of law have frequently noted that there is a close relationship between morality and legal reasoning. […] It is hardly surprising, or unique, then, that the Jewish legal system, including the responsa, display the same characteristic of morality as do others. Indeed, it has often been argued that Jewish law elevates ethics to the status of law and that individual cases become specific opportunities for rabbis to operationalize the ethical values of the Jewish tradition by applying them to concrete matters.[17]

> These concerns about the impact of context and perspective on legal decision making are fundamental to feminist jurisprudence. Feminists argue that law rests upon narratives and is composed of narratives. Narratives are not abstract and general but concrete and sharply specific. By dropping crucial contextual elements, a jurist may distort the nature of a case. A feminist approach to law demands an expanded notion of legal relevance that renders admissible more richly particularized accounts and wider temporal boundaries than classical legal argumentation would admit.[18]

I agree strongly that context and narrative are important when rendering ethical halakhic decisions. I also resonate with Dr. Adler's feminist approach to Jewish law. I, too, claim that the particular aspects of different methods of feeding and how those impact people in various ways are important to rendering ethical halakhic decisions that are still rooted in Jewish tradition. Because of these convictions, one of my struggles with the task I am attempting is that not all patients are the same. Just as there is a wide array of eating preferences among people who can

[17] Ellenson, David. "Jewish Legal Interpretation: Literary, Scriptural, Social, and Ethical Perspectives." Edited by Peter J. Haas. *Semeia 34: Biblical Hermeneutics in Jewish Moral Discourse* (Scholars Press), 1985: 105.
[18] Adler, Rachel. "Innovation and Authority: A Feminist Reading of the 'Women's Minyan' Responsum." Edited by Walter Jacob and Moshe Zemer. *Gender Issues in Jewish Law: Essays and Responsa* (Berghahn Books), 2001: 6.

eat, there is also variance among those who cannot eat. Some of the differences arise from the particular medical conditions that lead people to depend on ANH for sustenance. Others arise from the different physical reactions people have to the method(s) of ANH being utilized. I cannot do justice to every individual case. I can, however, acknowledge some of the possibilities and theorize a framework for thinking through those possibilities in a more proactive way.

Halakhic Sources on Nutrition and Medicine

With the medical advancement of ANH, there are multiple ways that medical professionals can deliver nutrition and hydration to patients who cannot orally ingest their sustenance. These ways include Nasogastric Tubes (NG tubes), Jejunostomy Tubes (J-tubes), Gastrostomy Tubes (G-tubes), and Total Parenteral Nutrition (TPN). NG tubes and G-tubes both deliver food to the stomach, though an NG tube is put in through a patient's nose and goes down the esophagus into the stomach, whereas the G-tube goes directly into the stomach. A J-tube enters the patient's lower bowel, which is below the stomach. Patients being sustained through use of a J-tube alone are not using their stomachs. TPN enters the body through a patient's veins, meaning the digestive system is not being used at all with this approach. There are also different ways to administer some of these feeding methods. There are automated pumps that deliver a very small amount of nutrition at a time over a long period of time, typically for 16-18 hours per day. There are also feedings called bolus feedings. A bolus feeding is when a person receives a can or two of medical formula all at once. Those living on bolus feedings alone will be fed at regular intervals throughout the day, which is less of an adjustment for the body since humans typically eat a few times a day. There are also those who live on a mix of automated feedings and bolus feedings. These are just a few of the important issues that should be noted when considering a proactive approach to halakha regarding ANH. I have included these details and a few others in the table on the following page:

Table A

ANH Method	Anatomy Involved	Nutrition Delivery Method(s)	Type(s) of Nutrition Used	Notes
Nasogastric Tube (NG Tube)	Tube goes through nose. Nutrition goes through esophagus to the stomach	-Feeding Pump -Bolus Feeds in some situations	Medical drinks and formulas	-Not ideal for long-term use. -Tubes need to be replaced every 1-4 weeks, alternating nostrils.
Gastrostomy Tube (PEG tube or G-tube)	Upper Intestine (Stomach)	-Bolus Feeds -Feeding Pump possible	-Medical drinks and formulas -Variety possible: includes drinks that are sold in stores for oral consumption by those who can eat -Homemade nutrition sometimes allowed	-Larger-gauge tubes possible -Tubes can be used to deliver nutrition and medicine
Jejunostomy Tube (J-tube)	Lower Intestine (Jejunum)	-Feeding Pump -Bolus Feeds possible for some	Medical drinks and formulas	-Tubes can be used to deliver nutrition and medicine -Smaller-gauge tubes only -Clogs often
Total Parenteral Nutrition (TPN)	Veins	Automated Pump	Medical solutions that are clear in color	-Nutrition delivered through a central line, a PICC line, or an IV -Nutrition is hard on the veins, so this method is not preferred for long-term use if another option is possible -This method is useful for those whose entire digestive systems are impacted by their condition

The table above is technical, taking the physical impacts of different feeding methods into account without getting at the more personal elements of what the experience is like to live being sustained by each method. The table does not answer questions such as how much autonomy a person can have while using the different methods. (Can the person prepare his own nutrition when using an automated pump? Can the person deliver her own bolus feeds? Does the person get any choice regarding when and how feedings are administered?) The table does not answer questions of whether people feel satiated when using the various methods. All of these issues are important when considering a fully reasoned halakhic response. Yet I have found that it is impossible to generalize peoples' experiences living on these different methods of ANH. The truth is, one person may sometimes feel satiated from the method of nutrition being used, while another may feel nothing but hunger through the entire experience of being sustained by ANH. One person may be able to prepare her own food pumps, or deliver her own bolus feeds, while another may be capable of taking initiative yet have a caretaker who usually takes care of such tasks. Depending on the reason(s) a person is on ANH, doctors will give people different restrictions and different privileges. Such differences do not depend as much on the method of ANH being used as they depend on the person's physical and mental state. Therefore, the use of narrative ethics is critical in determining what may or may not be halakhically appropriate in each case. The details of a particular person's situation need to be taken into account. The most I can do is acknowledge the broad narrative areas (such as autonomy and satiation) that should be considered, and begin to construct a halakha that can be applied to this variety of possibilities.

The majority of halakhic sources on ANH begin with an analysis of *b.Ḥullin* 103b. There are several important Hebrew terms in *b.Ḥullin* 103b that help to explain the halakhic issues involved in eating. Initially, the primary concern of the halakhic thinkers of the Talmud was

kashrut. In *b.Ḥullin* 103b, the rabbis were trying to determine at what point a man would be liable for eating non-kosher meat. The term used to describe the size of food large enough to render someone liable is referred to as *k'zayit*, "like an olive." This same quantity of food is used in *b.Pesaḥim* 115b to describe the amount of *matzah* one must swallow to fulfill the commandment. From the descriptions in *b.Pesaḥim* and *b.Ḥullin*, it does not seem like a *k'zayit* of food is as small as a lot of the olives we see today. Talmudic hyperbole and centuries of interpretation render the legal definition of the *k'zayit* as a little bigger than that.[19] It is also worth noting that *b.Pesaḥim* and *b.Ḥullin* refer to different types of eating. *B.Pesaḥim* refers to ritualized eating, whereas *b.Ḥullin* refers to what it is permissible to eat and what is not acceptable for Jewish people to eat.

When talking about what happened to the *k'zayit*, two important terms emerge: *ha'naat garon* and *ha'naat m'ayim*.[20] In the Talmud, the terms are both in masculine singular possessive form, making them *ha'naat g'rono* (enjoyment of his throat) and *ha'naat me'av* (enjoyment of his insides). These terms are helpful in a few ways. First of all, these terms tell us that we are considering the halakhic category of *ha'naah*, enjoyment. The category of *ha'naah* helps narrow down what the discussion is about. This particular discussion is not about praising God for a commandment, but is instead about enjoyment or benefit from a particular element. In this case, the element from which we are benefitting is food. Next we can consider the following: How is that enjoyment, benefit, or pleasure derived from eating? According to *b.Ḥullin* 103b, there are two ways we may derive enjoyment from our food. *Ha'naat garon* translates to something such as "enjoyment of the throat" and has to do with enjoying the taste of the food as the food is getting closer to the back of the throat but before the food goes down the esophagus into the

[19] Steinsaltz, Adin, ed. *The Talmud: The Steinsaltz Edition.* New York: Random House, 1989: 187, 288.
[20] *b.Ḥullin* 103b.

stomach. *Ha'naat m'ayim* can be translated to something such as "enjoyment of the insides" and deals with the reality that once food enters the stomach, it helps us to feel satiated and we derive pleasure from avoiding the painful sensation of hunger.

The Hebrew for the word *m'ayim* is not referring to one part of the digestive system. In this case, the term could mean "the intestines," which would arguably refer to either the upper intestine (the stomach) or the lower intestine (the Jejunum). This lack of differentiation needs to be noted here because NG tubes and G-tubes have nutrition entering the stomach before going into the lower intestine, whereas a J-tube enters the digestive track lower down, already in the lower intestine. It could be argued that *m'ayim* could include the lower part of the digestive track, not just the esophagus and the stomach, which are both higher in the digestive track. This may be an important element to consider since those being nourished through a J-tube alone often have much more trouble feeling any sense of satiation. The jejunum has a smaller surface area than the stomach, so it can be hard to put larger amounts of nutrition through a J-tube. When this is the case, people are often hungry all the time or almost all of the time, meaning those on J-tubes would not necessarily experience *ha'naat m'ayim* often or at all.

