

CAREGIVER DO'S AND DON'TS

By: Cherie Monarch



As caregivers, it can be extremely challenging and difficult to navigate and have conversation with our loved ones when they are experiencing an eating disorder. We never seem to be able to support our loved ones in a way they need or say the proper words that correctly convey our love, support, and compassion. It is important to understand that everything about an eating disorder can be counterintuitive. Often times, what we think would be the appropriate thing to say or do is the absolute wrong thing. Here is a list of caregiver do's and don'ts. I hope this helps you navigate the journey with your loved one.

DO'S:

- ❖ DO understand that eating disorders are NOT A CHOICE. Your loved one did not choose to have an eating disorder.
- ❖ DO know that eating disorders are brain-based biological illnesses.
- ❖ DO recognize that eating disorders are serious and deadly. Treat your loved one as you would if they had cancer. This is no different. It is just as life-threatening.
- ❖ DO understand that often times an inherent part of an eating disorder is that your loved one is unable to recognize they are sick and require care and support. This is known as anosognosia. We have to want recovery for them, until they can want it for themselves.
- ❖ DO know that early diagnosis, intervention, and treatment will typically result in the best outcome. Time is of essence when seeking support and treatment for your loved one. Do not delay.
- ❖ DO realize that just as the treatment team is an expert on eating disorders, you are the expert on your loved one.
- ❖ DO understand that COMMUNICATION and COLLABORATION between the caregiver, treatment team, and your loved one are essential to recovery. All must communicate openly, honestly, and frequently. The eating disorder can only hide in the dark.
- ❖ DO remind your loved one that they are loved! That you are standing by their side and will support them on their journey to recovery.

- ❖ DO understand that your loved one must have essential, complete, life-saving nutrition. They will not recover without it.
- ❖ DO recognize how stressful mealtimes and after can be for your loved one. It's like putting a plate of tarantulas before an arachnophobe. Ask them how you can best support them during this time.
- ❖ DO know that it's not your fault and you are not to blame. You could not cause an eating disorder if you wanted to.
- ❖ DO recognize RECOVERY is a JOURNEY. It's not a sprint, it's not a marathon. Those have a known beginning and a known end. It is a journey that is not defined by time. A path with many twists, turns, and moguls in the road. Do understand there is not a quick and easy solution.
- ❖ DO speak openly and honestly with your loved one in a calm and compassionate manner. Express your feelings and your concerns from "your" perspective using non-judgmental "I" statements. It is very likely your loved one senses how you are feeling and dancing around the subject will only complicate matters and delay treatment.
- ❖ DO practice active listening and empathy, so that when you're frustrated, you can respond in a loving way.
- ❖ DO get educated about eating disorders. Be armed with knowledge and be your loved one's advocate, even when they are unable to advocate for themselves.
- ❖ DO learn to tolerate you and your loved ones distress when your loved one is feeling pain, is struggling, or you are unwilling to support the demands of the eating disorder.
- ❖ DO realize that you will have to make hard decisions; choices that do not support the eating disorder. It may be necessary to remove your loved one from school, physical activities, internships, and college especially when they promote eating less, exercising more, and not actively participating in treatment and health. It is painful to feel like you are upsetting or disappointing your loved one when you have to remove them from life. However it is imperative for you to remember that your loved one may lose their life if you are not steadfast. Life must stop until they are well.
- ❖ Do understand that you cannot rescue your loved one from life. Empower them to make their own decisions and to be accountable for those choices.
- ❖ DO model normal eating behavior and movement. Please know you are a role model for your loved one. They are watching.
- ❖ DO plan activities that do not involve food. Remember to incorporate fun, games, laughter, and play in your family life.

- ❖ DO realize that parents, caretakers, and families must be a united front against the eating disorder. A crack in the window will create a large gaping hole for the eating disorder to climb through and continue to hold your loved one hostage. Everyone must sing the same song.
- ❖ DO ask your loved one how you can best support them, what they need from you, and express an interest to be involved in their treatment so that you can learn tools and skills to help support them in their journey to recovery.
- ❖ DO learn to compliment your loved one on their qualities and characteristics that are not physical and share what you appreciate about them as a person.
- ❖ DO recognize, that families are an integral piece and an asset in your loved ones recovery.
- ❖ DO remember that your loved one is so much more than just an eating disorder.
- ❖ DO validate difficulty and distress and allow space and time for your loved one to experience it without judgment.
- ❖ DO recognize that self-care is not selfish, it's essential.
- ❖ DO seek and receive support, whether it's from clinicians, support groups, or friends and family. There are online support groups for families that have a loved one with an eating disorder.
- ❖ DO know that your loved one cares about you, no matter what words come out of their mouth. Understand that lying, deceit, and manipulation are part of the eating disorder. They are not trying to hurt you and may deeply regret their words. Try not to take it personally. This is the eating disorder talking, not your loved one.
- ❖ DO understand this will likely be one of the most difficult journeys of your loved one's life. Surround them with love, compassion, and empathy. Just BE there.
- ❖ DO recognize that time and patience is essential on this journey. Treatment and recovery cannot be rushed.
- ❖ DO understand that your loved one can absolutely recover from an eating disorder. Do not doubt it for one moment. If you don't believe, your loved one won't believe. There is HOPE!

