

# LIVING WITH POST SEPSIS SYNDROME



**It was a few months  
after I was discharged  
from the hospital...**



**that I realized I still wasn't feeling well.**

I was always tired, and having recurrent throat and respiratory infections. I was grateful to be alive; and yet, really, really, sad. Guilt for feeling sad followed, and I was equally mentally and physically exhausted.

One desperate night I searched on Facebook for sepsis and toxic shock survivors. I private messaged anyone who had posted about either topic hoping to find someone to speak to; but my messages were swallowed by Facebook filters. Add loneliness to the list. I had never heard of the term, Post-Sepsis Syndrome, so I thought I was going crazy as well.

When I couldn't find it, I decided to try and build it. I wanted to be the support that I had so desperately searched for. I hope that the Begin Again Foundation can help provide that to you.

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Watching Audrey struggle after her hospitalization was hard on the entire family. It was a helpless feeling because there was nothing I could do beyond support her emotionally; but, having never gone through this myself, I didn't know the best way to do that.

*Marc & Audrey*

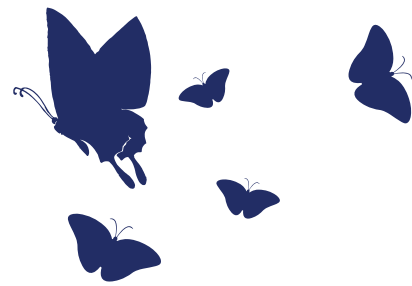
Marc & Audrey Leishman  
Founders of Begin Again Foundation



**Audrey Leishman**  
Sepsis Survivor



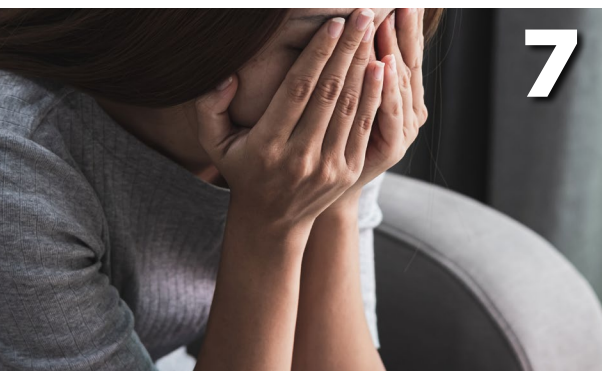
# LIVING WITH POST SEPSIS SYNDROME



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THE INFORMATION IN THIS BOOKLET IS FOR EDUCATIONAL AND INFORMATIONAL PURPOSES ONLY. IT IS NOT INTENDED TO BE A SUBSTITUTE FOR PROFESSIONAL MEDICAL ADVICE, DIAGNOSIS OR TREATMENT. ALWAYS SEEK THE ADVICE OF YOUR PHYSICIAN OR A QUALIFIED HEALTHCARE PROVIDER WITH ANY QUESTIONS CONCERNING ANY OF THE INFORMATION CONTAINED IN THIS BOOKLET.



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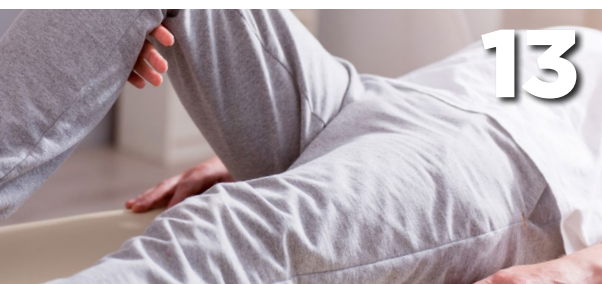
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**POST-SEPSIS  
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OVERVIEW**





