Friend for Life

Cancer Support Network

Facing cancer, with someone who's been there

Peer Navigator Manual

A guidebook for Friend for Life Volunteers



Friend for Life Cancer Support Network
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Mission and Welcome

Our Mission:

To help persons diagnosed with cancer and their loved ones navigate the path through diagnosis, treatment and recovery by pairing them with a



trained survivor of a similar experience so they can face cancer with someone who's been there.

Welcome and thank you

Without you and others like you, there would be no Friend for Life Cancer Support Network. Our Volunteers are the heart and soul of the organization.

This manual is dedicated to

Joan Steiner

Friend for Life's first Director

Friend for Life Cancer Support Network

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Our History

Friend for Life was founded in Louisville, Kentucky in 1988 as a not-for-profit 501 (c) 3 organization.

The Initial Match

The first match for Friend for Life was the pairing of co-founders **Phil Bramblette** and **Chuck Sandmann**. "Through conversations and discussions of 'what ifs,' Phil developed a vision for what could be and should be for patients facing the diagnosis of cancer. He felt that if enough like-minded individuals were to develop a program of support for patients that was based on personal experience, it would offer hope and encouragement to the patient undergoing therapy. I was blessed to have the acquaintance of such a like-minded person (Chuck) and introduced these gentlemen in the stately environs of a Hardees restaurant. One must understand that these connections were made before the convenience of such things as cell phones and email. Phil and Chuck networked and followed multiple leads to talk to people all over the US that had formed similar groups. They put all the pieces together and that resulted in the organization we now know as FFL. This group was built on the faith of 'if you build it, they will come' and 20 years later, they are still coming."

- Judy Hubbs Sisk, RN, OCN, at FFL's 20th anniversary celebration, 2008





Friend for Life co-founders Phil Bramblette (I) and Chuck Sandmann

Who We Are and What We Do

Who We Are

Our Volunteers

Our Volunteers are the heart and soul of Friend for Life and include Peer Navigators, Board Members, and Supporters.

What We Do

Friend for Life matches persons facing any form of cancer with a Peer Navigator who has experienced the same form of cancer and/or course of treatment. Understanding that cancer affects the family, friends and co-workers, support is also available for these supporters.

What is a Peer Navigator?

A Peer Navigator (PN) is a cancer survivor or caregiver trained by healthcare professionals to support others going through the emotional, psychological and practical uncertainties posed by a cancer diagnosis and treatments. Peer Navigators do not advise or participate in medical decisions, but serve as sounding boards to help the patient or caregiver sort through the roller-coaster of thoughts and feelings in order to gain a sense of stability and feel more prepared to make decisions.

What are Your Values?

By ranking the following values, you will get a clearer picture of what you value most.

Below, you will find a list of 12 values arranged in alphabetical order.

Study the list carefully, then place a $\underline{1}$ next to the value that is most important to you, a $\underline{2}$ next to the value that is second most important, and on until you have numbered all 12 values.

When you have finished ranking all of the values, go back and check over your list. Take all the time you need to think about this so that the end result is a true representation of <u>your</u> values.

 Beauty (beauty of nature, of the arts)
 Comfort—a pleasurable, successful life
 Equality (equal opportunity for all)
 Freedom (independence, freedom of choice)
 Friendship (close relationships with others)
 National defense (protection from attack)
 Peace—a world free of conflict
 Personal security (safe, free from worry)
 Respect (treated well, admired by others)
 Salvation (saved, eternal life)
 Self-fulfillment (development of self-potential)
Wisdom (mature understanding of life)

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At any time, if you have concerns or just want to talk things over with staff, please call us.

502.893.0643 or 866.374.3634

Friend for Life Core Values

- **Listening**: Central to the role of a Peer Navigator is to actively *listen* to the person you are supporting
- Respect: The person you are supporting may make decisions that are different from ones you would make. Your role is to listen without judging or criticizing.
- Compassion: Have empathy for the person you are supporting.
- Self-care: Take care of you. This may mean telling FFL staff that you
 are unable to take on a new contact at a particular time, or that
 you need support yourself. Contact the staff that's what we're
 here for.
- Openness and Acceptance: We can always learn from others. It
 doesn't mean we need to change our own beliefs; just be open to
 the person you are supporting and accept them as they are.
- Collaboration: Friend for Life collaborates with many other organizations. We encourage you to seek out and participate in community, regional and national resources that interest you.
- Confidentiality: What you and your referral talk about stays
 between the two of you. There are two exceptions: if you feel your
 referral is at risk for harming him/herself or another person. If this is the
 case, please contact the suicide and crisis hotline: 988, and let FFL staff
 know. At any time, if you have concerns or just want to talk things over
 with staff, please call us: 502.893.0643.
- Ongoing Learning: The world of cancer care is constantly changing.
 FFL will provide opportunities for continuing education from time
 to time. We encourage you to participate in these and pursue
 more that interest you.

Peer Navigator Please Do's

Contact your Referral as soon as possible...

...preferably within 24 hours of accepting your assignment. As you know, cancer is not a 9 to 5, weekday experience. If it will be a day or two before you will have time for a good conversation, please contact your Referral to determine when both of you will have time, without distractions, to talk.

Be yourself.

You won't have all the answers and are not a wizard. Your Referral is looking for another human being who has gone through the experience they are facing. Be honest, but try to keep the overall focus hopeful ad encouraging.

