

# <u>The Koach Eitan Halachic Guide to</u> <u>Living with Aphasia and Disability within Judaism:</u> <u>A Handbook for Inclusion</u>

This booklet is a guide to highlight various *halachot* (Jewish laws) and to suggest some communal provisions to assist those suffering from Aphasia and other language impairments. Please note that this guide is not meant to be exhaustive, rather it is intended to raise awareness and initiate conversation for the sake of creating greater acceptance, inclusion, understanding and belonging for those living with language impairments within the Jewish community. If you have any comments or suggestions to add for future editions, I would be grateful for your feedback.

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# I. What is Aphasia?

According to ASHA (The American Speech-Language-Hearing Association)<sup>1</sup>, Aphasia is a language disorder that affects how people communicate. It is caused by damage to the language centers, located in the left side of the brain, that control understanding, speaking, and using sign language. Aphasia does not signify a decrease in intelligence or disrupt thinking. However, it may affect one's ability to communicate. Aphasia may also make it hard for individuals to understand, to read, and to write. Aphasia can affect people in different ways, and no two people will experience the same changes or recovery. The severity and recovery of aphasia depends on a number of things—including the cause, the extent of damage to the brain, family support, and treatment.

Aphasia can lead to difficulty communicating, understanding language, reading, and writing:

- People with Aphasia may find that they experience one or several of these things:
- Inability to produce the words that they want to say—difficulty articulating the words that are "on the tip of your tongue."
- Saying the wrong word. One may say something related in meaning (like "fish" instead of "chicken") or in sound (like "art" instead of "arm"). Sometimes, one might use a word that is not related in meaning or in sound (like "radio" for "ball").
- Switching sounds in words. For example, one might say "wish dasher" for "dishwasher."
- Creation of new words—like "thratble"—that do not have meaning (either by themselves or together in sentences with real words) to other people.
- Repetition of common words or phrases.
- Difficulty saying sentences. One may find it easier to say single words.

Similarly, one may have trouble doing any or all of the following tasks:

- Recognizing an object by its name. For example, if someone asks for a fork, one may give them a spoon.
- Following directions.
- Understanding what others are communicating, especially if they are speaking quickly or about an unfamiliar topic.
- Understanding when multiple people are talking or when there are a lot of distractions around.
- Understanding language that is not straightforward. Some examples of such language include jokes, puns, sarcasm, and phrases like "better late than never."

<sup>&</sup>lt;sup>1</sup> <u>https://www.asha.org/public/speech/disorders/aphasia/</u>. Thanks to Julie Shulman M.S., CCC-SLP for bringing this excellent definition to my attention.



- Recognizing the meanings behind words.
- Reading and Writing

Beyond this, one may have trouble:

- Reading signs, forms, books, and computer screens
- Spelling and putting words together to form sentences
- Using numbers or doing math. For example, it may be hard to tell time, count money, or add and subtract.

Aphasia is most often caused by a stroke. However, any change to the brain can cause aphasia, including traumatic brain injury. Other causes may include brain infections, brain tumors, and other brain disorders that may worsen over time.

# II. How does having Aphasia effect Participation in Jewish observant life?

As mentioned above, Aphasia can affect people in different ways which means that the effects of Aphasia regarding Jewish observant life will differ from person to person. However, if you were to ask my friend Eitan Ashman (and yes, I have done so!), he would tell you that Aphasia can devastate one's ability to participate in Jewish life. Can Eitan read from a *siddur* (prayer book)? No. Can he study Torah from sacred books? No. Does he have the confidence to recite the blessings when being called up to the Torah? No. Is the noise of many people in synagogue distracting and agitating? Yes. Is Eitan's inability to have a free flow conversation frustrating? Absolutely!

Beyond this, it is important to remember that Aphasia is most often caused by a stroke, which means that many people with Aphasia often suffer from additional physical limitations caused by their stroke, and these may impede their ability to stand, or sit for a prolonged period, or perform actions which require dexterity (such as laying *tefillin*/phylacteries). Moreover, it is important to consider the fact that many synagogues are not fully accessible for those who are disabled. Given this, those in a wheelchair (for example) may literally struggle to find a place in synagogue.