**What is Post-Sepsis Syndrome (PSS)?**

**What are the symptoms of Post-Sepsis Syndrome?**

**Who is at risk for Post-Sepsis Syndrome?**

**What causes Post-Sepsis Syndrome?**

**Are there any Post-Sepsis Syndrome complications that are life-threatening?**

**Is Post-Intensive Care Syndrome (PICS) the same thing as Post-Sepsis Syndrome?**

**Is Post-COVID Syndrome (PCS) the same thing as Post-Sepsis Syndrome?**

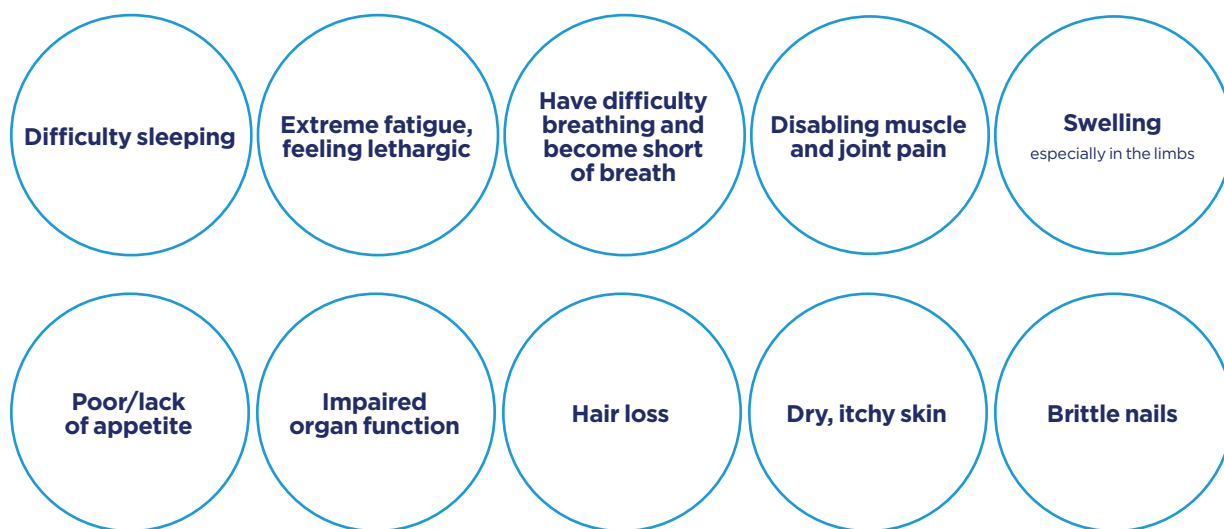
**Does Post-Sepsis Syndrome shorten your lifespan?**

# WHAT IS POST-SEPSIS SYNDROME (PSS)?

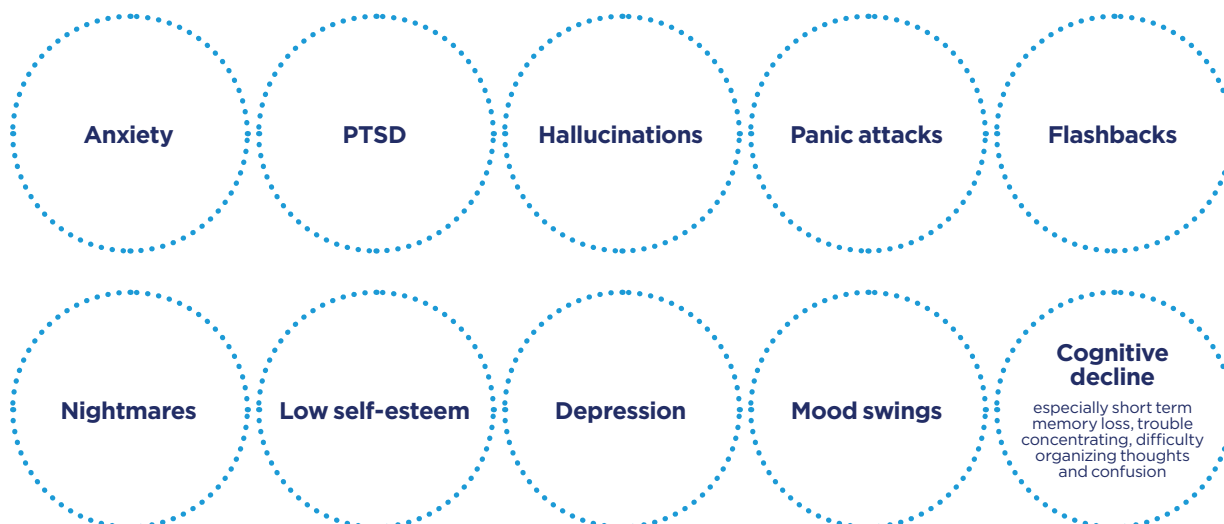
Post-Sepsis Syndrome consists of varied physical and psychological symptoms that persist long after discharge from the hospital. The intensity and duration of symptoms varies for everyone.

