THE TransplantTalk SC MENTOR PROJECT

MENTOR TRAINING WORKSHOP AGENDA

Welcome and Introductions – 10 min

The Mentor Project – 30 min

- The Mentor Project Description, Goals
  - Mentor Team, Information, Confidentiality, and Disclaimer Forms
  - Why Mentor?
  - Introduction of Attendees Using “30-Second Story”

The Mentor’s Education - 20 min

- Resources - Social Work Team
- Transplant Process
  - Preparing for Transplant
  - The “List” – Basic Facts
  - Organ Donation - Basic Facts
- Transplant Experience
  - Phases of Transplantation
  - Emotional Stages/Coping Behaviors

Break - 10 min

The Mentoring Process - 30 min

- You’re Not Listening (Exercise)
- Ways We Mentor Rolls and Responsibilities
- Types of Mentoring Relationships
- Communication Skills (Listening Exercises)
  - Stop, Look and Listen
  - Open-Closed Ended Questions

Golden Rules

Red Flags

Mentoring

Scenarios and Discussion - 30 min

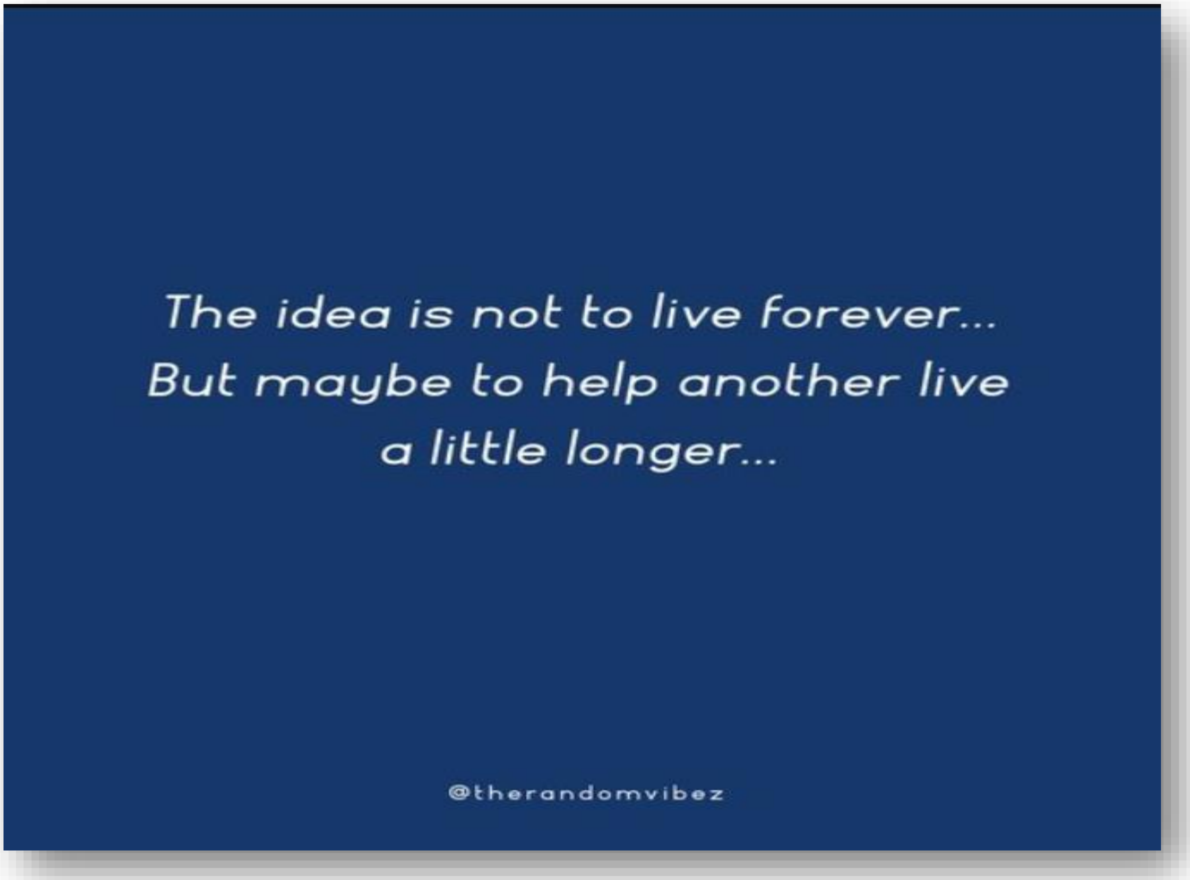
Small Group Role Play and Discussion

Referrals and Reports - 15 min

Referral Process

Forms and Reporting

Wrap-Up



The idea is not to live forever...
But maybe to help another live
a little longer...

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What Is the TransplantTalk SC MENTOR PROJECT?

PURPOSE: Sharing specialized knowledge gained from personal experience, and providing hope that helps overcome fear.

MISSION: To provide confidential, individualized, one-on-one support for people at pre-transplantation through personal contact with a trained mentor.

MENTORS: Transplant recipients desirable up to 3 years or more of post-transplantation experience.

Learning that you or a family member needs a transplant, going through the evaluation process, waiting for the call, having the surgery, recovering, and then adjusting to "chronic wellness" – life after transplant – can be a wonderful yet an emotional and stressful time.

Support from friends, family and the transplant center team can certainly help, but talking to someone who has been in the same situation is often the best way to calm nerves and realize the positive outcomes.

The Mentor Project is a patient service program offered by the TransplantTalk SC Group that provides one-to-one contact between people living successfully after the transplant experience and people who are new or adjusting to the experience of the transplantation process.

Qualifications and Responsibilities

Mentor Qualifications:

- Recommended by a member of the TransplantTalk SC/MUSC team
- At least 3 years post-transplant
- Possess a healthy perspective on both the pros and cons of transplantation
- Has a positive attitude and is emotionally stable
- Completes The Mentor Training Workshop
- Is committed to The Mentor Project and its guidelines
- Is willing to accept referrals as able (unless notified)
- Understands and agrees to abide by confidentiality and disclaimer policies

Qualifications and Responsibilities (continued)

Role and Responsibilities:

- Works within the referral process
- Makes the initial contact with the mentee within 72-hours of receiving referral
- Listens and provides support
- Shares personal experiences, but does not give medical advice
- Keeps everything confidential
- Follows up with future contacts or meetings agreed upon with mentee
- Reports mentoring per Mentor Project guidelines.

