



Pediatric Caregiver Volunteer Manual

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Section 1

History and Purpose

Mission

To provide personalized peer support empowering those affected by cancer and its treatment.

Vision

To be a global leader in providing peer support to enhance the well-being of those affected by cancer and its treatment while advancing evidence based research.

History

After recovering from cancer Scott Hamilton, an Olympic gold medalist in figure skating, identified three angels who helped him through his journey. Scott's oncologist at Cleveland Clinic was his first angel; his oncology nurse was the second; and his family and friends were his third. What he thought was missing was a fourth angel: someone who had been there and would understand what he was feeling. His idea to create a program in which cancer survivors and patients could talk with their peers about the cancer experience has brought about the survivor-to-patient/caregiver 4th Angel Mentoring Program. In 2014, a need was identified to expand the program to include the caregivers of pediatric patients receiving cancer treatment.

The 4th Angel Mentoring Program is an innovative, interactive approach to cancer support in which patients and caregivers are matched with trained volunteers. While emphasizing one-on-one contact, matches are primarily made based on similar age and cancer experiences to best empower caregivers and patients with knowledge, awareness, hope and a helping hand.

In general, here are some of the reasons people seek out a 4th Angel Mentor:

- To talk to someone who knows what it's like
- To share thoughts with someone who doesn't have an emotional connection to the mentee's family members or friends
- To obtain specific information about treatment, how to deal with daily demands, etc.
- To reduce feelings of isolation

Section 2

Becoming a Mentor

Role of the 4th Angel Mentor

As a 4th Angel pediatric caregiver mentor, you can use your experience to offer one-on-one support to someone caring for a child receiving cancer treatment. You will be able to offer unique comfort and reassurance by allowing current caregivers to express their feelings, share their fears, and ask questions in a confidential and trustworthy environment.

Mentors take on many roles, but being a listener is most important. If you think back to your experience, perhaps you needed someone to speak with during difficult times. You may have needed emotional support or information about the road ahead from someone who had similar experiences.

Mentoring can be a rewarding, yet challenging experience. Helping someone else deal with cancer may remind you of difficult times during your own experience or you may feel the person you are mentoring is not receptive to your comments. We'll give you some helpful tools to handle these situations in this manual.

The person you are mentoring wants to talk to someone who has been there or they would not have contacted the 4th Angel Mentoring Program. However, what they want to talk about or how much personal information they choose to share differs by individual. Your mentee might want encouragement or inspiration or might have a specific concern that they don't feel comfortable talking about with family or friends. Or they may need pointers from you on what to expect and how to deal with the issues they face.

Answering medical questions is **not** a part of your role as a mentor. If your mentee asks for advice about treatments, doctors or medications, encourage them to contact their healthcare team.

4th Angel Mentor Criteria

- In order to be a pediatric caregiver mentor, the child should be at least six months into treatment.
- Prior to beginning a mentoring relationship, complete the 4th Angel mentor training and become familiar with this manual.
- Possess a positive outlook and supportive nature.
- While flexible, being a 4th Angel mentor to an individual may require a regular, ongoing commitment of time.
- If you are unavailable for an extended period of time please contact a 4th Angel Mentoring Program coordinator so that you are not contacted for a match during that time. **In addition, please contact a program coordinator with any changes in contact information or the child's health status.**
- Provide feedback: Once you have made initial contact and spoken with your mentee, we ask that you send us a feedback form to let us know how the match went and any additional suggestions, questions or comments you may have for improving the program.

The 4th Angel Matching Process

The best match occurs when mentors and mentees have as much in common as possible. Not only does it make communication easier, but mutual understanding is enhanced as well.

- Diagnosis, stage, treatments, age and gender are the primary characteristics used to match you with a caregiver with whom you can relate.
- A 4th Angel Mentoring Program coordinator will provide information needed to make initial contact with your mentee. You will receive their phone or email contact information as well as the child's diagnosis, treatment(s), age, and other pertinent background information.
- It is important to make initial contact within 1 to 3 days, by phone or email (whichever your mentee prefers). See Section 3 for additional information on making initial contact.
- It is important to note that, in some cases, a mentor and mentee may not be compatible. Whatever the reason, we encourage mentors/mentees to contact a 4th Angel Mentoring Program coordinator if one or both parties do not feel the match was compatible. If desired, the caregiver may request a new mentor.

- After contact has been made, both mentor and mentee complete a feedback form.
- From the time of initial contact and onward, it is up to you and your mentee to determine how frequently you would like to connect. Length and frequency of contact varies with each match.

Section 3

Contacting Your Mentee

By Phone

- Introduce yourself as a mentor from the 4th Angel Mentoring Program and ask if it is a good time to talk.
- Ask how you can be of help or if they have any questions or concerns they would like to discuss.
- **Before ending the conversation, it is important to offer another time to talk.**

By Email

- Introduce yourself as a mentor from the 4th Angel Mentoring Program.
- Ask how you can be of help or if they have any questions or concerns they would like to discuss.
- Offer to continue emailing or, if they prefer, to transition to phone.
- Note: you may want to avoid abbreviations such as LOL or BTW; not everyone knows what they mean.