## WHAT ARE THE SYMPTOMS OF POST-SEPSIS SYNDROME?

### Physical



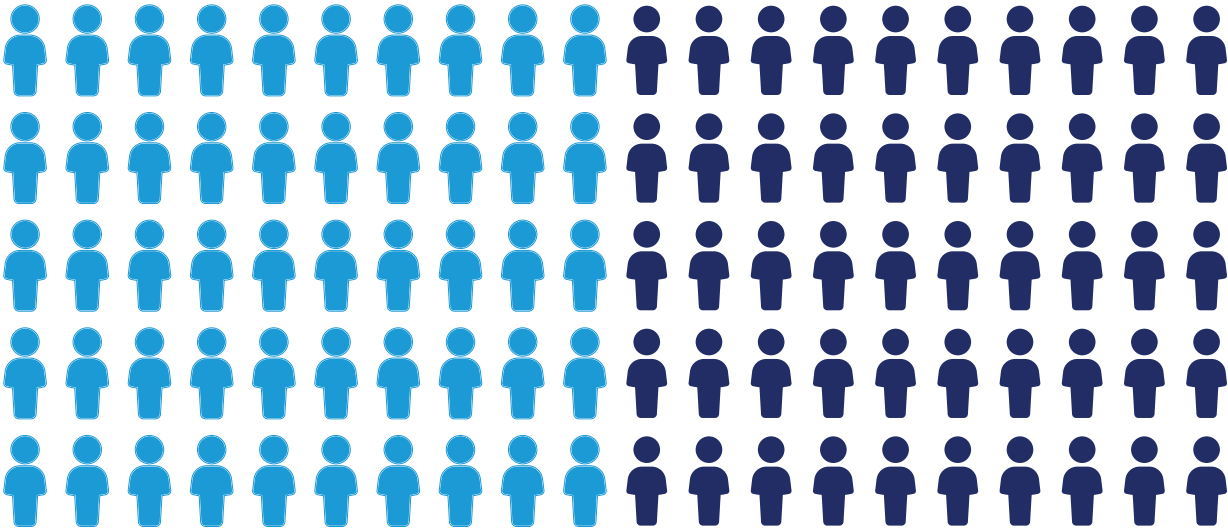
### Psychological/emotional





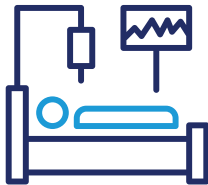
# WHO IS AT RISK FOR POST-SEPSIS SYNDROME?

All survivors are at risk.



Up to 50% of survivors will experience Post-Sepsis Syndrome.

Those at higher risk include survivors:



Admitted to the ICU



Age 65 and older



With preexisting medical conditions

# WHAT CAUSES POST-SEPSIS SYNDROME?

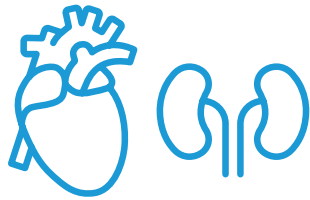
The exact cause is not known and needs further study.

