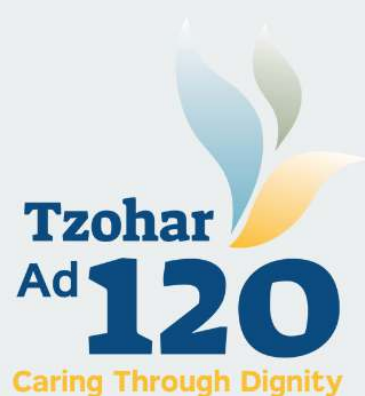


A Guide for Celebrating Pesach and the Seder Night

**FOR *FAMILIES CARING FOR A
LOVED ONE WITH DEMENTIA***



We welcome the chance to share this guide which is the result of the collaboration between Tzohar and Emda.

The days of Pesach, the seder night, and the period leading up to it are defined by deviation from routine, and large family gatherings.

Even for healthy people, times like these can be accompanied by feelings of joy combined with anxiety and stress.

For a person with dementia, these emotions can present themselves in a particularly exaggerated fashion and can even have lasting negative impacts on our loved ones coping with the effects of this condition,

Understanding the challenges in coping with this time period, and being best prepared to address them, can be beneficial to the patient and their families as a whole.

Our sincere hope is that the advice presented here can assist everyone to celebrate Pesach with enhanced joy and tranquility.

With all the obstacles that come with caring for a loved one with dementia please remember... You are not alone!

With any questions or if we can be of assistance be in touch and we will be happy to help.

Chag Kasher Ve'Sameach!

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Before the Holiday

1. Preparations for Pesach

- a. **Cleaning for the Holiday:** A person with dementia is not always aware of time and space, and therefore changes in their surroundings can bring about feelings of anxiety and confusion. In order to reduce these emotions, it is best to begin the cleaning as close as possible to the holiday and only perform the required tasks - primarily getting rid of the chametz from one's home. One should make sure to do this without increased stress and by committing to a non-pressured environment.
- b. **Organizing Closets and Cupboards:** It is important to remember that cleaning one's house is not specifically connected to the halachot of Pesach there is no halachic requirement to clean beyond ridding the house of chametz.

Generally, routine is good for people with dementia. Therefore, it is better not to juxtapose the holiday with tasks accompanied by changes in the physical space that come about as the result of cleaning or re-organizing. If one nonetheless decides to do, it is advisable to organize the home and closets when the dementia patient is not present. If they are present and the process is aggravating them, one may try to include them in the process. If this isn't possible, one should stop and resume at a different time.

- c. **Coping With the Stressful Atmosphere Before the Holiday:** There can often be certain preparations for Pesach which can be stressful at times for any family. It is advisable to refrain from such activities when a person with dementia is at home. The pressure and stress can cause anxiety that a person suffering from dementia cannot cope with and it is best to act methodically and slowly when near them. This is true as well regarding conduct around those caring for dementia patients: one should make sure that the stress of Pesach cleaning does not bring them to feel overwhelmed or unable to provide for the needs of the patient.

2. Biyur Chametz

- a. Even though the custom is to make sure to get rid of every crumb of chametz from one's home, the halacha does not require one to do so. **According to halacha, one only needs to get rid of pieces of chametz about the size of a matchbox ('Kezayit') or greater.** In most homes, after a routine



cleaning, crumbs of this size are eliminated (these types of crumbs are found generally in children's backpacks, the car, and of course the kitchen). Since there is no obligation to remove smaller crumbs, the accepted protocol is to remove crumbs in accordance with one's abilities and we should certainly take into account the amount of distress potentially caused to the dementia patient associated with this process.

- b. If the person with dementia cannot check for chametz on their own, one of their family members should check for them, even if they do not live in their household.
- c. One should nullify the chametz in one's household after bedikat chametz the night before Pesach and once again after biyur chametz in the morning before Pesach (the text appears in the beginning of the Hagaddah).

3. Selling Chametz

When it comes to a person with dementia who regularly sells their chametz, one may sell their chametz for them if it is impossible for them to actively consent to the transaction.

If one is not accustomed to selling the chametz, it is preferable that it is burned. But if this is too much of a burden, one may sell the chametz.

4. The Fast of the Firstborn

A first-born son with dementia who is unable to remember that the eve of Pesach is also the 'Fast of the Firstborn' is exempt from fasting.

5. Planning to Include a Patient with Dementia in the Holiday Meals

The fundamental principle regarding caring for a patient with dementia is that one should determine how to act based on the wellbeing of that individual. Any change to the routine of the dementia patient can cause them confusion, unrest, feelings of being lost, and other manifestations of mental decline. Therefore, one should evaluate closely whether a loved one with dementia is able to leave the comfort of their home, for how long, and most importantly will they 'gain' anything from the experience, or will the change just serve to cause them unnecessary aggravation.

On the other hand, taking part in the joy of being with family, hearing familiar tunes and prayers, and other aspects of the seder can benefit them and lift



their emotions. Therefore, one should carefully weigh these considerations in deciding whether to have a patient with dementia join for the holiday.