As you establish a deeper relationship with your mentee, keep this advice in mind:

Follow your mentee's lead. If they want to talk, be a good listener, but if they do not, respect their wishes. In such a circumstance, you may ask if they would like you to call back at another time, or you may share a personal experience you think would be supportive.

Remember that your mentee might not want to talk about the diagnosis or treatment all the time. Your match may want to talk about hobbies or interests. It is good to share a laugh or enjoy a conversation about something other than cancer.

Each mentor/mentee relationship is unique. Sometimes calls are short and frequent, while other times mentors/mentees only have one or two lengthy conversations. The purpose of mentoring is to be supportive of the caregiver, whether the person wants a long-term relationship, wants to talk to several mentors briefly or just wants a one-time conversation to gather information.

With each connection, ask if there is anything specific they want to discuss; be the one to open the door so your mentee feels comfortable asking questions.

Contact a 4th Angel Mentoring Program coordinator if issues become complex or if you are uncomfortable handling questions. If your mentee becomes too dependent, needs more time or support than you have available, or has a complex family or medical situation, please contact a 4th Angel Mentoring Program coordinator.

Section 4

Confidentiality & Mentoring

Confidentiality

When you are matched with a caregiver, you will be provided with basic—but confidential—information such as diagnosis, treatment, first name and contact information. The 4th Angel mentoring process naturally includes sharing private information between mentor/mentee. Mentors are obligated to keep all information confidential.

Mentors are not permitted to share identifying information with family or friends. Mentors can talk about their mentee and experience in general terms, but need to guard against giving out any information which might identify them or disclose personal details about their experiences. Confidentiality is imperative. **Failure to keep personal information confidential will result in dismissal from the 4th Angel Mentoring Program.**

IN CASE OF EMERGENCY

If your mentee talks about destructive behavior, suicidal thoughts, or has a medical emergency, you must report the situation immediately by calling 911.

- Obtain as much contact information (first and last name, phone and address if possible) from your mentee in order to provide this to your local 911 operator.
- Inform the mentee that their safety and well-being is a priority, and that you are trained to call for emergency assistance when needed.
- After assistance is obtained for the mentee, please inform a 4th Angel Mentoring Program coordinator.

Tips for Effective Mentoring

An effective mentor keeps the conversation focused on present concerns by utilizing empathy, genuineness, respect and self-disclosure. While discussing general topics is an important part of mentoring, one of your goals is to tactfully bring the conversation around to helping your mentee cope with important issues related to the child's diagnosis and treatment. Your mentee may feel afraid or worried; it's normal for them to try to avoid their concerns by talking about irrelevant subjects. Gently and patiently redirect if your mentee digresses. Here is a brief breakdown of each quality and how to utilize it in your mentorship:

Conveying Empathy

Empathy is when you listen to your mentee share an experience and you are able to relate to how they feel. You may relate based on the child's diagnosis and/or treatment experience. You may remember moments when you felt self-conscious and afraid. You can share how you went through similar feelings and how you got through difficult times.

Genuineness

Genuineness is when our words truthfully match our feelings. Genuineness is easy to discern; if you are genuine in your conversations with your mentee, it will show, and it will encourage them to trust you more readily.

Respect

Respect, in a mentorship, is to show regard or consideration for your match while not dismissing their feelings. Acknowledge your mentee's feelings as valuable and worthwhile, even if you did not experience the same. Being aware that people come from different backgrounds and cultures and have experienced different situations is essential in being a mentor.

Self-Disclosure

Self-disclosure is when you share your feelings and experiences with your mentee in an effort to be helpful and supportive. What you share should be meaningful, pertinent, and well-timed. Share your experiences and feelings in an effort to help them, and not to fulfill your own emotional needs.

Set Realistic Expectations

The clearer the expectations, the less likely you will encounter boundary issues. Upon initial contact with your mentee, be realistic about your role and how often you will communicate with each other.

Additionally, as a 4th Angel Mentor, set realistic expectations for yourself. Should the mentee's needs extend beyond the scope of mentoring, set limits and defer issues back to the patient's health care team or to a 4th Angel Mentoring Program coordinator.

Mentee Needs

The 4th Angel relationship is intended for mentee support. The relationship is focused on the needs of the mentee with the 4th Angel mentor providing active listening, education, guidance and hope to the caregiver.

Mentors may not provide money, transportation or medications to their mentee. If you feel your mentee needs such assistance, suggest they contact their social worker or health care team for local resources.

Personal Disclosure

Only disclose needed personal information, while protecting your privacy and maintaining boundaries. Do not share any personal information that is not relevant to the mentoring relationship.

Be an Active Listener

When speaking on the phone, give your mentee plenty of opportunity to speak by showing that you listen well. Sometimes silence is okay as it encourages others to share more and speak freely. Do not interrupt, but quietly acknowledge that you are listening.

