



Life With Aortic Disease: Caring For Your Mental Health

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Note to providers:

Thank you for giving your patient information about the mental health impact of aortic disease on patients. We kindly request that for EACH book or postcard you give to the patient, that you would please scan the QR code and fill out three questions. This should take less than one minute. Or, you can use url: <https://redcap.link/MHAAD-Provider>

If you do not have a QR code reader on your phone, you can download one via the app store on your phone.

The three questions are:

1. Region you live in
2. Medical department
3. Patient vascular description (ie. Type A dissection, aortic aneurysm)



FOR PROVIDERS

Note to recipients of the booklet:

If you are the **PERSON WITH OR AT RISK OF AORTIC DISEASE** please use patient code or link: <https://redcap.link/MHAAD-Patient>

If you are a **CAREGIVER**, please use the caregiver code or link: <https://redcap.link/MHAAD-Caregiver>

If you do not have a QR code reader on your phone, you can download one via the app store on your phone.

As part of the initial QR code contact you will be asked to provide:

1. Region you live in
2. Who referred you to this booklet
3. Your vascular findings or diagnosis
4. Approximate time frame from initial and most recent event (aortic surgery or dissection)
5. Other basic demographics
6. Any feedback you have



FOR PATIENTS



FOR CAREGIVERS

You will also have the option to consent to re-contact for research. We would like to contact you (either via text or email, whichever is your preference) at 1 month and 6 months to ask questions about your mental health through a survey called the MacNew health survey and to ask about what interventions you may have looked into or used. The MacNew survey is a 27-question tool used to assess and evaluate health related quality of life in patients with heart disease.

There will also be a consent if you allow us to contact you in the future for studies that you may qualify for.



Dear Friends,

As genetic counselors in the aortic disease (AD) community, it has been our pleasure to get to know many families over the course of our careers. We are privileged to become part of their lives as they learn to incorporate an aortic aneurysm or dissection diagnosis into it. In this role, we have witnessed (and ourselves experienced) many emotional highs and lows as people cope with the diagnosis. As more awareness and attention is being brought to mental health in the general population, our desire was to create a practical resource to do the same within the aortic disease community.

Often, people immediately focus on the medical management of their condition, without sufficient acknowledgment of the significant emotional burdens that result from these conditions. With this booklet, we hope to bring some light to these issues, to acknowledge you aren't alone in feeling alone, and to empower you with some vocabulary, support, and resources to find outlets that help you and your loved ones thrive and live your best lives.

There are some things this resource is not:

- It is not an endorsement of any particular app or website
- It certainly is not a comprehensive resource
- It should not be used in isolation
- It is not a replacement for professional help

That being said, please think of this booklet as the beginning of a larger conversation concerning wellbeing. We hope that you choose to join the conversation and further the dialogue with us (see feedback opportunity on prior page) and with each other. Our AD community will only grow richer and healthier as we share with, encourage and support one another.

We appreciate and honor your choice to spend some time with this booklet and hope that you find it helpful. We are constantly inspired by and grateful to our patients who teach us more than they will ever realize.

Please remember to practice self-care and have compassion for yourself and your loved ones. Please seek appropriate professional assistance as needed. While mental health emergencies are rare, they can occur. Please be aware of emergency resources at the end of this booklet.

Our best wishes,

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This booklet is not meant to add stress to your life or be overwhelming. You do not have to read this all at one time. There does need to be some time for self-processing and reflection. Instead, put it on a shelf or next to your bed, read a section that speaks to you, or share a section with a loved one. Use it as a resource over time. Use the information and support that you need, when you need it, at your own pace.



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1

Words of Advice from Aortic Dissection Survivors

Words of Advice from Aortic Dissection Survivors



- **Strive to have a consistent exercise program** that doesn't cause too much strain or pressure. Walking, pilates, recumbent biking or rowing. Don't let yourself get too tired or sore. For me it throws me into a flare that backslides progress and creates a depression/defeat cycle.
- Do not let the disease define you or it will consume you. **Continue living your life**, think positive, find purpose and passion.
- **Mantras before surgery:** life is kind, there is always a best case scenario, knowledge is power. Imagine the positive outcome. Make plans for after discharge. Make a list of food to cook or things to do after discharge. Be honest (not with every detail) to your child. He/she feels it anyway when things are not going to be okay! Hug and cry with your partner. Have someone to alternate with you to stay with your child at the hospital.
- **The most difficult is that some people just don't understand the mental toll not being "normal" can take on you.** Having a rare connective tissue disorder doesn't give a lot of room for people to relate, you feel misunderstood. Going to counseling, actually being in a counseling group, gave me a lot more perspective on life.
- Allow yourself time to grieve when getting upsetting news. Throw yourself a pity party, **but then pull yourself up and LIVE.**
- You can't pick the music life plays but **you can choose how you dance to it!**
- Finding a therapist that understands what I've been through and can really help me overcome my anxiety and PTSD instead of offering generic advice. **What I've found helpful is to have a good support system** and to not be afraid to take meds that help my mental health.



I try to remember that I am not alone in this. Others have gone through similar struggles and this too shall pass.



- Take it day by day, or quite literally hour by hour. You're going to have highs and lows, but **you can always go to sleep and try again tomorrow.**
- **The Calm App has helped my husband and I to sleep and rest after his surgeries.** I love the book, "How to Help Your Child Through a Parents Serious Illness" by Kathleen McCue. It helped me to know how to talk to my kids during surgeries and ICU stays.
- **Aura app is amazing** for meditation.
- **Having a faith-based support group has been very helpful** for those of us who are caregivers as well as for the family members affected by connective tissue disease.
- My faith as a Christian has been essential to approaching daunting health issues such as ascending aortic aneurysm surgery, and the massive unexpected complications that arose after surgery. Having my friends and family praying for me, giving me scripture verses of encouragement and believing that God would get me through terribly difficult moments was absolutely essential to facing some challenging physical issues with courage and hope. That positive mindset, and **faith carried me through when even the doctors didn't know how to treat my needs.**
- As a spouse and parent of people with vascular disease, **I needed a counselor to help me process all of the difficulties my loved ones had.**
- **Have patience and awareness** - a mindset of listening and learning - without judging.

2

Aortic Disease Definitions

The Basics Of Aortic Disease

Medical terms can be hard to understand, especially in an urgent situation where there may be pain, confusion and a lot of information coming at you and your loved ones all at once. Let's go through a little anatomy course regarding the aorta and arteries.

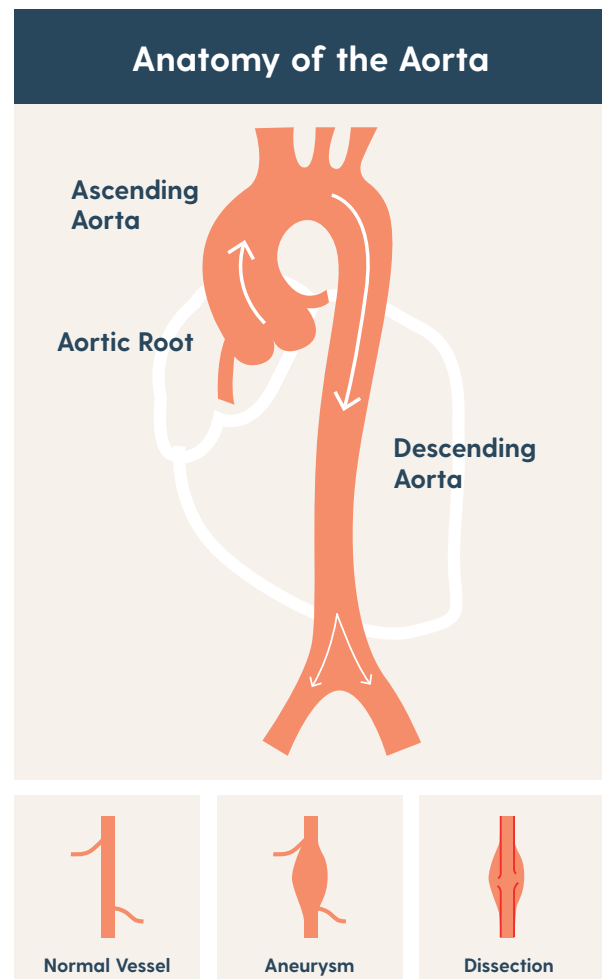
The **aorta** is the long "candy cane-shaped tube" that leaves the heart, arches in the chest, and goes down through the abdomen, where it branches into the iliac arteries, the main arteries that bring blood to the legs. Blood flows from the heart, into the aorta and then into branch arteries that come off the aorta at different locations to bring oxygenated blood to the rest of the body.

The first part of the aorta as it leaves the heart is the **aortic root** (this is where the coronary arteries come off of the aorta and allow some blood flow back to the heart to allow it to function.) The next part of the aorta is the ascending aorta as it continues to move up into the right side of the chest, followed by the arch, and then the descending aorta that comes down the left side of your body and turns into the abdominal aorta.

An **aortic aneurysm** is an enlargement, dilation, or widening of the aorta at a particular location.

An **aortic dissection** is a tear of the aorta.

The aorta and arteries are like a paper towel tube with a layer of cardboard and a layer of paper towel surrounding it. In a dissection, blood can tear through the "cardboard" or first layer and can create a second tube or tunnel where blood now flows through. It is essentially unzipping the two layers to create a second



tunnel of blood flow. The original aortic tunnel is called the "true lumen" and the second, newly created tunnel is called the "false lumen." Sometimes the blood rips through both layers, causing a rupture of blood into the chest cavity, which is an emergency situation.

A dissection in the aortic root and/or ascending aorta can impact blood flow back to the heart by impacting the coronary arteries or can cause blood to fill the sac around the heart, so it is

not able to pump blood and function, causing the need for urgent/emergent surgery. With a type A dissection, there is often a thoracic aortic aneurysm (root or ascending aorta) that develops first, and it gets bigger and thinner until a tear happens. (One big difference is that in Vascular Ehlers Danlos syndrome, dissections can occur without an aneurysm).

Sometimes the dissection is isolated to the first part of the aorta (thoracic aorta). This is called a **Type A dissection**. Sometimes the dissection can essentially “unzipper” the entire aorta down into the abdomen or even into some of the branch vessels off of the aorta.

Sometimes a dissection starts in the descending aorta (called a **Type B dissection**). With a type B dissection, often there is not an aneurysm beforehand in the descending aorta. Surgery is not always indicated in a type B dissection, it depends on if blood is getting to all the correct organs (kidney, colon, etc) through the two tunnels or lumens, if there was actually a rupture, or if there is large dilation of the lumens, indicating that a rupture could happen.

Aneurysms or dissections may occur in arteries as well, most often when someone has specific genetic predispositions to aortic or arterial weakness. Thus, seeing a genetics professional for genetic testing can help determine risk, and guide imaging protocols to look at the aorta and arteries over time.

SURGERIES:

For thoracic aortic aneurysms, the aneurysmal or dissected area is cut out and replaced by a dacron graft. The aortic valve is the valve that allows blood to leave the heart and go into the aorta. Sometimes if there is damage to the aortic valve due to stretching from the aneurysm or due to tiny holes or fenestrations in it, the valve may have to be replaced by a mechanical, cadaver or other tissue valve. If the valve is left intact, this is referred to as a valve-sparing aortic root replacement. If you replace the valve this is a valve-replacement surgery.

For other parts of the aorta, either dacron grafts or stent material may be used.

For repair of arteries, graft can be used. But other technologies, such as putting in coils or clipping off an outpouching aneurysm, may also be indicated.



3

Overview of Mental Health Conditions

Overview of Mental Health Conditions

A mental health (MH) condition is a condition that affects a person's thinking, feeling, behavior or mood. Mental health conditions can impact your daily living and your ability to relate to others. MANY people experience these conditions, so please know that if you are experiencing any sort of MH challenges, you are NOT alone.

Though very common, MH conditions are often hidden. Some people don't like to talk about having mental health challenges – or they may feel afraid and uncertain about what they're experiencing. MH conditions can impact anyone, at any age, of any racial or ethnic background, and any socio-economic status. Awareness and dialogue are essential! So, let's talk about mental health...

A MH condition isn't typically the result of one event. Many factors can contribute:

- Genetics: MH conditions can run in families
- Life circumstances: changes in relationship status, housing changes, financial hardship,

being diagnosed with or living with a chronic condition

- Early life trauma: traumatic events early in life can change how someone responds to stress and fear
- Lifestyle: drug and/or alcohol abuse can put people at different risks for MH concerns
- Brain: biochemical processes and brain "wiring" also play a role
- Physiological effects: a medical condition may have effects on the body that can contribute to MH symptoms

Everyone experiences stress in their lives and it is a normal response to everyday pressures; it is usually short-term. The reality is that sadness, fear, and anger are normal, healthy and adaptive responses to both large and small problems in our lives. Chronic or long-term stress seems never-ending and can negatively impact your health. Examples are working in a toxic environment every day or fighting with your spouse constantly.

Some Numbers¹

1 IN 5
U.S. ADULTS
experience MH
concerns each year

1 IN 20
U.S. ADULTS
experience serious MH
concerns each year

1 IN 6 U.S. YOUTH
AGED 6-17
experience a MH
condition each year

¹Substance Abuse and Mental Health Services Administration. (2021). Key substance use and mental health indicators in the United States: Results from the 2020 National Survey on Drug Use and Health (HHS Publication No. PEP21-07-01-003, NSDUH Series H-56). Rockville, MD: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration. Retrieved from <https://www.samhsa.gov/data/>

None of this means that you're broken, damaged, or that you or your family did something "wrong." Having challenges with your MH is not your fault. For most people, recognition, support and treatment of MH challenges can get you over rough patches in your life and get you back to meaningful relationships and a good quality of life.

A few important points in regards to AD and mental health:

- Having a strong emotional response when faced with a new diagnosis or event is normal. For some people, this big emotional response is visible and obvious. However, to others, it may be perceived like a lack of emotion, or essentially an emotional withdrawal or shutdown. These are both normal coping strategies to difficult situations.
- To live with AD is to live with chronic illness uncertainty. Illness uncertainty disrupts our perception of control; one way of coping is to reclaim control to the extent we are able. We may not be able to control the unpredictability of our symptoms, but we can control the strategies with which we meet those symptoms. Having a plan in place that works to maximize health and cope with potential complications can go a long way toward providing greater certainty.

MH conditions can include diagnoses like anxiety or depression, but can also include ADHD (Attention Deficit Hyperactivity Disorder), eating disorders, bipolar or OCD (Obsessive Compulsive

Disorder), schizophrenia and others. All of these should be discussed with your primary care physician and treated very seriously.

In our aortic disease (AD) community, there are lots of specific factors to consider, like living with the risk of sudden death, experiencing an emergency dissection (tear of the aorta), preparing for and healing from a major surgery, uncertainty about the future, and being in community with others who you care for but are also at risk of sudden events or poor outcomes. Each one of these things alone can be a large emotional burden to carry. Then you start adding all the pressure, worry and uncertainty – layer upon layer – and it can be overwhelming.

The first thing we have to say is, "YES, this is a lot." And the burden may change from day to day. So, we want to validate those emotions that even though you may feel like everything "should" be fine, sometimes we just are not okay. Sometimes we are overtly NOT okay, and sometimes, we appear okay and then something triggers us – that flip of the switch that leads to an over-the-top emotional reaction.

Our brains are complex. Our emotions are complex. Our actions, reactions, perceptions are definitely complex. Especially after the 2020 pandemic, talking about mental health challenges has hopefully become a little easier and a little less-stigmatizing. But it is still hard. And, sometimes even harder still to access the care providers and support tools we need to get to a healthier place mentally. You may "look healthy" and have a "great life" and, and, and... But, each of us has a lifetime of experiences, relationships, expectations and pressures that we have to manage. So, please rest assured, EVERY SINGLE PERSON struggles with mental health challenges at some point in their life.

What MH challenges are we (mostly) talking about?

