Frontotemporal Dementia or FTD

Frontotemporal dementia (frontotemporal lobar degeneration) is an umbrella term for a diverse group of uncommon disorders that primarily affect the frontal and temporal lobes of the brain — the areas generally associated with personality, behavior and language.

In frontotemporal dementia, portions of these lobes shrink (atrophy). Signs and symptoms vary, depending upon the portion of the brain affected.

Some people with frontotemporal dementia undergo dramatic changes in their personality and become socially inappropriate, impulsive or emotionally indifferent, while others lose the ability to use language.

Frontotemporal dementia is often misdiagnosed as a psychiatric problem or as Alzheimer’s disease. But frontotemporal dementia tends to occur at a younger age than does Alzheimer’s disease, generally between the ages of 40 and 45.

There are a number of different diseases that cause frontotemporal degenerations. The two most prominent are 1) a group of brain disorders involving the protein tau and 2) a group of brain disorders involving the protein called TDP43. For reasons that are not yet known, these two groups have a preference for the frontal and temporal lobes that cause dementia.

FTD used to be called Pick’s disease after Arnold Pick, a physician who in 1892 first described a patient with distinct symptoms affecting language. Some doctors still use the term “Pick’s disease.” Other terms you may see used to describe FTD include frontotemporal disorders, frontotemporal degenerations and frontal lobe disorders.

Frontotemporal degenerations are inherited in about a third of all cases. Genetic counseling and testing is available now in individuals with family histories of frontotemporal degenerations. There are no known risk factors for any frontotemporal degenerations except for a family history or a similar disorder.

For more information on frontotemporal dementia read more on our web site alz.org.

Community Conversation

Learn more about Alzheimer’s and memory loss. Share your thoughts about how we can help the people in your community. Bring a friend who has been touched by memory loss! Light refreshments will be provided.

Tuesday April 4 | 6 – 7:30 p.m.
Farmington Public Library
101 North A St. | Farmington, MO 63640
Registration is requested. Call 800.272.3900 to register. Click here to download a flier to share.

New Frontotemporal Support Group

4th Wednesdays of the each month, 7 p.m.
Alzheimer’s Association St. Louis Chapter Office
Call 1.800.272.3900 for more information

Save Our Walk Dates and Plan to Participate!

St. Louis Area
Belleville September 30
Cape Girardeau September 16
Edwardsville September 23
Farmington September 9
Jefferson Co. October 7
Lincoln Co. October 14
Poplar Bluff September 23
Rolla September 30
St. Charles September 16
St. Louis Washington September 9
Washington

And for our neighbors to the West/South:
Branson September 9
Columbia October 1
Jefferson City September 17
Joplin August 26
Lake of the Ozarks October 7
Macon Co. September 16
Sedalia September 9
Springfield September 16
West Plains September 30

LUNCH & LEARN

Join us for an Alzheimer’s Research Lunch & Learn

Wednesday, March 29, 11:30 a.m. – 12:30 p.m., St. Louis Chapter Office

Helpline volunteer Andrea Denny and colleagues from The Charles F. and Joanne Knight Alzheimer’s Disease Research Center (Knight ADRC) at Washington University School of Medicine are offering volunteers an update on the latest research efforts at the Knight ADRC.

Bring your own lunch or enjoy light snacks. RSVP to Pam Gordon at PGordon@alz.org or 314.801.0462.
Celebrate, Learn and Connect at our New Volunteer Forums!

For some years, the St. Louis Chapter has held an Annual Volunteer Appreciation event in St. Louis during April, National Volunteer Appreciation Month. This year, we are excited to take a different approach for recognition by hosting Volunteer Forums several times a year. The first Volunteer Forums will be in late April and early May at three different locations in our service area: Illinois, St. Louis and Cape Girardeau.

In addition to celebrating you, we will be offering the opportunity to learn about how Alzheimer’s and dementia present in people with developmental disability or Down’s syndrome, and time to connect with volunteers in other roles in the organization. The last 30 minutes of the program will offer a time for volunteers in like roles to gather with their supervisor.