Your Personal “30-Second Story”

Without rushing, try to condense your story into a brief 30-second summary that will accomplish the following:

- Introduce yourself and The Mentor Project. Explain your reason for calling or being there in person
- Set a friendly tone to encourage conversation. Put the mentee and any others in the room at ease. Make them smile!
- Be sure the mentee understands that you are a volunteer, not a paid professional.
- Share your story in a way that puts you on common ground with a mentee.

Hints:

- Introduce yourself as a Volunteer with the TransplantTalk SC Mentor Project.
- Example introduction might be, “I’m a volunteer with The Mentor Project. I’ve had a kidney transplant just like you. The coordinator said that you might like to talk with someone who’s been through a transplant before…”
- Before launching into your story, pay attention to the mentee. Make sure by observation to see if this is a good time to visit.
- If you are making a phone call, it’s a good idea to ask, “Is this a convenient time to talk?” Call back later if there is any doubt.
- Limit your talk to only the highlights. Let them ask for the details. This is MOST important. Remember: it’s not about you, but about THEM.
- Watch your body language…not too close…not too far…look them in the eyes. Be prepared to listen. **Take caution about touching the patient or bed, if visiting in person.

Examples:

- Hi, I'm ____________. I received a liver transplant 10 years ago and I'm now a volunteer with the TransplantTalk SC Mentor Project. Mentors are folks who have received a transplant and are now willing to talk with people who are on the waiting list. I had a mentor when I was waiting and talking to her helped me so much. It can be really nice to talk to someone who has been through this experience. I got a call that you might like to talk to someone who has had a transplant. Is that right? Do you have some questions I might be able to answer, or would you like to hear a little bit more about my experience?

- Hi, I'm _____________, a volunteer with the TransplantTalk SC Mentor Project. (Use Nurse or Social Workers name) said you might like to talk with someone who's had a transplant. After living with dilated Cardiomyopathy and congestive heart failure for 10 years, I received my new heart in 2002…no more wacky heart rhythms for me! What have you been thinking about today?

Your Personal "30-Second Story" After you practice writing your "30-Second Story" and decide how you want to introduce yourself, take time to write your story here. Use it as a guide until you are comfortable saying it "from your heart."

Transplant Resources

All South Carolina residents who are solid organ transplant candidates, may qualify for Mentor services offered by TransplantTalk SC (TTSC), the Organ Support Group in the region. ***The focus of what will be offered in the early stages of our relationship with the mentee are mentor type, or those human services by transplant recipients that have been down the transplant path and have been trained in assisting mentee's.*** For the pre-transplant patient, or mentee, the patient contacts members of TTSC team expressing interest in this resource offered. The initial services would include providing resources to help the mentee with basic human services specifically related to the transplant that may be encountered. That would include some immediate direct contacts to assist the mentee as provided in this section where human assistance may be included. These services may also be complemented with the support of the mentee's social worker at the hospital. It should be noted that TTSC provides the Mentor services as an independent non-profit service.

PROGRAMS AND SERVICES – The initial and primary personal service offered by the Mentors of TransplantTalk SC at the present include mentoring the pre-transplant patient. As patients who have navigated the transplant path, our goal is to relate what our experiences may have been like. We feel that relating our experience to pre-transplant may create a higher comfort level. In addition, we offer rather detailed research that includes contacts for other needed services that range from medication, health insurance, housing to emergency assistance. We will provide each mentee with a document that includes the details of the valuable resources. The following are some established services that will be included in the document.

Insurance and Medication

- **Medication Access Program (MAP) 1-800-736-2273 ext. 0131 or 706-721-0131:** The MAP program assists patients in enrolling in pharmaceutical assistance programs for free medications. Must be a resident of South Carolina, meet financial criteria, and have limited to no coverage for prescription medications.
- Emergency Medication Assistance Program - Contact Transplant Center Social Worker.

- **Patient Assistance Programs (PAP):** Programs through individual drug companies that provide medications for free or at reduced costs for uninsured patients for their particular drug only. Check online sites, MAP or your physician's office (needymeds.org). Details will be provided later for this future service.

- **Medicare Part B and D 1-800-772-1213:** Both of these Medicare programs provide some prescription drug coverage when criteria are met. Contact the Social Security or Medicare Hotline for more information (www.ssa.gov).

Housing

- **Ronald McDonald House 843-723-7957:** Housing for pediatric families up to age 18. Can assist those up to 21 on a case-by-case basis. 35 private rooms with private bath facilities, kitchen, and meals provided each evening. Special transplant wing with private accommodations. It is located at 81 Gadsden Street. www.rmhc.charleston.org

- **Fisher House 843-805-8200: serves veterans** with a variety of patient needs. Located at 150 Wentworth Street and only about a half mile from MUSC. **It is solely for veterans and veterans' families**. It consists of 32 rooms and a dining room.

TRANSPLANT SUPPORT GROUPS

TransplantTalk SC Support Group – 843-619-1164

Second Chance Support Group - 803-394-2364

Additional Local Insurance Resources

- **South Carolina Department of Insurance Office** – 803-737-6160; info@doi.sc.gov. For questions related to current health insurance issues, loss of insurance issues and options to obtain insurance. Ask to speak to the health insurance section (www.doi.sc.gov).

- **Benefits Navigator Program 866-968-7842:** Provides accurate work incentive information to people between the ages of 14-65 who receive disability income. Including Social Security benefits and state benefits regarding work related issues. Trained professionals talk with clients to utilize work incentives such as PASS plans, and trial work period through Social Security.

- **Partners for Healthy Children (PHC) SC DHHS – 888-549-0820; Office of Health Programs – 803-898-3202; www.scdhhs.cov. Authorized under Title XXI of the Social Security Act.** This program provides Medicaid coverage for children who live in families with low income or below 208% of the Federal Poverty Level. The available plans include Medicaid and the Children's Health Insurance Program (CHIP).

- **COBRA Health Coverage www.doi.gov:** Provides continuation of insurance coverage when no longer eligible through a group employer. Must be done within 60-days of ending your employment. The Consolidated Omnibus Budget Reconciliation Act (COBRA) gives workers and their families who lose their health benefits the right to choose to continue group health benefits provided by their group health plan for limited periods of time under certain circumstances such as voluntary or involuntary job loss, reduction in the hours worked, transition between jobs, death, divorce, and other life events.

- **Medicare A, B and D 1-800-MEDICARE**: Health insurance coverage for individuals over 65 receiving Social Security retirement benefits or under 65 that are receiving disability benefits. Part A - hospital insurance is free, Part B- medical insurance has a monthly premium and Part D - prescription coverage has an additional premium, and you must select a plan. For more information see: www.medicare.gov.