Anxiety

Everyone experiences anxiety, whether you have to give a big speech or are driving on a busy highway in a new city. But, when feelings of intense fear and distress become overwhelming and impact our daily living, an anxiety disorder may be the cause. Anxiety disorders are the most common MH concern in the United States, affecting nearly 30% of adults at some point in their lives. (APA; [psychiatry.org](https://www.psychiatry.org))

Common anxiety signs and symptoms include:

- Feeling nervous, restless or tense
- Irritability
- A disproportionate or inappropriate reaction to a mild stressor
- Having a sense of impending danger, panic or doom
- Having an increased heart rate
- Breathing rapidly (hyperventilation)
- Sweating or trembling
- Feeling weak or tired
- Trouble concentrating or thinking about anything other than the present worry; difficulty making decisions
- Having trouble sleeping
- Experiencing gastrointestinal (GI) problems
- Having difficulty controlling worry; racing thoughts
- Having the urge to avoid things that trigger anxiety



In some cases, people can experience a panic attack, which is a sudden surge of overwhelming fear that usually comes without warning and without any obvious physical reason. Physical symptoms can include: racing heartbeat, difficulty breathing or chest pain, lightheadedness and/or sweating. Panic attacks can even happen while you are asleep.

Many people experience occasional panic attacks. However, these episodes can be especially scary for people with heart disease. A panic attack is not dangerous, but it can be frightening because it comes out of nowhere and makes you feel “crazy” or “out of control.” Repeated panic attacks and/or continued fear of having more can be characterized as a panic disorder.

ANXIETY

Anxiety is an emotion characterized by feelings of tension, worried thoughts and physical changes like increased blood pressure. People with anxiety disorders usually have recurring intrusive thoughts or concerns. They may avoid certain situations out of worry. They may also have physical symptoms such as sweating, trembling, dizziness or a rapid heartbeat.

Adapted from the Encyclopedia of Psychology

Application to AD:

- Anxiety over upcoming aortic surgery
- Anxiety over what new scans will show and the need for further intervention
- Anxiety over how this impacts job, family, etc.
- Anxiety that every chest pain or different heartbeat will be a major event
- Fear of making your condition worse
- Fear of exertion
- AD symptoms trigger anxiety symptoms; anxiety symptoms feel like AD symptoms which increases anxiety symptoms resulting in a vicious mind-body cycle

Depression

Clinical depression is more than just feeling sad or going through a rough patch. Symptoms can vary from person to person, but for most individuals with depression, the persistent feeling of sadness and loss of interest changes how they are able to function daily over a long period of time (> 2 weeks). You just can't "snap out of it." Common symptoms include:

- Changes in sleep
- Changes in appetite
- Lack of concentration
- Loss of energy
- Lack of interest in activities
- Hopelessness or guilty thoughts
- Changes in movement (less activity or agitation)
- Physical aches and pains
- Suicidal thoughts or thoughts about death in general

DEPRESSION

Depression causes feelings of sadness and/or a loss of interest in activities you once enjoyed. It can lead to a variety of emotional and physical problems and can decrease your ability to function at work and at home.

- American Psychiatric Association

Some will only experience one depressive episode in a lifetime, but for many, depressive disorder recurs. Without treatment, episodes may last a few months to several years. Depression affects an estimated one in 15 adults (6.7%) in any given year. And one in six people (16.6%) will experience depression at some time in their life. (APA; [psychiatry.org](https://www.psychiatry.org))

Application to AD:

- Depressed that you can't exercise like you used to. As well, changes in physical activity can result in a depressed mood
- Depressed that you perceive yourself to be a burden to your family members
- Depressed because you feel like your future is very uncertain
- Depression over exposure to grief and loss after a stressful event (like surgery or dissection)

Post-traumatic stress disorder

Traumatic events – such as a natural disaster, war/combat, assault or serious accident – can have lasting effects on a person’s mental health. While many people will have short term responses to life-threatening events, some will develop longer term symptoms that can lead to a diagnosis of Post-traumatic Stress Disorder (PTSD). PTSD often coexists with anxiety, depression and substance abuse/misuse.

PTSD affects approximately 3.5% of U.S. adults every year, and an estimated one in 11 people will be diagnosed with PTSD in their lifetime. Women are twice as likely as men to have PTSD. U.S. Latinos, African Americans, and American Indians have been reported to be disproportionately affected and have higher rates of PTSD than non-Latino whites. (APA; [psychiatry.org](https://www.psychiatry.org))

PTSD

Post-traumatic stress disorder (PTSD) is a psychiatric disorder that may occur in people who have experienced or witnessed a traumatic event such as a natural disaster, a serious accident, a terrorist act, war/combat, or rape or who have been threatened with death, sexual violence or serious injury.

- American Psychiatric Association

Symptoms generally fall into these broad responses:

- Re-experiencing type symptoms, such as recurring, involuntary and intrusive distressing memories, which can include flashbacks of the trauma, bad dreams and intrusive thoughts.
- Avoidance, which can include staying away from certain places or objects that are reminders of the traumatic event. A person might actively avoid a place or person that

might activate overwhelming symptoms (like a hospital).

- Cognitive and mood symptoms, which can include trouble recalling the event, negative thoughts about one’s self. A person may also feel numb, guilty, worried or depressed and have difficulty remembering the traumatic event.
- Arousal symptoms, such as hyper-vigilance. Examples might include being intensely startled by stimuli that resembles the trauma, trouble sleeping or outbursts of anger.

Symptoms of PTSD usually begin within three months after experiencing or being exposed to a traumatic event. Occasionally, symptoms may emerge years afterward. For a diagnosis of PTSD, symptoms must last more than one month.

Medical trauma or medical PTSD

Medical trauma refers to a patient’s mental and physical response to a negative or traumatic experience in a medical setting. The experience may involve illness, injury, pain, invasive or frightening procedures, and/or distressing or dismissive medical treatment. Medical PTSD refers to symptoms that meet the criteria for post-traumatic stress disorder (PTSD) originating from trauma in a medical setting.

Both PTSD and medical PTSD can lead to anxiety, depression and chronic pain. There is a lot of overlap, and using one term or the other to describe yourself doesn’t mean your experience was any “easier” or “harder” than anyone else’s. As well, the experience of trauma is subjective, meaning that if you experienced an event as traumatic, then you’ve experienced trauma. This also makes trauma – particularly medical trauma – complex. When you’re trying to heal, your care approach is going to look vastly different from someone else because you’ll have different reactions, experiences, and triggers.

Vicarious trauma:

For many people with AD, there may be a family history of similar events, or exposure to other people with similar stories through support groups. Being in community with others with AD predisposition can be very powerful in a positive way, but also can result in vicarious trauma.

Vicarious trauma is an ongoing process of change over time that results from witnessing or hearing about other people's pain and suffering. It may feel overwhelming to hear about an intense trauma occurring to someone you have met or may have even built a deep relationship with. Listening to traumatic stories can also trigger memories of your own previous traumas or future worries. Vicarious trauma is similar to direct trauma. It carries many of the same symptoms and can be treated in many of the same ways.

Trauma Triggers:

A trigger is a person, place, feeling or thing that immediately induces a stress-based physical or emotional response based on a past traumatic experience. Triggers can be internally generated by feelings of stress, anger or sadness, or have causes rooted in the external environment. The trigger itself does not have to be frightening or traumatic, but can be an "everyday" exposure.

Triggers can also be very specific and personal to an individual. It may be a sound, smell, place, people, thought, or event. The process of connecting a traumatic experience to a trauma trigger is called traumatic coupling. When a trauma is triggered, our body responds.²

One theory about our stress response is the fight, flight or flee response to stress (see infographic). A second theory is the tend and befriend response, that says when threatened or stressed, humans typically affiliate with one another instead of attacking each other. This is particularly true for females. When social interactions are comforting, stress levels decrease. So, when there's a stressor, people will instinctively seek out support from others.

It can be very difficult to interpret or understand why you are having such an exaggerated or physical response to a trigger, and harder to "decouple" our body's response to a trigger. But, that's where therapy and other strategies can help.

Application to AD:

- Returning to a hospital, doctor's office or getting a scan may be triggering or traumatic.
- "Anniversary dates" of an aortic event can reactivate thoughts and feelings from the actual event; these times may impact peaks of anxiety and depression.
- Hearing someone else's personal story about aortic disease may be triggering or traumatic, especially if that person is of a similar age or is very relatable.
- Some personal responses from the community include: hearing/seeing helicopters, ambulances, or beeping, smelling rubbing alcohol. Anecdotally, many report that too many sounds all at once (like hearing too many people speaking) can also be triggering.

² <https://www.nicabm.com/how-the-nervous-system-responds-to-trauma/>

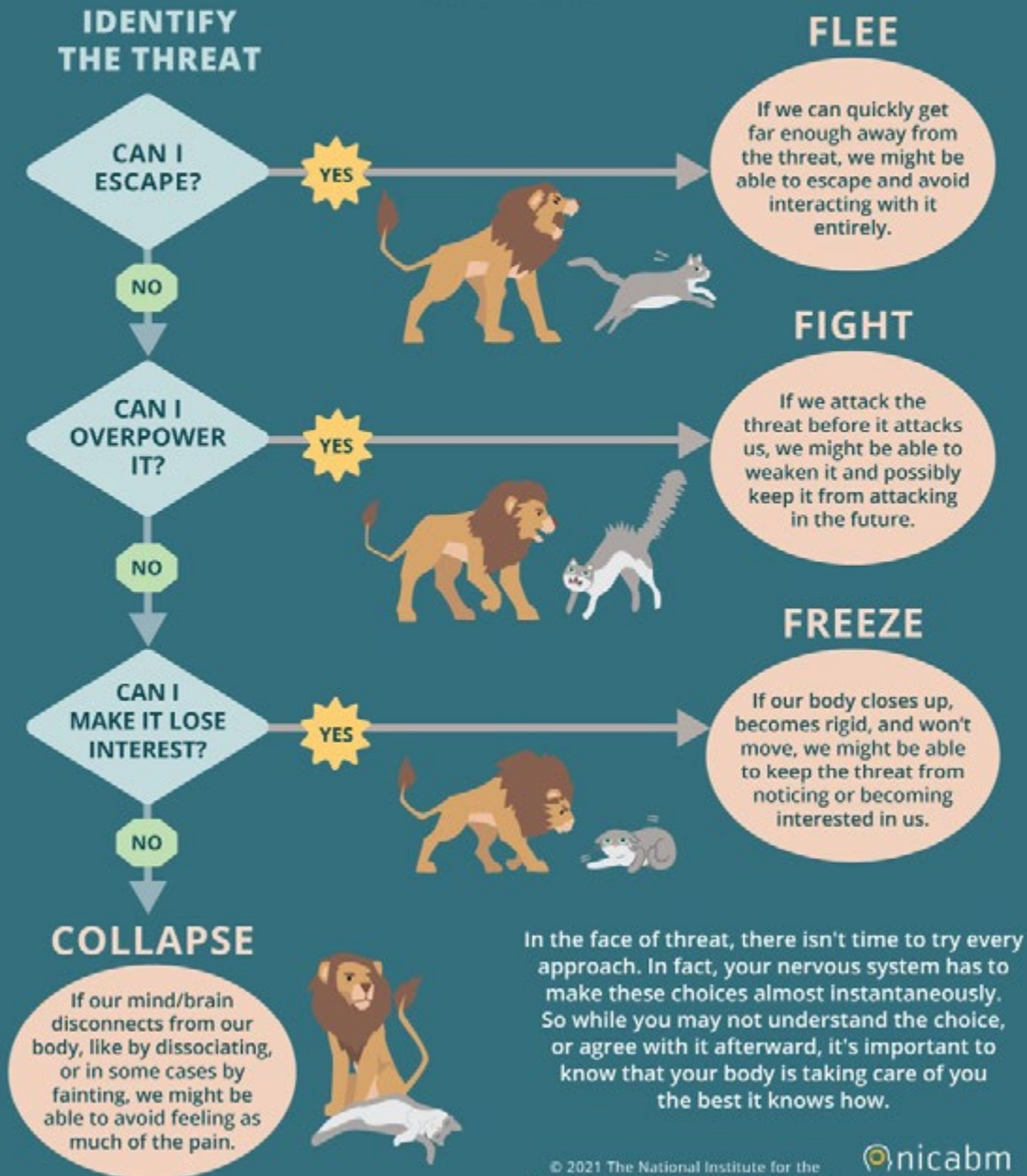
³ Alonzo AA, The experience of chronic illness and post-traumatic stress disorder: the consequences of cumulative adversity, Social Science & Medicine, Volume 50, Issue 10, 2000.

⁴ Ryder, A.L., Azcarate, P.M. & Cohen, B.E. PTSD and Physical Health. Curr Psychiatry Rep 20, 116 (2018). <https://doi.org/10.1007/s11920-018-0977-9>

HOW THE NERVOUS SYSTEM RESPONDS TO TRAUMA

Adapted from Ruth Lanius, MD, PhD

How does your nervous system figure out how to respond in a crisis?
It's a split-second, unconscious process designed to choose the best option for keeping you safe.
Here's how it works:



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 www.nicabm.com

Chronic illness and trauma:

Although an aortic surgery or dissection is a traumatic medical event, there is also literature to suggest a link between chronic illness and medical trauma.¹

Additionally, recent studies have demonstrated a clear link between PTSD and a greater burden of ongoing physical health symptoms and illnesses including cardiovascular, dermatological, gastrointestinal, genitourinary, musculoskeletal, neurological, and pulmonary concerns.

Application to AD:

Many patients with untreated mental health issues related to aortic disease can experience vague or unknown fatigue, GI distress or headaches that may not be medically or biochemically related to their aortic disease predisposition, but related to the chronic stress they feel because of the condition.

Substance abuse/misuse/addiction

Drug or medication (hereafter called substance) misuse, abuse, and addiction are all serious public health challenges. Since all of these deal with the use of illegal substances and inappropriate use of legal substances (e.g., tobacco, alcohol, prescription medication), a lot of people commonly use these terms interchangeably, but there are differences.

SUBSTANCE USE DISORDER

Substance use disorder (SUD) is a complex condition in which there is uncontrolled use of a substance despite harmful consequences. People with SUD have an intense focus on using a certain substance(s) such as alcohol, tobacco, or illicit drugs, to the point where the person's ability to function in day to day life becomes impaired. People keep using the substance even when they know it is causing or will cause problems. The most severe SUDs are sometimes called addictions. –*American Psychiatric Association*

What is substance misuse?

Substance misuse is generally associated with prescription medicines that are meant to be taken as directed by doctors. If taken differently, there can be adverse side effects. Substance misuse happens when these medications are taken for a purpose that is not consistent with legal or medical guidelines. Examples of this include:

- Taking the incorrect dose
- Taking the substance at the wrong time
- Forgetting to take a dose
- Stopping the use of a substance too soon
- Taking a substance for reasons other than why it was prescribed
- Taking a substance that was not prescribed to you

What is substance abuse?

Substance abuse happens when drugs, including alcohol, illicit drugs, or any psychoactive substances (alcohol, caffeine, nicotine, marijuana, and certain pain medicines) are misused to get high or inflict self-harm. It is also known as substance use disorder (SUD) since people who abuse substances experience significantly altered thinking, behavior, and body functions.

¹Alonzo AA, The experience of chronic illness and post-traumatic stress disorder: the consequences of cumulative adversity, *Social Science & Medicine*, Volume 50, Issue 10,2000



What is substance addiction?

Substance addiction is a brain disorder that manifests as the uncontrollable use of a substance despite its consequences. People with substance addiction have a physical and/or psychological need to take a substance because they suffer intense or debilitating withdrawal symptoms when they go without that substance.

Substance use disorder and mental health conditions are often closely related; one may cause the other, or they may occur at the same time. As well, both genetics and environmental factors (exposure to trauma for example) can impact the presence of mental health disorders and substance use disorders in a family.

There is more information about this in section 13.

Application to AD:

- Increasing use of alcohol or marijuana to help relieve the stress of an aortic event or to avoid dealing with the emotions triggered by an aortic event
- Continuing to solely rely upon pain medication to function instead of seeking a holistic approach to be able to decrease medication dosage

Insomnia

Insomnia is a common sleep disorder that can make it hard to fall asleep, hard to stay asleep, or cause you to wake up too early and not be able to get back to sleep. You may still feel tired when you wake up. Insomnia can zap not only your energy level and mood but also your health, cognitive ability and quality of life. It can be chronic or short-term.