Be Accepting

Acknowledge your mentee's point of view and feelings by using reflective statements such as, "I can hear in your voice how worried you are about your child," or "I can understand how upset you are with the doctor for not calling you back right away." Use your personal story when it's appropriate; it can help validate your mentee's feelings, but be sparing. The relationship is about them, not you.

Avoid:

- **Distractions**
Allow plenty of time to talk when you contact your mentee. Choose a time when you can focus and try not to rush the conversation. Set aside quiet, uninterrupted time so you can give them your undivided attention.
- **Judgment**
It is important to remember all feelings are appropriate and worthy of respect, even if you do not understand how your mentee is feeling. Be prepared to accept various emotions from them without casting judgment, especially if what they are feeling differs from your experience.
- **Argument or Criticism**
Your mentee may make comments that seem unreasonable or even irrational. As you may have experienced, dealing with cancer and its treatment can be highly emotional and they may respond to you with seemingly unreasonable feelings. During discussions, maintain calm acceptance and refrain from disapproval or criticism.

Ask Mindful Questions

Encourage self-exploration by asking open-ended questions, which require more than yes or no answers. For example, if your mentee is working through a tough treatment decision, you might encourage them to examine their feelings by asking, “What did the oncologist recommend?” and “How do you feel about that?” If your mentee is concerned about managing the household in addition to their new responsibilities, you may want to ask, “How have you managed these responsibilities so far?” or “What do you feel are the priorities?”

Responses

Appropriate responses are just as important as active listening. Sometimes what we say can cause people to emotionally shut down and stop listening. There may be times when showing empathy is challenging. It is important to respond in a way that encourages dialogue and avoids insensitive phrases. See examples below of “shut down” versus “open dialogue” responses:

Shut Down Responses	Open Dialogue Responses
God never sends more than you can handle/everything happens for a reason	When you have had difficult experiences in the past, what has helped you?
I know just how you feel.	I can relate to that feeling. May I share with you how I coped?
Just call me if you need help.	Let me know if there’s something you need help with and we can work out a time to talk. Can you tell me about your support system? Have you been in contact with a social worker at your child’s local treatment center? They are helpful in identifying and accessing services.
I don’t see what you’re complaining about.	Sometimes the smallest thing seems overwhelming. On those days, I found it helpful to_____. Would you be interested in coming up with some ideas to help you through this situation?
Well, look on the bright side!	What are some things that make you happy?
It could be worse.	This must be one of the most difficult

things you've had to deal with in life. What difficulties have you overcome thus far?

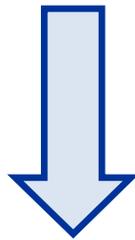
You should try harder to be positive.

Sometimes it's tough to be cheerful and upbeat and we just need to vent once in a while. I'm listening.

Everything will be okay!

I understand that this is an uncertain time for you. I remember similar feelings and what helped me was _____.

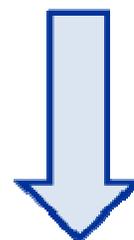
Summary of 4th Angel Mentor Role



Do: Provide support and actively listen
Don't: Expect to work miracles



Do: Discuss possible solutions with your mentee
Don't: Take the steps for them



Do: Guide your mentee to discover their inner strengths
Don't: Solve their problems

Section 5

Emotions and Impact

Your mentee may face many emotional and physical challenges in the months ahead. There may be instances when being a mentor opens the door to painful or worrisome times in your life. **If mentoring becomes uncomfortable in any way, contact a 4th Angel Mentoring Program coordinator.**

Emotions

Each mentoring relationship is unique. Your mentee's child may be recently diagnosed or in the midst of treatment. Their emotions and circumstances may be different from those discussed here. When a serious illness is involved, feelings may change from day to day or even minute to minute. These feelings are normal and your mentee may feel more than one emotion at any given time. Your mentee's emotions may be different from those you experienced. **If their emotions or behaviors become concerning, contact a 4th Angel Mentoring Program coordinator.**

Denial

Denial is a defense mechanism used to give ourselves time to adjust to a traumatic and painful situation. Your mentee might not believe or cannot accept the diagnosis or the necessity for treatment.

How you can help: Encourage your mentee to talk by asking open-ended questions and avoid pointing out that you think they are in denial. Instead, start a conversation by using personal examples and suggest they express their feelings to their doctor.

Anger

Anger is an emotion that we often use to disguise other, more painful emotions, such as fear, panic, frustration, anxiety, sadness or helplessness. Sometimes anger is directed at doctors, friends or family, oneself, a higher being, or even the cancer itself. Anger might show itself as resentment, irritation, or misdirected statements that are ways of releasing painful emotions.

How you can help: Do not feel you need to diffuse the anger or convince your mentee that everything is okay. Let them speak without criticizing or judging them for their feelings. If needed, you can use some of the listening techniques or responses from Section 4. You may need to listen to your mentee vent several times before their anger seems to dissipate. If the mentee demonstrates prolonged anger, contact a 4th Angel program coordinator.