- **Palmetto Project – Independent non-profit:** Includes Healthcare, Medicaid, Medicare, hearing aids and private insurance. See Insure SC for more www.insure-sc-org 843-577- 4122, sc@palmettoproject.org

Additional National Resources

- **American Association of Kidney Patients (AAKP) www.aakp.org:** Non-profit, membership based, national voluntary health organization that provides education, support and advocacy services to kidney patients and their families

- **American Liver Foundation www.liverfoundation.org:** Non-profit national voluntary health agency dedicated to preventing, treating, and curing hepatitis and all liver diseases through research, education, and support groups.

- **Donate Life America www.donatelife.net:** Not-for-profit alliance of national organization and local coalitions across the US dedicated to inspiring people to donate life through organ, eye, and tissue donation to save, or improve the lives of patients.

- **Donate Life South Carolina www.donatelifesc.org:** The state coalition composed of representatives from transplant related agencies dedicated to being an advocate for organ, tissue, and eye donation.

- **We Are Sharing Hope – www.SharingHopeSC.org; info@SharingHopeSC.org:** 800- 462-0755 Non-profit organ and tissue recovery organization serving families making a decision regarding organ donation. Also sponsors Transplant Advocacy Groups.

- **National Kidney Foundation serving South Carolina (NKF) www.kidneysc.org; 803- 799-3870 or 855-653-2273:** Dedicated to preventing kidney and urinary tract diseases, improving the health and well-being of individuals affected by these diseases, and increase the availability of all organs for transplant. Services focuses on patient education, research, advocacy, and organ donation awareness.

- **Transplant Recipient International Organization, Inc. (TRIO) www.trioweb.org:** Nonprofit international organization working to improve the quality of life for transplant candidates, recipients, their families, and donor family members through education, advocacy, support, and awareness.

- **Transplant Living www.transplantliving.org:** Project of UNOS designed to support the relationship between patient and his/her physician. Information related to transplant pre- and post-operative.

- **United Network for Organ Sharing (UNOS) www.unos.org:** UNOS is a private, nonprofit organization that administers the National Organ Procurement and Transplantation Network (OPTN) and the U.S. Scientific Registry under contracts with the U.S. Department of Health & Human Services. UNOS manages the US organ donation system under contract with OPTN. Call Kelly Roberts at 804-782-4729.

A transplant is the ultimate legacy a person can leave and the greatest gift of community service we can give.

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The Transplant Process

Medical Evaluation

- **Referral** -The transplant process begins with a doctor's recommendation to a transplant center. Medical appointments are scheduled.
- **Evaluate & Decide** - A medical team at a transplant center decides if the patient is a good candidate to receive a transplant. At the end of the evaluation the team either:
  - Does not recommend patient for a transplant.
  - Sets goals the patient must reach to become a transplant candidate.
  - Recommends patient for a transplant.

Waiting List

- Patient is registered with the United Network for Organ Sharing (UNOS)
- Wait begins for the correct match
- Organ is made available to be donated
- Match list is created and printed
- Organ is offered to a transplant center where there is a match
- Recipient is notified of a "potential" match and instructed what to do next.

PREPARING FOR TRANSPLANT

Be Prepared

- Emphasize with mentees the importance of being ready and help them to understand that the call for the new organ could come at any time. That doesn't mean sitting by the phone waiting for it to ring. In fact, it is best for them to go on with their usual activities and enjoy life. Discuss how planning ahead can help the process go more smoothly when the time comes for receiving the new organ.
- Make sure the transplant coordinator has a list of telephone numbers where they can be reached 24 hours a day.
- If address or phone number **changes**, let the team know immediately.
- Carry a cell phone at all times.
- Discuss with the transplant center how to be contacted if you have travel planned.
- Keep a diary or notebook. Write down any questions or concerns to discuss with the transplant team during scheduled visits.

Stay Positive

As the patient prepares for new organ(s), mental health is important. Managing stress and anxiety that comes from waiting is an important goal for this period. There are many different ways to deal with stress. Help your mentee to discover the best way for them to manage their stress level. Encourage contact with Mentor to get support.

Learn As Much As You Can

- Knowing what to expect helps some people relax. That is one reason it is good to learn as much as possible about the upcoming transplant.
- Do not be afraid to ask questions of the transplant team.
- Encourage them to read everything they can about surgery and the medicines they will be taking. Share your knowledge and resources that helped you during this time.

Get Support

- Have them ask their transplant team about local support groups. These groups are designed to help talk about the feelings about transplant (worries about the surgeries and concerns about the future).
- Encourage your mentee to attend support group meetings at his/her transplant center. Some find it helpful to talk to others waiting for transplants or who have already received a transplant (i.e., SC Transplant Talk Group!)
- An additional option is to talk about feelings with a psychologist or social worker. It is common to feel nervous or depressed during this process. Most transplant centers have a psychologist or a social worker on the transplant team to help.
- Remind your mentee that this could be a rough time for family and friends as well. Even though they are the one getting the transplant, others may need help with their feelings.

Learn to Relax

Just waiting for a transplant can be stressful. If your mentee has trouble sleeping or feels anxious about the transplant, he/she should ask the psychologist or social worker to show him exercises and techniques that can help to relax. There are also many books and audiotapes on relaxation available at the library or local bookstore.

Try to live while you are waiting instead of waiting to live…

Stay healthy

Some people manage stress by staying active. The transplant team or physician can help work out a program that meets their personal needs. You can encourage your mentee by discussing the following areas:

- Create and stick to a daily exercise program.
- Participate in activities he has always enjoyed and try a few new ones.
- Keep up with dental health, eye care, blood sugars, and blood pressure.
- Keeping weight under control is important.

Staying healthy in order to be ready for transplant is very important. Your mentee needs to keep the transplant team informed and up to date of their health and let them know if they are having any problems.

PREPARING FOR THE HOSPITAL STAY

Patients should make a list of items they will want to take to the hospital. When the call comes, you don't want to think about packing. Pack a bag ahead of time. If they are prepared, they will feel more comfortable and in control. Many patients stay in the hospital for a long period of time waiting for the transplant. Let them know it is okay to personalize your private room with cards and pictures. And it is okay to dress in regular clothes instead of hospital gowns. Check with hospital personnel for protocol.