Chronic insomnia is when a person experiences sleeping difficulties and related daytime symptoms, like fatigue and attention issues, at least three days per week for more than three months or repeatedly over years. It is estimated that about 10% of people have chronic insomnia disorder. It is believed that between 15% and 20% of adults experience short-term insomnia in any given year.⁴

Often, short-term insomnia can be traced to an external cause, such as a life stressor or major

INSOMNIA

Insomnia is defined as difficulty either falling or staying asleep that is accompanied by daytime impairments related to those sleep troubles.

—American Academy of Sleep Medicine



Good sleep hygiene tips:

Maintain the same bedtime and wake time every day, even on weekends

Reserve use of the bed for only sex and sleep

Get out of bed if falling asleep is taking too long or causing anxiety

Do not consume caffeine, alcohol, or nicotine, especially near bedtime

Maintain a healthy lifestyle with good exercise

Avoid napping

Keep the bedroom both dark and quiet

Refrain from watching television, computer, phone before bed

Do not check the clock to see how long it is taking to fall asleep

Avoid eating large meals too close to bedtime

Talk to doctor about supplementation (melatonin, etc)

illness. People who tend to be light sleepers are more likely to experience short-term insomnia than others. There are additional, more rare types of insomnia.

Many people experience occasional bouts of sleeping difficulties, but these are only categorized as insomnia when they cause a person distress and begin to negatively affect aspects of their life, like work or relationships.

Both short-term and chronic insomnia share certain symptoms. One aspect of those symptoms relates to nighttime sleep, when a person experiences at least one of these types of sleep issues:

- Trouble falling asleep
- Trouble staying asleep throughout the night
- Unwanted early morning waking
- Resisting sleeping at one's bedtime (for children and teens)
- Difficulty sleeping without a caregiver's help (for children and teens)

In addition, a person with insomnia will have at least one of several daytime symptoms related to their sleeping problems:

- Fatigue
- Impaired attention or memory
- Trouble with work, school, or social performance
- Irritability or disturbed mood
- Sleepiness
- Behavioral issues, like hyperactivity or aggressiveness
- Decreased motivation
- Increased accidents or mistakes
- Worries about or discontent with one's sleep

Application to AD:

- Let's be honest, what doesn't keep you awake worrying about your heart health? On top of all the other national and global issues, there is A LOT keeping our brains too busy at night! It can specifically include a fear of dying.
- Sidenote: some people with Marfan or Loeys-Dietz syndrome, or increased weight may experience sleep apnea (a common condition in which your breathing stops and restarts many times while you sleep). This may also result in waking up frequently and should be evaluated by a pulmonary physician.

A word on Post-traumatic growth

After a traumatic event like an aortic dissection or aortic surgery, many individuals not only show remarkable resilience, but actually thrive, a phenomenon called "post-traumatic growth" or PTG. It is defined as the positive psychological change that is experienced as a result of the struggle with highly challenging life circumstances.

PTG is different from resilience. Resiliency is the personal attribute or ability to bounce back. PTG refers to what can happen when someone who has difficulty bouncing back experiences a traumatic event that challenges his or her core beliefs, causing them to endure psychological struggle (even a mental health diagnosis such as post-traumatic stress disorder). But through this struggle, they are able to ultimately find a sense of personal growth.

POST-TRAUMATIC GROWTH

Post-Traumatic Growth is the positive psychological change that some individuals experience after a life crisis or traumatic event. Post-traumatic growth doesn't deny deep distress, but rather posits that adversity can unintentionally yield changes in understanding oneself, others, and the world. Post-traumatic growth can, in fact, co-exist with post-traumatic stress disorder. —*Psychology Today*

To evaluate whether and to what extent someone has achieved growth after a trauma, psychologists use a variety of self-report scales. One that was developed by Tedeschi and Calhoun is the Post-Traumatic Growth Inventory (PTGI) (Journal of Traumatic Stress, 1996). It looks for positive responses in five areas:

- Personal strength
- Relationships with others
- Appreciation of life
- New possibilities in life
- Spiritual change

Essentially, after experiencing the event and emotionally processing all the good, the bad, and the ugly thoughts, PTG involves coming to a place where you can acknowledge the event and its

difficulties, but can also embrace how it may bring a positive aspect to your view of yourself, your relationships, your world and/or your faith.

Application to AD:

- After AD, some people who work excessively may realize the importance of better balance and more quality family time
- Some people may feel compelled to volunteer or financially give to support groups or their hospital out of gratitude and the need to “pay it back” or “pay it forward”
- An AD may cause some people to turn inwards or upwards and develop a stronger sense of identity, purpose, or spiritual calling

Five Domains of Post-Traumatic Growth

Personal strength

- Stronger for the experience
- Better able to handle hardship
- More wisdom and maturity

Relationships with others

- Stronger family and social ties
- Sense of belonging

Appreciation for life

- Greater gratitude, hope, leadership, love, spirituality, and teamwork

New possibilities in life

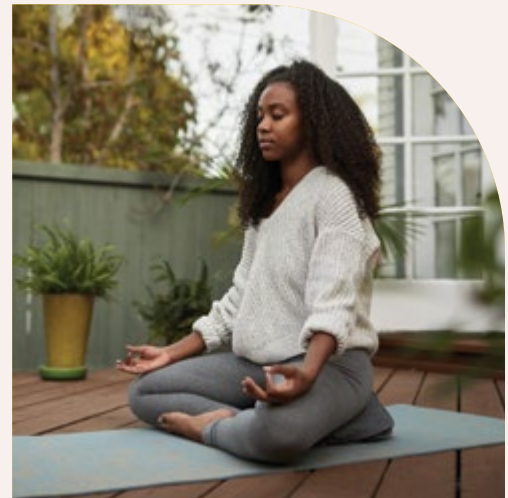
- Reprioritize values and time commitments
- Accomplish goals that would have been delayed

Spiritual change

- Readjust spiritual beliefs to encompass trauma or revise spiritual beliefs altogether

4

Mental Health, Aortic Disease, and the Literature



Overall, studies show between a 20-30% risk of anxiety, depression or PTSD in patients impacted by aortic aneurysm or dissection

4

What does the medical literature say about mental health and aortic dissection?

Aortic dissections (AD) affect roughly 4-5 per 100,000 individuals within the United States (6). While considered uncommon, these traumatic events can have as high as a 50% mortality risk. They may require extensive surgical procedures, complex recoveries, and in some cases the possibility of further surgery and screening.¹ Individuals may have an acute event requiring emergency surgery and, for some an aneurysm or dissection becomes a chronic problem,

with routine surveillance through imaging recommended, knowing that a surgery is looming in the future. Additionally, some patients' vascular disease is related to an underlying genetic disorder, impacting a lot of different health aspects. While each patient experience is different, patients and their families may be left with lasting emotional distress or trauma that may take the form of anxiety, depression, or post-traumatic stress disorder (PTSD).

The Aortic Dissection Collaborative, formed in 2019, compiled a literature review of studies that specifically focused on mental health topics related to a diagnosis of aortic disease (either aneurysm or dissection). Nineteen articles were identified to meet the criteria, and large topic matters suggest that patients and families dealing with aortic dissection (AD) saw impacts in mental health, physical abilities, relationship and family life, and financial burden.¹ In another study directly surveying patients, a theme that emerged was patients dealing with mental health issues not addressed by their care team, but directly correlated to their aortic event. This included fear of uncertainty and death, and the struggle of feeling isolated while dealing with undiagnosed anxiety and/or depression.²

Another diagnosis identified is Post-traumatic stress disorder (PTSD). While this has not been studied in depth, a large cohort study on 295 adult survivors of a surgical dissection found that 1 in every 5 patients screened positive for PTSD based on the questions asked by the survey, but very few had undergone assessment or treatment.³



This is such an important topic impacting patients, but not a lot of research OR practical tools addressing mental health in those affected by aortic aneurysm or dissection. Thus, the goal of this project was to take this topic from “needs more attention” to creating a tangible resource that gives patients information on a myriad of mental health topics all related to aortic dissection in order to provide support moving forward.

– GRETCHEN MACCARRICK

¹ Ilonzo N, Taubenfeld E, Yousif MD, Henoud C, Howitt J, Wohlaer M, D’Oria M, MacCarrick G; Aortic Dissection Collaborative. The mental health impact of aortic dissection. *Semin Vasc Surg.* 2022 Mar;35(1):88-99.

² Meinschmidt G, Berdajs D, Moser-Starck R, Frick A, Gross S, Schurr U, Eckstein FS, Hunziker S, Schaefer R. Perceived Need for Psychosocial Support After Aortic Dissection: Cross-Sectional Survey. *J Particip Med.* 2020 Jul 6;12(3):e15447.

³ Pasadyn SR, Roselli EE, Artis AS, Pasadyn CL, Phelan D, Hurley K, Desai MY, Blackstone EH. From Tear to Fear: Posttraumatic Stress Disorder in Patients With Acute Type A Aortic Dissection. *J Am Heart Assoc.* 2020 May 5;9(9):e015060. doi: 10.1161/JAHA.119.015060. Epub 2020 Apr 28. PMID: 32340520; PMCID: PMC7428551.

5

Grief and Loss in Aortic Dissection

Grief, loss and aortic dissection

You may be picking up this booklet after just getting a diagnosis of an aneurysm or just having experienced an aortic dissection. You may be twenty or thirty years into this diagnosis. Everyone's story and way of coping and reacting to "the diagnosis" may be very different, but what is similar is that somewhere along your path, you will likely experience feelings of grief, isolation and lack of control.

For many people, when it comes to getting yearly scans, or around anniversaries of the aortic dissection or surgery, your emotions can be on high alert. And, let's face it, whereas some people may expect you to "get over it," the complexity of grief and loss means our emotional responses and the stages of grief are often unpredictable.

Although some professionals may suggest that the stages of grief are experienced in a nice and orderly way, the reality is more...messy.

The stages of grief and loss can vary widely, including how long they last. Some stages can last longer than others, and there's no set length of time for grief in general. The stages don't occur in the same order or at the same time for everyone. You can experience the stages in any order, repeat stages, and even experience multiple stages at the same time.

Grief is deeply personal, so it's impossible to predict how long the stages of grief and loss will take. However, there is a way to tell if your grief is healthy. While grief always involves a number of intense emotions, you should eventually begin to feel like you're working through them and making progress.

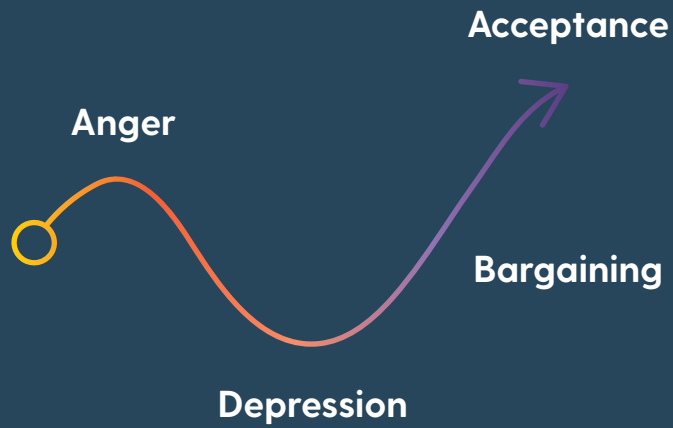
What are areas of grief and loss in aortic disease?

People usually associate grief and loss when someone in their life passes away, which is certainly true. And, if there is a family history of aortic disease or you are involved in aortic disease support networks, this can be an added layer of grief. But, there is also grief in getting a diagnosis and/or having an event. The future of your personal health and all that implies for you and your family may be altered or have to be re-framed.

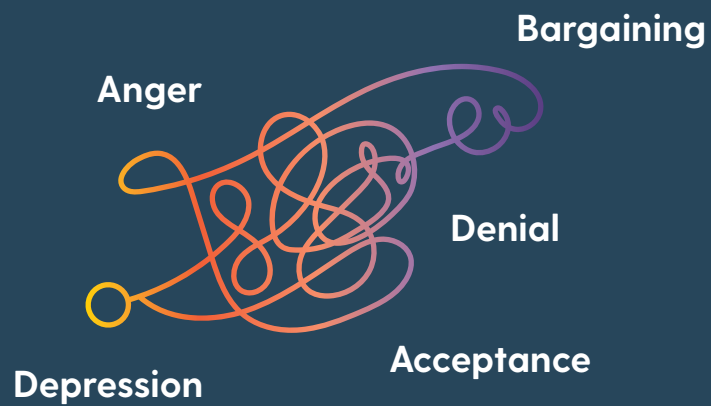
Some examples of loss, grief or uncertainty in aortic disease patients:

1. Your reality or perception of being a "healthy" person and the future that implied
2. The perception that others may see you as fragile or a burden
3. How this diagnosis impacts your social network interactions and time
4. Family planning: Not only what is your potential risk with a pregnancy, but also having to make hard decisions about having children and to what degree you may employ testing in embryos or in a pregnancy.
5. Family members: Are they at risk? Did you pass this onto your children?
6. Potential loss of identity through having to modify your free-time sports and activities
7. Potential loss or significant changes to current or future profession if it is physically unsafe for you

The experience you expected:



The experience you got:





As care providers, we often tell patients that it is our job to keep you healthy until old age; your job is to make sure you have a life that is worth living.

8. Worry about jobs or potentially leaving a job in relation to its insurance options and coverage
9. Potential loss of finances or perception of becoming a financial burden
10. Missing life events due to physician visits, surgeries or hospitalizations
11. How the diagnosis may be impacting your sexual relationships
12. Orientation of your diagnosis into your faith beliefs
13. Having to deal with questions of death and mortality

This is just a smattering of potential issues or questions that may impact a family dealing with aortic disease. While everyone experiences grief differently, if you ever feel like you're stuck and are unable to move forward, it may be time to seek help.

But, we want to end on a high note. In all of this, there will be people (physicians, family, friends, support networks) who can provide great support by sometimes just showing up and being there for you. You will find out new aspects about your character, perseverance, humor and resilience. You will experience love and support in ways you never would have dreamed. There will be challenges, but there will also be tremendous growth and revelation.

6

All Things Therapy

All Things Therapy

What is therapy?

Therapy or psychotherapy (also called talk therapy or usually just “therapy”) is a form of treatment aimed at relieving emotional distress and mental health challenges. It is provided by a variety of trained professionals (psychiatrists, psychologists, social workers, or licensed counselors), and involves examining and gaining insight into life choices and difficulties faced by individuals, couples, or families.

Therapy sessions refer to structured meetings between a licensed provider and a patient with a goal of improving some aspect of the patient’s life. Talking with a therapist or counselor can help you deal with thoughts, feelings, behaviors, symptoms, stresses, goals, past experiences and other areas that can promote your recovery. It encompasses many types of treatment and is practiced by a range of clinicians using a variety of strategies. The critical aspect is that the patient works collaboratively with the therapist and can identify improvement and positive change over time. It is a time and cost investment, but the benefits can be life-changing (or at least life-improving).

It is very normal to feel nervous about starting therapy, and talking with a therapist about personal issues can be tough. But, it can help you come to new insight into problems in your life, emotional adjustment, and a sense of being heard and supported.

Some benefits of therapy can include:

- Feeling stronger in the face of challenges
- Changing behaviors that hold you back

- Looking at ways of thinking that affect how you feel
- Healing pains from the past
- Building relationship skills
- Figuring out your goals
- Strengthening your self-confidence
- Handling strong emotions like fear, grief or anger

How do I know whether therapy could help me?

If you feel depressed, overwhelmed by daily life, or unable to connect with the people around you, it’s very likely that a therapist will be able to help. Other signs that you could benefit from therapy include the realization that you’ve been overreacting to small setbacks or triggers, or a feeling of being “stuck” or mentally fatigued.

Finding a therapist

Finding a therapist can seem daunting, especially for those of low-income or without comprehensive insurance. Researchers have found that the bond between you and your therapist is likely to have a big impact on your growth. That’s why it’s important to do your research, ask questions, and pay attention to your own responses in your search for the therapist that’s right for you.

As you contact potential therapists, keep a few things in mind:

- What issues do you want to address? These can be specific or vague.



- Are there any specific traits you'd like in a therapist? For example, are you more comfortable with someone who shares your gender?
- How much can you realistically afford to spend per session? Do you want someone who offers sliding-scale prices or payment plans?
- Where will therapy fit into your schedule? Do you need a therapist who can see you on a specific day of the week? Or someone who has nighttime sessions?
- Do they offer online sessions?