Just like the symptoms of Post-Sepsis Syndrome being varied from person to person, so to may be its underlying cause in each patient. Some symptoms may be attributed to damage suffered from sepsis and its treatment. Others are thought to be related to a combination of factors like - pre-existing conditions, changes to the immune system, intestinal barrier dysfunction and potential negative changes to normal cell function.

# ARE THERE ANY POST-SEPSIS SYNDROME COMPLICATIONS THAT ARE LIFE-THREATENING?

While most symptoms of Post-Sepsis Syndrome aren't life-threatening, there CAN be long-term health complications to the function of your bodily systems.

You may experience:



## LONG-TERM Organ dysfunction

Chronic cardiovascular disease

Chronic lung disease

Chronic kidney disease



## LONG-TERM Worsening cognitive decline/ increased risk for

Dementia

Epilepsy

Parkinson's disease



## LONG-TERM Immunosuppression/ increased risk for

Infections

Gastrointestinal issues

Chronic inflammatory disease

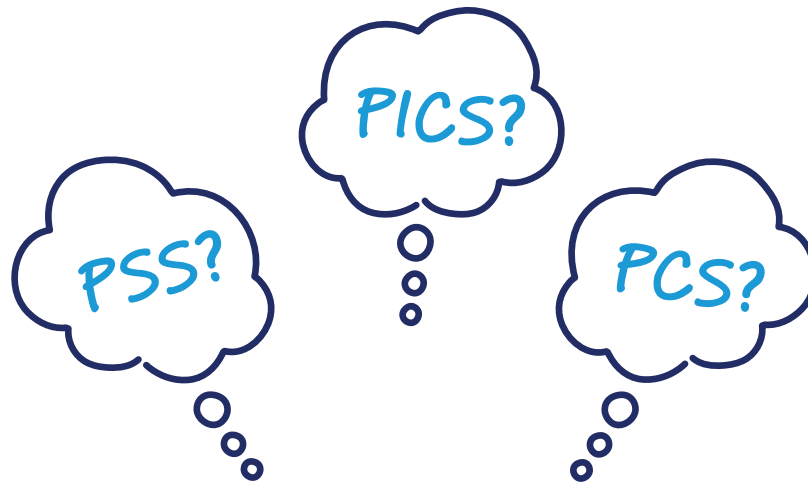


## LONG-TERM Muscular/skeletal

Weakness

Nerve damage

Dysphagia  
(difficulty swallowing)



## IS POST-INTENSIVE CARE SYNDROME (PICS) THE SAME THING AS POST-SEPSIS SYNDROME?

**No.**

They can overlap. They are related but distinct conditions. While PICS is limited to people treated in the ICU, Post-Sepsis Syndrome can occur in any individual who has been treated for sepsis regardless of an admission to the ICU.

## IS POST-COVID SYNDROME (PCS) THE SAME THING AS POST-SEPSIS SYNDROME?

**No.**

People who experienced severe cases of COVID-19 had viral sepsis. The symptoms are almost identical to Post-Sepsis Syndrome with the sometime addition of a loss to taste and smell or persistent cough. The medical community is still researching the relationship between the two syndromes.

## DOES POST-SEPSIS SYNDROME SHORTEN YOUR LIFESPAN?

**Not for everyone.**

While Post-Sepsis Syndrome mortality rate isn't well studied, the mortality rate for sepsis is up to 50% for those who experience septic shock. Current research shows varying rates of life expectancy after sepsis but indicate up to a third of survivors will die within a year of sepsis and up to half of survivors will die within 5 years.

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**POST-SEPSIS  
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TREATMENT  
OVERVIEW**





**What can I do if I think I have Post-Sepsis Syndrome?**

**How can I help my doctor?**

**What types of treatment and interventions might help me?**

**Are there other naturopathic treatments that might help me?**

**How can my loved ones help me with Post-Sepsis Syndrome?**

**How can I find a trauma informed therapist?**

## WHAT CAN I DO IF I THINK I HAVE POST-SEPSIS SYNDROME?

Use a care journal to document your symptoms and report them to everyone on your care team. Your family can also help you recognize and report symptoms. There is not a specific diagnostic test to identify Post-Sepsis Syndrome. Your provider will diagnose you based on symptoms and condition.