Fear/Worry

Worry is a feeling of concern about something bad that might happen. Fear is an unpleasant emotion caused by being aware of danger. Fear and worry are often the two most common and persistent feelings caregivers experience. Your mentee might be concerned about things such as money, employment, appearance, treatment side effects, death and loneliness.

How you can help: Encourage your mentee to learn about cancer and the treatment prescribed by talking with the child's health care team or by referring them to some of the resources in Section 7. Share personal experiences about how you coped with worries and concerns if appropriate. As always, listen and let them know that you hear and understand their fears and worries.

Anxiety

Anxiety is distress or uneasiness of mind caused by fear of danger or misfortune. Anxiety can include rapid heartbeat, lack of appetite, inability to sleep, feeling weak or dizzy, headaches or muscle pains, nausea, tightness in the chest or throat, shortness of breath, inability to concentrate, inability to stop worrying or imagining catastrophic results, feelings of helplessness or failure.

How you can help: Please suggest that your mentee speak with their healthcare team about any of these symptoms. While you don't want to give medical advice, you *can* mention that anxiety is something many caregivers experience to some degree. You may share appropriate personal experiences, however, keep in mind that the mentee should seek professional resources. If your mentee continues to complain about symptoms and does not seek medical advice, please speak with a 4th Angel Mentoring Program coordinator. Untreated continual anxiety can lead to serious health conditions.

Helplessness

Helplessness is the feeling of weakness, dependence, and of being unable to help oneself. Your mentee might mention lack of control or frustration with interruptions in daily routine.

How you can help: Guide your mentee's focus to areas of their life in which they retain control. Education about cancer and treatments is a powerful place to start. Encourage your mentee to ask questions—of doctors, nurses, insurance providers or billing offices—when confusing situations occur. Let your mentee know that while the long-term future may not be predictable, making more manageable plans is a positive step. Listening and sharing personal experience helps, too.

Hopelessness

Hopelessness is feeling desperate, beyond optimism, or having a lack of hope for a resolution.

How you can help: Sharing your inspiring story helps provide hope and reassurance. Support groups and professional counseling are valuable resources to encourage. Alternatively, if your mentee is spiritual or religious, you might suggest they speak to a spiritual leader. Be mindful that you and your mentee may have different spiritual or religious beliefs.

Sadness and Depression

Sadness is a normal response and is characterized by feelings of despair. Depression is a more serious condition in which feelings of despair are more constant or overwhelming. **Clinical depression** is a condition in which sadness is more intense and prolonged than would generally be expected and medical advice should be sought. Signs of depression might include comments about not sleeping, having no interest in family/friends or hobbies, lack of appetite, feeling listless, hopeless or that life has no meaning.

How you can help: Sometimes just listening can help. Being available to your mentee offers supportive presence. If you think your mentee may be experiencing clinical depression, you might recommend that they talk about feelings of lingering sadness or despair with a doctor, psychologist, nurse, social worker or spiritual leader, and inform a 4th Angel Mentoring Program coordinator.

Guilt

Guilt is a feeling of responsibility for a wrongdoing. Your mentee might make remarks about feeling responsible for lifestyle choices that may have contributed to their child's diagnosis. Expressions such as, "I beat myself up about..." or, "I should have taken them to the doctor earlier..." are typical of those experiencing guilt.

How you can help: You can reassure your mentee that feeling occasional guilt is normal, and share similar experiences if you are comfortable doing so. Empathize and gently encourage your mentee to focus on what they can do moving forward.

Loneliness

Loneliness is a feeling of solitude or isolation. Your mentee may mention that people don't seem to call or visit as often as they used to, or express feelings of not wanting company or contact. They might say that others do not understand what they are going through.

How you can help: Feeling lonely might be one of the reasons your mentee wanted to speak with a mentor. Talking on the phone each week may be enough. However, your mentee may want more or in-person contact, in which case a support group might be a good suggestion. Refer to the list of resources in Section 7.

Section 6

Cancer's Impact on Relationships

Self

Your mentee may feel as if they have given up their role as a partner, parent, or sibling in order to deal with the child's diagnosis, which may result in confusion, stress or negative feelings. Some may not want to impose by asking for help, yet they may desperately want or need it. Below are some potential concerns that mentees may have about taking time for themselves and accepting help from others, along with suggestions on how you might respond as a mentor.

Concern: "I don't want to be around people. I just don't have the energy..."

Suggested Response: "Just because someone drops off a meal or prescription doesn't mean you have to invite them in. Meet them at the door, thank them, and provide a quick update on how you and/or the family are feeling."

Concern: It is very hard to see peoples' lives moving forward in a normal way while I have a sick child to take care of."

Suggested Response: "I can relate to how you feel. Keep in mind you are in the process of developing your own new routines, and this process looks different for everyone."

Concern: "I don't want to bother anyone."

Suggested Response: "Many people probably want to help. If you have offered help to someone in need before, how did that person handle your offer? Does that change your feelings about someone bringing you a meal or running an errand for you?"