Therapy and Counseling accreditations:

LPC or LPCC (Licensed Professional Counselor or Clinical Counselor): Counseling and formal diagnostics assessment

LSW or LCSW (Licensed Social Worker or Licensed Clinical Social Worker): Counseling and trained in community mental health issues

LMFT (Licensed Marriage and Family Therapist): Primarily focused on counseling and psychotherapy for individuals, couples, families and groups

LP (Licensed Psychologist): Counseling and able to provide psychological testing, assessment and official diagnosis

Health Psychologist: A subfield of psychology that explores how biological, psychological, and social factors affect health

Psychiatrist: Able to diagnose and prescribe medication but might not provide counseling

PMHNP (Psychiatric and Mental Health Nurse Practitioner): Able to diagnose and prescribe medication but might not provide counseling

Remember, you will spend a lot of time with this professional, so it is important that you like and trust them, feel a mutual sense of respect, and enter into a therapeutic alliance with them. “Therapeutic alliance or relationship” basically means that there is mutual engagement on both of your parts doing the work of therapy to effect beneficial change for the patient. It’s the “bond” that develops in the therapy room. There has to be a lot of trust in that room to feel safe, to be honest and open, to resist the urge to impress or please the professional at the expense of showing vulnerability, and to experience genuine growth.

In this, however, YOU have responsibility as well.

Don’t be afraid to ask questions of your therapist; it is a major investment for both/all of you and you want to try and find a good match. It’s ideal to find a therapist with the skills and experience to take on your biggest specific needs. It is not always easy, but in the long run it is worth the investment to not let the trap of proximity, cost or insurance coverage dictate your choice of a therapist.

Choose Mental Health has compiled a list of 40 common interview questions that you can ask a potential therapist to help gauge compatibility. These questions are broken down into separate categories and, while you don’t have to ask EVERY question, they are a good starting point for interviewing and getting to know a new or potential therapist.¹

To find a therapist:

If you plan to pay for therapy through your insurance plan, your first step might be to look through your plan’s provider network.

Ask someone you trust. A referral from a friend, colleague, or doctor you trust is another way to find a therapist who might be a good fit for you. But, it’s important to recognize that you may have different needs and goals with your therapy than the person giving you the recommendation. A good match for someone you trust may not be a good match for you.

A number of mental health organizations maintain up-to-date, searchable databases of licensed therapists. Your search could start as simply as typing in your ZIP code to generate a list of counselors in your area. You may also be able to search for specialty care, like marriage and family counselors or therapists who focus on trauma.

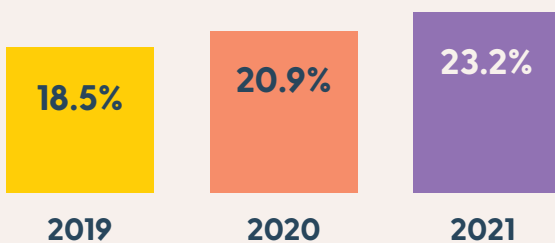
Some of the most commonly used online search tools include:

- American Psychological Association (<https://locator.apa.org/>)
- [Enter your state] Psychological Association in Google
- American Association of Marriage and Family Therapists (<https://www.AAMFT.org>)
- Association of LGBTQ+ Psychiatrists (<https://aglp.memberclicks.net/aglp-referral>)
- Psychology Today: Find a therapist (<https://www.psychologytoday.com/us>)

¹<https://choosementalhealth.org/finding-a-local-therapist/>



How common is it to see a therapist? In general, it is common, however, we don't have any really good data about how many people impacted by aortic disease access mental health services.



Mental Health Treatments Among Adults: United States, 2019 - 2021

Adults ages 18–44 receiving mental health treatment in the past 12 months increased from 2019 to 2021

Source: National Center for Health Statistics, National Health Interview Survey, 2019–2021. For more information, visit www.cdc.gov/nchs/products/databriefs/db444.html.

Types of Therapy

Group therapy: Involves one or more psychologists who lead a group of roughly 5-15 patients. Some people attend individual therapy in addition to groups, while others participate in groups only. Group leaders should be familiar with the clinical condition and the special problems faced by patients with that illness. The therapist should have understanding of core group therapy processes and group therapy leadership skills to ensure the group format is effective. Group therapy can be harder to find and coordinate due to multiple schedules to accommodate. You can find a certified group therapist through a search engine at the American Group Psychotherapy Association (<https://agpa.org/>).

You can also check out sesh groups: <https://www.seshgroups.com/> for virtual group mental health support.

Marriage or Couples therapy: both members of the couple are seen together to help couples understand and resolve conflicts to improve their relationship. It's intended to give couples the tools to communicate with more compassion and less fear while learning how to problem-solve and deal with conflict in a healthy manner.

Family therapy: involves all/multiple members of the family to help develop and maintain healthy boundaries, facilitate cohesion and communication and promote problem-solving by a better understanding of family dynamics.



I'm nervous about starting therapy. Is that normal?

Yes! The decision to start therapy is usually not made lightly, and the prospect of sharing your innermost thoughts and feelings with a stranger can cause doubt, anxiety, or fear. Typically, pre-session anxiety will decrease as you get to know your therapist, see how the process works, and start to see results as the weeks go by. If you continue to feel anxious about therapy even several sessions in, discuss the feelings directly with your therapist.

Therapy and finances

If you have insurance, it is a good idea to find out whether your plan limits the number of sessions you can attend each year and whether using an out-of-network therapist will affect your out-of-pocket costs. Also, planning to have an HSA or FSA

(health or flexible savings account, usually through employer) to cover therapy costs may be a good option.

While some therapists charge a set fee per session, others offer a sliding scale based on the client's income. In many locations, low- or no-cost therapy is available for low-income clients, often through universities or other therapist training programs.

Many therapists don't accept insurance because the rate of reimbursement by insurance companies is so low the provider couldn't maintain a business practice. You can ask about sliding-scale options from the therapist, or also look into partial reimbursement from insurance by submitting receipts. You should understand the therapist's fee structure before setting up an appointment.

What type of therapy is right for me?

There are many types of therapy and figuring out which may be best for you often comes down to your needs, the therapeutic relationship, and the specialty of the provider.

A therapist usually draws on one or more theories of psychotherapy, which acts as a roadmap for the therapist.

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There are many types of therapy and figuring out which may be best for you often comes down to your needs, the therapeutic relationship, and the specialty of the provider.



Types of Therapy

You can check out [Psychology Today](#) for full explanations of many different types of therapy. Some therapies that may be most applicable to patients in our community include:

Acceptance and commitment therapy

An action-oriented approach to therapy that stems from traditional behavior therapy and cognitive behavioral therapy. Patients learn to stop avoiding, denying, and struggling with their inner emotions and, instead, accept that these deeper feelings are appropriate responses to certain situations that should not prevent them from moving forward in their lives. With this understanding, patients begin to accept their hardships and commit to making necessary changes in their behavior, regardless of what is going on in their lives and how they feel about it.

Cognitive behavior therapy

A short-term therapy based on the idea that the way someone thinks and feels affects the way he or she behaves. CBT aims to help patients resolve present-day challenges like depression or anxiety, relationship problems, anger issues, stress, or other common concerns that negatively affect mental health and quality of life. The goal of treatment is to help patients identify, challenge, and change maladaptive thought patterns in order to change their responses to difficult situations.

Cognitive processing therapy

A short-term therapy that helps the patient who has undergone significant trauma to evaluate his or her thoughts surrounding the trauma, particularly maladaptive or self-blaming thoughts that may be exacerbating PTSD symptoms, and conditions including anxiety and depression that exist after the experience. The patient will then learn to challenge those thoughts and take a new perspective when appropriate.

Emotion-focused

A short-term therapy that aims to improve couple relationships by improving the physical and emotional bond occurring in a distressed couple.

Family systems therapy

A form of therapy that helps individuals resolve their problems in the context of their family units, where many problems are likely to begin. Each family member works together with the others to better understand their group dynamic and how their individual actions affect each other and the family unit as a whole. One of the most important premises of family systems therapy is that what happens to one member of a family happens to everyone in the family.

Marriage (or marriage and family therapy)

This type of therapy focuses on communication, coping skills, constructive problem-solving, as well as ways to build trust and strengthen healthy relationships in a family system.

Strength-based therapy

A type of positive therapy that focuses on the individual's internal strengths and resourcefulness, rather than weaknesses, failures, and shortcomings. This focus sets up a positive mindset that helps the patient build on their best qualities, find strengths, improve resilience, and change their worldview to one that is more positive.

Trauma-focused CBT

A therapy that directly addresses the impact of traumatic events. Therapies are based on the theory that negative emotions connected to the memories of the traumatic event and how the person thinks about the trauma will lead to PTSD symptoms. Core features include education about normal reactions to trauma, coping skills and gradual exposure to memories with the goal or reconditioning their response to triggers.

An additional word on trauma therapy, specifically EMDR (Eye movement desensitization and reprocessing)

EMDR therapy is a mental health treatment technique that involves moving your eyes a specific way while you process traumatic memories. EMDR's goal is to help you heal from trauma or other distressing life experiences. Sometimes an experience is simply too large, painful, or shocking for a person to process by themselves. So, a therapist can help reprocess this experience with EMDR therapy. In three of the eight phases, known as the "reprocessing" phases, there is use of dual attention bilateral stimulation (BLS). Dual attention BLS activates the client's information processing system while keeping the client anchored in the present moment. It can be side to side eye movements, sounds, or taps that the patient follows physically while mentally focusing on and processing the trauma event.

More information can be found at <https://www.emdr.com/frequent-questions/>



Online Therapy Options

There are many options available to you. Private-practice, local therapists may also have online options and may be more established in their practice (i.e. may have more experience). The research hasn't yet shown that stand-alone therapy online or via texting is effective for everyone in every situation. As well, since information is being transmitted online, the situation makes privacy leaks and hacks more of a concern. Technology problems can also make it difficult to access treatment when you really need it. The point is, there are many options available to fit your needs. Find what works for you.

Company	Accept Insurance?	24/7 support?	Psychiatry/ medication support?	Text/ Video/ Phone
BetterHelp	No	Yes	No	TVP
TalkSpace	Yes	Yes	Yes	TVP
ReGain		Yes		
Wellnite	Yes	Yes	Yes	TVP
Amwell	Yes	Yes	Yes	TVP
Teladoc			Yes	TVP
Online-Therapy	No	No	No	TVP
TeenCounseling (13-19yo)	No	No	No	TVP
LiveHealth Online	Yes	Yes	Yes	VP
Cerebral	Yes	No	Yes	VP



Online Therapy Options, continued

Company	Accept Insurance?	24/7 support?	Psychiatry/ medication support?	Text/ Video/ Phone
MDLive	Yes	No	Yes	VP
ETherapyPro	No	No	No	TVP
Doctor On Demand	Yes	Yes	Yes	VP
Teladoc Health	Yes	Yes	Yes	TVP
Calmerriy	No	No	No	TVP
7 Cups	No	Yes	No	TVP
Pride Counseling (LGBTQ+)	No	Yes	No	TVP
Circles (group counseling)	No	Yes	No	TVP
Monument (alcohol addiction)	Yes	Yes	Yes	TVP
Faithful Counseling (Christian-based)	No	No	No	TVP
Ayana Therapy (BIPOC)	No		No	TVP

[https://www.healthline.com/health/our-top-10-online-therapy-picks#A-quick-look-at-the-10-best-therapy-services-of-2022:](https://www.healthline.com/health/our-top-10-online-therapy-picks#A-quick-look-at-the-10-best-therapy-services-of-2022)

<https://www.verywellmind.com/best-online-therapy-4691206>

<https://www.forbes.com/health/mind/best-online-therapy/>

<https://www.everydayhealth.com/emotional-health/best-online-therapy/>

<https://www.onlinetherapy.com/best-online-therapy/>

<https://www.forbes.com/health/mind/best-online-therapy/>

<https://www.everydayhealth.com/emotional-health/best-online-therapy/>

<https://www.onlinetherapy.com/best-online-therapy/>

7

Barriers and Disparities in Accessing Care

Barriers and Disparities in Accessing Care

We acknowledge that there are often barriers to finding mental health guidance and services, some of which are out of your control. But, we hope that with the information and resources provided in this booklet and some perseverance, you are able to find the help that you may need.

Some barriers include:

1. **Financial barriers:** Even with insurance, there can be expensive co-pays and deductibles, and many therapists may not take insurance. Be sure to ask about sliding scales or financial assistance. Some hospitals offer post-event cardiac groups that may be free or have reduced prices.
2. **Lack of mental health care professionals and services:** A main barrier is a lack of available services due to a combination of high demand for services and a low supply of trained professionals. It will likely take some dedicated time and effort to find a mental health treatment regimen that works for you. But, it is worth putting in the work to create a good care plan and team. Don't be afraid to ask your community (friends and families) for resources and services!
3. **Your medical providers don't address mental health issues and/or education.** Many physicians have limited time to address MH concerns in an appointment, so make sure to prioritize this topic if it is your main concern. Sometimes other staff in the office may have good advice or referrals.
4. **Social stigma of mental health treatment and conditions:** While "we" (society) have made great strides in decreasing negative attitudes or perceptions towards those who seek mental health guidance, some people still view getting help as weakness, or mental health challenges as a "defect." That is a result of ignorance and remains their problem, not yours. Being mentally and emotionally healthy is one of the most important gifts you can give to yourself and your friends and family.
5. **LGBTQ barriers to care:** Members of the LGBTQ community may also encounter bullying, stigma and prejudice based on their sexual orientation or gender identity. They may have actually encountered this from their medical providers. The Trevor Project's 2020 National Survey on LGBTQ Youth Mental Health queried more than 40,000 diverse 13-24 year olds and examined factors that may disproportionately impact the LGBTQ community, including discrimination, housing instability, barriers to affirming health care, subjection to conversion therapy, and suicide. The survey also highlights how safe spaces and social support positively impact the wellbeing of LGBTQ youth.

Source

Breaking Barriers To Quality Mental Health Care for LGBTQ youth (Trevor Project 2020 National survey); (<https://www.thetrevorproject.org/survey-2020/?section=Introduction>)

Some statistics:

- 54% LGBTQ youth reported wanting to get mental health services this past year but did not receive it.
- Statistically significant within-group differences were found with Black (62%), LatinX (62%) and Asian American (60%) youth reporting higher levels of NOT receiving care compared to White (53%), American Indian/Alaskan Native (53%) and multirace (55%) individuals.
- LGBTQ youth who lived in the South reported the highest levels of unmet mental health care needs (58% compared to youth in the Northeast who reported the lowest levels (47%).
- 68% of LGBTQ youth reported symptoms of generalized anxiety disorder in the past two weeks.



Reported barriers to MH care by LGBTQ community

In this survey, LGBTQ youth described universal barriers common to many people as well as barriers specific to their community:



6. **Racial and ethnic barriers to accessing treatment; accessing a “culturally competent” therapist.** In order to be a culturally competent counselor, a person must be open-minded and recognize that valuing and respecting cultural differences requires a commitment to life-long learning and being able to make sound ethical decisions within diverse cultural contexts.

Know that some of this advice comes from a place of privilege and that many people DON'T have the time, energy, money or other resources to access mental health services. Different ethnic groups also have different prejudices against those who need mental health services, and may also experience decreased access. Unfortunately, providers may also be less likely to bring up pain or mental health issues in a uniform way to all patients, regardless of race, age, sex or gender. There is no easy solution for this, but hopefully some of the websites mentioned can help overcome some obstacles.

- There are significant disparities in mental health care accessibility. A CDC survey (<https://www.cdc.gov/nchs/products/databriefs/db380.htm>) finds that White adults are most likely to find services.
- According to research from the American Psychological Association and the Bureau of Labor Statistics, 84% of psychologists, 67% of social workers, and 88% of mental health counselors are White.



Barriers can also include a lack of diverse representation in the mental health field, language barriers, and implicit (automatic and unintentional) bias. People are less likely to seek help if they think their doctor can't understand or empathize with their background or cultural differences and experiences. **There is inequality due to race in the United States. It's a fact.** Being treated or perceived as “less than” because of the color of your skin can be stressful and even traumatizing. As well, those impacted by socioeconomic disparities such as health, educational, social and economic resources may have more challenges in accessing quality care. And in addition, these disparities may contribute to worse mental health outcomes.