DON'TS:

- ❖ DON'T ever comment on your loved one's physical being- size, weight, shape, underweight, etc. Don't disparage your own body.

- ❖ DON'T ignore the problem and hope that it magically goes away. It is imperative to have open and honest communication about receiving treatment and to set boundaries about when to intervene.
- ❖ DON'T ever tell your loved one just eat, why can't you eat like a normal person, or question what they are eating. If it were that simple, they would not have an eating disorder.
- ❖ DON'T assume when your loved one is weight restored, that everything will be normal and ED thoughts will magically disappear. This is typically when anxiety levels are at their highest.
- ❖ DON'T argue with your loved one, "no you aren't fat" "your thighs are not fat" "you are smaller than your friend"- this is like pouring fuel on the eating disorder and will typically lead to more behaviors and restriction. They don't need you to tell them they are not fat, they just need you to understand how they feel. This shows compassion.
- ❖ DON'T tell a loved one who has gained weight or has anorexia that they LOOK better, healthier, or like they are getting well. Do not comment on their physical being.
- ❖ DON'T skip meals or talk about your diet or wanting to lose weight in front of your loved one. This is like drinking alcohol in front of your loved one who is trying to recover from alcoholism.
- ❖ DON'T enable your loved one's food restriction. Understand this is part of the eating disorder. Don't purchase their special foods or have your whole family go vegetarian because you believe this is supporting your loved one. This is actually strengthening the eating disorder.
- ❖ DON'T physically try to make them eat by shoving food in their face or pinning them to the ground. Encourage them with love and trust. Please understand how terrifying the act of eating can be for some.
- ❖ DON'T expect yourself to be perfect on this journey. Our loved ones do not come with a handbook on how to obtain recovery. You will make mistakes on this journey. Just own them. In fact, it is important to role model that no one is perfect and every day is a new beginning.
- ❖ DON'T discuss the financial burdens or cost in front of your loved one. This just adds additional burden and guilt and may compel them to refuse treatment. Their focus needs to be on recovery.
- ❖ DON'T yell and scream at your loved one. This will just increase the negative messages playing in their head. DON'T tell them- I'm disappointed in you, you're being ridiculous, why won't you just eat, I can't do this anymore, I can't deal with you,

why can't you be like your friends, how can you do this to your mother, to your family, you only think about yourself, you're so selfish... this will only serve to reinforce the messages the eating disorder is already telling them.

- ❖ DON'T panic. Please seek appropriate support and education for yourself.
- ❖ DON'T display anger or make your love conditional and dependent on wellness. They did not choose to have an eating disorder. They need your love and compassion more than ever.
- ❖ DON'T negotiate with the eating disorder. Maintaining very clear and firm boundaries as to what can be tolerated is essential. If there are consequences for non-compliance, then those consequences must become a reality for failure to comply. There need to be clear rules and guidelines and consistent follow-through. You must remain strong.
- ❖ DON'T walk on eggshells. It is critical that you be open and honest and not fear upsetting your loved one with the eating disorder. The eating disorder thrives on intimidation. Don't let it scare you.
- ❖ DON'T assume you have no voice because your loved one is over 18. They cannot be treated like an adult if they don't have the basic skill down of eating or being able to do life.
- ❖ DON'T let the eating disorder fracture the family. This is extremely difficult, but please recognize the eating disorder wants to divide and paralyze the family, because then there is no one to fight the eating disorder.
- ❖ DON'T conclude that your loved one is not physically compromised because their labs are normal. This is more common than not, especially for restrictive disorders. Often times labs won't be abnormal until they are in medical crisis.
- ❖ DON'T ever give up or lose hope. This can be a long journey. Please know that people recover every single day. Recovery is absolutely possible. Do not doubt that for one moment. Hold that HOPE for them.