Here are some things they may want to take with them:

- Medical history, including a list of current medications they are taking
- Health records, such as blood sugar, blood pressure, and temperature readings, last time they ate, etc.
- Light jacket, extra socks, pillow, blanket
- Pen or notebook for questions and concerns he may want to discuss with the transplant team
- Change for the vending machines and snacks in case the cafeteria is closed
- Relaxing things such as music, books, computer, family photos
- Cell phone and charger
- Create a list of people to notify when the call comes to go to the hospital
    - Set up a telephone calling tree
    - Email group
    - Facebook group/ Caring Bridge site
    - Remember to include their mentor on the notify list

Mentee's Steps to feel more in control during their hospital stay

- Participate in decisions, when possible, to make sure his personal healthcare needs are addressed
- Choose an advocate: someone to represent and speak for him as needed
- Listen and learn and ask questions to be an informed patient

Life after Transplant

It is normal to feel out of sorts and anxious following a transplant. To make those first few weeks easier, you might suggest these tips:

- Take all medications on time every time. Make a list and have it accessible
- Become very familiar with all medications – appearance, side effects, and purpose
- Learn to take vital signs as recommended (blood pressure, temperature, blood sugar, etc.)
- Rest whether you think you need to or not
- Keep all appointments Call mentor as needed
- Expect emotional swings

Fact or Fiction: Organ Donation

Who can be a donor?

If you are over the age of 18, you can indicate your desire to become an organ donor on your driver's license or by signing up with the state donor registry on their website at **www.donatelifesc.org.** It is important to tell your family your wishes to be a donor.

What is the age limit of donation?

There is no specific age limit. Whether or not a person can be a donor depends on each individual and their medical history.

Does donation delay the funeral and is a donor's body disfigured?

No, the donation process does not delay the funeral services and the donor's body will not be disfigured. The body can be viewed if the family so desires.

Is it against my religion to donate?

Religious leaders of all faiths support donation because it is a gift of life. If you have questions or concerns, talk with your religious leader.

How much does donation cost?

The donor and the donor's family do not pay for any of the costs of donation. Funeral costs are not part of the donation cost.

Will my hospital care change if I have agreed to be a donor?

The medical team will always have your best interest in mind and will do everything they can to save your life. A person must be declared brain dead by at least two doctors before any organs are removed for donation.

Is there a black market for organs?

It is illegal and unsafe to sell organs in the United States.

How many people can be helped by donation?

Over 60 people can be helped through the organ, tissue, and eye donation from one donor

Organ Placement

Organ placement in the United States is coordinated through the United Network for Organ Sharing (UNOS). The criteria for matching organs are based on UNOS guidelines and subject to change. UNOS has 11 regions. visit: www.unos.org.

New criteria have recently (2021) been implemented by UNOS. The best source of current information on How the List works is **UNOS.org**

It is important to convey that the placement of organs is done in a fair and just manner. It also has strict oversite by governmental agencies.

When a mentee is quizzing about “how the list works”, they are likely talking about gaining hope through understanding, about enduring the wait, and managing the stress of the unknown.

The Transplant Experience

PSYCHOSOCIAL PHASES OF TRANSPLANTATION

Patient learns that transplant is needed

- Disbelief
- Denial

- Anger
- Feels lost and doesn't know what to do next

Patient is evaluated

- Anxiety – will they be accepted as a candidate?
- Relieved that there is "something" offered for improved health
- Overwhelmed with all the new information and to do list

Patient is listed and waiting for a donor

- Impatience and frustration as the wait time lengthens
- Fear of being forgotten by the team, being dropped off the list
- Guilt about hoping for a donor organ
- Putting life on hold: afraid to leave the house
- Continue to think positive

Donor Organ Becomes Available

- Relieved: May be ready and eager for transplant
- Reluctant: Last minute doubts if this is the right thing to do
- Fear about the surgery - Fear about the future

Transplant Surgery Completed

- Relief: surgery is behind them—they survived
- Well-being – maybe not?
- Anxiety about what will happen next
- Depression can be common
- Coping with many changes and new medical routines
- Begin to adapt to a "new normal"

Living with Transplant – first year

- Adapting to physical changes to their body, learning the new normal
- Anticipation of new improved life
- Concerned with rejection and infection
- Learning as much as possible to stay healthy
- Thankful for the "gift of life" that they have received.

Living with Transplant - future

- Treatment verses Cure - Chronic Wellness
- Adapting and accepting

- Dealing with health issues that were not expected as they arise
- Give Back - Become a mentor with SC Transplant Talk Mentor Project!

Coping Behaviors

Denial

- Ignores or denies their diagnosis
- Repeatedly asks for opinions from different doctors even though he or she has received the same answer several times
- Removes themselves from the situation and doesn't want to think about it
- Begins to twist information around

Anger

- May become demanding
- Blames others, doctors, and healthcare professionals for their situation
- Doesn't understand why this is happening to them
- Acting out in ways to feel in control

Vulnerable or Helpless

- Unable to make decisions, not able to complete simple daily tasks
- Relies heavily on others to manage their illness
- Can feel overwhelmed by their situation
- Questions their decision whether they have made the right decisions
- May "give up" and just accept things as they are
- May feel they have no power over the situation

Guilt

- Blame themselves for their illness
- Feels responsible for things out of their control
- Expresses the feeling of unworthiness

Anxiety

- Nervous
- Disjointed thoughts
- Frets over everything

Frustration

- Speaks with sharp remarks
- Becomes upset over small things

- May make problems seem worse than they really are

Fear

- May hold back from doing things
- Feels uneasy and may avoid certain situations
- Worries about what is not known
- Tries to find answers and come up with explanations
- Has trouble concentrating
- Is afraid to do what they can do or to try new things

Depression

- Cries or feels sad a lot
- Withdraws from family and friends
- Changes in appetite
- Changes in sleep habits
- Has trouble concentrating
- Stops doing they once enjoyed
- Loses a sense of hope

Hope and Acceptance

- Feels happy and has a sense of well-being
- Plans for the future
- Has a positive outlook
- Takes care of himself or herself
- Begins to enjoy the" new normal" of life after transplant

The Mentoring Process

WAYS WE MENTOR

Contact with a mentee can begin with:

- Hospital Visit
- Phone Call
- By email

After receiving referral make first contact

- Introduce yourself using the “30-Second Story”
- If meeting in person, dress neatly
- If meeting is on the telephone, make sure it is a good time to talk
- Be sure to make contact when you have time to talk

Meet the mentee where they are

- Use good listening skills
- Be aware of circumstances at the time of contact

Ask about caregiver’s needs - concerns could include:

- How to take care of myself (fatigue, anxiety)
- How to support my partner
- Fear of losing spouse
- Spousal guilt

NOTE: There are Mentors specifically trained to work with family members

Be aware of limits

- Don’t take circumstances personally – there are no failures
- You may encounter different personalities than your own
- Maintain personal boundaries in your mentoring role
    - Do not give financial assistance
    - Do not set up dependency through counseling
    - Ask yourself “If this is a part of my experience?”
    - If in doubt, don’t do it.
- Time constraints, both yours and the Mentee’s
- Health priorities
- Be able to recognize manipulation