## III. Some general remarks about Access & Inclusion

There are numerous *halachot* (Jewish laws) in the *Shulchan Aruch* (Code of Jewish Law) which emphasize the importance of inclusion. For example, we are taught<sup>2</sup> that the *bimah* (Torah reading platform) should be in the center of the synagogue so that 'everyone can hear' the Torah reading. Similarly, we are instructed<sup>3</sup> that when the Torah is raised, it should be done so in a manner that 'all men and women should see the writing'. What these laws come to teach us is that synagogues should be built in a way that makes everyone feel connected to the prayer service, so that everyone can feel a part of Jewish communal life.

<sup>&</sup>lt;sup>2</sup> Shulchan Aruch Orach Chaim 150:5

<sup>&</sup>lt;sup>3</sup> Shulchan Aruch Orach Chaim 134:2



Unfortunately, many synagogues are built in a way that they do not even fulfil these responsibilities, and it would be an understatement to say that this is regrettable. Still, drawing both on the letter and the spirit of these halachot, **Rabbis and community leaders should invest whatever resources they have at their disposal to ensure that their synagogue is as physically inclusive and accessible as possible.** 

### IV. Aphasia & the Shaliach Tzibbur (Cantor/Prayer Leader)

We have previously noted that those who suffer from Aphasia struggle to read from books. Of course, prayer can and should be from the heart, while spontaneous verbal prayers are often brief yet powerful<sup>4</sup>. Still, if someone with Aphasia wishes to participate in a traditional synagogue service, they will likely find it difficult. Alongside this, the sheer length of the synagogue prayers, especially the Shabbat and Festival synagogue prayers, can themselves be very difficult for those suffering from Aphasia,

Before proceeding, note should be made of the *'Siddur Lakol'* which was recently launched by JWeb<sup>5</sup> and which uses the Picture Exchange Communication System (PECS). This resource should certainly be used by anyone who finds it helpful.

However, when we speak of the synagogue we must speak about the role of the *Shaliach Tzibbur* (Cantor/Prayer Leader) whose formal role is to include those who are unable to read from a *siddur* (prayer book) and to pray for those who are unable to pray<sup>6</sup>. As the Rambam<sup>7</sup> explains, 'when the *Shaliach Tzibbur* prays and the congregation listens and responds "Amen" after each and every blessing, it is considered as if they prayed themselves'. Given this, whenever the *Shaliach Tzibbur* leads the prayers for the community, they should pause to consider the fact that other people are truly relying on their prayers to fulfil their own prayer obligations. As a result, the *Shaliach Tzibbur* has the opportunity to say a proper "Amen". On this theme it is important to add that while those who can respond *Amen* to blessings can do so, the *halacha* is that 'whoever hears a blessing while intending to fulfil their duty fulfils their duty even if they do not respond *Amen*.<sup>8</sup>

# V. Aphasia & Aliyot LaTorah (Call-ups to the Torah)

Though Aphasia is a speech impairment, *halachic* (Jewish legal) authorities regard someone with Aphasia as one who technically can speak and hear.<sup>9</sup> This means that while someone with Aphasia may be exempt from fulfilling certain *halachic* duties due to their specific limitations, in general, they are considered to be 'obligated to fulfill the *mitzvot* (commandments)'. Consequently, if an

<sup>&</sup>lt;sup>4</sup> Recall Moshe's brief yet powerful prayer about his sister Miriam: 'El Na Refa Na La' (Bemidbar 12:13)

<sup>&</sup>lt;sup>5</sup> To download a copy of Siddur LaKol, see <u>https://www.jweb.org.uk/s/A4-Siddur-Lakol-Inner-Pages v1-RH-Web v2.pdf</u>

<sup>&</sup>lt;sup>6</sup> See Rosh Hashanah 34b

<sup>&</sup>lt;sup>7</sup> Rambam, *Hilchot Tefillah* 8:9

<sup>&</sup>lt;sup>8</sup> *Hilchot Brachot* 1:11 as explained by Rabbi Yosef Zvi Rimon who was asked this question in relation to those suffering with Aphasia.

<sup>9</sup> See Responsa Minchat Asher Vol. 3 No. 11



individual suffering from Aphasia can recite the *Birkot HaTorah* (the blessings over the Torah), then they can certainly have an *Aliyah LaTorah*.<sup>10</sup> If they need assistance whereby someone recites each word of the *Birkot HaTorah* which they then repeat, then this may be done.<sup>11</sup> If someone else can ascend with them to recite the *Birkot HaTorah* to which they can respond "*Amen*", then this would be effective. And if someone else recites the blessing and they cannot respond *Amen* but intend to do so, then it is considered as if they themselves recited this blessing.

