



## Passover Haggadah Insert 5782 (2022)

At Passover, we celebrate freedom. As we recount the story of Exodus and rejoice in our escape from slavery, we are urged to include the stranger in our midst, reminded that we, too, were “strangers in the land of Egypt.” (Exodus 22:20). Unfortunately, many with chronic health conditions (often invisible illnesses) may remain strangers in various ways. Some may be isolated because of the nature of their illness or pain; others may feel compelled to mask their symptoms to conform to perceived expectations and do not feel comfortable sharing their authentic selves. Further, as the Haggadah tells us to invite all who are hungry, we should reflect on the financial hardships many with chronic health conditions face. Limitations on the ability to work and the cost of medications and therapies can lead to very difficult financial choices. While we express gratitude for the freedoms we have, let’s remember those among us who do not have the freedom to live as they would like.

### Let’s make this year different than any other year with the following:

- Let’s invite people experiencing chronic health conditions in a way that opens a door to sharing their needs without feeling like it’s a burden.
- Let’s accommodate their needs through creative solutions.
- Let’s invite them to be with us in person or virtually.
- Let’s be understanding and supportive of those for whom health is unpredictable, especially when the effort to arrive at a Passover Seder, let alone prepare one themselves, may just be overwhelming.
- Let’s do our best to ensure everyone in our communities has an opportunity to connect and share in this tradition.

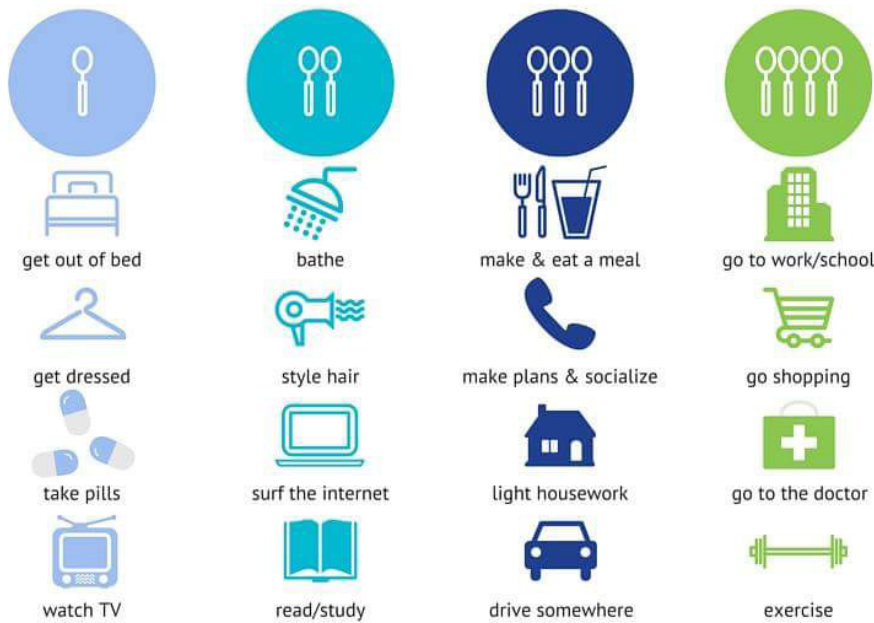
## Spoon Theory

Many people with chronic health conditions plan around and ration their energy throughout the day. Christine Miserandino used a bouquet of spoons to explain to her best friend, who already knew a lot about the medical aspects of her Lupus, what it was like to live with the disease. Spoons became the tangible representation of the amount of mental and physical energy she had available for activities of living (e.g., getting out of bed, taking a shower, making breakfast) and productive tasks (e.g., going to class or doing work). Each activity required a number of spoons, and, as she explained “when your ‘spoons’ are gone, they are gone.”



The Spoon Theory is a creative way to explain to healthy friends and family what it's like living with a chronic illness. Dysautonomia patients often have limited energy, represented by spoons. Doing too much in one day can leave you short on spoons the next day.

**If you only had 12 spoons per day, how would you use them?** Take away 1 spoon if you didn't sleep well last night, forgot to take your meds, or skipped a meal. Take away 4 spoons if you have a cold.



The Spoon Theory was written by Christine Miserando, which you can check out on her website [www.butyoudontlooksick.com](http://www.butyoudontlooksick.com).

www.dysautonomiainternational.org

She chose spoons because she wanted her friend to hold something that could be taken away, since most people with chronic conditions feel a ‘loss’ of a life they once knew. She shares, “I can never make it go away and I can’t forget about it, I always have to think about it...I hate feeling left out, having to choose to stay home, or to not get things done that I want to.” As Christine explains, “the beautiful ability to not think and just do” is a freedom many with chronic health conditions don’t have.

If you invite someone with a chronic health condition to your Seder, do not be upset if they need to change plans at the last minute. Consider

creating a virtual way for them to participate, and, if they do join you at your table, feel special because they are actively choosing to give you one (or several) of their spoons.

Additionally, this Passover, consider adding a spoon (or spoons) to your Seder plate to remind us that not everyone has the freedom of energy to live life as they wish. Let the spoon also serve as a symbol of nourishment, empathy and care we might extend to those with chronic health conditions and other disabilities who may benefit from our support.

To learn more about JFS Jewish Disability Advocates, resources, activities and how to support individuals with chronic health conditions, visit [jewishfamilyservice.org/JDA](http://jewishfamilyservice.org/JDA)

Below is a special version of Dayeinu that you are encouraged to include in your Seder.

## **Dayeinu (We are enough)**

If we must plan each day based on the limited amount of energy or number of spoons we have.

**Dayeinu (We are enough)**

If we only have one spoon to get out of bed. **Dayeinu (We are enough)**

If we can get out of bed and get dressed, but don't have enough spoons to do work or go to school. **Dayeinu (We are enough)**

If we go to work or school and have no spoons left to talk with our partner or family.

**Dayeinu (We are enough)**

If we talk with our partner or family but eat frozen dinners because we do not have a spoon left to make a meal. **Dayeinu (We are enough)**

If we make a meal but have piles of laundry because we do not have spoons to do both.

**Dayeinu (We are enough)**

If we do laundry but are wiped out and do not have any spoons for the planned dinner with friends and must send our regrets. **Dayeinu (We are enough)**

If we exceed our energy limit on one day and can't get out of bed the next day. **Dayeinu (We are enough)**

If we mask our pain or suffering to avoid stigma, shame, or embarrassment. **Dayeinu (We are enough)**

If we have to explain ourselves to people who say, "Well, you don't look sick." **Dayeinu (We are enough)**

If we need help but don't know how to ask.

**Dayeinu (We are enough)**

If the freedom we seek is from the bondage of our bodies or the bondage of exhaustion. **Dayeinu (We are enough)**

If we don't feel "fine" and share our challenges with others.

**Dayeinu (We are enough)**

If we connect with others who give us support and understanding. **Dayeinu (We are enough)**

**Dayeinu. Dayeinu, Dayeinu! We are all enough!**