Mentee will determine the degree of involvement in the mentor relationship

- May be a one-time contact, a simple Q and A session
- May be difficult to get in contact with…try at least 3 times
- May only want intermittent contact
- May be on-going throughout the transplant process
- Remember you can, but don’t have to become friends

Use Mentor supervision team as needed

- Mentor team – mentor, mentee, mentor coordinator, mentor director, transplant coordinator, social worker, clinical nurse, physician
- Seek help if mentee is at risk
- Remember "red flags" – issues that cause you to be alarmed Tough situations you may encounter

Tough situations you may encounter

- Mentee is taken off the UNOS waiting list
- Original mentor dies and you are asked to accept the mentee
- Mentee tells you of drug, tobacco, or alcohol use
- Mentee's spouse leaves, significant marital issues
- Mentee refused donor "gift" when the call came in
- Living donor is having second thoughts

Post-Transplant situations you may encounter

- Questions and curiosity about the donor
- Transplant outcome not as anticipated
- Post-transplant complications, rejection, infection, CMV
- Frustration with outpatient follow-up schedule and frequency
- It's a treatment not a cure
- Difficulty re-entering "normal lifestyle" – New Normal
- Changes in personal relationships – **TBD???**

Facing Transplant friend/mentee death

- Very real possibility
- Survivor guilt
- Condolences
- Talk to someone you trust about your feelings

Always Remember

Take Care of Yourself!!

LISTENING SKILLS

NON-LISTENING

*Interrupting Speaking

*Keeping a “poker face” (no expression)

*Communicating boredom through your tone of voice

*Yawning/stretching

*Leaning away from speaker

*Looking at walls/ceiling/floor

*Glancing at watch or clock

*Giving immediate attention to any chance interruption

*Fidgeting (tapping foot or fingers, playing with ring/pencil, cracking knuckles)

*Crossing arms across chest indicated closed communication

ACTIVE LISTENING

*Make eye contact

*Leaning in toward the speaker

*Use facial expression to show interest

*Sit facing speaker

*Nodding head affirmatively

*Raising eyebrows

*Use expressive hand gestures

*Take caution when reaching to touch

*Communicating appreciation and interest through vocal sounds, (Hmm, Oh! Ah…I See)

*Leave spaces for silence. Pause before you respond to the speaker to show that you are really listening and you’re considering what he or she has to say.

Techniques for Being an Active Listener

Maintain An Unbiased Attitude

This lets the mentee know that you are trying to understand what they are feeling. It shows you are listening to their side of the story.

Do Not Judge

Accept your mentee regardless of the choices they may make or have made. You are there to share the knowledge of your experience, to let them know options and to be a positive example. It is up to the mentee to make the final decisions about what choices they will make.

Pay Attention

Focus on what the mentee is telling you. Attend with your body language by keeping eye contact and responding with simple words – I see, hmmm, ok, etc.).

Use Their Words

Repeat back to the mentee what they stated. This takes practice but shows that you listened to what was said. (So, what you're saying is that the medicine is making you extremely tired and you don't want to leave the house). Try to hear the feelings in their words.

Know When Not To Give Advice

Remember that you don't always have to offer solutions. The person will not want you to solve their problems. They may just need someone to listen to them and understand what they are feeling.

Ask Good Questions

Sometimes you will want to find out more information about what the person is feeling so that you will understand why they are feeling a certain way.

Use Open-Ended Questions

Ask a question that will require more than a "yes" or a "no" answer. "How are you handling taking all your medication on time?" Instead of "Are you taking all your medication on time?"

Accept limits

An important part of listening is to allow your mentee to change the direction or stop a discussion. If your mentee does not want to talk, don't continue to ask questions to keep them talking. Let them know that you will be available when they want to talk to with you.

Helpful Things to Do or Say Instead of Giving Advice

- Be quiet and listen. Find out the facts if you don't know.
- Share your experience.
- Help with problem-solving steps.
- Don't try to be a therapist!

- Talk to your mentor coordinator/manager if you have concerns that your mentee may need additional professional help.

- Don’t get overloaded in a single conversation. Stop for today. Let them know you will talk again soon.

Some Helpful Expressions and Words:

I don’t know….

What you are feeling is normal….

I remember feeling that way too…

You don’t have to be cheerful all the time…

Feeling sad/angry/discouraged/ etc. is okay…

It’s ok to be scared…

I will be here for you…

How can I help you sort out this situation…

Let me tell you about some available resources…

I don’t have all the answers, but I can share with you what worked for me and for others…

Let’s take one step at a time…

How Emotional Distress Affects Learning

Affects Ability to:

- Concentrate
- Remember
- Process Information

***Emotional distress can lead to increased stress levels**

Mentees Commonly Feel:

- Increased anxiety – overwhelmed, nervous
- Increased anger – impatient, frustrated, loss of control
- Increased depression – hopeless, helpless

Keep in mind that your mentees may not be aware of these emotions and may need to express their feelings prior to learning new information. Also remind them that medication side effects can heighten these feelings.

Factors That Aide in Learning:

- Privacy and comfort
- Limited distractions
- Use common terms
- Let the mentee direct the conversation
- Keep to the important information
- Look for mentee fatigue---STOP!

Open/Closed Ended Questions

Open-ended questions

Open-ended questions are questions that allow you to gather more in-depth information about the mentee. These types of questions allow for broad answers based on the mentee’s thoughts and feelings.

Sample Initial Phrases

How…?

What…?

How do you feel…?

Would you tell me more about…?

Closed-Ended Questions

Closed-ended questions have one-word answers. Even though they allow you to gather information about the mentee, these questions can send the conversation into a dead end.

Sample Initial Phrases

When…?

Where…?

Who…?

Are you…?

Do you mean…?

Is it…?

Note: “Why?” questions are considered open-ended questions. However, some mentors have stated that “Why?” questions have left their mentees feeling as if they need to defend their actions and/or feelings. You do not want to leave the impression that you are judging the mentee in any way.

Golden Rules for MENTORS

Golden Rule 1: Speak from your own experiences.

Golden Rule 2: Listen more than you speak.

Golden Rule 3: Do not give medical advice.

Golden Rule 4: Keep information confidential.

Golden Rule 5: Be open-minded to differences.

Golden Rule 6: Be alert to Red Flags.

Golden Rule 7: You have the right to turn down an assignment and the mentee has the right to refuse services.

Golden Rule 8: Mentoring is not about you.

Golden Rule 9: Take care of yourself!