## VI. Inclusion volunteers

As mentioned above, blessings & prayers can be recited by someone else while enabling those suffering from Aphasia to be regarded as if they themselves have recited the prayers. Beyond this, we know that those with Aphasia often suffer from additional physical limitations which may mean that they need assistance to ascend to the *bimah* (Torah reading platform). The question is: *who should do this*?

The answer is that every community establish an inclusion team, made up of men and women, and guided by community members with disabilities, such that at any given service during the week and on Shabbat and Holidays, there is an identified inclusion volunteer available both in the men's and women's section to help worshippers perform a series of tasks including: helping someone get a *siddur* (prayer book), helping them put on their *tallit* (prayer shawl), helping them lay *tefillin* (phylacteries), helping them get food at the *kiddush* (food buffet at the end of the service).

## VII. Access, Seating & Parking

We previously noted that 'Rabbis and community leaders should invest resources to ensure that their synagogue is as physically inclusive and accessible as possible.' Here are some concrete examples of what this means:

Every **public building, including synagogues and other community centers, must be accessible.** This means that if the entrance is not on street level, there should be a ramp. Doors should be wide enough for a wheelchair or scooter to enter without difficulty. If the building has more than one floor, there should be a functioning elevator.<sup>12</sup>

However, access and inclusion demand far more than this. If, for example, those in wheelchairs or motorized scooters are limited to sit in the back of a synagogue, then this is not inclusion! If there is no ramp to the *bimah* (Torah reading platform) or to the *Aron Kodesh* (ark), then this is not inclusion! And if there is no designated area to park motorized scooters near the entrance of the synagogue, then this is not inclusion! Every synagogue

<sup>&</sup>lt;sup>10</sup> Ibid.

<sup>&</sup>lt;sup>11</sup> Clearly, this must be done with sensitivity to avoid significant *tircha d'tzibura* (significant delays in the prayer service). <sup>12</sup> As should be clear, all of these must be functioning. For a heartrending description where perception and reality don't match, see <u>https://blogs.timesofisrael.com/a-waste-of-an-outfit/?fbclid=IwAR3fA2dyJzluV0852MBzgYgz-315klV9eLoityvpVKV2nmNQRk48g6P9Mvk</u>



should ensure that there building is accessible prior to being asked. It would be a shame for synagogues to only provide access and inclusion once someone has visited there and felt marginalized.

# VIII. Announcements and Sermon

Just as the *Shaliach Tzibbur* (Cantor/Prayer Leader) should ensure that their voice is loud, and clear, so too, all those who deliver announcements in synagogues should do so in a loud and clear voice. Beyond this, it is important to note that those with Aphasia struggle to read any information on a screen or in a newsletter. Given this, when a community representative states: 'and all the information can be found in the synagogue newsletter', this excludes those who cannot read this information.

With this in mind we'd like to suggest that all crucial information should be spoken as well as written in newsletters. Beyond this, synagogues should provide an option to members to receive an MP3 recorded message with key information, along with the newsletter.

On a different point, there are times when events occur in synagogues when the membership are invited to stand up (e.g. in order to honor the *Sefer Torah*/Torah scroll or a visiting guest). Though no offence is intended, this can frustrate those who are physically disabled for whom standing up is either difficult or impossible. It is advisable to add the words 'if possible' such that the instruction would be 'if possible, please stand up'.

Following conversation for people with Aphasia can be difficult. If someone in the audience has Aphasia, sermons should be said in a loud, clear voice, and in a somewhat animated manner so the person can focus his attention on the speaker. Sermons should be kept simple and concise so that they are easier to follow.

# IX. Talking to a Rabbi

Undoubtedly, digital platforms are incredibly helpful to talk and meet with congregants who wish to discuss various spiritual and halachic issues. However, when I meet with Eitan, I do so face to face, because anything else would not be effective or helpful. While Rabbis may prefer – for a variety of reasons – to talk with congregants over the phone or via zoom, they should be aware that this presents a difficulty for those suffering for Aphasia, and they should meet with these individuals in person.

