

Involving Volunteers in a Multidisciplinary ALS Clinic

Nicole Lessard Yarab, RN, BA

Emory ALS Center

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I have no conflicts of interest to report.

I am not receiving commercial support for this presentation.

Objectives

Participants will be able to:

- Identify 2 areas for volunteer involvement
- Describe the role of the volunteer at ALS Clinic
- Define the framework needed to create and implement a volunteer program at their center

Background



Emory ALS Clinic



- Academic institution
- The Emory Clinic, Neurology Department
- 250 patients followed
- 17-21 patients/clinic
- Multidisciplinary ALS Clinic held twice a month

Challenges

- Funding
- Staffing
- Time
- Communication
- Size of patient population
- Infrastructure/Space
- Privacy

The ALS Clinic Team



Volunteer Program



Two ways to volunteer

- ALS Clinic volunteer
- ALS Clinic fundraising activities



Fundraising



EMORY
ALS CENTER

Clinic Volunteers

“Lay”

- Family members of past patients
- Friends of ALS community
- Started program-09/2007
- Lead volunteer-12/2007

Vendor/professional

- MDA
 - » (Muscular Dystrophy Association)
- ALS Association
- Hospice
- Wheelchair specialist
- Home Health Respiratory Therapist

The “Lay” Volunteer

- Offer refreshments
- Photograph patients
- Visit with PALS during downtime
- Share personal story/experience
- Offer a hug or a friendly ear



Lead Volunteer

- Point person
- Coordinates volunteers
- Liaison between clinic nurse and lay volunteers

The Vendor Volunteer

Assist staff with:

- Administrative and operational tasks
- Education and equipment demonstration



Vendor volunteers



- Assist Emory therapists
- Weigh patients
- Escorting patients to clinic rooms
- Discuss hospice services
- Assist with loaner equipment
- Discuss assistance available from non-profit ALS organizations

Criteria for Volunteering

- “Lay”
 - » Personal connection to ALS
- Vendor
 - » Proven dedication to optimizing care for ALS community
- Follow institution’s guidelines
 - » Complete privacy training
 - » Sign confidentiality statement and liability waiver
 - » ID badges
 - » Vaccination
- Professional conduct & dress

Confidentiality Statement

Emory Healthcare
CONFIDENTIALITY STATEMENT
Volunteer – ALS Clinic

It is the policy of Emory University Hospital, Crawford Long Hospital, Emory Healthcare, Inc., The Emory Clinic, Inc., Emory Children's Center, Wesley Woods Center of Emory University, Dialysis Access Center of Atlanta and Emory Specialty Associates ("Emory") and other affiliates as appropriate that any patient, financial, employee, payroll and business related information is strictly confidential and/or proprietary information.

I understand that, in the course of my role as a Volunteer I may learn information which is confidential under federal and state law or which is considered confidential and/or proprietary by Emory, including but not limited to patient medical information, other information considered personal by patients and their families. I agree to keep confidential all such information, whether verbal, written or computerized, which I may learn. I will not discuss patient or family information with anyone not immediately concerned with or involved with a particular patient's care or treatment and then only as necessary for my duties as a volunteer at Emory. In addition, I will not discuss patient or organizational information in public areas (such as elevators, cafeterias, etc.) during this time.

I HAVE READ THE ABOVE CONFIDENTIALITY STATEMENT AND I AGREE TO COMPLY FULLY WITH ITS TERMS

Please print your name clearly

Signature

Date

Privacy Training

Emory Healthcare

Patient Privacy Training Acknowledgment

I certify that I have read and understand the Emory Healthcare (EHC) Patient Privacy training. I play a key role in protecting the privacy of EHC patient information and understand the importance of patient privacy. I have had an opportunity to ask questions regarding the privacy training I received.

Signature

Date

Name (Print)

Clinical Outcomes

- Clinic operations more efficient
- Safe, caring environment
 - » Not just “clinical” experience
- Increased patient/family satisfaction
- Increased staff satisfaction
- Rewarding & therapeutic experience for volunteers

Volunteer Feedback

Feedback

- “Being a volunteer for ALS Clinic has been a great experience for me. Just being there for patients and families ...I believe that I comfort them, knowing that I understand what they are going through in tough times with ALS day to day.”
 - Gina Sue Wilson, husband died of ALS 2 ½ years ago

Feedback

- “Volunteering is a privilege. The whole team always warmly welcomes us and treats the volunteers with trust, respect and confidence. You make each volunteer feel like a valued member of the team. I like being a regular person, caregiver, survivor (so to speak) of ALS and all that it means. Because of my experiences, I have a personal perspective to offer to PALS and their families. I’m comfortable and fearless. I have courage to share. The ALS experience brings people together. We are one family.”

– Cynthia Douthat, husband and father died of ALS

Feedback

- “I consider it a privilege to participate in ALS Clinic. It’s inspiring to see the love and dedication of staff, volunteers, family and patients. Being able to help answer questions, make suggestions, retrain or give a word of encouragement gives me an incredible feeling of satisfaction. There is also the opportunity to learn something new. ALS patients are very resourceful and inventive and that information can then be passed on to others thru us.”

- Valeria Schaefer, home health respiratory therapist

Recommendations

- Check with your institution for their volunteer guidelines
- Create criteria for volunteering at your center
- Identify a lead volunteer
- Invite participation of interested parties
 - » family members of previous ALS patients
 - » vendors who support the ALS community
- ***Recognize what new volunteers experience

A very special thank you to our volunteers

- Karen Duffy-lead volunteer
- Melissa Carpenter
- Tana Criner
- Polly Hogue
- Amanda Mowrey
- Cheryl Prince
- Jane Scudder
- Gina Sue Wilson
- Victoria Cunneen
- Tina Haney
- Wade Holley
- Crystal Jackson
- Rob Kelley
- Valeria Schaefer
- Chad Jones
- Cindy McCall
- Steve Parker
- Weesie Walker

Nicole Lessard Yarab, RN, BA
ALS Nurse Clinician
Emory ALS Center
1365 Clifton Road, NE
Atlanta, GA 30322 USA

nlessar@emory.edu

www.neurology.emory.edu/ALS