



Volunteer Training Manual

The Ulman Cancer Fund for Young Adults

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www.ulmancancerfund.org

www.ulmanfund.org/HelpingOthersFight

I. The Ulman Cancer Fund for Young Adults

{Our Mission} The Ulman Cancer Fund for Young Adults enhances lives by supporting, educating, and connecting young adults, and their loved ones, affected by cancer.

Each year, over 72,000 young adults, aged 15-39, are diagnosed with cancer - that's one every eight minutes. 10,000 young adults die from cancer every year - that's one every hour. Of the 14 million cancer survivors living in the United States, 1 in 10 is under the age of 40. 1 in every 100 college students is a cancer survivor. We are here to ensure that none of these young adults have to face cancer alone.

Over the past thirty years, cancer incidence in young adults has increased more than any other age group, but survival rates have not improved at all. This may be due to late diagnosis, lack of health insurance, infrequent physical exams, or physician negligence. Young adults also have unique needs that must be addressed when they are diagnosed with cancer, including issues related to fertility, relationships, sexuality, parenting, financial management, health insurance, career planning, education, and finding peer support.

The Ulman Cancer Fund was founded in 1997 by Doug Ulman, a three-time cancer survivor by age 20, when he discovered the stark lack of resources and support for young adults facing a cancer diagnosis or the diagnosis of a loved one. What began as a grassroots, family initiative is now a diverse, comprehensive organization affecting real change in the lives of young adults and their loved ones all across the country.

Since our inception, we have awarded over \$250,000 in college scholarships, distributed over 15,000 *No Way* guidebooks to individuals and cancer centers in all 50 states, provided Patient Navigation services to over 500 young adults and families each year, and activated thousands of people in the fight against cancer. We spend 83% of our funds on mission-related programming.

{Helping Others Fight}

The mission of UCF's Helping Others Fight program is to directly support individuals and families affected by cancer through volunteer service and companionship. Individuals and groups of volunteers provide relief and comfort to local cancer patients and their loved ones and ensure that no one has to face cancer alone.

{UCF Programs & Events: How We Change Lives}

Patient Navigation Program: UCF Patient Navigators improve the ability of young adults to manage their own cancer experience and long-term survivorship. This program is offered at the University of Maryland Greenebaum Cancer Center, Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, GBMC Sandra & Malcom Berman Cancer Institute, and (in early 2013) the Comprehensive Cancer Center at the Walter Reed National Military Medical Center. Remote Patient Navigation is also provided through our office for young adults living outside of the local area. www.ulmanfund.org/patientnavigation

Support Groups: We continue to provide direct support and connections through several support groups for young adults impacted by cancer. These professionally facilitated groups meet in Columbia, Baltimore, Towson, and Annapolis.

National College Scholarship Program: These competitive awards support the financial needs of young adults whose lives have been impacted by cancer and are seeking a higher education. www.ulmanfund.org/scholarship

Cancer to 5K: A free, 12-week training program designed to introduce or reintroduce cancer survivors to physical activity by providing them with the training program, coaches, encouragement, and support necessary to complete a 5K road race. www.cancerto5k.com

Team FIGHT: An endurance training program through which men and women of all ages train together for specific events to raise funds and awareness through sport. Since the program's creation in 2008, over 1,000 people have raced with Team FIGHT on behalf of young adults affected by cancer. www.teamfight.org

4K for Cancer: Every spring, 120+ college-aged cyclists embark on a 70-day, 4000-mile bicycle journey across the country. Riders can choose routes from Baltimore, MD to Seattle, WA, Portland, OR, San Francisco, CA, or San Diego, CA. This year, the 4K has added a Run Across America, from San Francisco, CA to Baltimore, MD. Each rider will spread awareness and raise funds to support the fight against cancer as they travel from coast to coast. www.4kforcancer.org

Board of Young Adults Advisors (BOYAA): A group of active, passionate young professionals working to support their peers impacted by cancer through philanthropy, community outreach, exciting events, and unique volunteer service. www.ulmanfund.org/BOYAA

II. Volunteer Eligibility Standards

Helping Others Fight volunteers should be:

- Positive
- Friendly
- Energetic
- Great listeners
- Compassionate
- Understanding
- Emotionally mature
- Non-judgmental

{Health Standards}

Volunteers should also remember that the clients we work with often have very compromised immune systems. Therefore, strict health standards must be enforced. Please excuse yourself from volunteer assignments for symptoms of respiratory or gastrointestinal illness. Any questions or changes regarding illness or general health status should be directed to the Helping Others Fight program specialists. To reduce the risk of infection or disease spread, we highly recommend that volunteers receive their flu vaccine and practice good infection control habits, such as regular hand washing.