Studies have shown that mental health services can be more effective when a patient feels that their therapist values cultural diversity.

In recent years there has been an expanding number of digital companies and nonprofits created to help people of color find a therapist they can trust – someone who is not only skilled in the best evidence-based treatments, but also culturally competent. In other words, a provider who is aware of their own world views, knowledgeable about diversity and trained to connect with different types of clients. While racial matching can be helpful, the most important thing is finding someone who leads with empathy and understanding.

Some questions to ask yourself:

Did my provider communicate effectively with me?

Is my provider willing to integrate my beliefs, practices, identity and cultural background into my treatment plan?

Did I feel like I was treated with respect and dignity?

Do I feel like my provider understands and relates well with me?

References

- Psychology today”<https://www.psychologytoday.com/us/therapists/>
- <https://mhanational.org/racism-and-mental-health>
- <https://www.self.com/story/marginalized-mental-health-resources>



Race-Specific Resources

Talking about mental health challenges within some communities may yield unique challenges and perspectives. Consider these race-specific resources for more tailored approaches to discussing MH:

Black community:

Sharing Hope is a three-part video series that explores the journey of mental wellness in Black communities through dialogue, storytelling and a guided discussion on the following topics:

- Youth and Mental Wellness: “How Do You Heal?”
- Community Leaders and Mental Wellness: “The Art of Healing”
- Black Families and Mental Wellness: “Smiling On Our Journey”

<https://www.nami.org/Support-Education/Mental-Health-Education/NAMI-Sharing-Hope-Mental-Wellness-in-the-Black-Community> or (google NAMI and sharing hope)

Hispanic community:

Compartiendo Esperanza is a three-part video series that explores the journey of mental wellness in Hispanic/Latinx communities through dialogue, storytelling and a guided discussion on the following topics:

- Youth and Mental Wellness: “Sanando Juntos”/“Healing Together”
- Community Leaders and Mental Wellness: “Las Raíces de Nuestra Sanación”/“The Roots of Our Healing”
- Latinx Families and Mental Wellness: “La Mesa”/“The Table”
- <https://www.nami.org/Support-Education/Mental-Health-Education/NAMI-Compartiendo-Esperanza-Mental-Wellness-in-the-Latinx-Community>

A conversation facilitator in Spanish called The Breyers Conversaciones Vainilla Digital Toolkit is available at <https://shor.by/LatinxTherapy> to help encourage, inspire and facilitate meaningful conversations with your family and friends.

Communities with Other Linguistic Backgrounds:

<https://www.nami.org/Support-Education/NAMI-Programs/NAMI-Family-Friends>

(English, Arabic, Farsi, Korean, Mandarin, Spanish, Vietnamese)



Some online resources that are specific to race, ethnicity or LGBTQ status are:

Resource	Website
ASIAN	
Asian Mental Health Collective	https://www.asianmhc.org/
South Asian Therapists	https://southasiantherapists.org/
Asians Do therapy	https://asiansdotherapy.com/
BLACK	
Therapy for Black Girls	https://therapyforblackgirls.com/
Black Men Heal	https://blackmenheal.org/
Therapy for Black Men	https://therapyforblackmen.org/
Melanin and Mental Health (Black and LatinX)	https://www.melaninandmentalhealth.com/
Black Emotional and Mental Health (BEAM)	https://wellness.beam.community/

Resource	Website
Mental Health Liberation (POC including Indigenous)	https://mentalhealthliberation.org/
The Loveland Foundation (Black females)	https://thelovelandfoundation.org/
Black Female Therapists	https://www.blackfemaletherapists.com/directory/
Black Girls Smile	https://www.blackgirlssmile.org/
Soulace	https://www.soulaceapp.com/
Boris L Henson Foundation	https://borislhensonfoundation.org/
LATINX	
LatinX therapy	https://latinxtherapy.com/
Therapy for LatinX	https://www.therapyforlatinx.com/
LatinX Therapists Action Network	https://latinxtherapistsactionnetwork.org/



Online Therapy Options: online resources specific to race, ethnicity or LGBTQ status, continued

Resource	Website
LGBTQ	
National Queer and Trans Therapists of Color Network (NQTTCN)	https://nqttn.com/en/
Sarbat (Sikh)	https://www.sarbat.net/what-we-do
Call Blackline (Black Femme les)	https://www.callblackline.com/
DEQH (Desi/South Asians)	https://www.deqh.org/
Keshet (Jewish)	https://www.keshetonline.org/youth/
Muslims for Progressive Values	https://www.mpvusa.org/lgbtqi-resources
Queer Crescent (Muslims)	https://www.queercrescent.org/
Beloved Arise (Faith organization)	https://www.belovedarise.org/
Dignity USA (Catholic)	http://www.dignityusa.org

Resource

Website

Pride Institute

<https://pride-institute.com/>

Pride Counseling

<https://www.pridecounseling.com/>

PFLAG

<https://pflag.org/>

Qchatspace (teens, Spanish option)

<https://www.qchatspace.org/>

Beloved Arise (Faith organization)

<https://www.belovedarise.org/>

Dignity USA (Catholic)

<http://www.dignityusa.org>

MUSLIM OR ISLAM

Institute for Muslim Mental health

<https://muslimmentalhealth.com/>

Maristan

<https://maristan.org/resources>

NATIVE

WE R NATIVE

<https://www.wernative.org/>



Online Therapy Options: online resources specific to race, ethnicity or LGBTQ status, continued

Resource	Website
POC	
Innopsych	https://www.innopsych.com/
Ayana Therapy	https://www.ayanatherapy.com/
Hurdle	https://www.hurdle.health/
Open Path Psychotherapy Collective	https://openpathcollective.org/
Inclusive Therapists	https://www.inclusivetherapists.com/
A Therapist like Me	https://www.atherapistlikeme.org/
Clinicians of Color	https://www.cliniciansofcolor.org/
AAKOMA project (Youth)	https://aakomaproject.org/

8

Medications

Many people may benefit from medications to address their mental health challenges. This could be for a long or shorter term. It is nothing to feel worry or shame over – remember all those biological influences! For some, this is managed by your primary care physician and for others, a psychiatrist may be the prescriber. It is important to understand who is responsible for prescription refills and the time frame to refill, so you are able to take the appropriate medications continuously.



People respond to medications in different ways, and it may take several tries to find the medication that is most effective with the fewest side effects.

In some cases, people find that a medication helps for a while, and then their symptoms come back. On the other hand, it often takes some time for a medication to be effective, so it is important to stick with the treatment plan and take medication as prescribed. Additionally, some people may require more than one medication. Each person, their brain biology and their reactions are unique.

If you are prescribed a medication:

- Tell the health care provider about all other medications, vitamins, and supplements you are already taking
- Remind the health care provider about any allergies and any problems you have had with medications in the past
- Make sure you understand how to take the medication before you start using it, and take your medication as instructed
- Talk to the health care provider about possible side effects and what to expect when taking medication

- Don't take medications prescribed for another person or give your medication to someone else
- When starting or adjusting a medication, keep track of unusual mental, emotional or physical symptoms to talk to your provider about
- Call a health care provider right away if you have any problems with your medication or are worried that it might be doing more harm than good. The health care provider will work with you to address any problems and determine next steps.

People should not stop taking a prescribed medication, even if they are feeling better, without the help of a healthcare provider. A healthcare provider can adjust the treatment plan and slowly and safely decrease the medication dose. It's important to give the body time to adjust to the change. Stopping a medication too soon may cause unpleasant or harmful side effects.

Pregnancy

If you are thinking about getting pregnant or have become pregnant, it is important to talk to your physicians about the safety of taking medications during pregnancy, and having a plan to down-titrate or stop the medication if it is unsafe for the fetus. And, there should be discussion about alternative management.

Examples specific to AD. This doesn't mean medications should not be used, but they need to be used in consultation with cardiology team and a plan for appropriate monitoring

- Some ADHD medications have stimulant properties that increase blood pressure
- Some antidepressants can impact heart rhythm (long QT)
- Some medications may increase bleeding risks that can have impact for those on anticoagulation for valve replacement



Medications

This page provides basic information about mental health medications, but it is not a complete source for all medications available and should not be used as a guide for making medical decisions. Please consult your providers.

Type of medication	What it treats	Examples of medication that may be used
Antidepressants	depression anxiety pain insomnia	<ul style="list-style-type: none">• selective serotonin reuptake inhibitors (SSRIs)• serotonin-norepinephrine reuptake inhibitors (SNRIs)• dopamine norepinephrine-dopamine reuptake inhibitors (DNDRI)• tricyclics (TCAs)• monoamine oxidase inhibitors (MAOIs)
Anti-anxiety medications	anxiety panic attacks	<ul style="list-style-type: none">• selective serotonin reuptake inhibitors (SSRIs)• serotonin-norepinephrine reuptake inhibitors (SNRIs)• benzodiazepines• beta blockers
Sleeping pills and minor tranquilizers	insomnia sleep disturbances	<ul style="list-style-type: none">• short-intermediate benzodiazepines• non-benzodiazepine receptor agonist (NBRA)• Sedating antidepressant (usually with concurrent depression/anxiety)

9

Self-Care and Other Therapeutic Ways to Manage Mental Health

Self-Care and Other Therapeutic Ways to Manage Mental Health

Mental health includes emotional, psychological, and social wellbeing. It has been found to be essential to one's overall health and quality of life. Self-care may be an over-hyped concept, but it is true! You need to take time and care for yourself to be "wholly" healthy – mind, body and soul. It looks different for everyone, but should promote health and happiness at its core.

- Self-care can help to maintain mental health.
- Self-care is taking time to do things that help to improve both your mental and physical health.



This can include everyday activities such as:

- Regular Exercise
- Healthy diet
- Regular sleep

Other self-care

- Practice gratitude
- Stay connected with others and your own feelings
- Practice healthy self-talk

There are a multitude of different types of therapies that someone may find beneficial to add to their lives as a part of their self-care and strategy for improving mental health, especially after a traumatic event such as an aortic dissection or heart surgery.

Recreational ways of improving mental health through self-care can include:

- Getting out into nature
- Visiting friends/family
- Crafting
- Listening to music you enjoy
- Cooking/baking
- Volunteer work

Basically, making time to do the things you love and to share your life with those you love! Most of these can be done at home and have been shown to improve people's moods and quality of life.

What sounds good to you?

Music Therapy

With the direction from a trained music therapist, musical responses can be used to assess a person's physical and emotional wellbeing. Music techniques may include drumming, learning music-assisted relaxation techniques, such as progressive muscle relaxation or deep breathing, playing instruments, such as hand percussion, writing song lyrics, learning to play a piano or a guitar, discussing the emotional reaction, or improvisation.

Music can help with relaxation and emotional awareness.

Dance Therapy

Under the direction of a dance therapist techniques may include mirroring, visible movement analysis, non-verbal metaphors, impactful imaginative techniques, meditative techniques, introspection, and immense focusing.

It creates options for dealing with problems by discovering the reasons for the patterns of behavior, expanding movement levels, improving self-esteem plus body image, developing better communication skills, and building better relationships.

Poetry Therapy/Bibliotherapy

In poetry therapy, a therapist uses the reading or writing of poetry in helping a person understand their feelings and those of others. This can also include the use of selected reading materials to aid in the therapeutic process. Through poetry sessions, a person can express their thoughts and emotions, and help them feel like part of a community.

The receptive/prescriptive component: In this form, the therapist introduces well-known poems. After reading the poem, the patient is encouraged to respond to the topic or express the feeling evoked.

The expressive/creative component: This component involves the use of creative writing. It can include poetry, letters, and journal entries that help the therapist to gain deeper insight. This technique can free up blocked emotions or buried memories.

The symbolic/ceremonial component: This is where metaphors and storytelling come in, helping individuals to explain complex emotions. It offers a creative outlet for people who enjoy artistic expression, making it a potentially beneficial addition to traditional therapy.

Art Therapy

Art therapy makes use of drawing, painting, collage, coloring, or sculpting as the creative techniques to help patients express themselves artistically. Patients then examine the psychological and emotional undertones in their art. Decoding the nonverbal messages, symbols, and metaphors takes place.

Gaining a better understanding of the feelings and behaviors behind the art can help reveal deeper issues. An art therapist can look at a piece that a person has created and then help them discuss the feelings involved in that creation. The act of creating art can also help soothe and promote relaxation.



Other Forms of Therapeutic interventions*

(*Please note, this is not a comprehensive list and these may/may not be covered by insurance)

Acupuncture

Acupuncture is based on an ancient Chinese treatment. An acupuncture practitioner will put small, thin needles into your skin at certain points on your body. Practitioners believe the needles can help to start the healing process in your body.

Aromatherapy

Aromatherapy uses essential oils to improve health and wellbeing. Essential oils are plant extracts. You can use aromatherapy oils through massage, in the bath, or by breathing them in.

Emotional freedom technique (Tapping)

- Similar to acupuncture, EFT focuses on the meridian points – or energy hot spots – to restore balance to your body's energy. It's believed that restoring this energy balance can relieve symptoms a negative experience or emotion may have caused.
 - Based on Chinese medicine, meridian points are thought of as areas of the body energy flows through. These pathways help balance energy flow to maintain health. Any imbalance can influence disease or sickness.
 - Proponents say the tapping helps you access your body's energy and send signals to the part of the brain that controls stress. They claim that stimulating the meridian points through EFT tapping can reduce the stress or negative emotion you feel, ultimately restoring balance to your disrupted energy.
-

Massage

Employing different types of massage, a massage therapist will use their hands to rub your body to help get rid of tension and help you to relax.

Mindfulness and Meditation

Mindfulness is a type of meditation. It is when you focus on your mind and body. It is a way of paying attention to the present moment. An example of mindfulness would be to focus on your breathing. Think about how it feels when you breathe in and out. When you practice meditation or mindfulness, you can learn to be more aware of your thoughts and feelings. Once you are more aware of your thoughts and feelings, you can learn to deal with them better. Mindfulness-based cognitive therapy (MBCT) is a combination of mindfulness and cognitive behavioral therapy (CBT).

Spiritual or energy healing

Spiritual or energy healers believe that energy in your body affects your mental and physical health. Reiki is a well-known energy healing therapy. A therapist puts their hands on, or above, your body in certain places. They believe that they can channel energy into you to help healing. You keep your clothes on while they do this. You can sit or lie down. Some people from African, Asian and Caribbean communities use spirit-based indigenous healing practices to help physical and mental health.

Pet therapy

There's some evidence to suggest that having a pet may help people who live with mental health conditions. Pets can provide reliable, close relationships. This could be important if you have limited or difficult relationships with other members of your social circle. Pets can help you manage feelings through distraction from symptoms and negative experiences. Pets can also encourage you to be physically active and to get outdoors more, which can be beneficial for mental health.

Equine therapy

Horse-assisted psychotherapy includes working with a therapist and horse trainer. It has been shown to help with physical and mental health issues. This includes not only riding, but petting, grooming, and feeding the horses as well. Horses are known for having the ability to pick up on human emotion and bond with people.

<https://www.goodtherapy.org/learn-about-therapy/types/equine-assisted-therapy>

Yoga therapy

- Yoga is a type of exercise in which you move your body into various positions in order to become more fit or flexible, to improve your breathing, and to relax your mind.
 - There are many types of yoga. For aneurysm patients, relaxation, meditative or stretching yoga should be used, NOT the types that involve heavy isometric positions.
-

Tai Chi

Described as a “meditation of movement” Tai chi is a mind-body Chinese exercise used to maintain strength and flexibility in a gentle and purposeful way.