Distinction between Food and Medicine

I will briefly discuss the difference between food and medicine in halakha now, and then explore some more of the implications in regards to food and medicine in relation to ANH. In *b.Pesaḥim* 25a-b, we read that we are allowed to heal ourselves with all forbidden things, except for "idolatry, forbidden sexual activity, and murder." One lesson we learn from this is that foods that are not kosher can be used to make medicine. Medicine and food are not the same, but medicine may be made out of food. In modern times, medicine can be delivered to the body through a secondary agent, such as taking a medication mixed in yogurt because a person is unable to swallow a pill and needs to crush it. Since crushed pills taste very bitter, most doctors

recommend mixing crushed pills with applesauce, yogurt, or something else that can be eaten. Thinking in terms of halakha, it would be unnecessary to mix a crushed pill with forbidden food products. A pill could be made with forbidden foods, though.[21]

B.Berakhot 36a-b talks some about medicine too. The discussion in *b.Berakhot* 36 is about the need to say a blessing over anything that we derive benefit from, and toward the end of 36a and beginning of 36b, there is a discussion over olive oil. The Talmud argues that a blessing is said over the primary ingredient and not a secondary ingredient. The discussion is over something called "*ali-garon*," which was used for a sore throat. The medicine is supposed to be mixed with olive oil on Shabbat, which means the olive oil has turned into a vehicle for the medicine. In using the medicine in olive oil, olive oil is only a secondary ingredient and therefore does not require a blessing. The Hebrew is referring to a primary ingredient and a secondary ingredient, and in the case of primary and secondary we are to bless over the primary ingredient. Saying a blessing over a secondary ingredient would be superfluous, and superfluous blessings are to be avoided because a superfluous blessing is a blessing said in vain (*berakha l'vatalah*).

The possibility of food changing statuses matters to me partially because my own argument is that categorizing elements is important. Halakha is quite invested in establishing categories, because it is through categories that we make sense of our world. I am arguing that details of different categories are important to a serious discussion of ANH and halakha, and that is where I will continue this exploration.[22,23]

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[21] For a discussion of medicine made with forbidden products, see CCAR Responsa Committee. "CCAR Responsum 5758.8, Medical Experimentation: Testing Drugs Made of Pork By-products." Edited by Mark Washofsky. *Reform Responsa for the Twenty-First Century* (Central Conference for American Rabbis), 2010: 139-149.

[22] This is where my discussion will be incomplete based on not having all of the halakhic resources, but I am going to write some of my initial understandings that still flow from the discussion I have been setting up.

[23] Refer to Table A for descriptions of different feeding methods. This chart will be useful to the reader while considering this section.

According to a classical understanding of the halakha, the method of ANH best suited to a traditional understanding of what it means to eat would be the NG tube. Because the NG tube delivers nutrition through the same route food travels when one eats in the natural manner, it might be argued that this method of ANH could fall under the category of *ha'naat garon*. Yet, NG tubes are usually a short-term method of feeding and are also often used in newborns. Neither of these groups are ones I am considering in this thesis. I have also heard that this method is rather unpleasant, resulting in a painful or tickling feeling in the back of the throat, as well as other problems. I find it doubtful that one could derive any sense of *ha'naah* from such a method, especially since with this method we are considering patients with short-term nutrition concerns who will likely be transitioned to a different feeding method if further care is needed. I do not wish to exclude anyone who is looking to live a Jewish ritual life while being nourished artificially. That is precisely what I am trying to avoid by doing this research. I just know those on this method do not tend to remain on it for long, and if they are newborns then they are not yet cognizant of *mitzvot*.

J-tubes and G-tubes do not provide *ha'naat garon*, but there are times when they can provide *ha'naat m'ayim*. Further, with these tubes patients sometimes have permission from their doctors to administer bolus feedings when they feel hunger. This type of volition is notable in regards to halakha, seeing as one argument against saying a blessing over artificial feedings is a lack of volition.[24] Also, those who are on automated feeding pumps may set up their own pumps, and this is a form of agency worth considering when coming up with a proactive, ethical halakhic response.

[24] CCAR Responsa Committee. "CCAR Responsum 5771.5, Reciting Blessings over Tube Feeding." *CCAR*. 2011. http://www.ccarnet.org/responsa/reciting-blessings-over-tube-feeding/ (accessed March 2015).

TPN is unlike the other forms of ANH in some key ways. The medical formula used in TPN is not a medical drink, like the ones used with the other methods of ANH. The formulas tailored for patients on TPN are clear in color and are stored in a freezer before use. Then, a bag of the clear medical formula is either attached to a patient's IV or put through an automated pump. Because the nutrition enters the veins, bypassing the digestive system entirely, there is no feeling that one is being fed. For the short amount of time I was on TPN, I did not even realize when I was having lipid fats put through my veins. Until someone told me otherwise, I thought it was just more saline or antibiotics. For others who depend on this method of ANH much longer than I did, there is at the least the possibility that the person may prepare his or her own food pump. People on this method long-term know when they are receiving their nourishment.[25] They can have the same sense of awareness of what is happening to them as those who are living their day-to-day lives on other methods of ANH, meaning that they have agency. They get to make decisions about their care, including the decision to go on TPN if the doctor has recommended it, and some of them take partial or full responsibility for preparing their food pumps and administering their feedings. Again, this is much different than considering a person who is unconscious and being nourished by ANH, or someone who is going to die within a few days or weeks and is barely conscious.

Attempt at a New Halakhic Response

The responsa literature I have read on issues of ANH does not come close to addressing the types of nuances I have addressed so far. As I have mentioned, there are good responsa available on end-of-life issues related to ANH, but that is a different category than the one I am addressing. I find it notable – and perhaps a bit disturbing – that I specifically asked the CCAR

[25] Because of the different nature of this method, further discussion of TPN is going to be one part of what I do in my next chapter, when I explore manna in Jewish tradition.

Responsa Committee about situations such as the ones I survived.[26] In the *sh'elah* I sent them, I tried to give them the details I thought they needed. I mentioned the different feeding methods that were my primary sources of nourishment, thinking that if I told them, they would know that differentiating the methods is important to a serious discussion of the halakha involved. Even with those prompts, they did not seek to understand the different methods of ANH and the implications those methods can have for patients. This is the *sh'elah* I sent them:

> Over the course of multiple life-threatening esophageal ruptures, I spent 6 months being fully sustained by feeding tubes – certain times only through a Jejunostomy tube (J-tube) and certain times through a combination of the J-tube and a Gastrostomy tube (G-tube). Throughout most of that time period, I was torturously conscious and aware of my situation. I asked an Orthodox friend of mine if there was a blessing I could say over my tube feedings, and she informed me that because tube feedings are not considered a form of eating, there was no blessing I could say. At the time I already felt that almost everything had been taken from me, so when I learned of this facet of *halakhah* I felt that I was being isolated from Judaism as well.
>
> I therefore ask this question of you: from the standpoint of our Reform responsa tradition, is it appropriate to recite a blessing over tube feeding?[27]

The committee failed to see the narrative component, even though I tried to provide it for their consideration. Failing to see the narrative component, they missed vital details, and parts of their response are so misinformed that those parts of their response are inaccurate. For example, the committee claimed that patients on ANH have no volition involved in their feedings. They claimed that being sustained by ANH is just like breathing, something we do without thinking about it. As I described above, some patients have quite a lot of involvement in their feedings. Also, the committee claimed that the body simply accepts the artificial food, and when doing a bolus feeding this is inaccurate. When doing a bolus feeding with a G-tube, for instance, the

[26] CCAR Responsa Committee, "CCAR Responsum 5771.5, Reciting Blessings over Tube Feeding."
[27] Ibid.

patient has to have the stomach muscles as relaxed as possible and focus on the act of being nourished. The feeling of satiation that results from a bolus feeding through a G-tube is worth that effort.

Another important element the committee missed is the emotional component. The tubes can become much more than just a way to get nourishment. Patients and their families form emotional bonds to the tubes. They can become part of one's identity, which can be a healthy response to dealing with a difficult and traumatic situation. There are many different types of medical implements that get inserted into the body or worn on the body. One critical difference between a type of feeding tube and something else such as an IV, PICC line, or brace of some sort is that the feeding tube becomes part of one's anatomy in a deeper way. When a person cannot use part of his or her anatomy for the act of eating, the feeding tube takes the place of the part of the body that cannot be used.

I formed complex relationships with each of my feeding tubes. They were part of me while I had them, and even though I did not want to keep them forever, when each was removed I cried because it was emotional to lose a medical implement that had kept me nourished when my esophagus could not be used for eating. Just like a person learns the strengths and limits of his or her body, I learned the limits and wonders of each feeding tube. I learned how much nutrition my body could tolerate through each tube, and I knew what would make me sick. I learned quickly that I knew my body better than the nurses and doctors, and I started directing them on how my tubes worked for me, including being clear about how much nutrition I could handle and what would make me sick. I learned that my tubes could be used for vomiting if it was necessary. I discovered that after each of my many barium swallow studies, I could open my tube over a sink after the test and let out the barium since barium is not healthy for the body

anyway. All of my tubes were stitched painfully into my body so that they would not slip out, and I had to figure out which clothing I could wear so as to try to decrease pain, and because they were coming out of my body I knew how to handle them best when receiving medications or feedings. They were temperamental and sometimes downright infuriating, especially the J-tubes, which clogged often and had to be replaced when a clog could not be cleared with water flushes or by reaming the tube with a straightened clothes hanger. Sometimes the tubes would open and cause messes, sometimes due to a clog in the tube. When this happened at night I would wake up in a puddle of tube formula. My G-tube was my favorite tube, because I was able to sometimes feel satiated and G-tubes do not clog like J-tubes do. Yet because the G-tube was the widest and the heaviest, it caused me a great deal of pain.

I listed these details to try to express that these tubes were part of my body at that time. All of us have imperfect bodies, and we learn how to live with our bodies' imperfections and, in the best-case scenarios, try to love even the flawed parts of ourselves. For example, if someone has bad knees, that person will learn the limits of his knees, learn what causes pain, and also ideally still love his knees because he knows life would be a lot harder without them. Bodies are imperfect. So were my tubes, but for the time being they were a functional part of my body, a part of my body meant to replace the esophagus I could not use.