6. Non-Jewish Caretakers

The preparations for Pesach and the seder night involve many changes to the routine that non-Jewish caretakers may not be aware of.

In order to assist them and the patient, it is imperative to inform them in advance about the general principles surrounding Pesach observance. It is advisable to prepare them for the complex new realities in the kitchen during the cleaning and koshering process, when parts of the kitchen may still be being used for chametz and other areas may already be kosher for Pesach, changes in food products during the holiday, the prohibition of bringing chametz into the house, the norms of seder night, etc.

The Seder Night

1. Recommendations

- a. In order to assist a person with dementia, it is recommended to shorten the duration of time outside the house and their known environment as much as possible.
- b. It is important to bring familiar objects to the seder night of significance to the dementia patient, such as the Haggadah they generally use, a specific pillow, etc. One should also pay close attention to the seating arrangements, placing them in a comfortable seat at a quiet part of the table.
- c. It is important that the person wears comfortable clothes that are easy to change if necessary. Therefore, it is preferable not to dress them in new clothing that might not be as comfortable for them.
- d. It is advisable to arrive at the seder night setting early when the atmosphere in the home is still calm, in order for the person with dementia to acclimate to an environment absent of noise or commotion.
- e. It is important to seat the person with dementia next to a person who can 'mediate' between him or her and the seder and provide for their needs throughout the evening.



- f. It is recommended to prepare a printed version of the main portions of the Haggadah (the parts one is obligated to say; see below) appearing in big letters and well-spaced for those with reading difficulty.
- g. A person with dementia is known to 'live in the present' and therefore one should adjust the evening to their needs and abilities. It is advisable – as much as possible – to offer them to be a participant in the seder night and read what they can. When one can see that their patience is waning, one should expedite the seder, sing less songs or conclude as soon as possible.
- h. It is important to enable the person to retire to their room to rest if necessary. If possible, an area should be set aside where they can rest that is further away from the noise of the seder table.
- i. When appropriate, one should plan the seder in advance in two stages: organizing a short seder focusing on encouraging participation of the person with dementia, and afterwards focusing on the children and the other participants.
- j. If the person with dementia is unable to participate at all in the seder night, it is commendable to perform for them a 'mini-seder' before the holiday begins. At this 'seder night', there should be a pleasant, communal atmosphere – preferably with close family members – and the integration of traditional foods such as matzah, karpas, charoset, etc., alongside holiday songs.
- k. If a person with dementia wants to lead the seder in the same manner as past years and we know that they will not succeed at managing this challenge, the format can be slightly adjusted whereby a different family member can run the entire seder while the dementia patient is allowed to lead whatever they can, so they will feel that they are leading the seder. Flexibility and compatibility with the dementia patient is both necessary and welcomed in cases like these.
- l. Familiar songs and tunes can uplift the spirit of a person with dementia and evoke pleasant memories. It is recommended to sing with them at all times - and especially on the seder night.
- m. It is important to prepare children and other participants for any unusual behaviors that may be exhibited by a guest with dementia and offer respectful and compassionate ways to respond.



- n. The seder night is a complex family gathering and therefore a dementia patient may at times express emotions of longing for the past or ask about the whereabouts of a deceased relative. One should talk about positive aspects of the relative and abstain from correcting the 'mistake'. It is possible to state that they are on their way, running late, or celebrating elsewhere and divert the conversation to another topic.
- o. **In summary**, seder night with a dementia patient can be challenging and one should be optimally prepared so that it can be enjoyed in as positive a manner as possible. **Remember that for patients with advanced stages of dementia, participating in the seder night is not an obligation!** While it can certainly be emotionally trying to recognize that dealing with a family member with dementia means that the typical joys of holidays of past years may no longer be attainable, for the sake of ourselves and our families, it is important not to be overly saddened or allow this to take over the seder and the holiday. Rather we must do our utmost to live in the present for the good of others around the table, even while being sure to relate to a loved one with dementia with the love and respect they need and deserve at this time.

2. Halachot

- a. Although it is a mitzvah not to eat a large meal close to the start of the Pesach, for a person with dementia this is permitted. One may eat during the seder even if the time for eating has not yet arrived.
- b. **A person with dementia is not obligated in the mitzvot of the seder night if they are not in a condition where they would be able to perform the rituals on their own.** Therefore, one should adjust the seder night routine for their specific abilities and make sure they don't feel burdened by it. The seder night experience is very important and can be created in a calm, stress-free fashion.
- c. **Matzah, Maror, and the Four Cups** -A person with dementia that has difficulty eating and swallowing or has very specific dietary restrictions is exempt from the mitzvah of eating at the seder. If it is possible for them to eat without it being a burden, they should eat a kezayit of matzah at the very least – a third (17 grams) or even a quarter (11 grams) of a sheet of matzah – and a medium sized leaf of lettuce for the mitzvah of maror (if this isn't possible – they should eat less than this and hear the bracha from someone else). For each cup of the four cups, one must drink the majority



of a revi'it – 44 cm³. Drinking of wine should follow the seder of the Haggadah. Therefore, a person with dementia who is not able to stay for the recitation of Hallel should only drink 3 cups.

d. The Story of Yetziat Mitzrayim (the Exodus from Egypt)

From a halachic perspective, one can tell the story of the exodus from Egypt in a few minutes. Of course, there is merit to enhancing the story-telling process as it is taught "anyone who expands their discourse on the exodus from Egypt is praiseworthy". Yet it is imperative not to extend the seder beyond the capabilities of the dementia patient. The more important halachically mandated parts (see below) should be recited slower, in order for the dementia patient to be able to follow along and take part in their recitation. In addition, the sections of song in the Haggadah, even if they are not important from a halachic perspective, can be a significant point of connection for a person with dementia to the seder and can bring up within them pleasant memories.