Please exercise your best judgment to avoid personal injury while volunteering with our clients, and notify the Helping Others Fight team of any major allergies before participating in volunteer assignments.

{Administrative Requirements}

1. Complete volunteer training
2. Submit to and pass background check
3. Fill out and return forms:
 - a. Volunteer waiver & photo release
 - b. Background check consent
 - c. Confidentiality Agreement
 - d. Volunteer Driver Policy

III. Volunteer Activities

You may participate in a variety of activities as a Helping Others Fight volunteer. The ultimate goal is to provide relief to the patient and their family, and to be a comforting and supportive presence in their lives during this immensely difficult time. To this end, you may help out patients with pet care, running errands, meal preparation and delivery, housekeeping, or transportation to and from treatment.

If you are comfortable doing so, you also may become a treatment companion for an individual undergoing active treatment in the area.

While your efforts may seem like small gestures, you will be helping to provide a sense of normalcy in their home that was lost when they heard the words, “You have cancer.” As a volunteer, you allow patients and caregivers to feel empowered and in control of their everyday needs, thus giving them precious time to focus on their wellness.

IV. General Conduct

{Confidentiality}

The Ulman Cancer Fund for Young Adults and the cancer centers that we work with respect and protect the privacy of all patients and their loved ones. Patient confidentiality is a legal requirement of all health care providers.

By agreeing to participate as a representative of UCF and the Helping Other Fight program, you must understand and agree to hold all patient information strictly confidential, and to share confidential or sensitive information only with the Helping Others Fight team. To achieve this goal, please handle all paperwork, forms, and conversations in a way that precludes accidental observation of confidential information.

Before completing any volunteer assignments, please review the information provided about HIPAA, the Health Insurance Portability and Accountability Act, which protects patients’ personal health information.

{General Volunteer Conduct}

Volunteers shall avoid the use of alcohol and drugs while participating in Helping Others Fight activities. Please do not appear on duty while under the influence of alcohol or drugs.

You may be offered a meal or a snack in a patient’s home. You may accept this offer while visiting a patient or family. Any meals or snacks eaten at a patient’s home must be done so at your own risk. However, if you will be at a residence or traveling for an extended period of time, we recommend bringing your own meal or snack.

DO NOT give your personal phone number, address, or email address to your client or their family members. This may convey to the clients that you are available at any time, and we do not want to put you in a position where you feel

the need to provide services to clients during your own personal time. When clients need to contact you, please instruct them to contact the Helping Others Fight program specialists or UCF staff at helpingothersfight@ulmanfund.org / (410) 964-0202 x.108. If there is an emergency, advise clients to call 911 immediately.

Your friends, family members, or other visitors may NOT accompany you to a patient's home. This is a breach of patient confidentiality, and your friends and family have not been trained and approved for this work as you have. While they may be well meaning, they may inadvertently say or do something inappropriate, and compromise the relationship we have built with our clients and their families.

Once you have confirmed your participation in an upcoming volunteer assignment, our clients are counting on you to show up! Please contact the patient/family if you expect to be more than 10 minutes late, especially if you are transporting them to or from treatment. Maintain regular communication with your Helping Others Fight program specialists before and after each visit to maintain accurate records. See Section 5, "Supervision & Support," for more information on the communication protocol for individual volunteer projects.

You may not administer medication to a patient. The caregiver or physician, prior to leaving the volunteer with the patient, should prepare medications. You may assist the patient by bringing the container with the pre-prepared dosage to the patient at a specific time. YOU do not prepare this dosage. You are also not permitted to dispense medical advice related to treatment or any other medical issues. Report any new or persistent issues to the Helping Others Fight team if they do not notify their physician.