What I see in this responsum is a *t'shuvah* written by people who did not take the time to consider, truly consider, the group of people about which I asked in my *sh'elah*. Those on the CCAR Responsa Committee who responded to my *sh'elah* did not consider the narrative components about which I tried to be explicit. I did not expect that those writing the *t'shuvah* would know what it is like to actually live on a form of ANH, and I would not wish that on

anyone, but I hoped that the committee members would consider the context with which I tried to provide them regarding what it is like to live on a method of ANH.

In dealing with the issue of women's prayer groups, Adler points out a similar type of contradiction: the ones writing the responsa and setting prohibitions do not know about that which they seek to address.[28] Adler writes,

> Amid this din of pettifogging and pontification, only Eliezer Berkovits *z"l* has simply maintained that how women pray when they are not in the presence of men is a question on which tradition has neither data nor policy nor perspective but, rather is "a complete vacuum," that may be filled now that the need has arisen. But for others engaged in prayer group legal polemics – both the defenders of the women graciously adducing permissions and their censorious opponents amassing prohibitions and stringencies – the notion of a halakhic vacuum in which women are free of any authority but their own seems the most intolerable possibility of all.[29]

Given that the resources I have found for ANH so far have little to do with the population I seek to discuss, I find that I need to find a way to stay rooted in Jewish tradition while making innovations. When someone finds a halakhic vacuum such as the one upon which I have stumbled, there is a certain empowerment inherent in filling that vacuum so that the person involved, and other Jewish people facing similar experiences, have resources in place that address and even sanctify their experiences. What I have found is that, even when an authority on halakha and medical ethics responds to issues of those living on ANH, the response is missing the elements I am trying to reach: elements that involve particular contexts of what it is like to be nourished by different types of ANH, and issues such as personal agency during the periods of being nourished artificially. The CCAR Responsa Committee, in their responsum on tube-feedings that I mentioned, cited Rabbi Waldenberg, a medical-halakhic authority. The part they cited says,

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[28] Adler, "Innovation and Authority," 26.
[29] Ibid. 26-27.

> It is common in a hospital setting that the patient being fed by a tube shares a room with another patient who eats in the usual manner and who can fulfill the patient's obligation (*v'sheyukhal l'hotzi'o*) by reciting the *birkat hamazon* (grace after meals) on his behalf. This can be a very reassuring thing for the tube-fed patient who is passionate about fulfilling the *mitzvot* and who is distressed (*mitzta'er*) when he is unable to do so.

The committee claims that such a response addresses the issues of isolation I mentioned in my *sh'elah*. Yet this portion of Waldenberg's response deals only with short-term implications of being on ANH. What about those who go home from the hospital, still being nourished artificially? What about those who spend months or years regaining their ability to swallow, and want to find a way to live a full, Jewish life during that time? What about those who have a condition that will eventually result in their death, but they have to live months or years unable to eat before dying? When thinking about these questions, I finally realized the need to shift my focus away from these sources – sources that focus on either death or short-term illness – to a focus on disability. Focusing on disability will allow me to deal with the emotional components of ANH that I mentioned above.

There are different definitions of what is meant by the term "disability." As Simi Linton discusses in depth, definitions of disability are often medical definitions that focus on physical or mental incapacities.[30] This medical model identifies the problem as being inherent in the person with the disability and aims at treating that person, not at trying to fix the social limitations that prevent people with disabilities from being able to function fully in society.[31] In contrast to this medical model, most of the literature in disability studies prefers to see disability as a marker of identity. Such a way of defining disability, Linton says, "has been used to build a coalition of people with significant impairments, people with behavioral or anatomical characteristics marked as deviant, and people who have or are suspected of having conditions [. . .] that make

[30] Linton, Simi. *Claiming Disability: Knowledge and Identity.* New York: New York University Press, 1998: 11.
[31] Ibid. 11.

them targets of discrimination."[32] This puts the stress on the social condition of having a disability as opposed to possible medical meanings of having a disability. When people with disabilities define themselves based on identity, the power is shifted to those with disabilities instead of medical institutions or, in the case of halakha, rabbis who likely know little to nothing about the groups of people they seek to address.

Interestingly, there is a responsum in which the CCAR Responsa Committee considered ANH in a non-medical way. In the responsum, the committee actually provided context and then presented both sides of the issue. The issue is that of force-feeding prisoners who are on hunger strikes.[33] In this responsum, the committee claimed that the issue could be seen as a political one, as opposed to a medical issue.[34] What I find notable about this is that, in this case, the committee focused on context and narrative and, because of their efforts, they were able to see ANH from a different perspective. While I acknowledge that the difference in context is clear and could not be ignored, not fully at least, I still wonder if this may provide precedent for viewing ANH in a different way than the traditional, medical model.

If the responsum I just mentioned can be seen as a sort of precedent, I am still left with a void that needs to be filled. I may not agree with how the CCAR Responsa Committee reached their decision in the *sh'elah* that I sent them several years ago, but because of their decision I understand that one of my goals needs to be applying different texts to this issue.

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[32]Ibid. 12.
[33] CCAR Responsa Committee. "CCAR Responsum 5766.3, Hunger Strike: On the Force-feeding of Prisoners." In *Reform Responsa for the Twenty-First Century*, edited by Mark Washofsky, 381-395. New York: CCAR Press, 2010: 381-395.
[34] Ibid. 383.

Shifting the Conversation

One text we might consider is *b.Ḥagigah* 16b.[35] In this section of the Talmud, the rabbis discuss some of the requirements associated with making offerings. One of the requirements is *semikhah*, the laying of hands on the animal. In this text, R. Jose relates a tradition from Abba Eleazar that, although women are not required to lay hands on offerings, he personally witnessed offerings being brought to the Women's court so that women could lay hands on them for their own spiritual fulfillment. Later rabbis object. Laying hands on offerings must be done with all of one's strength, and if the women are not required to do so, doesn't their action constitute illegitimately causing a holy animal to work? Their spiritual satisfaction would not be a sufficient excuse for working the animal. These later rabbis try to resolve the objection by arguing that what the women were doing was a token *semikhah*, since they were not using all of their strength when laying their hands on the animal but were told to lay their hands lightly on the animal: i.e. it was not a "real" *semikhah*. This argument partially delegitimizes the women's actions, but it is significant that it does not forbid doing something which is not the halakhic "real thing," in order to offer spiritual fulfillment to a halakhically disadvantaged group.

The same reasoning might be applied to cases of people on ANH engaging in actions such as blessing the source of their nourishment. The blessing will not carry the same halakhic weight, not in the traditional sense, because those being nourished through artificial means are not classified as eaters and therefore do not have the same religious obligations that eaters have. Yet, if non-eaters feel a sense of fulfillment through engaging in rituals or blessings but with no requirement, perhaps that can lessen some of the feelings of isolation caused by being sustained by ANH.

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[35] I express great appreciation to Dr. Rachel Adler, who mentioned that this text is one I might consider in doing this work.

Another text we might consider is *Mishna Berura* 17:1, which explains that those who are blind are still obligated to say the *berakha* over *tzittzit*.[36] Technically, we are commanded to see the *tzittzit*, and of course a blind person cannot do that. Yet as Elliot Dorff explained, the Hebrew ראה (*ra'ah*) can be read either as "to see" or "to experience."[37] Those who cannot see the *tzittzit* still have the ability to experience them through touch, and those who cannot see are still able to pray.

Such an idea can be applied to those who cannot eat, too, because those on ANH are still experiencing the receiving of nutrition. They are not receiving nutrition in the traditional manner. They are experiencing it in a different way. Therefore, it might be argued that those on ANH can take part in certain *berakhot* and *mitzvot*. Some of the ways they can do this will be different than those whose nutrition falls under the classical definition of *akhilah*, but it seems that Mishnah Berura 17:1 and Dorff's explanation provide us with another entry point for transforming the halakhic discussion.

Using different texts such as these and applying them to ANH provides an opportunity to include those who are aware of what is happening to them, have agency, and may survive or live for a prolonged period of time on ANH. It is abundantly clear that I still have a lot of research to do to take this project even further. For the time being, I have laid out a framework for trying to contextualize the different variables involved in those living day-to-day lives on ANH, and I have discussed why these variables matter when making informed halakhic decisions. I have also begun the task of bringing different texts to bear on the issue of those living with ANH. Previous work has dealt with issues encountered at end-of-life, or by those who are unconscious. These halakhic decisions were not written for those who were on the ANH, because those on ANH

[36] I would like to express great appreciation to Rabbi Elliot Dorff, who explained in part why a blind person saying the *berakha* over tzittzit is still important. His explanation led me to find this text.
[37] Rabbi Elliot Dorff, in conversation with the author, February 22, 2015.

cannot make the same type of decisions about their care if they are very close to death or are unconscious. I am seeking to provide for ways for those who are able to have agency in their own Jewish lives while living on ANH.

Chapter 3:
Food in the Human Imagination

> *Dis-moi ce dont tu as envie, je te dirai ce que tu es.* Tell me what you crave, and I will tell you what you are.
>
> Food is our common experience from birth to death. Food has the power both to give life and to take it, to nourish the body and mind or to infect them. What we do with food determines the quality of our health and defines our humanity.
>
> Who are you, though, if you can't eat or drink? What is your Food Self? How do you live – with people, with community, with culture, with history, with yourself – without the food and drink as fundamental as breathing and as essential as joy? Who are you if you're reduced to smelling the apricots? *Tell me what you crave, and I will tell you what you are.*[38]

In this thesis, I started out by writing about "eating" and "food" as general ideas. I noted that both are instrumental in forming cultures and sustaining relationships with other people. There are other layers involved in the complexity of our food relationships, though, and I want to try to explore some of them. One of the complexities arises from the idea of our food cravings. If the purpose of food were as simple as sustaining us, cravings must be useless. Yet without cravings, animals might not be interested enough in food to eat it. With no source of nourishment, living beings perish. So to some extent, we *need* to *want* food.