Red Flags

Red Flags are anything that can interfere with the person's health before or after transplant. It can be a medical, mental, emotional, or physical issue.

Red Flag 1: Mentee does not feel transplant is necessary.

Red Flag 2: Missing medication doses.

Red Flag 3: Reports feeling so good they are not going to follow medical advice.

Red Flag 4: Abusing alcohol or drugs.

Red Flag 5: Ignoring physical symptoms

Red Flag 6: Family dynamics are negatively impacting decisions being made.

If you ever have concerns about your mentee's safety, please let your lead mentor know immediately. If you identify any of these behaviors or changes in your mentee:

- Encourage your mentee to call the living donor coordinator, social worker. Your mentee may need the team's help.
- Call your lead mentor to tell them about this potential situation.

More Tips to Help with the Mentoring Process

When a request is made to accept a mentee assignment, take it seriously.

- If it is not a good time for you (sick, going on vacation, too busy at work, etc.), please decline the request for assignment of a mentee. Being honest will not keep you from being asked to mentor again.

Mentees are waiting for the call from a mentor, so please follow the guidelines for "timely contacts."

Once initial contact has been made, send an email, or call The Mentor Project Team to let them know that contact was made.

- If you have not been able to speak with the mentee after three tries or if the contact information is not correct, let the team know immediately. Please do not wait until the end of the month at report time.

Keep a record of all your contacts if you find that helpful.

- Try to do this immediately after contact with your mentee. This will help you be a better mentor. In today's busy times, it is hard to remember all of the information. What you write down is confidential and for your use only.

Send in your reporting as directed by TransplantTalk SC Mentor Project guidelines

- If something changes in your life and you no longer are able to actively participate, please call or email The TransplantTalk SC Mentor Project Team. Once circumstances clear up, you can always go back into the rotation for a new mentee to be assigned.

- Mentors volunteer for 1-year periods unless they request to be removed from the active list. At the end of each year, you will be asked if you want to stay active.

Mentor Quick Guide

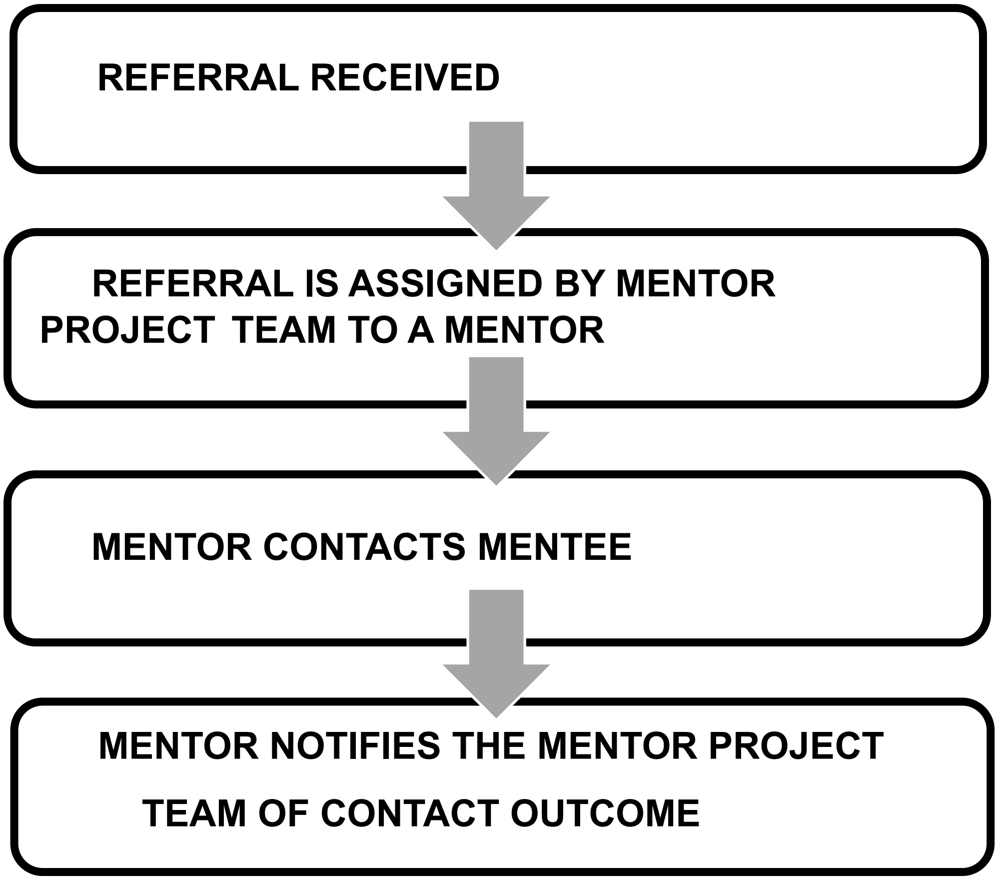
- If you are healthy and available, accept mentor assignments when asked. Let the program team know if you are unable to accept at any time.
- Follow the mentor guidelines and the TransplantTalk SC Mentor Project Training Manual. Only use TransplantTalk SC Mentoring approved publications.
- Remember you are volunteers for the TransplantTalk SC Mentoring, not the transplant center.
- Check your email regularly or listen to your voice messages for referral assignments.
- Remember to introduce yourself as a TransplantTalk SC mentor.
- Share with your mentees based on your own personal experiences.
- Remember, confidentiality is vital!
- Make the initial contact with your mentee within three days of assignment.
- Let the TransplantTalk SC Mentor team know when the initial mentee contact is made.
- Follow up with your mentee periodically to see if all is well.
- ***Be a good listener.**
- Always ask if this is a good time to visit or talk.
- Try to attend support groups or orientation classes if you can.
- Remember there are different levels of the mentoring relationship – ranging from a one-time call to regular contacts to a friendship.

- Try to attend TransplantTalk SC events when possible.
- Support the TransplantTalk SC mission as well as TransplantTalk SC Mentor Project's goals and objectives.
- Call or email The SC Transplant Talk Mentor Team with any questions or concerns.
- **Enjoy keeping the gift of mentoring through being a mentor.**

How Referrals are Assigned

- **Referrals Are Received Via:**
    - Hospital, Phone Call or Email

Referral Flow Chart



SCENARIOS FOR PRACTICE

LIFESTYLE CONCERNS

1. Will I be able to go back to work? When?
2. I love to garden! Can I continue after the transplant?
3. I volunteer at my church in the nursery. Will I have to give this up?
4. Can I get too many germs from kissing my spouse?
5. I'm planning a trip to Europe in September. Is there anything special I should do?