Concern: "My bills and my house are a mess!"

Suggested Response: Perhaps you can try to break up larger chores into smaller manageable tasks. You can keep a short list of these tasks so you can cross things off and feel as though you've accomplished something for the day. Also, allow yourself a break. You are busy caring for your sick child; the tidiness of your house may not be as important as it used to be and that is okay.

Concern: "The organization of my family life and activities is suffering."

Suggested Response: These days, families are busier than ever. Consider allowing other family members and friends to take and participate in events for your other children.

Sick Child

Your mentee may express how being a caregiver for a child in cancer treatment is challenging. The child may become very dependent on their caregiver. This can lead to both positive and negative emotions. The child's age at diagnosis will likely impact the different behaviors and experiences that emerge.

How you can help:

- Do not feel like you have to give advice on how to handle their child's emotions.
- Keep an open dialogue on how these feelings make them feel as a caregiver, as they may share many of the same feelings their child is experiencing.
- Encourage honesty and developmentally appropriate language when the caregiver is communicating with the child about the diagnosis and treatment.
- Encourage developing a relationship with the healthcare professionals that offer expert advice on these topics (child life specialists, child psychologists, and social workers).

Below are some concerns that caregivers may have regarding the child in treatment and suggested responses.

Concern: "My child isn't acting like themselves."

Suggested Response: It is possible that your child is feeling isolated or angry because they can no longer do the things they are used to doing. They may feel like they have lost control over their own life. It may be helpful to find a way to create age appropriate situations that they have control over.

Concern: "My child isn't motivated to do anything."

Suggested Response: Your child looks to you to see how they should act. Model a positive outlook to pass on to them, while also acknowledging/validating their feelings. Plan activities around the time the child is likely to be able to participate. This will foster a sense of control and allow for inclusion and participation in events.

Concern: "I never know what's going to happen when I go to the clinic or hospital."

Suggested Response: It is understandable that unanticipated events may lead to real anxiety for both you and your child. Your ability to adapt has a great impact on the response of your child. Be prepared as best you can and respond proactively to unforeseen circumstances.

Concern: “I am struggling with getting my child to take their medication.”

Suggested Response: Be creative and reward any attempt. For pills, practice with small items first, then gradually increase the size of the items they are attempting to swallow (sprinkles, tic-tacs, mini m&ms, etc.). Your child life specialist may have some other great ideas to help with this.

Concern: “My child wants me to do everything for them.”

Suggested Response: Encourage your child to perform as many of the activities for themselves as they are able (feeding, brushing their teeth, etc.) This will help them maintain a sense of control and independence. If you are having trouble getting the child to complete these types of activities, you may offer choices on how to complete the activity. For example, “Do you want to brush your teeth before or after you take your pills?” Your child will need to do both things, but has a choice in which order to complete these tasks.

Concern: “We as a family feel like we’re missing out on everything.”

Suggested Response: If big celebrations are unable to occur, celebrate small things instead; wherever the setting.

Siblings

Breaking the news to a child that their sibling has a serious illness may be an emotional experience. While the children in your mentee’s family may know about the diagnosis, they may still have questions or worries, and they may or may not be open to talking about them. Children of different ages may react differently to this news. Refer your mentee to support services such as child life, social work and psychology at their hospital. Utilize this link for more helpful ideas for age-appropriate conversations.

<http://my.clevelandclinic.org/ccf/media/files/Cancer/12-CNR-084-what-to-say.pdf>

Other suggestions that may help foster normal relationships with siblings:

- Encourage family activities as much as possible
- Avoid isolating siblings from one another
- Maintain routines as much as possible

Family

During this uncertain time, family members may disagree, argue, withdraw or become uncomfortable with each other. Your mentee may express that they are experiencing family adjustment issues and may seek guidance from you on how to resolve them. For

example, there may be family disagreements on where the patient should receive care, and which physician or treatment option they should choose. It may help your mentee to know that disagreements usually arise from frustration, anger, feeling helpless or worry. In addition, sometimes family members withdraw from each other when dealing with cancer. They may not know how to talk with someone about cancer, or it may be too painful. Sometimes they are dealing with feelings of guilt or sadness, or may just feel left out.

The first step is to listen to your mentee's concerns, then if you are comfortable disclose your experiences. Share with them what helped you resolve family issues. Some common suggestions are listed below, and more resources are available in Section 7.

- Suggest they schedule a time where family members can meet to discuss their concerns.
- Remind your mentee that acknowledging their family members' opinions is valued.
- Encourage them to keep their family members informed of important information such as changes in condition, upcoming appointments, or treatments.
- Encourage them to let their family members know that coming together and being supportive of one another is important for them to move forward and for their wellbeing.
- Encourage your mentee to re-open the lines of communication by suggesting that they reach out directly to the person who has withdrawn to show that they care and that they may need their help.
- Suggest speaking with a social worker at their local health care center, or seeking professional services such as individual, couple or family counseling.
- Offer the 4th Angel Caregiver Mentoring Program.
- Suggest enlisting a family member or friend to communicate with other family members if appropriate.