What do we do when that which sustains us is not enough to make us feel fulfilled? There is a difference between being sustained so that survival is possible, and being pleased with the way we are sustained. By definition, having a craving means that someone feels a need for something specific. There is a void present until the craving can be fulfilled. Some variation of the original craving may do. For example, there are many different recipes available now for gluten-free foods. When someone is diagnosed with Celiac Disease and has to shift to a gluten-free diet, the transition is difficult and can be very upsetting. Having recipes available so that the

[38] Reiner, 13-14. See also page 12, where Reiner quotes Anthelme Brillat-Savarin from 1826: "Tell me what you eat, and I will tell you what you are."

person with Celiac Disease can still eat many of the foods he or she liked before can help because specific food cravings are more likely to have a way to be satisfied. People with diabetes also have to struggle with specific food restrictions, and having sugar-free options available readily in stores can make it easier for people to comply with their diets.

We crave foods, and those cravings shape our imaginations and help us to form our realities. Part of the challenge with studying Artificial Hydration and Nutrition (ANH) the way I am trying to do has been to figure out how to express adequately the differences between what we need and what we want. The principle of "moderation" is helpful for most diets, the idea that we should not have too much or too little. Moderation does not look the same for a person on ANH, because the person on ANH does not eat and drink the same way. The nutrients that go into the person's body still need to be balanced, but this is achieved in a medical way that is far-removed from the realm of the choices most eaters make each day. People on ANH do not have the luxury of making many decisions. Yet even in the absence of decision-making, people on ANH still have cravings.

When trying to find ways that I might think about different forms of ANH using a Jewish framework, I could not help but return again and again to the idea that perhaps we can learn something by studying manna. The Exodus from Egypt is a powerful part of our Jewish storied past, and it is a part of our shared Jewish story that can give us some insight into food in the Jewish imagination. In Deuteronomy 8:3, we read: "[God] subjected you to the hardship of hunger and then gave you manna to eat, which neither you nor your ancestors had ever known, in order to teach you that a human being does not live on bread alone, but that one may live on anything that *Adonai* decrees."[39] Just as the Israelites did not know what manna was, and it kept

[39] Translation adapted from Eskenazi, Tamara Cohn, and Andrea L. Weiss, eds. *The Torah: A Women's Commentary.* New York: URJ Press, 2008: 1094-1095.

them alive anyway, the different methods of ANH were unknown until recently. Even once artificial feeding methods were discovered, many advances were made in more recent history. Artificial feeding, as we know it today, did not exist until the 20th century.[40] Even with the more-advanced methods we have today, there are significant risks associated with artificial feeding, as well as myriad of unpleasant or even dangerous side effects. With methods such as NG tubes, G-tubes, and J-tubes, risks include serious infection, death, and perforations of the anatomy involved with whichever method of feeding is being used. With all forms of ANH, there is also the risk that the body will reject the artificial nutrition being provided. So even today, with all of the medical advances that were made in the 20th century, there are no guarantees for patients who need ANH to survive. The fact that ANH as we know it today is a recent medical development, as well as the problems associated with ANH that can lead to suffering and complaints by patients, seems to provide a link between manna and ANH.

Manna in Jewish Text

In the Torah, there are two narratives that deal heavily with the concept of manna. The first is in Exodus 16, and the second is in Numbers 11. Both of these narratives tell the reader some about what manna was, as well as some of the complaints that the Israelites had regarding the manna. The first mention of manna in the Torah occurs in Exodus 16:15. Upon seeing the manna that had fallen to the earth, they ask "מן הוא (*mahn hu*)," which has been translated as "what is it?" by various translations.[41] The way the Israelites asked this question is how manna got its name, which in Hebrew is מן (*mahn*).

[40] For an overview of the history of ANH, see: Durkin, Terri, and Maggie Vescovich. "Historical & Current Perspectives on Artificial Hydration Nutrition in Homecare." *American Speech-Language-Hearing Association.* Conference Presentations, 2011.

[41] See, for example, Eskenazi and Weiss, 395. The Hebrew for "what is it?" would normally be *mah hu*. Sarna's *JPS Torah Commentary* for Exodus notes on page 89 that *mahn hu* could be an ancient dialectic variant.

The awareness that manna is named after a question is noteworthy. Such a concept raises the question of what it would feel like to be fed or sustained by something that was previously unknown. As I discussed in the previous chapter, our constructs of food and eating begin to crystallize when we are very young. We know what constitutes as food, and we know what does not. Food is such a major part of our lives that we are not necessarily conscious of how deeply ingrained our understandings and beliefs are until those constructs are challenged. The manna the Israelites were provided in the desert forced them to expand their ideas of what "food" can mean. For those being sustained by ANH, constructs of "eating" and "food" also have to be reconsidered and stretched. I was conscious when my surgeon told me I would be sustained by a J-tube and explained to me what that meant, and I was very confused even though I was an intelligent graduate student in my 20s at the time. A compassionate surgeon was sitting in front of me, telling me that the J-tube would keep me alive while they tried to heal my body, yet because I had such deeply rooted beliefs about the ways people need to eat food to survive, I could not grasp fully everything he was telling me. Some of my immediate thoughts were something along the lines of, "But if people don't eat, they die. So I am going to die. But wait…that's not what he is saying. So *what* is going on? And *what* is going to sustain me through treatment?" My attempts to define for myself the new sustenance keeping me alive seem quite similar to the response of the Israelites to the manna: *mahn hu*, what is this? If we were to imagine the Israelites saying this upon investigating the manna, I think we might hear shock in their voices, the shock that contains that numb kind of disbelief that results when the very foundations of your existence, survival, and reality are being shaken in a major way.

From the text in Exodus and the text in Numbers, we are able to learn a little about what *man* may have been like. Exodus 16:13-14 describes how the manna fell from the heavens at

night so that when the Israelites woke up, a "fine and flaky substance" was on the ground for them to gather and eat.[42] There are different Biblical accounts of how it may have tasted, with the account in Exodus 16:31 saying it was "like wafers in honey" and the account in Numbers 11:8 saying it tasted like "rich cream." Sarna notes that Bekhor Shor and Ibn Ezra suggest that the disparity may be explained by the difference between how manna tasted raw and how it tasted cooked.[43]

The first manna narrative in Exodus 16 takes place shortly after the Israelites crossed the Sea of Reeds, meaning this account takes place toward the very beginning of their time wandering in the desert. Sarna explains that the Israelites were faced with four crises on their way to Sinai, three being a reflection of the harsh realities of wandering in the desert and one caused by other people.[44] The first three crises were a lack of drinking water, a shortage of food, and then there is mention of a separate instance of a lack of water. The fourth crisis was a war waged on the Israelites by a wild tribe they came across in the desert. Sarna explains that all four of these crises left Israel in a precarious situation, and that each of the crises meant the Israelites were in dire need of help. Certainly, any of these four crises could have led to the death of the Israelites. Each of the life-threatening difficulties the Israelites faced gave God a chance to prove that God could, and would, take care of the people. Sarna points out that the fact the people complained is also understandable, though somehow in the first three crises the Israelites appear to be judged negatively for their behavior.[45]

Such negative judgment has carried over into modern readings of the text. I have heard many sermons related to how the Israelites lacked faith in God during their time wandering in the

[42] New JPS Translation, taken from: Sarna, Nahum N. *The JPS Torah Commentary: Exodus.* Philadelphia: The Jewish Publication Society, 2001, 88-89.
[43] Ibid. 92.
[44] Ibid. 83.
[45] Ibid. 83.

desert. Before I had been hungry myself, I listened to the words of rabbis I still admire and thought they were right. I took those sermons as lessons: lessons about thinking positively, lessons about having faith in the Eternal God and having faith that God loves the Jewish people, and lessons about not complaining as long as I am somewhat safe and receiving whatever care I need. Then, when I knew what it was like to be deprived of basic human necessities such as food and water, I started to rethink such an approach to the plight of the Israelites. I started to see that the issue is much more complex than what the text of our Torah implies, and it is also more complex than the responses of commentators who claim that the Israelites needed to have a more perfect faith in God. Being forced to redefine deeply engrained concepts such as "food" and "eating" is beyond difficult. Such shifts in reality are, in fact, quite shocking and deeply unsettling. Such shifts in reality take serious adjustment, but when the shift occurs suddenly and with no adequate warning, there is no time to adjust in a way that might be seen as more graceful by onlookers who cannot imagine the full weight of the confusion and loss involved.

In both of the manna narratives we find in the Torah, the Israelites complained about the source of their nutrition. Technically, they were being kept alive through the manna that God provided for them. The fact that they were being kept alive, yet were not satisfied fully, gets at the difference between what we *want* and what we *need*. A closer look at Numbers 11 will help in further exploring such a distinction. In Numbers 11:4-5, some of the Israelites were seized by a "gluttonous craving" during which they desperately craved meat and wept for the foods they no longer had available to them. After they cried out to Moses, Moses cried out to God, and God responded with anger. God responded by saying that the Israelites would be provided with enough meat so that they would eat it "not one day, not two, not even five days or ten or twenty,

but a whole month, until it comes out of your nostrils and becomes loathsome to you."[46] When some of the Israelites gathered and ate the quail that God sent, "The meat was still between their teeth, not yet chewed, when the anger of *Adonai* blazed forth against the people and *Adonai* struck the people with a very severe plague. That place was named Kibroth-hattaavah, because the people who had the craving were buried there."[47] Eskenazi and Weiss point out that the sin that caused the people to be buried in this place, which translates to "Graves of Craving," was that the people were not satisfied with just the manna. They required more, and when God provided meat to those among the Israelites who had been seized with the gluttonous craving, that group of Israelites actually tried to eat it.[48]

On first reading this text, it appears that God was showing the most vengeful side of God possible. It is true that the God we see in this passage is an angry God, but what happened in this narrative should be considered more carefully given the subject matter of this thesis and this chapter. I have been writing about the difference between what we *want* and what we *need*. The Israelites were being sustained by the manna that God provided. They just did not always *like* the way they were being sustained. They had cravings because of the lack of variety in their diet. The fact that they had cravings is understandable. To have cravings is human. It was the actions of those rebellious Israelites with the gluttonous craving that was the problem. They not only had the craving; when given the chance, they acted on their craving and ate the quail that God provided even though God's promise to send meat was presented as an angry threat.