Meditation App Options

Company	Website	Cost month/year
Healthy minds innovation	https://hminnovations.org/meditation-app	Free
Calm	https://www.calm.com/	\$14.99/ \$69.99
Insight Timer	https://insighttimer.com/	\$9.99/ \$59.99
Meditation Studio	https://meditationstudioapp.com/	\$7.99/ \$49.99
The Mindfulness app	https://www.themindfulnessapp.com/	\$9.99/ \$59.99
Mindfulness With Petit BamBou	https://www.petitbambou.com/en	free \$71.99 yearly \$280 lifetime
Balance: Meditation & Sleep	https://www.balanceapp.com/	\$11.99/ \$69.99



Meditation App Options, continued

Company	Website	Cost month/year
Breethe	https://breethe.com/	\$12.99/ \$89.99
Waking Up <i>*includes advanced practices</i>	https://www.wakingup.com/	Only yearly, but refund available if you do not gain value
Ten Percent Happier Meditation	https://www.tenpercent.com/	\$9.99/ \$99.99
Meditopia	https://meditopia.com/en/	\$9.99/ \$59.99
Headspace	https://www.headspace.com/	\$12.99/ \$69.99
Buddhify <i>*includes very short practices</i>	https://buddhify.com/	Free/ \$30 yearly
Unplug	https://www.unplug.com/	Free trial

Company	Website	Cost month/year
Simple Habit	https://www.simplehabit.com/	Free app download, with in-app purchases
Aura	https://www.aurahealth.io/	\$11.99/ \$59.99
Smiling Mind	https://www.smilingmind.com.au/	Free
iBreathe	https://www.jadelizardsoftware.com/ibreathe	Free app download, with in-app purchases
Breathe+		\$0.99

Many have free trials available

Sources:

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<https://www.verywellmind.com/best-meditation-apps-4767322>

<https://www.womenshealthmag.com/health/g25178771/best-meditation-apps/>

<https://www.lifewire.com/best-meditation-apps-4767531>

<https://www.healthline.com/health/mental-health/top-meditation-iphone-android-apps>

10

Journaling as a Tool for Mental Health Wellness

Journaling as a Tool for Mental Health Wellness

Expressing yourself creatively, like when you write in a journal, is great for relieving stress and helping focus. You can use a journal to develop healthy habits, set and work toward goals, or manage your mental health and improve anxiety, stress, or depression. Even just a few minutes a day can make a world of difference to your mental wellbeing.



Journaling can be handwritten or digital.

Common benefits of journaling

There are many reasons why people enjoy journaling. The process of writing is inherently therapeutic. It can help you organize your thoughts, express yourself, and process and deal with your emotions – both good and bad – in a healthy way.

Journaling has lots of other benefits. It can be used to:

- Reduce stress, anxious thoughts and feelings
- Challenge your unhealthy and negative thought patterns
- Process your emotions more effectively
- Identify and track goals to help you achieve them
- Figure out resolutions to problems
- Track problems so you can recognize triggers
- Find inspiration

- Improve self-confidence
- Improve mood
- Understand, prioritize, and face your fears so you can overcome them
- Identify and address negative thoughts and behaviors
- Start a habit of using self-talk and creating mantras
- Identify things that trigger your anxiety
- Decrease feelings of distress
- Remind yourself of what you can, and cannot, control
- Prioritize your responsibilities so you can focus on the most important things first
- Encounter and process traumatic events

Like anything, sometimes people feel they need to jump in and be perfect, or that they need to write pages and pages of meaningful, reflective prose. But journaling can start as something much simpler! Pick a time and place, then set a time limit. It can be as quick as 5 minutes, and you can work your way up in time for a daily practice, or if flexibility is more your style, that's fine, too!



Journaling can be powerful before, during and after events including in the hospital.



Don't be a perfectionist! Don't edit yourself or worry about grammar, punctuations, and spelling. Just let it flow!

Be open to journaling whenever and however you want. Journals can be artistic, full of doodles, advice, words, quotes, random brainstorming, bullet-pointed lists, or a combination of these. You can even use prompt questions to help you start. For managing depression, using gratitude prompts can also be helpful. Above all, especially in the beginning, don't worry about what you're writing. Your goal is to keep going; the longer you journal, the better you'll become in organizing your thoughts in a way that is most helpful for you.

Your journal can be private or you can share it. If you are in therapy, it may be a prompt for conversation with your therapist. It can serve as notes for difficult conversations, or it can be just yours alone.

Journaling has also been found to contribute to better physical health.

Citation

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18 Journal Prompts for Mental Health

1. List X things you're grateful for.

2. Talk about the day you just had (evening journal).

3. Talk about your goals for the day (morning journal).

4. Identify a personal or professional goal; list X ways you'll work towards achieving it.

5. List your coping mechanisms and discuss how well they're working for you.

6. Do a 5 and 5 entry: Where you were 5 years ago; Where you want to be in 5 more years.

7. Write a letter to your 10/20/40-year old self.

8. Write a letter to your body; it can be an apology letter, a love letter, or a motivational letter.

9. Describe who you are to someone you don't know.

10. Write down X emotions you regularly feel.

11. Write a REMINDER entry to read on a bad day.

12. Talk about the best goal you've ever reached.

13. If you could be granted 3 wishes...

14. What's your purpose in life?

15. Revisit your first memory.

16. What is your biggest challenge in life right now?

17. What do you want to improve on?

18. What were the worst and best days of your life?

Journaling during traumatic events and in the ICU

It has been shown that journaling can help a person recover more quickly from traumatic events. Writing things down allows you to process what has occurred and see the good side of life, even when things are difficult. Journaling also allows you to directly confront the things you've experienced instead of avoiding them and not taking the time to process them. When you journal, you are both recording and processing the events of a particular time period. You remember and reflect upon the details of the events, which then helps you retain those memories for a significantly larger amount of time.

Additionally, journaling allows you to analyze past events for patterns. As you look at your

journal over time, you may begin to see particular patterns emerge, whether in your own behavior or in the behavior of others. Once you spot these patterns, you can respond in your life.

Multiple studies have been performed that have shown journaling to be a helpful tool for both the patient and the family. Some uses that have been reported include:

- Helping to decrease stress, anxiety, depression and PTSD by providing a place for notes, a calendar to write down events, visitors, goals. (citations below)
- Tracking daily activity and building a timeline of health related events
- Expressing emotions
- Tracking visitors and allowing the journal to be a log for them to leave messages

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11

Religion, Spirituality and Mental Health

Religion, Spirituality and Mental Health



Religion and spirituality are among the most important cultural factors that give structure and meaning to human values, behaviors, and experiences. While religion and spirituality are similar in foundation, they are very different in practice.

Religion is an organized, community-based system of beliefs, while spirituality is a sense of connection to something bigger than ourselves. Both help a person look within and understand themselves while also figuring out the greater answer of how they fit into the rest of the world. And, both can have a positive impact on mental health. Religion and spirituality can help a person tolerate stress by generating peace, purpose, and meaning.

Analyses of the literature on effects of religion and spirituality on mental health have shown that they can benefit patients in the following ways:

1. by providing social integration and support from the faith community
2. by offering a framework for meaning making
3. by providing a personal bond with god or other divine beings
4. by offering the possibility of performing private and public religious activities
5. by stimulating a healthy lifestyle (ie. staying away from high-risk health behaviors, such as smoking, drinking alcohol or overindulging in food)

However, religion could also be a double-edged sword. People who believe in a loving and forgiving god experience lower levels of stress and anxiety and have more optimistic thoughts, whereas religions that believe in a punishing god are associated with higher levels of anxiety, depression and other mental health challenges, as they can cause intense guilt, remorse, shame, fear and negative dysfunctional thoughts. Additionally, serious health events can challenge one's belief systems, causing layers of emotion to work through and emphasizing the importance of ongoing attention to changing mental health.

Not only can spirituality or religion help with coping and recovery in aortic dissection or surgery cases as well as the existential questioning that may come with it, but it may also help patients cope with other changes that accompany aortic events. For example, we know that these events interrupt routines, cause dependency on others, and impact finances. So, not only do people depend upon their spirituality to deal with the aortic event but also to cope with its impact on other aspects of their relationships and life.

It is worthwhile to consider how your spirituality or religion may impact your health, decision-making and coping.



Sources of spiritual care to consider while in the hospital:

(adapted from Mueller, et al)

Physician and other health care provide acknowledgement and support of a patient's spiritual needs

Chaplains

Family and friends

Community resources (e.g. clergy, parish nurses, support groups)

Readily available religious texts and artifacts

Chapels

Quiet rooms, meditation rooms

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12

The Importance of Deep Breathing



Breathing is so important it needs its own section!



12

The Importance of Deep Breathing

Deep breathing also goes by the names of diaphragmatic breathing, abdominal breathing, belly breathing, and paced respiration. When you breathe deeply, the air coming in through your nose fully fills your lungs, and the lower belly rises. This type of breathing is a great way to reset your natural

breathing tendencies. Most of us never want to stick our gut out, which can lead to shallow breathing. Learning to breathe with your belly is key.

Why is slow, deep breathing so powerful? First, a little biology...

The nervous system plays a crucial role on our road to mental wellbeing.

It is our own personal instruction manual for navigating the world. Our nervous system affects the way we think, feel, and act. You could think of it as a sophisticated supercomputer that stores and processes information which is then used as your template for navigating the world, so it is important to understand HOW it works and HOW we can regulate it when it falls out of balance. An unbalanced nervous system goes into what is referred to as a state of dysregulation. Short bursts of dysregulation are normal. Longer, extended periods of dysregulation often go hand in hand with symptoms of anxiety and depression.

Your autonomic nervous system is split into two parts. Both parts are always active.

- One part, the sympathetic nervous system, controls your fight-or-flight responses.
- The other part, the parasympathetic nervous system, controls your rest-and-relax or rest-and-digest response. An important part of the parasympathetic nervous system is the vagus nerve.

- In Latin, the word “vagus” means wandering, which is very fitting, because this nerve stretches from the brain stem down to the colon, connecting to the middle ear, vocal cords, heart, lungs, and intestines along the way. The longest and most complicated of the body’s 12 cranial nerves (each connects the brain to other parts of the body), the vagus nerve plays many roles, affecting our emotional states, heart rate, inflammation levels, blood pressure, and digestion. The vagus nerve has a profound impact on our sense of safety and connection.

Dysregulation of the system:

We are constantly and unconsciously reading our environment for cues of safety or danger and then adjusting our behavior to stay safe, depending on our circumstances.

If our nervous system is well regulated, we will respond appropriately to our circumstances and threats (thoughts, feelings, and behaviors), but once the threat is gone, our nervous system should return to baseline (homeostasis).


If our nervous system is dysregulated, however, it is reacting to present circumstances on the basis of past stressors rather than current ones.

Deep breathing has been shown to be beneficial for:

- Anxiety
- Depression
- Gastrointestinal issues
- Sleep
- Stress
- Relaxed muscles
- Reduced blood pressure
- Mild weight loss (reducing cortisol)
- Improved focus

It gets “stuck” in a threat response, even once the threat has passed. So we still have physiological and biochemical manifestations of threat, even though our circumstances are safe. Dysregulation will cause us to overreact or under-react, which can be unhelpful to living a healthy balanced life, resulting in relationship conflict or acting out in self-destructive ways, for example. We are basically using our more primitive, emotional and reflexive part of our brain rather than our rational, organized and planning functions.

So, the vagus nerve is like the highway of information for the parasympathetic nervous (rest and relax) system, which is why deep breathing, which helps to moderate the communication between sympathetic and parasympathetic nervous systems, is so helpful. You can think of breathing like controls on a car, with a gas pedal (shallow breathing) and the brakes (deep breathing). You are the driver!



Deep breathing activates the parasympathetic nervous system and the vagus nerve which helps oversee mood, digestion, and heart rate. It also sends more oxygen to your brain and other organs.

Deep breathing resets the body and provides space for more deliberate and helpful skills. It won't change your perspective, emotions or thoughts without further steps.

You can check out some of the mindfulness apps for guided breathing, or consider these other breathing exercises:

Nose-mouth breathing: This exercise is all about alternating your breathing pattern. To perform nose-mouth breathing, you'll want to inhale through your nose and exhale through your mouth. While you can pace your breathing any way you'd like, it's best to take long, slow breaths when alternating between the mouth and nostrils. Breathe in through your nostrils, filling your lungs until they're full. Then, gently release that air through your mouth until there's no more air to exhale. Try to work up to 5-6 seconds. This can be very helpful when trying to fall asleep.

Alternate nostril breathing: This exercise uses your thumb and pointer finger to alternate blocking one nostril.

- Lift right hand up toward nose.
- Exhale completely and then use your right thumb to close the right nostril.
- Inhale through the left nostril and then close the left nostril with your fingers.
- Open the right nostril and exhale through this side.
- Inhale through the right nostril and then close this nostril.
- Open the left nostril and exhale through the left side.
- This is one cycle.

Square breathing: Draw a square in the air while breathing in and drawing one side, hold breath while drawing across the top, exhale while drawing down, and hold while drawing across bottom. Repeat.

Breath focus technique: This deep breathing technique uses imagery or focus words and phrases. Imagine inhaling “peace, power, energy” and exhaling “tension, anxiety.”

13

A Word on Pain

A Word on Pain

Everyone experiences physical pain at some point in life. Pertinent to this group, there is acute pain, which lasts for about 3-6 months and may be post-surgical or associated with an acute dissection. As well, some people with aortic dissection have genetic syndromes that have accompanying musculoskeletal concerns like hypermobility, scoliosis, and/or osteoarthritis. This type of pain often exists for >3-6 months and is called chronic or persistent pain. Pain can also encompass headaches, migraines, neuropathies, fibromyalgia and arthritis.

Living with daily pain is physically and emotionally stressful. Chronic stress is known to change the levels of stress hormones and neurochemicals found within your brain and nervous system; these can affect your mood, thinking and behavior. Disrupting your body's balance of these chemicals, and the frustration caused by all these physical and emotional changes can bring on depression or anxiety. Research shows that those with chronic

pain are 3-4 times more likely to have depression or anxiety than those who are pain-free.

Just like finding a good mental health provider or team, it can be challenging to find a good pain team. The first step is to talk to your current primary care doctor or other health care team members about the impact of pain on your life.

Here are some specific things you should discuss with your doctor:

- Are you able to work?
- Are you able to engage in social activities?
- Can you exercise?
- How is your sleep?
- Are you able to shop for and prepare meals for yourself?
- Are you able to do chores like laundry and cleaning?

Chronic pain can...

- Affect your ability to function at home and work
- Affect your ability to participate in social activities and hobbies
- Affect your ability to do movement and exercise
- Cause sleep disturbances causing more fatigue
- Cause difficulty with concentration
- Cause decreased appetite
- Cause mood changes

All of these impact quality of life, so it is important to get help for pain management in addition to mental health support.

Good information can be found at the Pain Foundation

- There is a PDF called “Living with chronic pain” in both English and Spanish (<https://uspainfoundation.org/resources/>) which is a comprehensive booklet on this topic.
- There is also a PDF called “Create your own pain management plan” that gives you prompts on setting goals and thinking through what treatment modalities you would be willing to try.



- Are you able to drive?
- Are you able to handle your medication schedule?
- Are you able to pay your bills?
- Are you able to dress and bathe?
- Can you climb stairs?

Some other ways to think or talk about your pain include:

- Pain scale: Don't underestimate your pain on the numerical scale. Doctors will often ask you to describe your pain intensity on a scale of 1-10, with 1-3 being pain that doesn't bother you much at all and 9-10 constituting an emergency. Sometimes people with chronic pain downgrade their pain because it is such a consistent part of their life that they are “used to” dealing with it. A good thing to do is use the pain scale as a range and describe certain daily activities (such as I wake up at a 4, but after an hour walking around the grocery store I am at a 6-8.)
- Describe your day and patterns in relation to what makes the pain worse or better.
- Talk about how the pain impacts your daily function, rather than feelings.
- Keep track of your pain and identify any triggers (certain positioning or activities that exacerbate pain; also what makes it feel better).
- Use metaphors and descriptors for pain (example: McGill pain questionnaire (you can google it!))
 - Pain can be mild, distressing or excruciating
 - It can be aching, sharp, dull, throbbing or tingling
 - It can be steady, rhythmic or brief
- Share your treatment history of medications, physical/aqua therapies, or other supplements or complementary procedures like massage or hypnosis. Did they work or not work? Did they bring short term or longer term relief?
- Set realistic goals for pain management in terms of time frame, function and what it will take to achieve goals. Be reasonable, be specific, and stick to the plan as fully as you can. That is the only way to know if it works!

You could also check out the Curable App (www.curablehealth.com). Curable is an online program and app designed to help people with persistent

pain reduce their symptoms and calm their nervous system.

The Curable program guides users through engaging audio lessons about modern pain science and teaches them how to apply a wide range of science-backed techniques to reduce their symptoms, including: pain tracking, cognitive behavioral therapy techniques, guided meditations, pain reduction visualizations, expressive writing techniques, and more.