## HOW CAN I HELP MY DOCTOR?



There are many doctors who may not have much experience with Post-Sepsis Syndrome or who received little training on it.

- **Talk with them and give them information on Post-Sepsis Syndrome when you see them. You can give them a copy of this resource.**
- **Work with them to assess your symptoms and exclude other causes of the symptoms you are experiencing.**
- **Ask them to assess you and monitor for preventable causes of hospital readmission.**
- **Ask them to review and adjust any long-term medications.**
- **Work with them to refer you to other professionals to help manage or resolve your symptoms.**

# WHAT TYPES OF TREATMENT AND INTERVENTIONS MIGHT HELP ME?

Your treatment for Post-Sepsis Syndrome will be individualized to the symptoms you are experiencing. With time, treatment and support many of the symptoms of Post-Sepsis Syndrome can resolve or improve. Treatments should address both your physical and mental health.

This could include some of the following:



## Medicine

Use of both prescription and over-the-counter medicines to relieve both physical and mental health symptoms.



## Physical Therapy

Optimizes or regains functional mobility and strength while also providing education and training to family and caregivers. This can help with joint pain, fatigue and overall physical wellbeing.



## Occupational Therapy

Optimizes or regains functional mobility in activities of daily living using adaptive techniques and tasks to maximize independence. This includes techniques to bathe, groom, dress and toilet independently.



## Speech Therapy

Optimizes or regains both cognitive and communication/speech deficits. Also treats issues with eating/swallowing. Treatment may include: cognitive-communication therapy to help attention and problem-solving, memory strategies and attention/concentration therapy.



## Dietician/Nutritionist

Optimizes diet to support recovery and overall wellbeing. Nutritional strategies may include: anti-inflammatory foods, targeted protein intake, antioxidant rich foods and optimal hydration.



## Counseling/Psychotherapy

Trauma-informed mental health understands the multiple coping mechanisms survivors may employ in response to medical trauma. Treatment may include: cognitive behavioral therapy, eye movement desensitization, reprocessing and sensorimotor therapy and group therapy/support groups.

# ARE THERE OTHER NATUROPATHIC TREATMENTS THAT MIGHT HELP ME?

Yes. Naturopathic Doctors (ND) take a holistic approach to patient care, emphasizing prevention and the body's own self-healing process. After examining and reviewing your case, they may recommend additional interventions to assist in your recovery. It is important to keep both your ND and the other doctors/therapists you are seeing informed on all treatments you are doing so they can work collaboratively. This is especially true with any diet, supplements, herbs and medicines you are taking to avoid any unwanted reactions.

Naturopathic interventions may include:



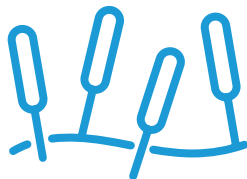
## Nutrition, supplements & herbs

to optimize the body's self-healing process.



## Hydrotherapy

for improved circulation and stress reduction



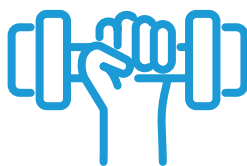
## Physical Medicine Therapies

like acupuncture and massage therapy involving manipulation of soft tissue, muscles and bones to address both physical and mental health injuries.



## Mind-Body techniques

like meditation, breathing exercise, yoga and biofeedback to help with PTSD, depression and anxiety.



## Lifestyle changes

like regular exercise, help with sleep routines and establishing healthy habits you can implement to reduce risk of future reinfection.



# HOW CAN MY LOVED ONES HELP ME WITH POST-SEPSIS SYNDROME?

Having the support of loved ones can be very helpful. First, encourage them to learn about Post-Sepsis Syndrome and share what symptoms you are experiencing with them. Sharing with them can help you know that you are not alone.

Then let them help you with:

- **Daily physical challenges**

Let them cook, clean, drive or do any task that you are not able to do yet independently.