When you call your Referral, ask if it is a good time for them to talk.

Follow up.

Please follow up with your Referral on a regular basis. The feedback we receive from Referrals is that they want their PN to follow up with them. Use whatever strategy works for you, to remind you to call, e-mail or write.

Learn to be comfortable with silence.

This will give your Referral time to reflect and process their thoughts.

Peer Navigator Please Don'ts

Please do not:

- give medical advice of any kind
- give un-asked for advice
- talk more than you listen
- give money or gifts to your Referral
- make promises you cannot keep
- talk about your Referral with others
- criticize doctors, physicians, medical institutions or other health care professionals to your Referral

Frequently Asked Questions

How long does it take to be matched with a Peer Navigator?

We try to complete a match as soon as possible, ideally within 24 hours. If staff knows that this process will take longer, we will let the caller know this and when to expect to hear from a PN.

What if Friend for Life does not have a satisfactory match for a caller?

In the event that we do not, we contact other peer support networks to find a good match. We also assist the caller in accessing other resources appropriate to their needs.

What's the best way to contact my Referral?

If the two of you live far apart, communication will usually take place by telephone, e-mail or Skype. If they live in the same area, you may want to meet in person. We leave this decision up to you and your Referral to determine what works best for you.

How often do I contact my Referral?

Please keep in touch weekly or bi-weekly with your Referral throughout treatment, unless they request otherwise. Some may need more frequent contact; some may want less. <u>Ask</u> your Referral what would she or he would prefer. Most PNs share their contact information with their Referral, but it is not required. Do what you feel comfortable with.

Does FFL evaluate the effectiveness of this peer support service?

Yes. Currently, staff send brief feedback surveys both to Referrals and to Peer Navigators. Results are used to guide topics to emphasize in Peer Navigator training and support.

Does Friend for Life provide support to a limited area?

No. If we have a good match, it does not matter if the two live in the same town, across the country, or even live in another country.

FAQ, continued

What if the match between the PN and Referral is not working out?

Either the PN or Referral are encouraged to contact the FFL office. Staff will work to find the most satisfactory solution to the situation.

I forgot to call my Referral for awhile and feel awful. What should I do?

You are human. Humans forget, make mistakes, say the wrong thing. The great thing is, humans can say "I'm so sorry. I should have called you (a week/month/whatever) ago. I hope you can forgive me." Most likely they will appreciate your honesty and human-ness. If you feel unable to bring yourself to contact your Referral, please let FFL staff know. We will help to smooth things over as best we can.

My Referral is seeing a doctor I do not like. What do I say?

We know this can be difficult, but please try to say <u>nothing</u>. The most you might say, *if* your Referral **on their own** expresses dissatisfaction with their medical care, is to ask if they have considered getting a second opinion. Please do not disparage any medical practitioner or give medical advice.

How do they get a second opinion?

Insurance providers will provide a list of physicians within their network. Also, most hospitals/cancer treatment centers have physician referral services.

FAQ, continued

What if I cannot continue to provide support to my Referral?

We understand that life does not always go as planned. Please let staff know if you are unable to continue your support of your Referral for any reason. We will find a new match for them.

What ages does Friend for Life serve?

FFL primarily serves adults diagnosed with cancer. However, we have several PNs who were diagnosed with cancer in their teens and are available to provide support to teens diagnosed with the cancers they have had.

How is Friend for Life funded?

Friend for Life receives funds through a variety of ways, including grants, individual donations, corporate sponsorships, fundraising events and additional opportunities (see page 19) where you can participate and benefit the organization with no additional cost to you.

Other Ways to Support FFL...at No Extra Cost to You

You can raise money for Friend for Life Cancer Support Network through simple, everyday actions that don't cost you a thing, and can even save you money.

- Register your Friend for Life Kroger Card here: https://www.kroger.com/account/enrollCommunityRewardsNow
- AmazonSmile: log on to: smile.amazon.com and choose Friend for Life Cancer Support Network as your charity

Our Staff

Executive Director **Judy Kasey Houlette** joined the organization in 1999 as a volunteer and became Director in November 2000. Judy holds a Master's degree with a double major in Counseling Psychology and Gerontology. Diagnosed with breast cancer during graduate school, Judy pursued additional training in psychosocial oncology. Judy has served as a consumer advocate and reviewer for various programs sponsored by the National Cancer Institute since 2004. She is a member of the Network Cancer Committee of Norton Cancer Institute and the Kentucky Cancer Consortium. Judy also serves on the Leadership Council for the Volunteer Management in Cancer Care Consortium (VMCC) and is Co-Chair of the Peer Mentors Committee.

Lori Beth 'LB' Miller has a Doctor of Education in Educational Leadership and decades of experience in higher education and student advocacy. However, after joining Friend for Life in 2018 as a Peer Navigator, her passion of serving students pivoted to serving individuals who are facing cancer or supporting a loved one through a cancer treatment journey. Actively involved as a Consumer Reviewer for the Breast Cancer Research Program in conjunction with the Department of Defense, a member of the Survivorship Leadership Council, and TrailBlazers Support Group, LB is always eager to champion a worthy cause. She is an avid fan of the outdoors and loves spending time on the water. She has been teaching self-defense courses for the last 18 years, where she loves to empower women. She lives in Lexington with her husband, Brian, and as a duo are always up for an adventure.

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