We hope you will plan to join us on one of these dates:

Monday, April 24 | Cape Girardeau 6-8 p.m. | Geraldine Hirsch Room Cape Girardeau Public Library

Wednesday, April 26 | Collinsville 6-8 p.m. | The Blum House 414 West Main Street

Saturday, May 6 | St. Louis 9:30-11:30 a.m. | Chapter Office

Interested in hearing the presentation? Join us by conference call (instructions will be provided when you RSVP) or watch a YouTube of the educational presentation on our YouTube channel after the last event.

Help us plan for how you would like to participate in a Volunteer Forum by RSVP’ing Here or to Erin Kelley, Volunteer Coordinator, at 314.801.0414.

Let’s Talk Volunteers - Giving and Receiving

Through Let’s Talk, a program unique to our Chapter, people with early-stage dementia are linked through a supervised telephone peer support program to share information and coping strategies, reduce social isolation and provide emotional support. The program provides a supportive environment where a person on each end of the phone can talk freely about the effects of dementia on their lives.

Two Saturday mornings a month Call Coordinator volunteers and “Early-stage call volunteers” meet at the St. Louis Chapter office for Let’s Talk activities. The morning starts with time to reconnect with fellow volunteers before volunteers callers pair make their way to one of the many office phones for calls. Each caller has a list of people they call on a regular basis and, once numbers are dialed, everyone settles into easy conversation. Volunteer Coordinators are on-hand to assist with technology and note taking, leaving the callers to concentrate on conversation and support. After calls are made, volunteers spend time visiting and talking about their morning’s work.

Let’s Talk is an ongoing program and individuals wishing to receive calls can apply to enroll any time by calling 800.272.3900. Those who would like to be call recipients should be residents of Missouri or Illinois.

Let’s Talk needs callers (who also have early-stage memory loss) to make friendly calls to and volunteers who would like to assist. Volunteers should be able to travel to the Alzheimer’s Association’s St. Louis Chapter office at 9370 Olive Blvd. in St. Louis County to participate in the program.

Let’s Talk Volunteers – Giving and Receiving

Ted Grazman, Let’s Talk Founder

To learn more about the program or volunteering, contact Pam Gordon at 314.801.0462 or PGordon@alz.org.
Go Purple!

June is Alzheimer’s Brain & Awareness Month! During this month is our annual Go Purple Alzheimer’s Awareness Campaign and the Longest Day fundraiser.

Why Go Purple

Go Purple presents an opportunity for faith communities, organizations, schools and social groups to help raise awareness about this disease and to be a positive influence for people to take action. As a result of your Go Purple event, awareness of the disease is heightened, myths are eliminated and people can be inspired to take action by seeking a diagnosis or calling the Association for help.

How to Go Purple

Going Purple is easy! There are many simple and more advanced activities that you can do to raise awareness about Alzheimer’s disease.

Examples of simple activities include:
- Set up a table after services or in the lunch room to distribute free Alzheimer’s information.
- Go Casual for worship or work. Wear a Casual for a Cause sticker and donate at least $1 per person. Use this for your team for The Longest Day.

Examples of more advanced activities include:
- Host an Alzheimer’s education program. Click here to see the free consumer education programs we offer.
- Participate in The Longest Day by doing something you love and raising funds for the activity. For example, host a chili cook-off to honor a loved one. For more information about The Longest Day, click here or contact Betsy Brown at bmbrown@alz.org or 314.801.0445.

Upon registration, you will receive your Go Purple packet with all the information you will need to set up, execute and promote your activity. You will receive END ALZ stickers and Alzheimer’s awareness ribbons.

To register, click here or call 800.272.3900.

For more information, contact Regina Lowe at rlowe@alz.org or 314.801.0448.

2017 Alzheimer’s Advocacy Forum

On March 27 – 29, more than 1,000 advocates will meet in Washington, D.C. to advocate for Alzheimer’s disease research and care and support services. Because of advocate support, the Alzheimer’s Association has experienced two consecutive years of historic funding increases at the National Institutes of Health for Alzheimer’s disease research funding.