- **Medical appointments**

Let them act as a second set of eye and ears by taking notes, asking questions and being a moral support for you.

- **Empathy and encouragement**

Let them help you with self-care and participate in activities that you enjoy – like a movie night, or a spa treatment, a drive or an outing to a park.

- **Social connection**

You may feel isolated and have anxiety about being out. Let them help you visit and get back out to your favorite spots that are within your energy and comfort level.



# HOW DO I FIND A TRAUMA-INFORMED THERAPIST?

While there isn't a national database specifically dedicated to trauma-informed therapist, there are resources and directories out there who can help you.

Here are a few:

**Call your insurance provider to ask for a list of providers in your area.**

## Psychology Today

**Psychology Today**

[www.psychologytoday.com/us/therapists/trauma-and-ptsd](http://www.psychologytoday.com/us/therapists/trauma-and-ptsd)

## GoodTherapy®

**Good Therapy**

[www.goodtherapy.org](http://www.goodtherapy.org)

## FindTreatment.gov

**Find Treatment**

[findtreatment.gov](http://findtreatment.gov)  
[findtreatment.gov/state-agencies](http://findtreatment.gov/state-agencies)

## **SAMHSA** Substance Abuse and Mental Health Services Administration

**SAMHSA**

Substance Abuse and Mental  
Health Services Administration

[www.samhsa.gov/find-support](http://www.samhsa.gov/find-support)

National Helpline  
1-800-662-HELP

## **HRSA**

Health Resources & Services Administration

**HRSA**

Health Resources &  
Services Administration

[findahealthcenter.hrsa.gov](http://findahealthcenter.hrsa.gov)

## Trauma Therapist Network

**Trauma Therapist Network**

[www.traumatherapistnetwork.com](http://www.traumatherapistnetwork.com)



## IMPORTANT

If you ever feel  
like you may hurt yourself  
or others, or have thoughts  
about suicide  
**get help right away!**



**Go to your nearest  
emergency department/location**

or contact



In a crisis?

**Text HOME to 741741**  
to connect with a  
volunteer Crisis  
Counselor

**CRISIS TEXT LINE |**

# WE SURVIVED SEPSIS.



**Sepsis can be treated easily if caught early.**

Scan, download resources like this in our resource library and share with your family and friends.

[beginagainfoundation.com/resource-library](https://beginagainfoundation.com/resource-library)

## **UNINSURED MEDICAL EXPENSES OR CASE MANAGEMENT ISSUES**

Our Leishline grant and case management programs may be able to help.

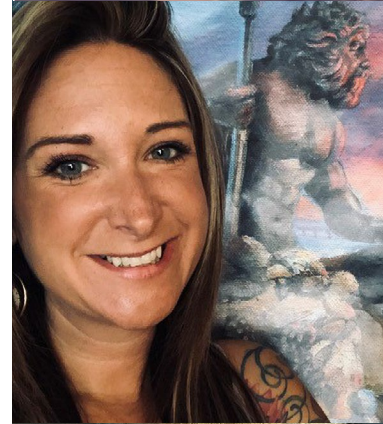
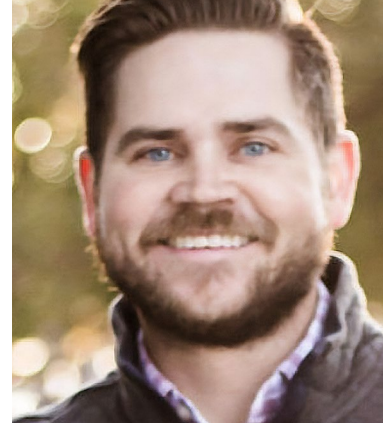
[beginagainfoundation.com/leishline](https://beginagainfoundation.com/leishline)

