



How to host an

EMPATHY DINNER

For awareness, fundraising,
or both

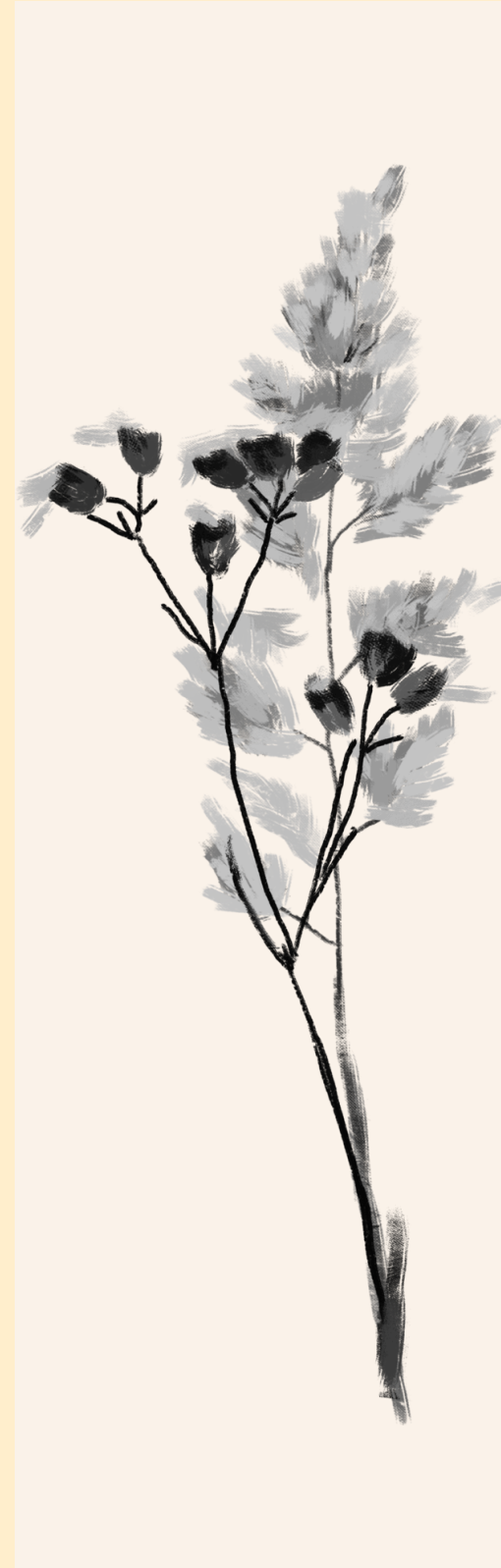


EMPATHY DINNER

Thank you for considering hosting an Empathy Dinner. We are glad you are taking this next step to increase ALS awareness, help people understand what others are going through, and potentially raise funds for the movement to end ALS! Your advocacy matters! Increasing awareness will bring us closer to a world free of ALS.

Donations go far with I AM ALS. In our five years, we have:

- Create a community of advocates who lead the way in ending ALS and improving the quality of life for people living with ALS and their caregivers
- Helped secure more than \$1 billion in federal ALS funding
- Quadrupled funding for ALS research under the Department of Defense
- Passed ACT for ALS, which provides people who do not qualify for clinical trials access to those therapies and participate in ALS research.
- Passed ALS Disability Insurance Access Act of 2019, which eliminated the five-month waiting period to access Social Security Disability Insurance benefits for people living with ALS.
- Provided support to thousands living with and impacted by ALS



THINGS TO CONSIDER



WHAT IS AN EMPATHY DINNER?

For some, it's an adventure; for others, it's a learning opportunity. When guests arrive at the dinner, they are assigned an ALS symptom, which could include a loss of speech, difficulty using one or both arms, spending time in a wheelchair, or an inability to feed themselves. Participants can select any or all of the daily challenges individuals with ALS face.



THE GOAL OF THE EMPATHY DINNER

We aim to create an engaging environment where attendees learn about and feel personally connected to the ALS community's journey. The evening will educate attendees on the daily challenges individuals living with ALS and their loved ones face, inspire empathy, and encourage actionable support through donations or volunteer efforts.



RAISING FUNDS

If you are planning to raise funds, consider setting ticket levels using unique names for various levels – “All in for xxxx”, “#1 Advocate”, “Raising the Bar” etc. Make sure you factor in the cost of the food, location, and other necessities.



THINGS TO CONSIDER



WHO TO ASK

Be bold and ask your friends, family, co-workers, neighbors, religious groups, non-ALS organizations you affiliate with, or anyone you know who wants to make a difference for the ALS community. Consider your event location and the number of people it can accommodate.



WHAT TO ASK

Invite your friends, family, and acquaintances to support this event, which is dedicated to raising awareness and making a meaningful impact in the ALS community.



WHEN TO ASK

It's never too early to start the conversation! The earlier you start, the more time you have to plan the details, gather supplies, raffle ideas, props, etc.



