

Checklist to Aid in the Planning of Brain Tissue Donation

You have made the selfless decision to become a brain donor upon death. So, what is next? Proper planning in advance can help ensure that your wishes are accounted for and honored at the time of your or a loved one's passing. The details of the process may vary from state to state.

To aid you, the following checklist was created to assist in putting your plans in place for a smooth process.

- Inform loved ones, doctors, caregivers, hospital/nursing home/home care/hospice, and attorney of your desire for tissue donation.
- Assure that you have a certified Living Will that specifically grants brain donation for research. Make certain document is readily available.

LOCATION: _____

- Assure Power of Attorney (POA) and Health Care Directive documents are completed and readily available.

LOCATION: _____

- Select funeral home and discuss arrangements. Inform the funeral home of your desire to be a brain tissue donor. (When a tissue donation will take place, there are certain necessary requirements needed to be fulfilled by the funeral home.)

FUNERAL HOME CONTACT INFORMATION:

- As health declines, reconfirm the above and be certain hospital/nursing home/home care/hospice are fully aware that the donation will be taking place. Provide them with all the appropriate names and phone numbers (i.e., family members, POA, NAF contact, funeral home, etc.). If you enter hospice care, notify the National Ataxia Foundation (see contact information below) with the contact information for the hospice organization.
- Designate one person who will contact the National Ataxia Foundation (see contact information below) as soon as death is imminent or has occurred.

At this point, the designated person will be put in touch with NAF's academic partner who will contact them to obtain a signature on an Informed Consent form. Once that has been received, our academic partner will then coordinate the process for the brain retrieval. Reminder: This must happen shortly after death occurs. When the retrieval has taken place, the tissue will be sent to NAF's academic partner's laboratory and the body will be delivered to the funeral home or wherever the family chooses. Keep in mind that tissue donation does not disrupt the timing and viewing for most traditional remembrance services and still allows for open casket if so desired.