Those on ANH also have cravings. As I will discuss below, these cravings can serve useful functions. Yet when a patient is put on some form of ANH, there is a good reason for that

[46] Numbers 11:19-20.
[47] Numbers 11:33-34.
[48] Eskenazi and Weiss, 858.

method of treatment. There are so many risks and side effects associated with ANH. Medical professionals choose such treatment in ill patients who cannot orally ingest their calories, or in those patients who cannot orally ingest enough nourishment to sustain them. In the case of those who are not allowed to eat at all, if a patient were to disobey the doctor's orders of nothing by mouth, that patient could die. I had actual holes in my esophagus. Those holes opened into the rest of my body, meaning anything I swallowed exited my esophagus and contributed to the infection that came very close to killing me. With either of my esophageal perforations, if I had chosen to go into the kitchen and get something to eat, I very well could have died. The same can be said for others who are being fully sustained by ANH. Either their digestive systems are not working at all, or eating could result in fatally choking or aspirating into the lungs. To stress again, ANH is a serious medical treatment with many risks. It is not a treatment option that medical professionals choose lightly. And when patients are on ANH, they are surrounded by food. Food is in their homes. Food can easily be found in hospitals. It would be so easy to "cheat" and eat food. But doing so could lead to the doctors' treatments failing or in worst-case scenarios "cheating" could lead to death. Those who are put on a method of ANH need to have faith in their doctors, just like the Israelites were supposed to have faith in God.

> "He subjected thee to the hardship of hunger when He gave thee manna to eat" (Deut. 8:3). R. Hananiah and R. Jonathan asked Menachem the Baker: Can this verse possibly intimate that the manna the Holy One gave to Israel was food that left them hungry? How did Menachem answer them? He set before his questioners two cucumbers, one whole and the other crushed, and asked, "How much is the whole one worth?" "Two silver zuz." "And how much the crushed one?" "One silver zuz." "But is not the crushed cucumber just as large as the whole one?" asked Menachem, and then, answering his own question, said, "Even as a man derives enjoyment from the taste of food, so he derives enjoyment from the appearance of food."[49]

[49] Ecclesiastes Rabbah 5:10, §1. Cited from: Bialik, Hayim Nahman, and Yehoshua Hana Ravnitky. *The Book of Legends, Sefer Ha'Aggadah: Legends from the Talmud and Midrash.* Translated by William G. Braude. New York: Schocken Books, 1992: 76.

The above text alludes to the enjoyment that one can get not just from the taste of food but also from the appearance. When people take time to truly experience the joys of eating, they notice not only the taste of the food, but also the texture, the appearance, the smell, and even small joys like what it feels like to pick up the food with whichever utensil is being used to eat it. When the Israelites were being sustained by manna, they lacked the full experience of eating to which they would have been accustomed.

Similarly, when one is being sustained by ANH, the process of being nourished does not come close to resembling the normal experience of eating. There is no taste, no pleasant sensation in the mouth that results from enjoying different textures or the act of chewing and swallowing, no tempting smells, and no colorful appearance to the nourishment. The different methods of ANH are different in this regard, seeing as some of the formulas that can be put through a G-tube are the same formulas that could be consumed orally. It always struck me as quite odd that the chocolate Ensure that I, or someone else, poured down my G-tube is the same Ensure that I can and do drink when not living on ANH. I could not taste the chocolate. Sometimes I liked to imagine I could, because I could at least smell that formula and knew I could one day taste it again. The formula that went into my J-tube, however, and is widely used in J-tubes, smells horrible. It is made by the same company that makes Ensure, and the cans in which it is packaged say that the formula is suitable for oral consumption and will taste better chilled. I cannot, for the life of me, imagine anyone ever deriving pleasure from drinking that formula. I never tried it, but I was not the only one who thought it smelled unappetizing. My family also found the smell to be quite unpleasant.

There was no illusion that what was being put into my body through the J-tubes was anything other than a medical necessity. It cost $17 per day to nourish me during my first

esophageal perforation, when all I had was a J-tube. When arrangements were being made for my care, someone from the hospital came into my room to explain to my family and me that my medical insurance would not cover my J-tube formula, and they asked what we wanted to do about it. I was a bit perplexed by the question, and responded by saying something to the effect of, "Well, I'm not eating food orally, and anything I would have been eating would have cost money. So why should this be a problem?" I knew then that it does not cost $17 per day to feed a person orally, or at least it does not have to cost that much, yet somehow putting a value to it further removed me from the natural process of eating. I am fortunate enough that I do not have to worry about going hungry when I can orally ingest my calories, so I have never tried to put a monetary value to what I consume in a day as an eater. Yet somehow, as a non-eater, the experience was different, just as almost every other part of being nourished as a non-eater was different.

In regards to this midrash, I find that the extreme case is TPN. TPN enters the body through a vein, and the medical formula concocted for patients on TPN is a clear fluid. The clear fluid looks like other clear fluids that are put through a vein, just as if it were an antibiotic or saline. These fluid mixes are stored in a refrigerator. There is no smell, the appearance does not look like anything edible, the liquid texture cannot even be felt because the fluid is in an IV bag. My experience being nourished by TPN is that I did not feel any sense of satiation. I did not feel anything at all. For all I knew, the medical professionals could have been giving me more saline. The only way I knew what was going into my body was if I asked.

With the J-tube and the G-tube, people can at least feel the liquid entering the body, even if there is no feeling of satiation to go along with the strange feeling of the liquid entering the stomach or lower bowel. Often, with the J-tube, I felt sick, especially in the early days when I

was learning what amount of nutrition my body could handle. Feeling sick from my feedings was an unpleasant and frightening side effect, but at least it was a *feeling* of some sort. My body was responding to being nourished. The process of being nourished by TPN is so far removed from what it is like to eat that, aside from perhaps having a chance at survival, there is not a connection to food such as the limited connection with food that is possible from the medical formulas administered through NG tubes, G-tubes, and J-tubes.

The Importance of Imagination in Sustaining Hope

> "And the taste of it was like the taste of cake (*leshad)* baked with oil" (Num. 11:8) – said R. Abbahu, "[Since the word for cake uses the same letters as the word for breast (*shad*), the meaning is:] Just as the infant tastes at the breast any number of tastes, so for the manna, whenever the Israelites ate it, they found in it a whole variety of flavors." There are those who say the meaning is, literally, a demon (*sheyd*) [which is spelled with the same letters], meaning, just as the demon can change into many colors, so the manna changed into a whole range of flavors.[50]

Before considering what this text might have to offer in terms of studying food deprivation, it should be noted that there is a word play within this text. Each Hebrew word is close to *shad*, which means breast. Because it is traditionally a woman's role to make bread, God miraculously producing bread (manna) for the Israelites shows one of the feminine aspects of God.[51] And of course, it is women whose bodies are able to produce food for their children, not men. Part of what this midrash does is illustrate the similarity between a woman breast-feeding her child and God miraculously raining down sustenance for the Israelites.

To be honest, this midrash troubles me considering the aspects of food deprivation I am studying. The text sounds apologetic, as if the rabbis who wrote the Talmud needed a way to back up the work of the commentators who described the Israelites' complaints as a lack of faith

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[50] *b.Yoma* 75a. Cited from: Neusner, Jacob, trans. *The Talmud of Babylonia, An American Translation: V.C: Yoma.* Atlanta: Scholars Press, 1994: 67.
[51] Eskenazi and Weiss, 394.

in God. The idea that people deprived of the foods they had been used to would *not* have cravings is an unrealistic expectation. Is it not possible that the Israelites could have had faith in God, and yet still have food cravings? Is it not possible that they could have complained, and yet still had faith in God?

While I find this midrashic text troubling on a few levels, the text redeems itself when I think about the importance of imagination. Perhaps manna could not taste like as many different flavors as this midrash makes it seem. But, perhaps, those Israelites who possessed an imagination strong enough to withstand such a limited diet learned ways to imagine that the manna tasted like almost whatever it was they were craving at any given moment. Just like those sustained by ANH need to find some way to imagine a better existence, the Israelites limited to manna had to find ways to cope with their monotonous diet.

Another point that strikes me about this midrash, in a positive way, is that the midrash might be read as a way of that the Israelites were able to look toward a brighter future even in the midst of their complaints and struggles. The fact that the Israelites had cravings meant they were still finding ways to cope so that they might survive, so that their children would live to make it to the Promised Land where they would have a better life.

It is a natural human reaction for people who are hungry to crave food, and this includes the Israelites. Even those observing religious fasts often think about how much joy they will feel when they reach the end of the fast and are able to eat again. There are some cases where a human does not enjoy the act of eating or the taste of food, and lacking that desire to eat is harmful in a similar way that not feeling pain can be dangerous. We need to feel hungry, and we need to *want* to eat, because keeping our bodies nourished contributes to our survival. Those who are very sick, or those who are nearing death, often do not crave food anymore. Such a reaction

is part of the body's natural process of shutting down completely so that death can occur. Sherwin Nuland talks about how a minimal food input can be part of the "slow drawing away from life" that occurs when people die of old age.[52] The opposite – being hungry and craving specific foods – is a sign of a will to live, a sign of vitality and hope.