How do I find a pain clinic?

- Ask your primary care doctor or specialist for a referral.
- Call your local hospital or medical center.
- Get help from a local pain support group.
- Search The Center to Advance Palliative Care (<https://www.capc.org/>) for a list of providers in each state.

What is Palliative Care?

Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the complex needs of the patient, not on the patient's prognosis. Though palliative care is often associated with hospice, it is actually appropriate at any age and at any stage in a serious illness. In other words, it is NOT limited to end-of-life care.

Pain control

While drug therapy for musculoskeletal pain is frequently prescribed and often helpful, it is associated with important risks and not all patients respond. The decision to use medications should be in the context of a shared decision-making model where both patient and prescriber evaluate the risks and benefits of various therapeutic choices.

There is research to suggest that the abuse or misuse of pain medications such as opioids, stimulants (ADHD medication) or sedatives/antidepressants, is common. This can also apply to substances such as alcohol or marijuana. Use of substances such as these can impact nerve cells in the brain and body, decreasing pain, but also causing feelings of euphoria (excitement/happiness, i.e. to get high).

To clarify, misuse of prescription drugs means taking a medication in a manner or dose other than prescribed (taken in a different way or in a larger quantity than prescribed); taking someone else's prescription, even for a legitimate medical complaint such as pain; or taking a medication to feel euphoria.





Holistic care for patients involves treating musculoskeletal pain, taking into account their other health conditions, lifestyle, patient preferences, and mental health. Lifestyle changes or other therapies such as weight loss, healthful eating, exercise, and relaxation techniques can be helpful along with assistive devices (such as braces or shoe orthotic inserts). Psychological counseling is also used to learn coping and relaxation strategies, and discussion on how pain may be impacting your relationships.

Pain Support groups

Much like aortic dissection support groups, there are pain support groups with all the same benefits, limitations and caveats. To decide whether a chronic pain support group might be right for you, ask yourself some questions:

- Do you feel isolated because of your chronic pain?
- Do you need more emotional support?
- Do you feel like no one in your life understands what you're going through?
- Do you need help finding ways to cope with your pain?

If you said yes to any of those questions, a pain-specific support group may be appropriate. Some of these include:

- [National Chronic Pain Support groups](#)
- [Pain Connection](#)
- [Pediatric Pain Warriors](#) (services for children with pain and their caregivers and siblings)
- [My Chronic Pain Team](#) (social network for those living with pain)
- [Chronic Pain Anonymous*](#) (CPA offers a 12-step program for living with chronic pain. This is similar to programs for addiction, such as Alcoholics Anonymous, but the organizations are not related. Please note that the 12 Steps are largely based on a belief in god or a higher power, so this program may not be appropriate for people who aren't religious or spiritual).

A word of advice: people online have a lot of opinions and stories of what has worked/not worked for them. It is always important to discuss your care plan with your healthcare providers.

14

Version You 2.0

Version You 2.0

IT TAKES TIME...

What takes time? Physically Healing... Trusting your body...physical activity.....emotional healing

Physically healing includes doctor visits, getting back to movement and daily living skills, getting strength back and reducing pain medicine and getting used to surgical scars.

Trusting your body

There is a physical and emotional healing that occurs after having an aortic dissection or even being diagnosed with an aortic aneurysm. That may include finding your new normal or version 2.0 of you.

Often people become very tuned into every ache, pain and/or cardiac flutter. This is normal and you may have to ask questions of your healthcare team to alleviate your fears. There are no dumb questions.

Your body may also change as part of a recovery process from surgery or dissection. There may be weight changes and scars. There may have been some complications with surgery that lead to breathing or speaking challenges. These may be only obvious to you or they may also be noticeable to others. Surgical scars have been associated with negative body image and lower self-confidence, but a good way to start mitigating this is to recognize the self-consciousness and feelings that this physical scar may bring up. (Ngaage and Agius, 2018)

For people with a family history of aortic aneurysm and dissection or those who are part of support groups, there is exposure to and knowledge of potential risks based on what

you observe in other people. Consistent medical evaluations and screening may be a constant reminder of poor outcomes that could loom over you. Every new physical feeling may have you wondering if you need to go to the emergency room. You know your body the best and are the best advocate for what pain or symptoms are new and not explainable by an activity you performed. But, this sense of self may be askew after a cardiac event. You will get back to your “new” normal, it just may take more time than you expected. Look forward to exploring what You 2.0 is going to look like.



Scars are not a sign of weakness, they are a badge of honor, strength and overcoming.

Pushing your body

Exercise and an active lifestyle are an important part of improving your heart health. But many people fear pushing their heart and aorta too far. This is why cardiac rehab can be an important resource; it is a safe space to push your body and find your limits while being closely monitored. Have realistic expectations about returning to physical activity after an event. In general, when you get back to you after a full recovery, exercises performed in moderation are highly encouraged, with avoidance of exercising to exhaustion and avoidance of heavy weight lifting

or isometric exercises. Many people experience a dissection after being intense athletes when younger. They may struggle with their identity related to activity with physical restrictions after surgery. Rest assured, there is more that you can do than can't do in terms of exercise, it may just take time and patience to explore what is safe and enjoyable for you.

Discussion about Disability

“Disability can be categorized into temporary or permanent, partial or total disability.” (Scura, 2022)

After an aortic dissection you may be on short-term medical disability for a few months, depending on the surgery, complications, and ability to perform job responsibilities. This is driven by you and your team to decide when you are ready to go back to work. This is known as temporary work disability, which is controlled by the Office of Disability Employment Policy.

Questions to consider when speaking with your medical team:

- Am I able to go back to work and continue with the type of work I currently do?
- If there are certain restrictions on what I am able to do, is my job able to accommodate me?
- Are there accommodations that I need or would like to make the workplace more accessible for me?
- What are the laws that protect patients on work disability and for how long? There may be state specific policies as well as your company may have specific policies. (Askjan.org is a great resource as well the Office of Disability Employment Policy (ODEP; <https://www.dol.gov/agencies/odep>)



Research has shown that long periods of time out of work may contribute to a decrease in people's physical and mental health. Temporary work disability is available to help patients continue to live comfortably and be able to return to work after an event such as open heart surgery. (Scura, 2022)

Trusting your body takes first trusting yourself – that you understand your condition, what you need to do to improve, and what symptoms might indicate a problem. To get there, you have to be your own health advocate.

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There are times that a patient may need to consider permanent disability. This can be a difficult decision to make, and the process of getting disability may be very challenging. It includes multiple steps and can be time-consuming, taking months to years.

General steps to apply for disability and helpful links provided below:

Step 1: Check your eligibility and the Inclusion criteria

- The Disability Starter kit: https://www.ssa.gov/disability/disability_starter_kits.htm

Step 2: The process includes an application, interview, and investigation by Social Security representative

- <https://www.ssa.gov/disability/Documents/Checklist%20-%20Adult.pdf>

Step 3: The two programs social security pays disability:

- Social Security Disability Insurance (SSDI) for insured workers, their disabled surviving spouses, and children (disabled before age 22) of disabled, retired, or deceased workers.
- Supplemental Security Income (SSI) for people with little or no income and resources.

Step 4: If there is trouble in accessing or getting approved for disability there are attorneys and advocates to help patients and those with a diagnosis of a connective tissue syndrome.

- <https://www.disability-benefits-help.org/>

A good first step may be to check out:

The Disability Starter kit: https://www.ssa.gov/disability/disability_starter_kits.htm

Information about free disability evaluation including process outline, conditions list, resources, and help finding an attorney: <https://www.disability-benefits-help.org>

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15

Communication Within Your Family

Communication Within Your Family

Partners/Spouses

When receiving a diagnosis or going through a severe illness, such as an aortic dissection, which is physically straining and can lead to further surgeries that may have extensive healing times, there is no one way or “right” way of coping. Communication is essential to help everyone impacted, including partners, children, and caregivers.

Talking to a partner about mental health issues can be difficult and scary. Some people don't have a lot of experience expressing emotions, or don't always have the words to express how they feel, so both parties should be patient with one another.

It is an incredibly vulnerable conversation to have. But opening yourself up to being honest with your partner can increase intimacy and trust in your relationship. And it is always a good thing when we tell our partners more about ourselves

because it gives them the opportunity not only to know us better, but to love us better.

When talking to a partner or spouse, consider talking somewhere private and comfortable for you both, and understand that some topics may be uncomfortable or difficult to discuss at first. Common reactions to or attitudes towards serious or sad information can be avoidance, denial or fear, but the benefit of talking through this is likely to outweigh any temporarily uncomfortable moments.

By talking and listening, it may help to put things in perspective, add reassurance or validate your own feelings, and help the person speaking feel supported and heard.

Give specific examples if you can, to help your partner understand what you are experiencing in regards to your mental health:

- What are your symptoms?

The power of “I” statements

“I feel” statements communicate how a speaker feels to help minimize defensiveness and conflict in conversations. Learning how to use “I feel” statements can be an effective way to improve how you communicate with others, particularly if you are dealing with difficult conversations or conflict.

These I-statements should state how the speaker is feeling, connect it to an issue, and offer a possible solution.

“I feel overwhelmed that another event is going to happen, to the point of having panic attacks that I have been keeping from you. I would like your help in finding someone to talk to.”

- What things are helping you to cope? What are things your partner can learn to help you?
- What kind of help do you think you need professionally or medically?
- **What do you need from them?** Is this conversation just to inform them? Let them know. Tell them you don't need anything different from them, you just want them to understand your experience. If you do need something from them, tell them what it is. Give them the opportunity to be the best partner they can be.
- What are you finding to be triggering, or making your mental health challenges worse? Are there things your partner does that make it worse?

Children

Speaking with a child about your aortic event or diagnosis can be difficult, especially when a parent's first reaction is to shelter a child and avoid anything that may upset or stress them out. Children understand their world at a very young age. It's important to be honest with them. It's also important to keep the lines of communication open, and be available to them as they process situations over time and as new questions arise.

Conversations will be different depending on the age of the child. Ultimately, the way a child reacts to a parent's sudden illness is dependent on developmental stage, temperament and experiences so far. With that said, there is unanimous agreement from the available research about the benefits of openly speaking to a child about events such as an illness or serious event in the family. From a very early age, children are able to sense when an adult is upset

or anxious. And, what they dream up in their own head as an explanation for why parents may be away or not feeling well can be more scary than the reality. It's also important for a child to know that a new parental behavior (such as being more distant or quiet) is not caused by something the child did.

By discussing what is going on in an age-appropriate manner, you may in fact be allowing your child to express emotion in a healthy way, acknowledging that it is okay to be sad or even anxious. Research has found that when children are excluded or ignored when a parent is hospitalized, it promotes feelings of sadness, loneliness, and uncertainty in the child. You want to help them understand their emotions and help give them tools for expressing how they feel. You also want to share your feelings, too.

Common reactions by kids when discussing serious health events include:

- Feelings of confusion, anger, or guilt
- Unsure or scared of how to act around you
- Acting clingy or seeking attention
- Trouble eating, sleeping, or keeping up/ focusing in school

Tips:

- Let them know their feelings are okay. No matter what they feel or how they may act out, you will always love them.
- Let them know you are getting good medical care.
- Tell them the truth with love and hope.
- Listen to them.
- Try to stay involved in their life. Even if it's just a short recap of the game or day at school.
- Watch for any behavioral changes.

How to approach the conversation with kids/ adolescents at different ages:

Children ages 3-6

- The ability to understand complex ideas is still forming, so keep the information simple.
- Talk to them about their own bodies and other health topics to normalize discussions about health.
- Children at this age can sense your emotion, even if they cannot understand the situation. Letting them know that it is okay to be sad or cry by seeing you express emotions is helpful to them. It is also important to try and remain calm as a model for them.

Children ages 7-11

- Children this age are likely to ask “why” questions. Because their brains are now capable of reasoning and understanding, you can be more fact-based in your discussions about health.
- Help them to understand their own emotions.
- At this age they want to be near their parents, which is a sign of affection – seeing their parents is helpful.

Preteens/Teens ages 12-18

- At this age, young adults are trying to find their own independence. Respect their privacy and way of coping.
- It can be helpful to actively listen to your kids as they are learning about this information and processing stressful events.
- Parents may consider posing questions for their children to think about.

- Adolescents may want to be present and take responsibility by adopting a supportive role towards the ill parent.

You are also giving a powerful gift to your child when talking to them about mental health challenges. These conversations help decrease the stigma and can equip them for good communication skills to use in future relationships. You are also teaching them that it is okay not to be okay all the time, and the importance of reaching out for help when you need it.

When it comes to being in the hospital, it will be important to learn the rules about children as visitors. It will also be important to talk to the child about what they may experience if they come to visit, how that may make them feel, and if they want to visit or not.

When your aortic aneurysm/dissection is genetic/hereditary and your child has the same condition or is at risk, this may also add another level of fear and anxiety to your child's coping. Not only are they worried about their parents, but this often leads to fear over their own future health and risk.

Children often benefit from therapy as well, regardless of heritability of the aortic dissection. A challenging medical event in a family member's life is trauma exposure for them as well. They deserve to access the same resources for mental health support as adults. And, often, having a trusted adult outside the family unit allows them to speak with more freedom. Children should be asked and encouraged to seek out all the support they may also need.

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16

A Space for Caregivers

Dear loved one,

You may be picking up this booklet because you are a caregiver – a friend, family member, loved one – of someone with aortic disease. Thank you for your caring and support. We know that you are the ones who are there every step of the way, watching them go off to surgery, sitting in the waiting room, praying, pacing, making the calls, filling out paperwork, and making all the followup plans. You also experience all of the emotions, but try to keep them in check for your loved one. On top of that, you are getting the brunt of emotions FROM your loved one. Frustrations, anger, resentment, loss of control, uncertainty about the future or the health of other loved ones. It's A LOT to carry.

Caregivers and patients both have concerns about medical treatment and surveillance as well as how the condition impacts daily life (Acosta 2019). The concerns and stressors caregivers face may be different, but are just as important to address.

The same foundations mentioned at the end of this booklet that offer support to patients with a history of aortic disease also include support groups for family and caregivers. And/or there are specific caregiver support groups.

While providing care, sometimes it's normal to push your own health, needs and feelings aside. Doing this for long periods of time is not good for YOUR health. And **you need to be healthy to help take care of your loved one** with aortic disease and all the other loved ones in your life.

The role of caregiver may be new to you. If so, don't worry. Most people "learn as they go" to

help their loved one through their medical issues. It's normal to feel confused and stressed. It's okay to be sad, angry; to feel grief, guilt, and loneliness. Feel all the feels!

Remember:

- In caregiving, we all make mistakes or use miswords. Forgive yourself, no one is perfect.
- Express your feelings. The mask of "everything is fine" can come off.
- Focus on things that are important. Let some of the small stuff go!
- Don't take any words said by your loved ones in anger too personally. They are probably expressing stress, fear and lack of control in words of anger towards you, someone who is not going to abandon them.

Ask for help

- Many people want to help, but don't know how. It's great to tell them specifically what your family unit may need. Be specific. Some people may say no, and that is okay, too.
 - Cook X meal
 - Clean house on X day
 - Pick up child from daycare X week
 - Mow the lawn

Make time for yourself

- Be active.
- Find ways to relax and take care of yourself, even if just for a few minutes at a time. A quick walk outside with some deep breathing can do a world of good.



- Find ways to connect with friends.
- Give yourself more time – time off work, ask friends to help with chores, etc. Take time to rest and reset.
- Remember to also keep up with your own health needs.
- Find ways to find meaning in life, just like the individual with AD needs to.

Going to medical visits with your loved one

Your loved one may want you to go to medical visits with them. Ask your loved one how involved you should be in the appointment. Should you take notes? Can you ask questions? Some ways to make appointments less stressful include:

- Know where you are going and leave with enough time to get there.

- Write down questions or information you want to be sure to give the provider.
- Keep a folder/binder of records. This should include an updated list of all providers and their contact information, as well as medicines with doses.
- Make sure everyone is clear on next steps.

It's important to ask the provider to clarify something you don't understand and communicate openly with them. This is especially true if there are new symptoms or changes in your loved one.