Friends

Like family members, friends have an emotional response when someone they care about is caring for a sick child, and sometimes they are at a loss as to how they might be supportive.

Your mentee may mention that their friends have fallen out of touch. Sometimes people feel uncomfortable and don't know what to say. Encourage your mentee to reach out to their friends and reconnect.

Overbearing Friend or Family Member

Your mentee may be unsure of how to handle an overbearing friend or family member who wants to take charge of the situation or continually provides unsolicited advice.

The key is to identify the person's comments as "opinions" or "suggestions" and to acknowledge their worth by thanking them.

For example, "You always have a possible solution for me and I appreciate that. I'll think about what you've suggested." In addition, if you can offer a personal experience it may give your mentee confidence knowing that you faced something similar.

Partner

Your mentee's partner may be just as anxious about the diagnosis, yet their concerns may be different. Caregiver demands may place additional strain on the relationship. A partner may be worried about:

- The child's treatment
- Their abilities to be a good caregiver
- Burdening their partner with their own anxieties

Some suggestions you can offer your mentee:

- Start conversations with "I feel..." not "You..." to avoid use of blaming statements. This may allow for a more open conversation.
- Share responsibilities at home and the care of the sick child.
- Include partners in treatment information and discussions with the medical team.
- Keep partners in the loop about what side effects might be expected from their child's treatments and what may be done to help alleviate them.
- Keep the lines of discussion open about the future, money, jobs and family. Support groups or social workers can be valuable tools in facilitating difficult discussions.
- Acknowledge that partners may need time apart to take care of chores, errands, or even to continue personal activities.
- Offer the 4th Angel Caregiver Mentoring Program.

Separation or Divorce

Caring for a child with cancer can cause significant stress and strain on the parent/partner relationship sometimes leading to separation or divorce. If your mentee is struggling to cope with separation or divorce, encourage them to speak with a social worker or a psychologist.

Aging Parents/Grandparents

Your mentee may be caring for an aging parent(s). They may have concerns about continuing to care for them during the child's treatment or how much information to share with them about the child's diagnosis.

Much depends on individual circumstances and resources; arrangements may have to be made to help care for their parents, either short term or long term. Their parent(s) may be in poor health and unable to cope with, or understand, the child's medical situation.

An oncology social worker at their cancer center may be able to assist them in locating community resources while assisting with family issues and concerns. Many cities have programs that offer older adult services as well.

Educators/Teachers

If the child is school age, it is very important that your mentee communicate with the child's teachers and school staff to keep them up to date. Encourage your mentee to talk to their social worker to start home schooling if necessary. When the child goes back to school, you may suggest they ask someone from their treatment clinic to speak with teaching staff and administration to make the transition easier for the child, their classmates, and other teachers in the school. Children going through treatment may need to take medication during the school day and need to be familiar with the school nurse. The school also needs to inform the mentee's family if any illnesses are going around school since a child in treatment has a weekend immune system. If their siblings are in the same school system, the staff at school can provide support to them as well. If you are seeking any additional information on educators and schools, please look into Children's Oncology Group in the References section.

Section 7

Resources

The Health Care Team

There are many different professionals that are available to assist children and their families throughout their healthcare experience. You may have had the benefit of utilizing these resources during your child's treatment, and if so, can encourage your mentee to reach out to them as well. If your mentee is seeking medical advice, refer them to their health care providers. If you are unfamiliar with these resources, you could still recommend any of the following to your mentee as well.

- Child Life Specialists
- Physicians
- Genetic Counselors
- Nurses
- Nutritionists
- Patient Educators
- Pharmacists
- Psychologists & Psychiatrists
- Social Workers

Child Life Specialists

Child life specialists are specially trained to assist children of all ages in understanding their diagnosis and treatment. The child life specialist can help the child find ways to cope with many emotions that come from having a chronic illness, and are also a good resource to explain a diagnosis to a child's siblings. They are also helpful in providing your child with an outlet to process through any of their questions, concerns, or anxieties related to diagnosis and treatment.

Children's responses to cancer may vary greatly based on each individual. It is important to understand that your child's reaction may be different than what your mentee might be experiencing with their child. Be mindful not to give direction on how to help their child, but instead share what you have found helpful with yours. If your mentee needs additional support, refer them to the child life specialist who can provide additional insight to the typical responses of children in similar situations.