Sample Answer: **Life after transplant is definitely different. I am more careful with heavy lifting and rigorous exercise, but I still enjoy similar things or have found new ways to create joy in my life. I am also more cautious about being exposed to contagious illnesses, but I do my best to live my life as close to it was before I became sick and needed a transplant. If there is anything you ever wonder if you should be doing, you should definitely ask your doctor and transplant team. What kind of work are you interested in doing? How do you think you could volunteer at your church if the nursery isn't the best choice?**

FINANCIAL CONCERNS

1. My COBRA plan is running out, and I may lose my insurance. What if it happens before my transplant? I can't afford to pay for this on my own.
2. I just don't have the money or resources like some celebrities do. I'm afraid I'll wait forever while people with connections and money get bumped ahead of me.
3. My roommate moved out without any notice. I can't afford the rent with just my disability check and the utilities will be shut off if I don't come up with a payment soon. I don't know what to do.

Sample Answer: **Financial and insurance concerns are very stressful. I was fortunate to be covered by my husband's insurance plan and only had a few hiccups that I can tell you about. I know that this is a large stress for transplant patients due to the cost of medicine, but I also know there are lots of resources offered through TBD???? and other organizations like MAP. I can share some resources I know of if you would like to see if they are able to help you out. You can also talk these things over with your social worker. Can you tell me more about your support system and plans for insurance after transplant?**

SCENARIOS FOR PRACTICE (continued)

MEDICAL CONCERNS

1. I have this lump on my neck. What do you think it is? Should I tell my doctor?
2. Why is it necessary to undergo all these tests during the evaluation process?
3. How will I know if I am rejecting my organ?
4. How often do I have to come back to the doctor and for what tests?
5. What do they do in a biopsy and how often will I have to have one? Will I have to have them forever after the transplant?

Sample Answer: **This is a great question for your doctor. I know that I always felt like I was asking too many questions or taking too much time from my doctor, but they are there to help you and need to be aware of all aspects of your health leading up to and after transplantation. How is your relationship with your doctor? What do you like about the transplant team?**

RELATIONSHIP CONCERNS

1. I am worried about my spouse. I think the waiting is harder for him than it is for me. I wish I didn't have to go through this.
2. This process is so stressful. I barely feel connected to my spouse.
3. I feel like I cannot connect to my partner anymore. They can't possibly understand what I am going through.
4. I never want to have sex with my partner anymore. Does sex after transplant get back to normal?

Sample Answer: **My spouse and I have definitely had ups and downs through this process. There was a time I even thought we might get a divorce. We ended up going to a counselor to try to get through some of the harder parts. It definitely isn't easy! TBD??? has a marriage retreat that can help you reconnect after transplant, and I would recommend your spouse get a caregiver mentor as well, so they have someone to talk to. How do you feel about seeking help for your relationship? What do you think you could do to help things with you and your partner?**

SCENARIOS FOR PRACTICE (continued)

WAITING

1. Why can't the transplant team tell me when I will get a transplant? I want to know how long it will take to get a transplant.
2. I've heard it takes minorities longer to get organs. How much longer will I have to wait because I'm African American?
3. I was at the hospital at the same time as another patient who waiting for a transplant. I found out that we had the same blood type, but he got his transplant first. Why did he go before me?
4. I found out the other day that a transplant patient died on the operating table. I am scared that this will happen to me. I'm not so sure I want to do this.
5. I have heard the medications can cause side effects. Besides, I think I'm doing okay on dialysis. I am not sure if a transplant is worth it.
6. I feel so guilty that someone has to die to save my life.
7. I've been on the waiting list for several weeks now and I still have not received word about when I will get a transplant. I am angry and scared

Sample Answer: **I had so many different feelings while I was waiting for a transplant. I definitely doubted going through the whole process and questioned if it would be worth the stress, financial burden and work, but it has been the best choice for me, and I have seen it really be a lifesaving option for so many. It is easy to get discouraged with long wait times. Have you looked at resources to help with living donation? What kinds of things can help you take your mind off of waiting?**

FEELINGS

1. I heard an ambulance siren yesterday and I felt terrible because I was hoping that this meant I would finally get my transplant. How could I think that?
2. They said I am going home tomorrow. I don't feel ready. What if something happens? I am scared.
3. How do I stay positive while I wait for the transplant call?

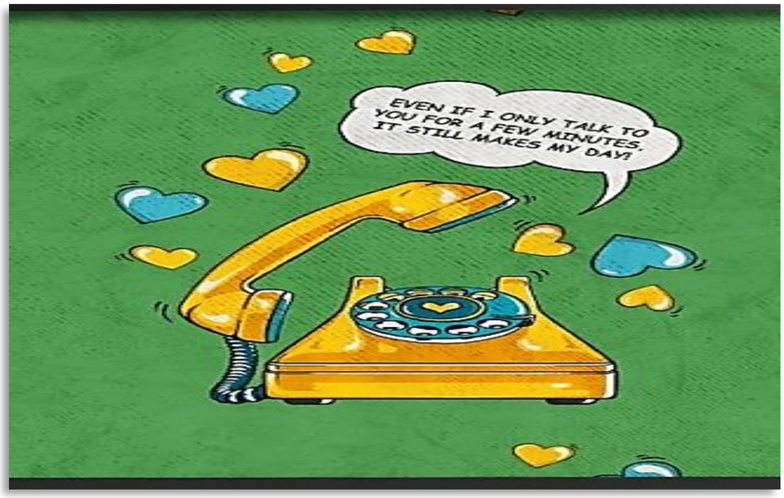
SCENARIOS FOR PRACTICE (continued)

Sample Answer: **It sounds like you are feeling very ________ (worried, discouraged, angry mad, etc.). You have every right to feel that way. I felt that way too. It always helped me to connect with my mentor and talk to my friends and family when I was upset. Also remember the things that made you happy before you were waiting and make time for them in your life. Can you tell me more about your family and friends and what kinds of things you like to do for one another?**

RED FLAGS

1. I don't know why I can't take my anti-rejection medicine all at one time. I'm too busy to remember to take it twice day and at the same time every day.
2. I'm supposed to spend the holidays with my sister. She has three kids that are all sick. I don't want to hurt her feelings, but I don't want to get sick. Maybe I should just go and keep my fingers crossed.
3. I can't take life on dialysis anymore. I don't have a good quality of life, and I might just stop going.
4. I can't handle this stress, wondering if I'm going to live or die. Don't tell anyone, but last night I just couldn't take it anymore and had a couple of drinks.