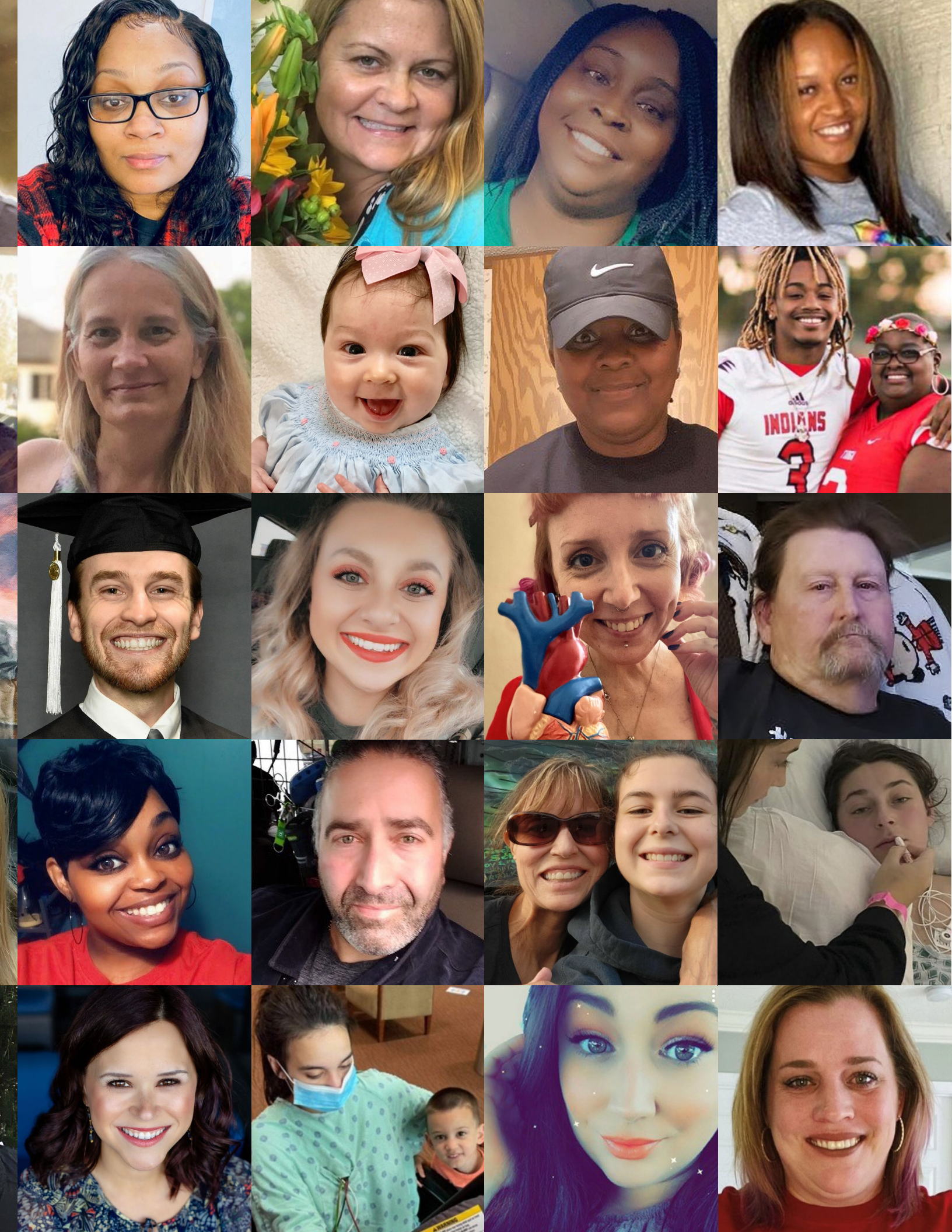
## **GENERAL INFORMATION**

[info@beginagainfoundation.com](mailto:info@beginagainfoundation.com)

[www.beginagainfoundation.com](https://www.beginagainfoundation.com)

**Begin Again Foundation is committed to helping survivors on their road to recovery!**







**BEGIN AGAIN FOUNDATION**

Saving lives. Supporting survivors.