Psychologists

Child psychologists are licensed professionals who can work with your mentee, his/her child, and siblings to help them cope with a variety of difficult feelings and reactions at diagnosis, during treatment, and after treatment. A pediatric psychologist is a type of child psychologist who has specialized training and experience in helping those living with medical illnesses, such as cancer. Psychologists can:

- Help the family to understand and adjust to a new diagnosis, treatment, or life beyond treatment
- Assess for mood concerns, such as anxiety and depression
- Address emotional, behavioral, social, or learning difficulties at home and/or school
- Help to discuss and problem-solve concerns about being treated differently by family and friends, returning to school and other activities, relapse, or other life topics, such as dating, fertility, and career/job
- Encourage or increase healthy behaviors such as sleep, diet, physical activity, and taking medications
- Teach coping skills to deal with difficult or negative feelings, stress, pain, physical changes, or treatment side effects
- Work with medical teams and schools to make sure needs are being met

Let your mentee know that receiving psychological care can be considered at any stage of the diagnosis. Your mentee may want to consider establishing care with a psychologist at initial diagnosis to prevent or address any concerns as early as possible. Share with your mentee that proactively addressing psychological well-being can help him/her, their child, and other family members feel more confident, relaxed, as well as improve mood and coping skills.

If psychological help is needed, encourage your mentee to ask a member of his/her child's cancer team (example: physician, social worker) or a pediatrician for a referral to a general or pediatric psychologist. Your mentee can check with his/her insurance company to see if they provide a list of local mental health providers. The American Psychological Association also provides a psychologist locator at <http://locator.apa.org>. It may be helpful to remind your mentee it may take time to find a psychologist and that the first psychologist seen may not be the "best fit." Mentees have the right to receive care from a qualified psychologist who they feel can meet their needs and address their concerns. Let your mentee know it is okay and appropriate to ask for additional psychology referrals from the oncology team or pediatrician if needed.

Social Workers

Pediatric oncology social workers are licensed professionals who are skilled in addressing counseling, support, education, advocacy and referrals to community resources. They can work with your mentee, his/her child and any other supports that your mentee identifies to help manage the day-to-day challenges associated with a cancer diagnosis and its treatment.

Pediatric oncology social workers can:

- Help a child and their family/supports cope from the moment of diagnosis throughout the course of treatment
- Provide emotional support and emotional interventions
- Navigate through the medical system, bridging the connections between the family and the medical team
- Identify and address needs including financial, insurance, disability, employment, prescription assistance, transportation, school interventions, lodging, advanced planning, survivorship and bereavement.
- Identify resources
- Advocate for the needs of the child and family

Support Groups

If your mentee is interested in a support group, encourage them to talk to their doctor, nurse or social worker to see what kind of groups might be a good fit. There are many options available. Groups may be online or in person; based on particular diagnosis or open to all kinds; for patients, caregivers, or both; focus on sadness and grief, etc.

Spiritual Help

Spirituality can include faith, religion, beliefs or values. Some people feel comfortable discussing faith and spirituality, but others may not. If your mentee is spiritual and has a community of faith, you might suggest they talk with their spiritual leader. If not, most hospitals have a chaplain who will be able to listen to spiritual concerns and perhaps help them find a spiritual home.

American Cancer Society

**<http://www.cancer.org/treatment/childrenandcancer/whenyourchildhascancer/>
800.227.2345**

American Cancer Society has a broad spectrum of information on cancer, its risk factors, prevention, treatment and more. They have an excellent list of resources based

on diagnosis. It also provides information to help parents of children with cancer know what to expect. Topics include coping with the diagnosis, dealing with financial and insurance issues, and nutrition for children with cancer.

American Childhood Cancer Organization <http://www.acco.org/mission-statement/> 1.855.858.2226

The mission is to provide information and support for children and adolescents with cancer and their families, to provide grassroots leadership through advocacy and awareness, and to support research leading to a cure for all children diagnosed with this life-threatening disease.

Be the Match <http://bethematch.org> 1.888.999.6743

A non-profit organization that is dedicated to helping every patient in need of life-saving bone marrow and cord blood transplants. They also provide one-on-one support to patients and their families throughout the transplant journey.

CANCERcare www.cancer.org 1.800.813.HOPE (4673)

Professional oncology social workers provide free emotional and practical support for people with cancer, caregivers, loved ones and the bereaved.

Oncology Social Workers are available Monday through Thursday from 9 a.m. - 7 p.m., Fridays from 9 a.m. - 5 p.m. (Eastern Time)

CANCERcare for Kids <http://www.cancer.org/tagged/children> 1.800. 813. 4673

This organization provides free, professional support services for parents, children and adolescents affected by cancer, as well as information about helping children understand cancer and additional resources.

Cancer.Net <http://www.cancer.net/navigating-cancer-care/children/childhood-cancer-resources> 1.888.651.3038

Cancer.Net offers the following resources to help when cancer is diagnosed in a child. Some resources include: Preparing your child for medical procedures, childhood cancer survivorship, late effects of childhood cancer and managing them, preserving fertility in children with cancer, and camps and retreats for families.

Caring Bridge <https://www.caringbridge.org/>

The Caring Bridge website allows people to easily get updates and offer support and encouragement. In times of need, the greatest source of hope and healing is the love of family and friends.

Chemocare www.chemocare.com

Consistent, up-to-date, and easy-to-read chemotherapy information; all content is provided by a team of medical professionals at Cleveland Clinic. This site is available in English and Spanish as well as additional languages utilizing Google Translate.