Therapy

An aortic event is stressful, and this can impact both romantic and family relationships. Marriage or family therapy can be helpful for everyone to process the stress and feelings associated with the aortic diagnosis. Sometimes hardship makes relationships stronger, sometimes weaker. It's important for all members of the family or friend units impacted by AD to have good mental health.

Challenges in couples can include learning how to support one another in this time, the changing roles within the relationship, changes in your sex life, making decisions about the future, and managing daily life.

Do not be ashamed or afraid to also seek individual therapy. Seeing a loved one in pain or experiencing uncertainty about your future together based on health concerns can be challenging, so make sure you are also getting the help you need and deserve.

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17

Support Networks

Support Networks

A support group is a gathering of people facing common issues to share what's troubling them. Through the sharing of experiences, they're able to offer support, encouragement, and comfort to the other group members, and receive the same in return. Sometimes other people who have "walked in your shoes" (as much as anyone can!) may empathize and have advice in ways that family members and friends may not be able to. Support groups may be peer or professionally led.

Support groups may be offered by a nonprofit advocacy organization, clinic, hospital or community organization. They also may be independent of any organization and run entirely by group members.

These are different from therapy support groups which are specific mental health treatment recommendations and are typically under the lead of a professional therapist.

Benefits of participating in a support group may include:

- Feeling less lonely, isolated or judged
- Reducing distress, depression, anxiety or fatigue
- Talking openly and honestly about your feelings
- Improving skills to cope with challenges
- Staying motivated to manage chronic conditions or stick to treatment plans
- Gaining a sense of empowerment, control or hope
- Improving understanding of a disease and your own experience with it
- Getting practical feedback about treatment options

- Learning about health, economic or social resources

Every group has members with different personalities, experiences with the common issue, and different life experiences. It is important to be open and patient and realize that everyone does have unique lives and ways of communicating and coping. Being involved with support communities is not for everyone at all times. Hopefully, though, these are safe spaces for everyone involved to ask questions, share, and feel less isolated. Sharing problems or issues tends to be cathartic, but, in some cases, hearing other's stories, which may be less or more severe, may be scary or add more anxiety. Additionally, while many members hopefully share advice about coping that is thoughtful and motivating, some individuals may reject attempts at help and sit in their pain, grief or anxiety, building a new identity around these feelings, which can be overwhelming to witness.

Sometimes people can feel scared or anxious about participating in a group setting. Rest assured, in most groups you can choose to speak (or not) as you feel comfortable. Well-run support groups usually set some boundaries or have intervening leaders so that participants don't feel attacked or one person doesn't dominate the conversation. No unsound medical advice should be given, nor should any promotion or selling of products. As well as privacy rules to make sure that "what happens in group stays in group," there is typically some structure or agenda to the meeting and the leader usually helps people stay on track.

It can be daunting to think about interacting with strangers when you feel you are already

in a fragile place. It's hard to ask for help and to receive it. It's also hard to admit that there may be an issue you need help with, and that everything is not "fine..." Just showing up is a big first step and likely everyone in that room or zoom call feels (or felt) the same way!

In order to get the most out of your support group, it is helpful to attend on a regular basis so you feel comfortable and get to know the members of your group. When you feel comfortable, participate! Your group members want to hear your story, your updates, and your words of wisdom. There is also tremendous power in "going first" and getting conversation flowing. Of course, like in any group setting, there will be people who rub you the wrong way and topics that may be sensitive or emotionally challenging. Treat others like you would like to be treated – with respect and patience. Everyone's life with aortic disease is different. Finally, if you've given a group a decent try and it is not a good fit or dynamics change with new members, it's okay to consider switching.

Groups can also be local, or online (either via meetings or forums). There are benefits and limitations here, too. Online support groups may allow more frequent or flexible participation and allow for those with rare conditions spread nationally or internationally to meet. But, it can also be difficult to interpret body language and facial expressions. There may be technical challenges or other distractions that interrupt the flow of the group. With online groups, expressing support and warmth to a co-member may not be as easy. Online forums may offer 24/7 support depending on who is online. Local groups may allow for more-community building and sharing of practical knowledge about local resources.

The discussions that occur in groups should be

helpful and productive. Some red flags may include if the facilitator isn't in control of the meeting, or having difficulties enforcing rules of privacy, respect, and time. This may represent lack of training or appropriate skill set. Think about the size of the group, whether people are committed and show up or whether the group is too big, so people don't have a chance to share and contribute.

Because much of what is discussed is sensitive, confidentiality should be enforced consistently. As well, if the group always ends leaving people feeling hopeless and/or is filled with griping and whining instead of hope and optimism, the energy of the group or the leader may not be conducive to your own personal growth or needs.

Some questions to consider asking before joining a support group:

- Is the group designed for people with a specific medical condition or certain stage of a disease?
- Does the group meet for a set period of time or does it continue indefinitely?
- Where does the group meet?
- At what times and how often does the group meet?
- Is there a facilitator or moderator?
- Has the facilitator undergone training?
- Is a mental health expert involved with the group?
- What are the guidelines for confidentiality?
- Are there established ground rules for group participation?
- What is a typical meeting like?
- Is it free, and if not, what are the fees?

Remember, a support group is not a substitute for regular medical care, but can be a helpful additional tool in your mental health toolbox.



Aortic dissection specific advocacy groups

Nonprofit advocacy groups dedicated to aortic disease offer many services, and support groups may be part of their programming. Many of these sites have personal stories, which can be powerful to read or view if you are not quite ready to participate in a group. You can also check in with your local hospital or cardiac rehab, as they may know or offer local services. You can check out these groups at:

Aortic Hope

<https://www.aortichope.org/>

Bicuspid Aortic Foundation

<https://www.bicuspidfoundation.org/>

**The John Ritter Foundation
for Aortic Health**

<https://johnritterfoundation.org/>

**Loeys-Dietz Syndrome
Foundation**

www.loeysdietz.org

Marfan Foundation

www.marfan.org

Mended Hearts

<https://mendedhearts.org/>

VEDS movement

www.thevedsmovement.org

Pain Foundation support groups (see pain section)

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How to Find Cardiac and Vascular Care

How to Find Cardiac and Vascular Care

After having an aortic event or surgery, it is important to make sure you have a strong health care team that may include multiple specialties and sometimes, depending on insurance and geographic location, may span multiple medical groups. THIS IS OKAY! But keeping everyone in the loop may take more effort on the side of the patient.

Each patient should have a:

- **Cardiothoracic and/or Vascular surgeon** – In charge of followup after surgery. They may prescribe medications right before or after surgery, but will eventually defer all medication surveillance to the patient's Primary care physician or Cardiologist. A vascular surgeon may continue to follow you for imaging after a type B (or descending aortic) dissection.
- **Cardiologist** – Physician specializing in the heart and the base of the aorta (aortic root and ascending aorta). This is the person who will monitor blood pressure, order echocardiograms and possibly other imaging, ekg's or holter monitors.
- **Primary Care Physician (PCP)** – Patient's general physician, in charge of the patient's overall health. Patients may need to see their primary care to get an initial referral to any specialist depending on their insurance.

Some vascular patients may have a Neuro-vascular physician on their team, to help with input and surveillance of dissections or aneurysms in the head or neck.

All physicians should be aware of your health history. BUT how do we find a doctor:

- Insurance network – Your insurance is

contracted with specific medical groups in your area. You can call your insurance to find out who they are contracted with or who is accepting new patients.

- Internet – All major medical institutions are likely to have Departments of Surgery, as well as a Cardiology department. There may also be specific clinics, for example Aortic Center Clinic, available for consultation or surveillance. (Be sure to call and clarify with their office that they take your insurance.)
- Referral from primary care or cardiologist – If your cardiologist or PCP are recommending you see a surgeon, they may have a set group that they will refer you to. If you would like a different group or get a second opinion, speak to whomever is referring you about your options.
- National support groups – These groups for patients of aortic aneurysm or dissection will have a directory of medical centers and contact information based on the patient's state and location.

Things to have handy at a new appointment:

- ID and Insurance Card
- Primary care physician (PCP) information
- Any recent CT/echo or reports to give the new medical group information regarding your past medical history. They may also request that you bring copies of IMAGES on disk if your imaging was done at a different medical or radiology site. Ask the scheduler on what to bring to best be prepared at your appointment.
- Patient Questions and Concerns

- Sometimes having a list of your medical diagnoses and surgical history with dates, locations and/or specialist physicians is a helpful tool to facilitate correct transfer of information.

Other Specialties that you may be referred to before or after aortic surgery

- Cardiac rehabilitation
- Genetics
- Hematology
- Pain management
- Psychology
- Rheumatology
- Dental

Getting the most out of your appointments

Positive feelings about your interactions with your doctor can help you get the best care possible. A 2022 survey revealed that many patient-provider relationships are defined by anxiety and fear. (This random double-opt-in survey of 2,005 nationally representative Americans was commissioned by PatientPoint between September 22 and September 30, 2022. It was conducted by market research company OnePoll.) Some findings from this survey include:

- 51% of patients were afraid to have conversations with providers about their health concerns and symptoms. Interestingly, more men than women reported dreading an interaction with their doctor or other provider (57% vs. 45%)
- 69% stated they worry they won't be able to understand the terminology their health care provider uses in response to their questions
- 48% reported they have left an appointment feeling confused
- 50% said they worry a provider will be insulted or get angry if they push to learn more about their condition
- 69% wanted to know how to better describe their symptoms before talking with their health care provider
- 39% have felt anxious before going to a doctor's appointment. Of these:
 - 38% worried about what they might learn about their health
 - 38% felt they didn't have enough information to help them prepare for their visit
 - 55% want their doctor to provide more details about treatments and medication

You should always feel comfortable asking questions of your physician. If you have anxiety over medical appointments, share that with your physician. This may be another reason to seek mental health support.

Before the appointment: PREPARE!

- **Write a list of prioritized questions/concerns**
- Consider bringing a trusted adult or family member with you to be a second set of ears or a note-taker. They may ask different questions. And, importantly, your friend or family member can provide emotional support, which is often much needed when dealing with a serious medical condition.
- Know where you are going, and give enough travel time so you are not feeling rushed when you arrive at the appointment.

During the appointment:

- Use your prepared list of questions and concerns, prioritizing your health issues/complaints in order of severity and/or concern. If you're interrupted, pick up where you left off. And don't wait until the end to bring up a serious concern or issue.
- Be honest with your doctor. Although some topics can seem embarrassing, your doctor has "seen it all" and is legally required to maintain your privacy.

- Take detailed notes at all appointments. Also, consider recording appointments with your phone – but ask first. Share the information with all members of your medical team at future appointments.
- If you don't understand what your doctor tells you, ask him/her to repeat the information and/or explain it in another way. If needed, ask for a language interpreter.
- When your doctor gives you a diagnosis, ask what led to this decision. Ask if testing will confirm the diagnosis. And ask if other conditions could be responsible for your symptoms.
- Listen carefully to recommendations for testing and treatments. Ask about pros and cons. Work with your doctor to make decisions together. And realize you have a right to refuse testing, treatments and/or medications, but don't make rash decisions.
- Keep copies of all important documents (test results, etc.) together and organized. Bring them to all appointments.
- If something doesn't seem right, speak up!
- If you share information you found online, be open to a conversation. Don't insist that your information is more relevant than what your doctor has.
- Be patient and calm during appointments.

After the appointment:

- Follow up on test results. Don't assume "no news is good news."
- If your hospital has an online access portal to records, make sure you are enrolled and know your passcodes.
- Learn the best way to communicate with your medical provider's office for prescriptions, questions, scheduling etc.

Cardiac Rehab

Cardiac rehab is a medically supervised program that is designed to help individuals who have experienced a cardiovascular event such as heart surgery for an aortic aneurysm or dissection.

Cardiac rehab is designed to improve your overall cardiac health through exercise training, education, and counseling.

These programs are facilitated by physicians, dietitians, occupational and physical therapists, pharmacists, nurses, and other allied health providers. The goal of cardiac rehab is to help the patients return to a healthy and active lifestyle after heart surgery and to give patients the tools and confidence to be able to monitor themselves through daily activities and knowing their own limits.

They can directly help with:

- Managing and understanding medications properly
- Adopting a healthier diet
- Reducing unhealthy habits such as smoking
- Reducing stress
- Returning to personal hobby and interests, including sexual activity

Ask your doctor if you are eligible to register for a cardiac rehab program.

What if I want a second opinion?

Wanting to ask for a second opinion can feel stressful or uncomfortable. You may also feel that you and your provider are not on the same page about management or treatment. There may always be personality or style differences, but you always want to have confidence and trust in the guidance you are given. It is your right as a patient to request or seek a second opinion. All patients should feel confident and comfortable with their physician. As a patient, if you have a good patient-provider relationship, you are more likely to be more honest and open about any concerns you have before or after surgery and as you recover.

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Emergency Situations

Emergency/Crisis Situations

If you find yourself or a loved one experiencing a mental health emergency (life-threatening situation in which someone is a danger to themselves or others) or mental health crisis (non-life-threatening, but the person is still severely distressed), it is important to get immediate help. This includes any threat to others, or an attempt of suicide or self-harm.

If you are worried that you or a loved one is in an emergency or nearing a crisis, seek help. Make sure to assess the urgency and immediacy of the situation to help determine where to start or who to call. Ask questions about intentions, plans and means:

- Is the person in danger of hurting themselves, others, or property?
- Do you need emergency assistance?
- Do you have time to start with a phone call for guidance and support from a mental health professional?

If a person says they are considering suicide:

- Take the person seriously
- Stay with them
- Ask questions about intentions, plans and means
- Help them remove lethal means
- Provide reassurance that help is available
- Call 988 or 911
- Escort them to mental health services or an emergency room

Emergency Medical Services, 911

If the situation is potentially life-threatening, **get immediate emergency assistance by calling 911**, available 24 hours a day. You can ask for a CIT officer (crisis intervention trained). Tell 911 if any weapons are involved.

988 Suicide & Crisis Lifeline

If you or someone you know is suicidal or in emotional distress, contact the 988 Suicide & Crisis Lifeline. The Lifeline provides 24/7, trained, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals in the United States. Call or text 988.

Some warning signs of mental health distress include:

- Feeling very sad, withdrawn or unmotivated (for more than two weeks)
- Planning to or trying to harm or kill oneself
- Out-of-control or risk-taking behaviors
- Overwhelming fear with a racing heart or fast breathing
- Sudden weight gain/loss or loss of appetite
- Severe mood swings
- Excessive use of drugs or alcohol
- Drastic changes in behavior, hygiene or sleeping habits
- Extreme difficulty in concentrating or staying still
- Intense worries or fears impacting daily activities

You've spotted the signs, but now what?

You can follow the Mental Health First Aid (MHFA) five-step action plan called ALGEE to help those who may be dealing with suicide, mental illness or substance use disorders. Here are the steps:

Assess for risk of suicide or harm – Some warning signs include threatening to hurt or kill oneself, seeking access to means to hurt or kill oneself, talking or writing about death and feeling hopeless.

Listen non-judgmentally – Use verbal and nonverbal skills such as open body posture, comfortable eye contact and other strategies to take part in appropriate conversation.

Give reassurance and information – Offer emotional support and practical help.

Encourage appropriate professional help – Types of professionals include primary care physicians, psychiatrists, social workers, counselors and certified peer specialists.

Encourage self-help and other support strategies – People with mental health challenges can support their own recovery and wellness through exercise, relaxation, meditation, participating in peer support groups and self-help books. (Give them this booklet!)

Seeking professional help can be overwhelming, but finding the right treatment can save someone's life. We hope this booklet will also help families to feel empowered and encouraged to self-assess their mental health status and get the help they deserve.



Here's another important resource to check out!

"Navigating a Mental Health Crisis: A NAMI Resource Guide for Those Experiencing a Mental Health Emergency" (Crisis Guide) provides important, potentially life-saving information for people experiencing mental health crises and their loved ones. This guide outlines what can contribute to a crisis, warning signs that a crisis is emerging, strategies to help de-escalate a crisis, available resources and so much more. It is available in English and Spanish. This is an EXCELLENT resource to review if you have someone in your life who has significant mental health challenges.

33-page PDF booklet available by google search: NAMI AND "mental health crisis" or <https://www.nami.org/Support-Education/Publications-Reports/Guides/Navigating-a-Mental-Health-Crisis>

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