In case of accident or emergency:

- Call 911 if necessary
- If patient falls, make them as comfortable as possible without lifting or moving them
- Call the Helping Others Fight program specialists at (410) 964-0202, and provide your name, the patient's name, and your volunteer status.
- Please follow up with the HOF team after the visit via email or phone after the visit
- If you experience personal injury, follow proper emergency procedures and contact the HOF team immediately

Volunteers will NOT:

- Be required to provide other services that were not originally agreed upon for your visit

- Be expected to provide medical or emotional assistance to clients or to other volunteers
- Provide unauthorized financial assistance to clients
- Transport clients' family members, unless previously authorized

V. Supervision and Support

{Communication and Record Keeping}

Before a volunteer assignment, the HOF team will contact you to confirm all relevant details.

- THE DAY BEFORE your assignment, call your client to confirm the details of your visit
 - o Ex: *"Hi, this is [NAME], I will be coming to your house at [TIME] to drive you to treatment. I drive a [TYPE OF CAR], and will be wearing a Helping Others Fight ID badge. See you tomorrow!"*
- WITHIN 24 HOURS AFTER YOUR VISIT, send a follow-up email to the HOF team (helpingothersfight@ulmanfund.org). Please report any concerns or grievances in this follow-up email. We want you to enjoy your experience with Helping Others Fight, so be honest and forthcoming with your feedback!

We recognize that support is necessary for our active volunteers. As we participation in volunteer projects continues, we will arrange supportive supervision groups to provide a forum for volunteers to discuss particular patient issues/concerns and for the HOF to become aware of issues in a patient's home.

In addition to your follow-up emails, please keep an accurate record of your visits on the Helping Others Fight timesheet, to be returned to the HOF team each month. You will be contacted to collect this information.

{Corrective Action}

If you no longer wish to participate in volunteer activities with Helping Others Fight, cannot keep up your assigned commitment, do not complete the required documentation, or fail to keep in regular contact with the HOF team, you may be designated as "inactive," and could require further training or reassignment.

You may be dismissed as a volunteer for gross misconduct, being under the influence of alcohol or drugs, theft of property or misuse of UCF materials, abuse or mistreatment of clients or other volunteers, failure to abide by HOF policies and procedures, failure to perform assigned duties, or incomplete documentation.

VI. Patient Interaction

Receiving a cancer diagnosis and undergoing active treatment for this disease affects every individual differently. While our clients are at different points in their cancer journey, some physical effects of cancer treatment may include:

- Nausea and fatigue
- Changes in physical appearance
- Cognitive changes
- Dietary changes and restrictions
- Chronic pain and other late effects
- Fertility is often affected by cancer treatments such as chemotherapy and radiation

Patients will also experience many emotional changes, which may include:

- Depression or sadness
- Body image concerns
- Stress
- Feelings of isolation
- Fear of recurrence and uncertainty about the future

In addition to the physical, mental, and emotional hurdles that patients and families must face, many of the individuals we serve are dealing with issues related to:

- Insurance and other financial stressors
- Transportation to and from treatment
- Child care
- Education & career planning
- Relationships

{Effective Communication}

In order to be a supportive and comforting presence in our clients' lives, please review these tips for being an effective communicator:

- Sometimes, it's best to *listen*, rather than lead the conversation. Take cues from the client to match their behavior.
- Be respectful at all times. Don't take it personally if your client is having a bad day. You will be working with individuals at vastly different stages in their cancer journey, and once you are aware of their situation, accept their mood changes and remain supportive and respectful.
- Use supportive body language while interacting:

- Eye contact
- Listen attentively while facing the patient
- Avoid distractions
- Conversations to avoid:
 - *“My uncle died of the same type of cancer...”*
 - For obvious reasons, this is awkward and disheartening to some.
 - *“I was diagnosed with pneumonia once, so I understand what it’s like...”*
 - As a cancer survivor, caregiver, or loved one of someone impacted by cancer, you will most likely be able to relate very well to your client. However, do not try to relate to them on a level that isn’t relevant to you.
 - *“Your treatment is wrong. I heard that you should try this instead...”*
 - Do not give medical advice to your client – this is their physician’s job, and the decision should be left to them and their family.
 - *“You should not be so sad...”*
 - Everyone deals with cancer differently. Sadness is part of the journey.

VII. Contacting the Helping Others Fight Team

{Program Specialists}

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