The role of hope cannot be underestimated in a person's ability to persist when faced with extremely difficult circumstances. Viktor Frankl, a Holocaust survivor, wrote of the power of hope:

> As we said before, any attempt to restore a man's inner strength in the camp had first to succeed in showing him some future goal. Nietzsche's words, "He who has a *why* to live for can bear with almost any *how*," could be the guiding motto for all psychotherapeutic and psychohygienic efforts regarding prisoners. Whenever there was an opportunity for it, one had to give them a why – an aim – for their lives, in order to strengthen them to bear the terrible *how* of their existence.[53]

For those who are faced with food deprivation, sometimes the aim that could lead to a continued effort to survive against all odds may be as simple as thinking about all the different foods they want to eat when the period of deprivation is in the past. Reiner's book about his experience living with nothing by mouth is full of descriptions of the foods on which he focused to help him get through the experience. And, as hard as I tried, I could not avoid my own food obsessions. With my first esophageal perforation, I tried very hard to ignore food, but it was impossible to avoid obsessing. During my second esophageal perforation, I wrote the following entry in my journal:

> Last time I went through this, I tried very hard not to think about food and what I wanted to eat at all, but this time I haven't been able to help it. Last time the meal I wanted most was chocolate chip pancakes and scrambled eggs. It took me awhile to work up to that, and I know this time I'll have to work my way up also.

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[52] Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter.* New York: Vintage Books, 1993: 50-51. Also note that on page 43, Nuland begins to explain that, technically, a person cannot die of old age. "Old age" is not an accepted cause of death that can be written on a death certificate.

[53] Frankl, Viktor E. *Man's Search for Meaning.* Translated by Ilse Lasch. Boston: Beacon Press, 1992: 76.

> At least I'll be able to have ice cream and things that soft. I'm already thinking about which milkshakes I want and such. And then later I have a whole list, like the Thai food my husband makes, the waffles my dad makes, broccoli, even things as simple as Ramen noodle soup! There are no words to describe the power I felt last time when I was allowed to eat again.[54]

For someone who has not been deprived of food and drink before, it might be hard to imagine that something as simple as a list of foods could give someone a true goal toward which to strive. It might be hard to imagine that imagining food could lead a person to keep fighting during a life-threatening ordeal. Yet, at that particular point in my life, my ability to imagine the foods I craved and envision myself eating such foods again helped to keep me focused on a full recovery, despite all of the suffering and the obstacles I had to overcome to reach my goal. I also used the word "power" to describe what it felt like to be able to eat again. Such an acknowledgment shows that for me, at that time, dreaming about all the foods I craved meant so much more than a typical food craving. For me during those struggles, when the scope of my life had been narrowed so radically, the goal of being able to eat again was one and the same as the goal of being able to feel in control of my life again. The goal of being able to eat again is what I knew would lead to my ability to continue pursuing all of the important aspects of my life that I was forced to put on hold because of my illness. Food was no longer *just* about food. Food and the act of eating came to take on the meaning of renewed life and vigor.

Another powerful example can be found in the Yiddish folk song "A Sudenyu."[55] This song is about a great feast that will happen when the messiah comes. Hopes for special delicacies intermingle with factors such as how amazing it would be to learn with Moses during this special feast. The foods that will be consumed, and the drinks that will be enjoyed, are important

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[54] October 25, 2009

[55] "A Sudenyu." In *Pearls of Yiddish Song*, edited by Eleanor Gordan Mlotek, & Joseph Mlotek, 170. New York: Workmen's Circle, 1988. Reproduced on JewishFolkSongs.com: http://www.jewishfolksongs.com/en/a-sudenyu (accessed March 2015).

elements, but their importance is part of a larger picture of hope. The hope that we find when listening to "A Sudenyu" is a hope for a time when the world will no longer be fractured, because the messiah has finally arrived. With the messiah's arrival, there will no longer be hunger or any of the other unpleasant circumstances we encounter in our world all the time. "A Sudenyu" is an example of people living in less than ideal conditions to envisioning the ideal future that can someday be the reality, if only they can endure all of the unpleasant aspects of their current existence. The cravings expressed in this Yiddish folk song are not just for delicious food and drink, but for a full and easier life.

This ties back well to the Israelites in the desert, only able to eat manna. The Israelites had to find a way to envision a better future. While in the desert, they lacked the power of choice. They lacked the power to provide for themselves. They were sustained because an entity with more power provided sustenance and protection. The manna could only be what someone else – in this case God – decided it could be. There is power inherent in making some choices for ourselves, such as what we eat and when we eat it. Some restrictions, such as keeping the laws of *kashrut*, still provide plenty of opportunities for choice. When a person is restricted to eating only one thing for an extended period of time – such as what happened with the Israelites and manna – that is quite a different experience. In those cases, our choices are more limited. Our choices may be as limited as trying to use our imaginations as a source of strength. Then, even though we are limited in a literal sense, we reclaim some of our power through our mental resources. That is what the Israelites had to do, that is what those living on ANH have to do, it is what those in the concentration camps had to do, and it is what those who sing hopeful songs such as "A Sudenyu" do. Even if some of us never reach that ideal future, imaging that future can get us through the restrictions, deprivation, and despair.

For those deprived of food and drink, the meaning of food takes on different meanings depending on what role food played in the person's life before the deprivation. In my case, I did not have children to feed, and I was in my early and mid-20s and had been immersed in my life as a graduate student before my esophageal perforations. When left to fend for myself, I would prepare simple meals that came out of boxes, or I would boil noodles or something else that was simple. Or I would buy food from a restaurant or just eat prepared foods from the grocery store. I am married, but my husband loves to cook and has taken on that role in our household. So for me, when I could not eat my thoughts of food were focused on the cravings themselves, as well as the desire to be able to enjoy the social aspects that go along with being able to eat and drink.

For others who play the role of the main provider of meals in their family lives, having food and drink severely limited or taken away entirely takes on other meanings as well. One remarkable example of such a group is the women of the concentration camp Terezín, who worked on a cookbook together during their time there.[56] The women of Terezín had not just lost the foods they loved, and they were not just starving. They had also lost their families and the role of providing food for their families. For them, talking about the foods they desired was linked to their wish to be taking care of their families as they had done before the Holocaust. The recipes in the cookbook are crude recipes. It would be hard to recreate the recipes based on what is found in the cookbook. The cookbook they compiled was not about writing down perfect recipes, though. Their communal work on this cookbook was about so much more: it was about keeping their hope alive, hope that they may someday be able to cook the foods they loved so

[56] de Silva, Cara, ed. *In Memory's Kitchen: A Legacy from the Women of Terezín.* Translated by Bianca Steiner Brown. Lanham: Rowan & Littlefield Publishing Group, Inc., 2006.

dearly for people they cared about once more, hope that they would survive to get the chance and, if not, at least leave something behind that they had created together.[57]

Reiner's experience with food deprivation had similar elements, because Reiner's wife worked outside of the home. Reiner is the one who did the grocery shopping, made school lunches for his sons, and cooked meals for his family. The following excerpts from his book are powerful testaments to some of the suffering he felt while he was unable to eat, as well as the contrast to how he felt when he could eat again:

> That cheesecake. The stocked refrigerator shelves I saw in the dark once would have been a grand measure of my domestic duty. It doesn't belong to me now. I've been replaced.[58]

> Rebuilding our home began, for me, by tasting the fried-egg sandwich and red velvet cupcake after Kaplan's pictures. Returning to my normal functions – taking the kids to and from school, grocery shopping, cooking, housecleaning, laundry, even dealing with the onerous medical bills – was the foundation of my restoration to the structure of parent and husband. Eating made life possible again.[59]

Though there are differences in how people respond to hunger based on the roles food played in their lives before facing deprivation, there are a few universal traits. One, like I have mentioned, is a preoccupation with food. Another similarity has to do with one of the psychological responses people have in regards to living in a state of hunger, being obsessed with food, and not being able to focus on higher intellectual or communal endeavors. Consider the following:

> Yes, in Terezín one has no courage, just worry.
> And now I must tell you my own story
> It isn't a thing that is gladly confessed
> But I am lazy and with food obsessed[60]

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[57] Ibid. xxv-xliii.
[58] Reiner, 124.
[59] Reiner, 232-33.
[60] de Silva, 83.

> It would be nobler to be able to say, "I learned to live without food. I accepted deprivation and survived, a stronger and better person." The truth is, I didn't. Nothing by mouth is a fate I hope won't return for another course. I was weak in the face of suffering and awful to the people around me. If hardship tests your character, I learned that my will to live triumphed, but I can't say the same about my dignity.[61]

I noticed a striking, and heartbreaking, similarity between the accounts of those who were starved or those who could not eat for a significant period of time. These accounts express some level of shame: shame at being so preoccupied with food, shame at not being able to think of higher intellectual endeavors, shame at being lowered to the status of a hungry animal with a narrowed focus of the world. For adults who had previously been able to eat, and who had previously been loving and supportive people that cared about the broader world around them, to suddenly be preoccupied with food – something that may have previously been taken for granted or seem minor compared to larger problems – to feel some sense of shame is understandable. I think that many of us would like to think that we could do a better job, that we could be stronger in the face of such adversity. Sometimes, though, survival has to be enough for that moment in time. And, if survival is not possible, the fight to survive is certainly a sign of strength.

By the way, I do not have enough of my own personal writing to cite it, but I was no exception. Looking back at how I behaved when I felt hungry and isolated, I feel shame, too. I have never considered myself to be a bad person. There is always room for improvement, but when I was hungry and suffering there were times when I acted horribly toward those I love. My family handled my outbursts, and I have since apologized multiple times but they understand – at least vaguely – where my anger stemmed from and therefore do not think I owe them an apology. Had I remained bitter and angry, that would be a different story entirely. Luckily, I have

[61] Reiner, 233.

grown back into the joyful, optimistic person I was before those two rough periods of suffering, hunger, and isolation.

