

Overview of the AFTD Support Group Facilitator Network

AFTD's mission is to improve the quality of life of people affected by FTD disorders and drive research to a cure. Our entire focus is on these less common and still poorly understood forms of dementia. In the absence of FTD specific treatment, targeted support groups are the most effective intervention. In 2015, we introduced an initiative to grow the number of FTD support groups across the country and create a network among facilitators of those groups to expand and increase the information and collaboration available to them.

We are offering to add tailored resources, education and support to those who lead FTD-specific support groups. As such, we invite support group leaders to affiliate with AFTD and gain access to these tailored resources and become part of the network of others who run FTD support groups. This process for affiliation is easy, flexible and is focused on those leading the group, arming them with resources and education to bring back to their members.

Logistics: AFTD invites individual FTD support group leaders to affiliate with us as an AFTD Support Group Facilitator volunteer. It is a relationship between the individual and AFTD. In becoming an AFTD volunteer, we ask the support group leader to adhere to all the policies and procedures outlined in our volunteer handbook and support group facilitator playbook, which you will receive upon training. From there, we require one AFTD training per year, but offer four web-based and one in-person at our annual education conference. Additionally, our affiliated group leaders will be invited to participate in networking/troubleshooting conference calls with others running FTD-groups nationally and gain rich resources from their peers. AFTD will also invite our affiliated leaders to help us learn more about our community, particularly to develop best practices for those running FTD-specific support groups. Below is a role description for this affiliation. If you'd like to explore this role more, please visit our volunteer page here:

<http://www.theaftd.org/get-involved/volunteer>

Thank you for your continued efforts to support this community!

Description of AFTD Volunteer Support Group Facilitator Role

Program: AFTD Support Services Program

Purpose

AFTD's national network of Support Groups is just one of the ways AFTD lives out its mission to provide every person with FTD and their caregiver(s) with access to high quality, effective support services. The dedicated volunteer facilitators donate time, effort and expertise to exchange resources, supports and insights with those in their local support group. In return, AFTD provides access to our comprehensive FTD network. This affiliation carries our pledge that AFTD is here for you as you provide such an important and needed service to our community.

This volunteer role is a mutual-benefit affiliation between AFTD and the Volunteer Support Group Facilitator. This agreement gives our volunteers' access to AFTD and to our network of experts. Additionally, our volunteer facilitators have access to FTD-tailored trainings and the most up-to-date materials and information to bring back to their support groups. AFTD's values of knowledge, collaboration, respect, dignity, and compassion are at the core of this role, which are reflected below:

Core Responsibilities

- Respect the privacy of all group members, caregivers, and/or diagnosed persons encountered in this role and hold confidential all contact information (refer to the affiliation agreement).
- Adhere to all AFTD policies and guidelines that govern volunteers and support group facilitators and maintain professionalism while representing AFTD.
- Participate in volunteer orientation and annual trainings as requested by AFTD.
- Act as a critical communication link between AFTD and caregivers and persons diagnosed with FTD in your support group, including informing the Support Services Manager of any issues that you feel need more training/support.
- Sign an affiliation agreement (this includes co-facilitators).
- Lead a support group on a recurrent and consistent basis (recommendation: once-a-month) at no cost to the participants.
- Publicize your support group in collaboration with the AFTD office.
- Identify and secure a consistent geographic location for your support group to be held.
- Support/assist new support group members through an introduction to, and expectations of, the group, and explanation of the "opt-in" registration process with AFTD.
- In collaboration with the Support Group Network and Support Services Manager, establish and follow best practices within your group.
- Submit requested documentation and brief quarterly reports of support group activities to Support Services Manager in a timely manner.
- Assure the FTD disease-related information shared in group is as accurate and reliable as possible.
- Use AFTD's resources and support to provide the support group members with the most up-to-date information.
- Participate in bi-annual conference calls with AFTD Support Services Manager, Regional Coordinators Volunteers, and fellow regional Facilitators.



The Association for
Frontotemporal Degeneration
Opening the gateway to help and a cure

Time Commitment

The hours are flexible; however, a monthly average of approximately 4-6 hours is expected, which includes reminder emails/calls to the group, prep time leading up to the group, leading the monthly group, a support group facilitator conference call two times per year, as well as attending at least one AFTD sponsored or recommended training opportunity (including our national conference) on an annual basis.

The term of service for this volunteer leadership role is one year. AFTD asks for a Support Group Facilitator Agreement to be signed and renewed annually, or, whenever there is a change in the facilitator.

Skills and Abilities

- Commitment to the mission of AFTD
- Solid knowledge of the various presentations of and issues related to frontotemporal degeneration (or willingness to learn)
- Strong listening skills
- Strong organizational skills
- Strong leadership skills
- Dependable and consistent
- Compassionate/empathetic
- Knowledge of group dynamic principles (or willingness to learn)
- Respect for diversity among members of your group
- Ability to separate your own needs from providing for the needs of group members
- Understanding and operation of a computer and basic software programs including email, Microsoft Word and Excel (or willingness to learn), and web-based meeting software.

Benefits

By volunteering with AFTD, support group facilitators become an integral piece in strengthening the national network of support available for the FTD community. Facilitators will become members of a professional, dedicated group that is changing the face of FTD. Volunteering with AFTD is personally rewarding, offering a unique role of bringing deep learning and connection to those experiencing FTD and its effects. So many caregivers have told us that the support groups are their life-lines. Being able to provide that space for conversation and support can be very rewarding.

Required Signature

Volunteer Support Group Facilitators will be required to sign two forms on an annual basis: 1.) a Volunteer Support Group Facilitator Agreement which summarizes expectations between AFTD and the facilitator and 2.) an Acknowledgment that reflects you received, read, and agree with AFTD's Volunteer Support Group Facilitator Playbook.