Children’s Oncology Group <https://www.childrensoncologygroup.org/>

The Children’s Oncology Group provides important information for children and their families from the time of diagnosis, through treatment and following cure. COG’s unparalleled collaborative efforts provide the information and support needed to answer important clinical questions in the fight against cancer.

Children’s Organ Transplant Association <http://cota.org/> 1.800.366.2682

The Children’s Organ Transplant Association (COTA) helps U.S. transplant families avoid financial ruin. Once the transplant is complete, families face significant transplant-related expenses, including medication; transportation to and from the center; lodging; and expenses while parents are out of work and often living with the hospitalized child far from home. In cases where a shortfall exists, COTA helps bridge the financial gap.

Make A Wish America <http://wish.org/> 1.602.279.9474

This organization can help children feel stronger, more energetic, more willing and able to battle their life-threatening medical conditions. For many, the wish marks a turning point in the fight against their illnesses. Doctors, nurses and other health professionals say the wish experience works in concert with medicine to make their patients feel better emotionally and even physically.

**National Cancer Institute <http://www.cancer.gov/types/childhood-cancers>
1.800.422.6237**

National Cancer Institute is the U.S. government’s principal agency for cancer research. The website offers current information about cancer prevention, screening, diagnosis, treatment, research and clinical trials. The information and resources on this page provide a starting point for understanding the basics of childhood cancer.

You can call with cancer related questions Monday through Friday 8 a.m. – 8 p.m. (Eastern Time); the service is available in both English and Spanish.

National Children’s Cancer Society <https://thenccs.org/> 1.314.241.1600

This organization helps families facing a childhood cancer diagnosis so that no family has to endure the costs and heartache of pediatric cancer alone.

National Institutes of Health (NIH) <http://www.nih.gov/health-information/nih-clinical-research-trials-you/parents-children> 1.301.496.4000

The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the nation’s medical research agency — making important discoveries that improve health and save lives. Children are not little adults, yet they are often given medicines and treatments that were only tested in adults. There is a lot of evidence that children’s developing brains and bodies can respond to medicines and treatments differently than how adults respond. The way to get the best treatments for children is through research designed specifically for them.

National Ronald McDonald (Lodging) <http://www.rmhc.org/> 1.630.623.7048

A network of local chapters have been making children happier and healthier by keeping families together – giving them a place to rest and refresh. A place that feels like home.

Pediatric Oncofertility Research Foundation <http://www.porf.org/> 1. 708.334.2704
PORF supports fertility restoration in children through: education, research, support, and funding. PORF is dedicated to providing you with the most relevant information possible to help you make the best decisions for your family.

Stupid Cancer “The Voice of Young Adult Cancer” (AYA)
<http://www.stupidcancer.org/> 1.877.735.4673

Stupid Cancer, a nonprofit organization, is the largest charity that comprehensively addresses young adult cancer through advocacy, research, support, outreach, awareness, mobile health and social media. Our innovative, award-winning and evidence-based programs and services serve as a global bullhorn to propel the young adult cancer movement forward.

Telling Kids About Cancer: <http://www.tellingkidsaboutcancer.com/Guide>. This link will help caregivers create a tool to make a plan for talking to a child about cancer. The ideas will be copied into a **conversation guide** that they can save and print out to use while they prepare for the talk with the child- or even during the talk. Other parts of the website include stories from other caregivers, age-appropriate advice, and other general information about talking with children about cancer.

Aging with Dignity “Voicing my Choices” <https://agingwithdignity.org/>
1.850.681.2010

Aging with Dignity and national experts have developed non-legal documents named “Voicing my Choices” to assist children and adolescents with expressing how they want to be cared for in case they become seriously ill.

Section 8

Frequently Asked Questions

How long should I stay in contact with my mentee? The duration of each match varies. Some mentors remain in contact with their mentees throughout their child's treatment; others check in periodically. Sometimes one or two calls may be adequate for your mentee; it depends on the individual.

How long does a typical match session last? The length and frequency of contact varies. Conversations and in-depth discussions may last longer while others may be brief check-in calls.

Is it appropriate to meet in person? The 4th Angel Mentoring Program does not facilitate meeting in person, nor is it expected. You should consider the importance of maintaining appropriate boundaries as well as your personal comfort with the direction of the mentoring relationship.

How much personal information should I share with my mentee? Should you give your mentee your cell number or address? How much information is too much? Stay within your comfort level and limit identifying information such as your street address.

When will I be matched?

Upon completing mentor training, you will be added to our database of active mentors. When a mentor request is received that matches your profile information, a 4th Angel Mentoring Program coordinator will contact you. The time frame may vary from a few weeks, months, or even longer before your first match and subsequent matches. This is due to our very specific matching process, which is based on diagnosis, stage, age, gender, treatments, procedures and the caregiver's personal needs.

Can I mentor more than one person at a time?

In some instances, you may already be mentoring someone when we contact you for another mentoring opportunity. If you are available and willing, you may mentor more than one person at a time. If you would rather not, just let us know and we will continue our mentor search and also keep you in mind for future matches.

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