The fact that people being deprived of regular nutrition sources complain and feel shame because of their complaining speaks to some of the immense difficulty of having natural cravings that have no chance of being fulfilled. Of the few cases I have studied – including my own lived experiences – there is sometimes a realization that the cravings are normal and perhaps even healthy. Yet when we are living our normal day-to-day lives, free of severe deprivation, we know that we should not complain too much. And, even when we are facing deprivation, with something like ANH we might have a logical understanding that we are being kept alive and are as safe as possible, and therefore should be grateful instead of angry or frustrated. There is a disparity between what we *need* and what we *want*, and that disparity cannot be reconciled in a satisfactory way. Life living with severe deprivation cannot be compared to normal life, and such disparity can cause generally good people to feel inadequate.

People on ANH and those who support them can turn to the story of the manna to work through issues arising from hunger. The Israelites faced a similar disparity, being sustained yet not always expressing joy – or even a grateful attitude – at the form of their sustenance. The fact that the Israelites complained has been met with criticism from commentators and other Jewish writings. They were seen as lacking faith in God. Could not the same be said about those on ANH who complain about the source of their nutrition? Could not the same be said about those who endured the cruelties of the concentration camps yet somehow survived? Are those facing deprivation not allowed to have cravings, yet also maintain their faith in God?

I cannot see the issue as being one with a simple answer. Plenty of Jews in the concentration camps maintained their faith in God. I, too, held on to my strong faith in God and,

if anything, my faith in God grew during my time suffering. The two issues are not mutually exclusive. If we wish to come to a fuller understanding of hunger – including the issues of cravings and complaints perhaps as a sign of hope and strength – then we should consider complexities such as the ones I tried to lay out in this section.

Chapter 4:
Conclusion: Where Do We Go From Here?

It is hard to imagine concluding this project in any satisfactory way when I realize how much work is still necessary to address this topic adequately. I started this thesis by stressing the importance of food and eating in the day-to-day lives of human beings. The importance of food encompasses many areas of life, including emotional, social, cultural, and religious. When a person is forced to become a non-eater for a period of time, that person is simultaneously forced into isolation from so many other parts of life. That isolation includes isolation from loved ones, friends, and others in society able to take part in the act of eating with no difficulty. A person who may have once been included fully in his or her family/friend group, religion, and culture finds him or herself inhabiting a life in which he or she has become Other. Yet that person is still a human being, ideally with the same urges to feel connected to other human beings and to that which brings hope.

For some people, one source of hope and comfort is religion. Jewish law has not dealt adequately with those who are on forms of ANH yet are still cognizant of what is happening, and who live day-to-day lives without food and without eating in the traditional manner. Because halakha has been geared toward those on ANH near the end of life, and is thus addressed not to the person on ANH but instead to loved ones and caretakers, agency has been denied to those dependent on ANH. Lack of agency marginalizes this population, adding a layer of isolation and suffering that exacerbates the problems of those fighting so courageously to survive a situation that is already hard enough. Such marginalization has occurred partially because those crafting the halakhic responses are ignoring crucial narrative components and, in doing so, are failing to see the full picture and the full person.

By using a feminist narrative approach to address this topic, I have sought to include those who have been ignored. I have argued that differentiating methods of ANH can be crucial for ethical decision-making. The differences in feeding methods have such different impacts on the people involved. Some are able to feel satiated sometimes, while others feel nothing but hunger. Some people have more freedom of choice in their feeding methods, including the ability to decide when they are hungry and would like to receive a feeding. Some people can even administer their feedings by themselves, or they can set up their own feeding pumps. Such factors should be taken into account when considering how such people might still live full Jewish lives while being dependent on ANH.

I have also attempted to apply an existing Jewish narrative to those living on ANH. By studying *manna*, my hope was to bring in a shared Jewish story that can help us to view living on artificial feedings in a different way. Living on artificial feedings is not just about whatever medical condition led to that state. Living on ANH is about being sustained by that which was previously unknown. Those living on ANH can be full of mixed emotions. Disappointment, frustration, and even anger at the inadequacy of the artificial food comingles with the gratefulness one can feel at being sustained so that life can continue once the medical danger has passed, or once physical rehabilitation has taken place so that a person can swallow again. Or, in the case of conditions such as ALS that will lead to death eventually, one might feel gratefulness at having the chance to live longer, even though being fed artificially cannot compare to eating beloved foods and engaging in the acts of eating with others.

By studying *manna* alongside ANH, my goal was to explore the power of the human imagination when facing deprivation. The power of the human imagination can help those facing deprivation to see beyond their undesirable state to a future goal that can be comforting during

the time of suffering. For the Israelites, one of the future goals was to get to the Land of Israel, where they could have a fresh start. While being deprived in the desert, they also entered into a sacred covenant with God that is binding and sacred to this day. For a person living on ANH, future goals tend to include being able to enjoy food again, and also being freed from the social and emotional isolation of being a non-eater in a world that is full of people who must eat normal food to survive. It is also important to restate that moments of expressed frustration when dealing with extreme deprivation are normal and even a sign of strength. Expressing frustration at the deprivation can be a sign that a person cares enough to keep fighting. It would be unreasonable to expect those dealing with deprivation not to get frustrated and even angry at times. Yet those feelings can be constructive ones that drive a suffering person to persevere.

Where to Go From Here

Taking into consideration the research that I have done so far, one potentially useful action to take to be more inclusive of those who cannot eat in our Jewish communities is to create readings and rituals that give those with a dysphagia more empowered ways to live out their Judaism. These readings and rituals should stay rooted in Jewish tradition, but should take into account the unique nature of the distinct narratives different people have while living on different methods of ANH. There are so many medical conditions that can lead to dysphagia or the necessity to be sustained by ANH. There is also a variety of methods of artificial feedings that create different realities for the people involved. Because of the different situations different mixes of these factors create for people living out their experiences, I encourage those looking for ways to live full Jewish lives to take some of my suggestions as a starting point while feeling empowered to shape the readings or rituals to their unique realities. Rabbis or loved ones can also alter the readings and rituals I craft so that they are appropriate to the particular situation involved.

The first reading I created for those being sustained by ANH is a *berakha* that could be recited over artificial feedings since according to classical halakha it is inappropriate to bless artificial feedings in the same ways Jews bless different foods. I started by crafting the English, and a rabbi better at writing liturgical Hebrew than I am wrote the Hebrew to accompany the blessing. Were I to rewrite this *berakha* now, I would change the word "Lord" to something more gender neutral. Otherwise, I still think the following *berakha* could be comforting for some people being sustained by ANH. The *berakha* focuses on healing and comfort, while also including the source of nourishment as a salient factor in the person's life:

Blessed are You, Lord our God, Ruler of the Universe, who has endowed doctors with the necessary wisdom to nourish and sustain us when we are unable. Blessed are you, God, Creator of all that sustains and nourishes us and all that aims to heal and comfort us. Amen.

בָּרוּךְ אַתָּה יי אֱלֹהֵינוּ מֶלֶךְ הָעוֹלָם, אֲשֶׁר הֶעֱנִיק מֻחָכְמָתוֹ לִבְשָׂר וָדָם וְנָתַן לָהֶם לְרַפֹּאוֹת וּלְקַיֵּים אֶת הַחוֹלִים. בָּרוּךְ אַתָּה יי מְקוֹר הַבְּרִיוּת, מַעֲיַן הַנֶּחָמוֹת.[62]

I have also started to think about other situations where we might benefit from having readings or blessings geared specifically toward those in our communities who have dysphagia. Because of the many food rituals associated with Jewish life, there are many areas where we could benefit from having special readings that acknowledge those in our community who cannot eat like almost everyone else. One holiday where food is so intertwined in ritual practice is Pesach, and for this reason I think it would be particularly hard to be a non-eater during Pesach. My esophageal perforations overlapped with the High Holidays, Sukkot, Hanukkah, and of course Shabbat. Even with all of my suffering, I was quite grateful that I never had to face being a Jew who could not eat on Pesach. I imagine it would be extremely difficult. I imagine it would be hard to have the courage to sit at the Seders with all of those who are able to eat.

[62] Berman, Courtney. *Kalsman Quarterly e-Newsletter*. Hebrew translation by Richard Sarason. Kalsman Institute on Judaism & Health, Winter 2010.

Though food is part of most Jewish sacred days, one who cannot eat can avoid the food more easily during other sacred days. Because of my thought processes surrounding what it is to be a Jew who cannot eat, I have started to craft readings and rituals to accompany Pesach.

The Jews of Bergen-Belsen left us with a beautiful example of a prayer to be offered by those who cannot keep some of the food commandments in the traditional manner. I modeled two readings based on this prayer that they composed in 1944:

> "Our Father in Heaven, behold it is evident and known to You that it is our desire to do your will and to celebrate the Festival of Pesach by eating matzah and by observing the prohibition of chametz. But our hearts are pained that the enslavement prevents us from eating matzah, and we are in danger of our lives. Behold we are ready to fulfill your commandment: 'And you shall live by them and not die by them.' Therefore, our prayer to You is that You may keep us alive and save us and rescue us speedily so that we may observe Your commandments and do Your will and serve You with a perfect heart. Amen." [63]

As the writers mention in the prayer, for the sake of survival, those in the concentration camps had to eat whatever was provided to them, meaning they had to eat *ḥametz* on Passover. Someone living with dysphagia may not need to eat *ḥametz* in order to survive. And yet, this prayer serves as a powerful example of liturgical creativity in the face of competing loyalties. Keeping Jewish tradition may be something about which one feels strongly, but remaining healthy and alive must inform one's level of Jewish practice since safeguarding life is an obligation that is more important than almost all other *mitzvot*.