# X. Simchat Torah & Purim

I previously mentioned that those with Aphasia struggle to maintain a dialogue especially over the phone or on zoom. That being said, those with Aphasia can be very sensitive to noise and will



certainly struggle to hear things in a noisy environment. This presents several issues in synagogue, especially on loud festivals such as *Simchat Torah & Purim*. While many synagogues have ceased to offer a live zoom stream of the *Megillah* as was done during the COVID pandemic, someone with Aphasia may benefit from hearing the Megillah in a quieter, in-person setting, or via a live stream while at home. **Synagogues should ensure that livestream options are available whenever halachically possible.** 

### XI. Pesach & Shavuot

Seder night, when the main mitzvah includes dialogue, can be an incredibly frustrating time for those with speech and language impairments. To make Seder night more inclusive, Koach Eitan has developed a Haggadah companion, containing shorter Divrei Torah which can be reviewed ahead of Pesach and shared in a more inclusive framework (Koach Eitan is now working on expanding this resource). **Overall, our recommendation is that less is more, and that we should do whatever is possible to include whoever is around the** Seder table. For tips on how to do so, see the 'Let's Talk' resource which can be found on the Koach Eitan website.

On *Shavuot*, where Torah study is often reliant on reading texts, we encourage teachers and communities to think more broadly about how ideas are shared in ways that can be more inclusive, and by using a range of resources beyond just the written word.

# XII. Chanukah

When it comes to *Chanukah*, assuming that the individual with Aphasia has the custom to light a *Chanukiah* and is able to light at least one candle themselves, then doing so means they have fulfilled the mitzvah of lighting *Chanukah* candles. Regarding the blessings, either the individual can recite the blessings, phrase by phrase or word by word after another person, or they can recite *Amen* in response to someone else reciting the blessing. If they cannot respond *Amen* but intend to do so, then it is considered as if they themselves recited this blessing. A tip that may help is to start singing the blessing through song.

# XIII. Mikvaot (Ritual Baths)

As should be clear, there are many areas where greater sensitivity needs to be shown to those with Aphasia and other speech impairments. Still, it seems appropriate to mention *Mikvaot*, given the sense of vulnerability of a woman who has come to a *Mikvah* to immerse but who may not necessarily be able to communicate her needs to the *Balanit* (*Mikveh* Lady). To date, *Balaniot* have not received training in terms of assisting those with speech impairments. However, having spoken with a leading trainer in this area, I believe that this is soon to change. Still, it seems wise for *Mikvaot* to have visual resources using a Picture Exchange Communication System (PECS) to help those with speech impairments communicate their needs.

# XIV. Blessing Cards



The traditional candle lighting blessing recited before the onset of Shabbat can be particularly daunting for individuals with aphasia or language impairments, as they can be lengthy and filled with unfamiliar words.

For some, the inability to read can feel overwhelming. For others, the challenge lies in simply articulating a blessing. Larger fonts can make reading easier, while icons that visually represent the themes of the blessings can help simplify the process. These tools can offer support when reading aloud, speaking, or merely imagining the words one wishes to share with their children that can become obstacles.

Given this, *Koach Eitan* have created a special card to enable and empower more people to participate in candle lighting and make it less likely for them to shy away from the blessing as a result of insecurities related to communication or speech difficulty.

Beyond this, we have also produced an Accessible Printable Blessing Card with Icons series envisioned and created by Binyamin Casper, Yael Harris Resnick, Malka Hubscher, Leora Ashman and Eli Stein, and we have done the same for the blessings given to children before *Yom Kippur*. To print these cards, visit <u>https://www.koacheitan.com/</u>

### XV. Be Proactive!

In conclusion, it is essential that rabbis and community leaders are proactive. If synagogues only provide access and only respond to issues of inclusion once someone has visited there and felt marginalized and rejected, then it is clear that we do not consider and we do not value access and inclusion for as much as we should. To be clear, being proactive isn't just about dealing with problems; it is about education. This is why <u>https://www.koacheitan.com/</u> hosts a range of educational videos & resources explaining more about Aphasia which we would urge you all to watch. Being proactive also demands that Rabbis and community leaders reach out to those in their community suffering from Aphasia and other speech impediments.

When someone experiences a stroke, they can immediately feel disconnected from their synagogue community. Aphasia can have a devastating effect on confidence, which is why many people with Aphasia avoid coming to synagogue even if they can physically do so. It is therefore essential that Rabbis and community leaders be educated about different disabilities so they can understand better, and proactively contact and visit these members who often feel as if they are invisible This sends the greatest message regarding acceptance, inclusion, understanding and belonging.