A large group comprised of staff, volunteers and partners of Association organization will represent the St. Louis Chapter at the forum, the nation’s premier Alzheimer’s diseases advocacy event.

Attendees will receive updates on evolving legislative priorities as well as training on how to demand action.

Alzheimer’s Champion Maria Shriver will receive Alzheimer’s Association Lifetime Achievement Award at the 2017 Advocacy Forum. Shriver is one of the nation’s premier Alzheimer’s advocates and founder of The Women’s Alzheimer’s Movement, a global alliance to raise awareness of the disease’s disproportionate effect on women and to raise funds for women-based research.

Liz Hernandez, Mexican-American Emmy-nominated television personality and journalist, will receive the Young Advocate Award. MSNBC journalist and caregiver Richard Lui will share his Alzheimer’s disease experience. Lui is an Alzheimer’s Association Celebrity Champion and an AARP Caregiving Champion.

This year, there will be 19 people attending the Advocacy Forum from the St. Louis Chapter!

Advocacy volunteers who are attending include:
- Sara Ellis
- Sandy Jaffe
- Greg Luzecky
- Jeanette Rettle
- Betty Robinson
- Fred Robinson
- Richard Rubin
- Lonnie Schicker
- Courtney Tine
- Teresa Yao

We wish these advocates and attendees from across the United States great success in Washington, D.C.
**Mission Conversation Calls**

Some of you may receive a call from Lisa Thompson. She’s a chapter staff member who is going to be taking on more responsibility for support groups. She’ll be contacting some of our support group facilitators to get to know you and to conduct what we call “Mission Conversations”, which are an opportunity for staff to get feedback from you. Please welcome her to the team and feel free to talk with her openly about your experience as a support group facilitator.

**New Support Group Inclusion/Exclusion Policy**

Support Groups should be welcoming and inclusive of diverse audiences. They are great for most people, but they are not for everyone.

- There are rare occasions when an attendee’s needs aren’t a good fit for what a support group has to offer. Once in a while, there have been situations when an attendee has been under the influence of alcohol/drugs or has had mental health issues that make it impossible for them to participate in a support group without causing disruption to the entire group process.
- For facilitators of groups for people with memory loss, there are frequently questions about how long that person should continue to participate in the group as their disease progresses.
- Finally, there is a question of how caregiver support groups should handle the ongoing participation of a group member once the person with dementia has passed away.

In order to better support facilitators and to maintain the integrity of our support groups, we have decided a clear policy on these inclusion/exclusion issues is needed.

Facilitators will receive information by email with our new policy statement. This policy can’t possibly cover all situations, so please let us know when we need to make exceptions. The policy is intended to help facilitators deal with difficult situations and not to tie the hands of a facilitator who needs flexibility in addressing a specific situation.

**Upcoming Events**

**Living with Alzheimer’s**

This is a 4-part program to get answers to your questions and hear from others who are facing this journey. This very interactive class is open to people with mild/early stage Alzheimer’s disease or dementia of any other type. Click here for more information. Registration is required. Call 800.272.3900.

**FREE Care Consultations Near You**

- Sat., March 25, 2017 | 9 a.m. - 3 p.m. | Flier
  - Jefferson County Library · Arnold Branch
  - 1701 Missouri State Rd. | Arnold, MO 63010
  - Please register by Friday, March 24, 2017.

- Wed., March 29, 2017 | 9 a.m. - 3 p.m. | Flier
  - Lutheran Family & Children Services
  - 3178 Blattner Dr. | Cape Girardeau, MO 63703
  - Please register by Monday, March 27, 2017.

- Sat., April 1, 2017 | 9 a.m. - 3 p.m. | Flier
  - Jefferson County Library · Northwest Branch
  - 5680 State Rd. | High Ridge, MO 63049
  - Please register by Friday, March 31, 2017.

- Fri., April 7, 2017 | 9 a.m. - 4 p.m. | Flier
  - Belleville Memorial Hospital · Memorial Care Center
  - 4315 Memorial Dr. | Belleville, IL 62226
  - Please register by Thursday, April 6, 2017.