Sample Answer: **I think it is important for you to talk to your transplant team right away about how you are feeling. I don't want you to do anything harmful for yourself. I am here for you to talk to, but I need to be sure you are making the best choices for your health. How are you feeling? How were you feeling yesterday? How do you want to feel tomorrow?**



Mentee Information Form

Disclaimer Acknowledgement

TransplantTalk SC Mentor/Mentee program was established to help pre-transplant organ Patients cope and speak with actual past organ recipients. Patients are given the chance to ask questions and talk about the emotions and feelings that they are experiencing in their time of uncertainty and unrest.

TransplantTalk SC mentors are not mental health providers, nor are they able to give any medical advice. They voluntarily offer to patient's facts about their experience as they went down the Transplant Path.

TransplantTalk SC is an independent 501c3 not for profit organization and has no official, nor legal, affiliation with Medical University of South Carolina (MUSC) or any of its employees; and

TransplantTalk SC mentors has had the opportunity to work along-side some of the most caring transplant professionals that includes predominantly MUSC nurses, coordinators, staff and doctors to offer the friendliest assistance that can possibly be provided to a cause that we mentor's care so deeply about.

***TransplantTalk SC Mentors will try at all times to maintain complete confidentiality with our mentees, but please understand that if at any time the TransplantTalk SC mentors notice or suspect any "Red Flags" during a conversation and/or they reasonably feel that that the mentee is a danger to themselves or others, the proper steps will be taken in accordance to the law and the Mentor/Mentee relationship will end immediately.**

Requesting a Mentor is not a requirement for a patient's transplant listing. This is a voluntary service that is being offered by mentors of TransplantTalk SC, the area organ support group. Please note that a patient can withdraw from the program at any time and for any reason. We ask that the following questionnaire be filled out to the best of the patient's comfort level. The response will help us match the mentee with the most appropriate mentor. TransplantTalk SC will attempt to match mentor and mentees by organ type if at all possible. In the event that a mentor is not available for a specific organ match, the mentee patient will be notified and offered a different mentor upon which the mentee can approve, or opt to not participate until a similar organ mentor candidate can be offered.
By signing below, the patient or guardian affirms that they have read and understand the disclaimer above and enter into the TransplantTalk SC Mentor/Mentee program willingly and can opt out at any time. At no time will TransplantTalk SC charge or expect compensation of any kind.

Patient/Guardian Name (Print) ____

Patient/Guardian Signature ____

Date: _____________

Name ____

Address ____

City ________________________________ **State** ______ **Zip Code** _____________

Cell # ____________________________**Home #** _____________________________

Email _________________________ **Organ(s)** ______________________________

AGE (yrs.):

0-17 _______ 18-30 _______ 31-45 ________ 46-60 _______ 60+ _______

Marital Status _________ **Spouse/Partner Name** ______________________________

Tell us about your children ____

____

Occupation ___________________ **Primary Language Spoken** __________________

Hobbies/Activities ____

____

____

Religious Preference __________________________ **Race/Ethnicity** _____________

Interest in Mentorship (Check all that apply to your interest):

Phone ________ Text _________ Video (FaceTime/Zoom/EST) ________ Email _________

In Hospital _________ In Person Meet up _________ In Person Home Visit _________

How long have you been diagnosed and how did you find out? ______________________

____

____

How long have you been on the transplant list OR when do you expect to be listed? ____

____

Tell us about your support group and caregivers. Would you like them to join us in

Conversation? ____

____

____

Use the rest of this page to tell us anything you want us to know or any questions you would like to ask. If we don't have the answer for you, we will do our best to get you the answer or put you in touch with the right person to answer it.

____

____

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____

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____

____

Mentor Information Form

DISCLAIMER Acknowledgement

TransplantTalk SC thanks you for taking time out of your lives to help mentor organ transplant patients facing the realities of life before, during, and after their transplants. As most of us know, this is a journey that we just could not walk alone and feel that we can help others by adding to the patients support team. We thank each of you for volunteering your time, compassion, and story.

TransplantTalk SC Mentor/Mentee program was established to help pre-transplant organ Patients cope and speak with actual past organ recipients. Patients are given the chance to ask questions and talk about the emotions and feelings that they are experiencing in their time of uncertainty and unrest. It is important that the patient understands and realizes that TransplantTalk SC mentors are not mental health providers nor are they able to give any medical advice. TransplantTalk SC is an independent community based 501c3 not for profit organization and has no official nor legal affiliation with Medical University of South Carolina (MUSC) or any of its employees; and TransplantTalk SC chooses to work alongside some of the most caring MUSC nurses, coordinators, staff and doctors to offer the friendliest assistance that can possibly be provided to a cause that we all care so deeply about.

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By signing below, the Mentor affirms that they have read and understand the disclaimer above and enter into the TransplantTalk SC Mentor/Mentee program willingly and can opt out at any time.

Mentor Name (Print)

____

Mentor Signature ________________________________ **Date:** ________________

Address ____

City ______________________ **State** _____________ **Zip Code** ____________

Cell # ____________________________________

Home# ________________________________

Email ____________________________ **Organ(s)** _______________________

AGE (yrs):

0-17 ________ 18-30 ________ 31-45 ________ 46-60 ________ 60+ ________

Transplant Year ___________ **Time since Transplanted (yrs):**

>1yr. ______ 1-3 ______ 3-5 ______ 5-10 ______ 10+ _________

Occupation _________________ **Primary Language Spoken** _______________

Any Second Languages Spoken? ____________________________________

Hobbies/Activities ____

____

____

Religious Preference ___________________ **Race/Ethnicity** _______________

How are you willing to contact Mentees (Check all that apply to your interest):

Phone ________ Text ________ Video (FaceTime/Zoom/EST) _______

Email ________ In Hospital ________ In Person Meet up ________

In Person Home Visit ________

Subjects you wish to avoid or feel uncomfortable discussing? ________________

Why do you want to be a mentor? ____

Use the rest of this page to tell us anything you would like us to know or anything that we can assist you with that would make it easier for you to be a mentor.

Post Communication Log

Mentee Name

First ________________________ **Last** _____________________________

Date ______________________ **Time (Start/Finish)** __________________________

Mentor interaction

Type: Text ______ Phone _______ Video_______ Email ________ In-Person ______

Location ______

How was your interaction with the Mentee? Scale of 1 to 10 with 1 being very positive, and 10 being extremely negative.

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**

Very Positive **Okay** **Very Negative**

Summary of interaction or notes you wish to remember. Please note any "RED FLAGS" that you feel may be of concern in the notes.

____

____

____

____

Mentor Signature __________________________ **Date** _____________________

Thank You for being willing to share your experience to support and guide someone else through theirs!