The minimum required recitation is: 1) *Kiddush*; 2) *Ma Nishtana* (the four questions); 3) "*Avadim Hayeenu*" until "*Harei Ze Meshubach*" – or at least the first sentence; 4) "*Metehcila Ovdei Avoda Zara*" until "*V'Yaakov V'Banav Yardu Mitzrayim*" – or at least the first sentence; 5) "*Rabban Gamliel Haya Omer Kol She Lo*" until "*B'chol dor va dor*"; 6) the beginning of *Hallel*; 7) the bracha of redemption ("*Asher Ga'Alanu*") and the second cup. If they have enough patience, one can add: "*Ttzei Ulmad*" until "*Utzum V'Rav*" and some of the explanatory parts in that section.

e. Birkat HaMazon and Hallel

The last section of the Haggadah is *Birkat HaMazon* and *Hallel*, accompanied by the third and fourth cups. At this stage, it is possible that the person with dementia will be tired. If the family members wish to extend the meal and the sections after it, it is possible for one relative to say a shortened version with the dementia patient. The Hallel that is after the seudah is comprised of two parts and two ending paragraphs; when there is a need to shorten – one can say only one section, which is the Hallel that one says on other days. The order is as follows: 1) *Birkat HaMazon* and the third cup; 2) *Hallel* – from "*Lo Lanu Hashem*" to "*Eli Atah V'Odekah*" (if necessary one may shorten this); 3) the blessing of Hallel – "*Y'Halelucha Hashem*" until "*Melech Mehulal BaTishbachot*" without the *Nishmat* prayer; 4) the fourth cup and the after-bracha on wine.



- f. **The Songs at the End of the Haggadah and Those During the Maggid**
The songs after *Hallel* have no halachic status. Even familiar tunes such as *Vehi She'amda* or *Dayenu* are sections of secondary halachic value. However, as noted, songs uplift the soul and the routine tunes of the seder night can bring joy to a person with dementia. One may deviate from the established order of the Haggadah in order to sing these songs even if the time has not come to sing them.

During Pesach

1. Chametz

- a. **Eating Chametz:** One should not feed a dementia patient chametz, even if they are unaware of what they are eating. If there is a very specific need, it is permitted, as explained below.
- b. **Kashrut:** Regarding a person with dementia who is fed using medical nutrition substances (such as Ensure) and this represents their primary food source, one should view this food as required for *pikuach nefesh* (a matter of life saving) and it is permitted to use it even if it is not kosher for Pesach. Understandably, if there is a kosher for Pesach substitute, one should use it.
- c. **Nutrition Via Nasogastric Tube or PEG:** One may administer these forms of nutrition even if the solutions are not kosher for Pesach, as this is not truly considered eating.
- d. **Medications** are generally not considered fit for eating and therefore one should not withhold medications that do or may contain chametz from a person with dementia.

2. Chol Hamoed

- a. Regarding a person with dementia who does not like the food unique to Pesach (such as matzot) – one should try to cook a broader spectrum of dishes and provide him or her with other foods (increasing the amount of fruits, feeding them flavorful kosher for Pesach crackers, etc). If the person with dementia requests to eat food that is not kosher for Pesach, one should due their utmost to try to offer him a compatible substitute.
- b. **Putting on Tefillin and Shaving:** A person with dementia may request to put on Tefillin or shave on Chol Hamoed – similar to his conduct during



the rest of the year. In both cases, there is no obligation to withhold this from him and one may let him conduct himself as he normally does.

- c. **Chol Hamoed is a challenging and confusing time** involving a deviation from routine. Yet this time also brings with it an opportunity for greater bonding as the family is more available and there is free time to spend with the dementia patient and connect with them. It is advisable to try and enjoy the shared experience and turn it into quality time.

Oftentimes, bringing up memories of childhood is a positive activity for people with dementia. It is possible to initiate a conversation with family members where the person shares memories of Pesach from their childhood: what they wore, what special customs they had, how the seder night looked, etc.

- d. **Being with a person with dementia can be a particular challenge for young children** (of course depending on the stage of dementia). Chol Hamoed allows for a more interactive setting between children and a relative with dementia – and this can be an opportunity for a more positive encounter. If the children ask about their relative's behavior, one can tell them that they are sick and sometimes the disease causes them to act in a manner that we wouldn't expect, but we love them just the way they are.