HOW TO ASK

Identifying your audience through text or email is an excellent first step. Check if most of your audience is available on the date you're considering for your event. If you're still finalizing the details, send a "Save the Date" as soon as you've decided on a date so that folks know to mark their calendars. This will give them an idea of what to expect.



MAKE AN IMPACT WITH EACH SYMPTOM

CREATE SIGNS OR NOTECARDS WITH THE
FOLLOWING “RULES,” EACH ASSOCIATED WITH
AN ALS SYMPTOM

LOSS OF USE OF LIMBS

Fine motor skills and the loss of use of arms and legs can be the initial symptoms for many ALS patients. Ankle or wrist weights can simulate difficulty in limb use. Ace bandages around the dominant hand will prevent attendees from inadvertently using their hands.

UNABLE TO SPEAK

ALS sometimes starts in the neck, throat, and mouth, with a bulbar onset. Additionally, the loss of intelligible speech or even enough ‘wind’ for speech can be a symptom of progression. Attendees wear a mask and communicate with a whiteboard.

UNABLE TO WALK

When walking becomes unsafe, the pALS moves to a wheelchair. Manual wheelchairs can be bulky and heavy and require a cALS, a caregiver strong enough to push them. Maneuvering in tight places and traveling in public have become more challenging.

UNABLE TO SELF-FEED

Weakness in arms and inability to control the arm to raise to mouth are the indications here. Additionally, when a pALS cannot chew or swallow safely—OR—when one cannot eat enough calories to maintain weight, a feeding tube may need to be placed. Attendees wear a bib or mask.

LACK OF STAMINA

When distance or “speed” is an issue and/or balance is a concern, in addition to safety, using a rollator makes a big difference. One of the benefits of the rollator is that it is a convenient place to sit and rest for a moment. Attendees use a rollator (if available).

LACK OF BALANCE - FALL PREVENTION

The very first medical device for ALS patients with mobility concerns is a cane. It helps with fall prevention and stability. It is widely accepted but still a sign of progression and weakness for many. Attendees will use a cane (if available).

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MUSCLE WEAKNESS + PARALYSIS

For Deb, the very first symptom was right arm weakness. “I could not open a standard door handle; I kept dropping things and broke more glassware than I cared to admit, loading and unloading the dishwasher! Hardest – I could no longer raise both arms when worshipping my Lord.” Arm weakness can start on either – or both – sides. Attendees will have their “paralyzed” arm in a sling, or use wrist/ankle weights.

LACK OF BALANCE - STABILITY

As stability changes around the house, a walker is often the easiest, safest device to keep a pALS upright and moving. Keyword upright. Many pALS resist using assistive devices, preferring to maintain independence and the perception of not needing help. Care Partners need to reassure pALS That safety is more important than what other people think. Attendees will use a walker (if available).

FOOT DROP - FALL PREVENTION

Falls are often precipitated by “foot drop, ” the inability to clear your foot through the stride of your step. Toes are stubbed, and tripping hazards become more prevalent. Tripping falls happen too often. Braces keep your toes from catching on the ground, sending you tumbling forward! Care partners, encourage your pALS to use the doctor's recommended medical assistive devices. Attendees will wear a brace or boot (if available).

NOTE:

The recommendations and tools provided here are just examples of the resources available to you. Feel free to make this dinner your own by customizing the dinner to fit your needs, expectations, and the resources you have on hand.

"We used what we had, borrowed what we could, and skipped what we couldn't accommodate." - Deb Winters

DURING THE EVENT

Consider the following:

- Have raffles for individuals to bid on (encourage local businesses to donate items worth \$10-\$25). The items can be biddable individually or in a basket.
- Play music in the background could be anything from the music loved by the person you know impacted by the disease or from musicians impacted by ALS (Roberta Flack, John Driskell Hopkins/Zac Brown Band, Jason Becker, Rebecca Luker, Aaron Lazar)
- If a TV or monitor is available, a slideshow with clips from I AM ALS that shares ALS stories
- Have signs on a tripod that engage your audience about I AM ALS and other organizations that are impactful to the ALS Community
- Share flyers with other important information available on the I AM ALS website, including upcoming events and IAA committees to join. Please see the QR code below:



DURING + AFTER THE EVENT - Q&A

Connect with your audience by moving around and checking if anyone needs help with the challenges or has questions about the symptoms.

Encourage your attendees to engage in a discussion about their experience. Some suggested discussion starters may include:

- What was your initial response when you saw the challenge you would face this evening?
- How did it make you feel?
- How has tonight's experience changed your perception of people with ALS and of people with disabilities in general?
- What was the most challenging part of maintaining the symptoms for the evening?
- Can you share an experience from this evening that was particularly impactful?
- Can you share a previous experience that you would handle differently now that you have had this experience?
- Who do you wish you had brought along with you this evening?
- Other than the symptoms you experienced, is there another symptom you perceive as even more difficult?
- Do you have a colleague or friend who has dealt with the stigma of disability that you now acknowledge deserves more empathy from you? Tell me more.
- What will you do differently starting now due to this experience?