The Jews of Bergen-Belsen were united in their inability to observe all of the mitzvot of Passover. By contrast, a person who is unable to eat because of medical challenges today is differentiated from the majority of the family group. Despite the difference in circumstances, I modeled two readings after what the Jews of Bergen-Belsen wrote. These are readings that I think could be meaningful to recite at the beginning of a Seder where there is a non-eater present.

[63] Levitt, Joy, and Michael Strassfeld, eds. *A Night of Questions: A Passover Haggadah.* Elkins Park: The Reconstructionist Press, 2000: 111.

The one who cannot eat could recite the first one. The second one is for the ones who can eat, which would most likely be every other person present at the Seder. The readings offer an acknowledgement that both the eaters and the non-eater(s) face different realities at that particular point in time, and that both of those realities carry their own pain and challenges. Again, I encourage those considering using readings such as these to change some of the language so that the words are appropriate to the situation. There are so many different possibilities for those with dysphagia, including the possibility that a person at the Seder could possibly drink a tiny amount of liquid or taste a tiny bit of the ritual foods and then wash out his or her mouth. Some people with dysphagia can even eat a small amount, even if they are almost fully dependent on ANH for survival. Therefore, the words I have written will not fit each person's reality perfectly.

Prayer for those who cannot eat:

God of life and love, sustenance and strength:
I sit at the Seder once again this year.
Such a familiar setting, yet now simultaneously foreign to me.
I have become an outsider, a non-eater, profoundly Other.
I am surrounded by the foods I know so well, ritual foods that enable Jews to enact the awe-filled exodus from Egypt.
My eyes see the inviting images.
My nose smells the tempting aromas.
Yet my mouth…
My mouth, it does nothing with these foods.
My mouth cannot be used for eating right now.
My throat cannot be used for swallowing.
My gullet must remain inactive.
Such a cruel contradiction: In my condition I cannot even consume the bread of affliction!
I desire, more than words can express, to fulfill Your commandment to eat the matzah, the maror, each and every edible symbol of the journey from slavery to freedom.
Alas, I cannot.
At this time, my God, I must safeguard my life by refraining from these mitzvot.
By doing so, I fulfill your sacred command to live by the mitzvot, and not die by them.
I pray that in the future, I can again fulfill the mitzvot associated with this holiday of redemption and freedom.
Approaching You from my isolated place, I humbly ask you, my God:

Calm me through Your Presence.
Lighten the weight of my suffering.
Multiply my feelings of connectedness so that I may find meaning, even now.
Bless me, O God, so that I can find my own way to move from shame to praise.[64]

Prayer for those who can eat:

God of life and love, sustenance and strength:
I sit at the Seder again this year.
Such a familiar setting, yet now foreign to my loved one who is struck with his/her own plague, the plague of dysphagia.
This is a plague I wish to never know.
I cannot imagine what my loved one is going through right now.
I sit here, able to partake of the bounty of food I see before my eyes.
Yet I share the table with one who cannot.
This pains me, Eternal One, because I wish for nothing more than to take away my loved one's suffering.
Dear God, please let it be known before You that I do not wish to add to any of the pain my loved one is feeling right now.
As I eat of the Passover foods, please help my loved one to find comfort in the knowledge that You are always with us all, and that I do not eat in front of him/her lightly.
I feel guilty sometimes, guilty that I need to eat to stay alive even though my loved one cannot eat at this time.
And yet, I am commanded to eat. I am commanded to eat because eating sustains my life, and the act of sustaining life whenever possible is one of Your highest commandments for us all.
My loved one is sustaining his/her life by *not* taking part in the Passover rituals.
I am sustaining my life by eating, and thus I will observe your Passover commandments.
Help us as a family, Eternal Source of comfort and joy, to feel connected to one another despite our differences at this time.
So I humbly approach you now, my God, to ask:

Comfort my loved one who cannot eat.
Lighten the weight of my suffering as I observe, powerless, my loved one's struggles.
Meld us together as a group despite our differences.
Bless me, O God, so that I can celebrate with as full a heart as possible, even now.

Aside from creative liturgy, there is great potential to build rituals appropriate to those who cannot eat. Humans, of course, have senses other than the sense of taste. Some rituals could be shaped around other senses, such as the senses of sight, smell, or touch. Since we already have Jewish traditions involving the other senses, coming up with rituals to replace food rituals is

[64] "From shame to praise" is a reference to *b.Pesaḥim* 116a.

not easy, it is not always something the one who cannot eat would even want. With holiday observances that involve rituals other than ones involving food, for some who cannot eat it is easier to observe those rituals and not try to replace the food rituals. When trying to replace food rituals with different rituals, we run the risk of furthering the non-eater's suffering by drawing more attention to the fact that he or she cannot eat at that moment in time. Sometimes, it can just be easier and less painful for the one who cannot eat to just take part in the rituals or *minhagim* (customs) that do not involve food. For example, on Hanukkah the one who cannot eat can take part in lighting the candles. The fact that he or she cannot consume oil does not need to be highlighted, not unless the person wants an alternate custom to take its place. In that case, perhaps the person could feel the oil under his or her fingers. When creating new rituals, customs, and readings, we walk a thin line. By working on this subject, I wish to minimize feelings of isolation caused by not being able to eat. At the same time, I am quite sensitive to the fact that drawing too much attention to the inability to eat can further the feelings of separation and isolation that I am seeking to diminish.

I also wish to stress, again, that people who cannot eat face different circumstances based on the particular method(s) of ANH being used and the medical condition that led to needing ANH. Sometimes, a person who cannot swallow anything is allowed to taste foods and then spit them out, or clean out his or her mouth. In such cases, there may be times when a person would wish to taste something such as wine on Shabbat and then wash out his or her mouth. This is not something that would typically be done at a gathering with anyone other than immediate family, seeing as it is not exactly an appetizing practice for others to watch and could embarrass the one who cannot eat. In the presence of close loved ones, however, such a practice could be empowering and make the person feel a little more included.

My experience with this type of situation was on New Year's Eve, when my family was having champagne and I could not. It had been about three months since I had eaten, and I wanted to be included, so I stood over the sink and put some champagne in my mouth. Then I carefully washed out my mouth. My surgeons allowed this type of behavior, though usually I only engaged in nightly gum-chewing, making sure I spit everything out and carefully brushed my teeth and washed out my mouth afterward. The practice of doctors allowing their patients to taste and then spit actually has some physical benefits. Such practices prevent the taste buds from disappearing, and they also ensure that a patient continues to use the muscles involved in chewing so that those do not weaken. Then, when a person transitions back to eating, the transition should be easier.

Every case is different. Some people cannot taste anything. Some may not have the muscle strength or coordination necessary to prevent accidental swallowing. Others may not have the strength of will in those moments to deal with the infuriating ability of being able to taste and chew something, but not swallow any of it. In my case, I made sure to keep my chewing to a couple hours at night because, once I started, it was an obsessive act that often just led to frustration and sore cheek muscles. The satisfaction of taste and of choosing different flavors of gum was pleasing in some ways, but there was so little satisfaction overall that it was really quite frustrating. I am grateful I maintained my taste buds and that the muscles used for chewing did not grow weak, but I found no fitting substitute for being able to actually eat and drink.

I tell some of those stories because I want to stress how very complicated this issue is. I have stressed over and over again the concept that there are a variety of different experiences that get lived out by those who cannot eat, depending on why they cannot eat and what form or forms

of ANH they are using. There are also complex emotions involved with each personal narrative. Some people who cannot eat want to avoid food whenever possible. Others might find some comfort in being around food and continuing to try to incorporate food-based rituals in their lives. And some people may feel one way some days and the opposite another day.

Feeding tubes clog and have to be replaced, especially J-tubes. They open at inopportune times and make messes. Feeding tubes and TPN have side effects that can be very difficult in terms of adjusting to the altered form of feeding. On a good day, with few side effects and if the tubes are running well and nothing has gone wrong, perhaps a person on ANH would want to incorporate food-based rituals into their Jewish lives. On other days, perhaps the suffering is just too much already and no ritual could lessen the feelings of frustration and isolation. I mentioned that I believe there to be a thin line that I am trying to navigate here. I think that is quite true. Again, my goal is to increase positive feelings and decrease feelings of isolation and otherness. Yet I am aware that some of my suggestions could increase positive feelings one day and increase suffering on another day. Those who cannot eat should be compassionate with themselves in determining what is best for them, and those in their lives should also try to be attentive to what is going to be most useful in helping them get through their period of time on ANH while feeling as supported as possible.

Especially because of all of the variance present amongst people who cannot eat, and because of the variety of different feeding methods, I know there is still a lot of work to be done on this topic. One way to proceed in the future may be to try to talk to other people who have faced periods of time living on ANH, or talk to their family members. Through asking questions about the feelings of others about Jewish practice while living on ANH, perhaps I could come up with more nuanced responses. Honestly, I suspect I would still find quite a lot of variety in what

is most useful to people during such a challenging medical intervention that permeates so many parts of a person's life.

While I know there is more work to be done, this thesis serves as a beginning to try to address, in a Jewish way, the lives of a group of people that have not previously been considered by halakha or Jewish ethicists. Medicine has advanced so that people can live for longer periods of time on Artificial Nutrition and Hydration. Those people can be quite aware of what is happening to them throughout most of the process, and they can lead lives outside of the hospital with their families while being sustained by artificial means. The fact that the nutrition is called "artificial" does not mean the human beings involved are artificial. They are still just as real as they were before they were put on an artificial form of nutrition, and they have the same needs to feel like they are valued members of the various groups to which they belong. For a Jewish person, one of those groups is the Jewish people. There is no doubt that losing the ability to eat and drink, even if temporary, is a huge loss that impacts many different areas of a person's life. Knowing that to be true, I have sought to construct a more proactive halakha and ethics for those who find themselves unable to eat for a period of time. While remaining sensitive to the reality that people have different experiences while on ANH, I hope this exploration has shed some light on ways that people can still lead full Jewish lives while living on ANH.

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