

# WHAT TO EXPECT AFTER DISCHARGE FROM ICU



**We are so thankful  
you're here to  
read this letter!**





**You've just fought and won the battle of your life.**

I needed community. I needed support from others who could understand what doctors seemingly didn't. We want you to know that you have a wealth of resources to support you during your recovery and we hope that the Begin Again Foundation can be one of them.

*Marc & Audrey*

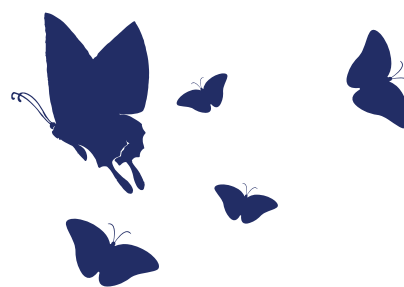
Marc & Audrey Leishman  
Founders of Begin Again Foundation



**Audrey Leishman**  
Sepsis Survivor



# WHAT TO EXPECT AFTER DISCHARGE FROM ICU



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## **DISCHARGE FROM THE INTENSIVE CARE UNIT**

Why am I being discharged from the ICU?

What if I'm not sure I'm ready?

What is a Step-Down Unit?

What happens while I'm in a Step-Down Unit?

What questions should I ask about my discharge from the ICU?

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## **DISCHARGE HOME**

What happens once I get home?

What is a discharge plan?

What is included in a discharge plan?

What questions should I ask about my discharge plan?

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## **ONCE AT HOME**

What happens once I am home?

Should I continue to keep a care journal/diary?

What else can I do to help my recovery?

I am concerned, when should I reach out to my care team?

Should I talk to a counselor or therapist?

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## **LONG LASTING EFFECTS OF SEPSIS**

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What are the symptoms of Post-Sepsis Syndrome?

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

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# **DISCHARGE FROM THE INTENSIVE CARE UNIT**





**Why am I being discharged from the ICU?**

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**What is a Step-Down Unit?**

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**What questions should I ask about my discharge from the ICU?**

## **WHY AM I BEING DISCHARGED FROM THE ICU?**

### **You are recovering!**

Your care team has looked at your vitals and determined you no longer require the level of specialized care, monitoring and organ support the ICU offers. This doesn't mean, however, that you are ready to go home just yet.

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## **WHAT IF I'M NOT SURE I'M READY?**

### **Talk to your doctors.**

Your body has been through a lot. You may have spent some time in a medically induced coma to help your body rest and focus on healing. You were under the influence of very strong drugs, and you may still be letting their effect dissipate. You have also made some great gains – improved breathing, maintaining a stable blood pressure and heart rate, better organ function and fighting off infection. You may have noticed you are attached to fewer and fewer monitors and machines! They will discuss what your next step is in your recovery. You will most likely be sent to a Step-Down Unit in the hospital.

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## **WHAT IS A STEP-DOWN UNIT?**

### **These units provide an intermediate level of care.**

Here you will continue to receive close monitoring and therapy to ensure you continue in your recovery.

*Also known as intermediate care unit or transitional care unit.*

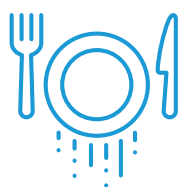


# WHAT HAPPENS WHILE I AM IN A STEP-DOWN UNIT?

## Your strength and stamina will continue to recover.

It will take time, patience and mostly likely physical/occupational/speech therapy to assist in making gains. You will have lost approximately 2% of your muscle mass each day during your illness.

## You will also work to make gains in your:



### Appetite

The care team may be weaning you from supplemental tube feedings and beginning to transition your diet back to solid foods. They will be monitoring how your gastrointestinal tract is digesting and processing more solid foods. You may also have medications that impact your appetite, cause nausea and changes in taste.



### Cognition

Along with memory, you may find it difficult to concentrate, organize, problem solve, make decisions and recall the 'right' word when talking. Time and therapy will assist in improving your cognitive function.



### Hearing and Vision

Some patients experience varying degrees of hearing and vision loss.



### Emotional

You will experience many emotions during your hospital stay. All are valid. You may benefit from psychotherapy/counseling to help with the powerful emotions that surface. These can include feelings of depression, frustration, anxiety, anger, isolation, strain with loved ones, gratitude to be alive, and any possible guilt that you may have. If you are feeling any of these, ask the care team to have mental health services begin seeing you.

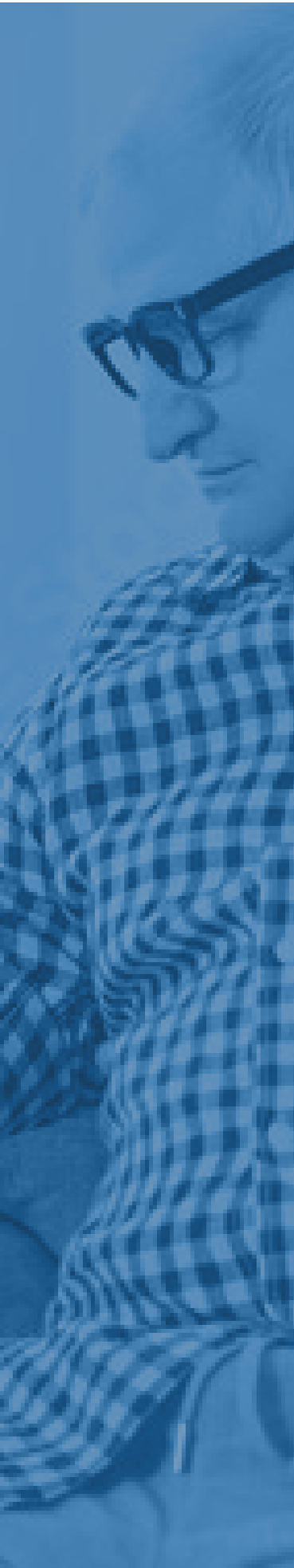






**WHAT TO  
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FROM ICU**

**DISCHARGE  
HOME**



**What happens once I get home?**

**What is a discharge plan?**

**What is included in a discharge plan?**

**What questions should I ask about my discharge plan?**



## WHAT HAPPENS ONCE I GET HOME?

**You will continue to experience physical and emotional effects.**

You were very ill, and it will take time for you to recover. Discharge home does not mean that your recovery is complete. Don't rush. You will work with the care team to create a discharge plan. You will receive homecare instructions to continue to make gains outside the hospital. Having experienced sepsis is scary and traumatic for you, your family and for your loved ones. You will need the support of those close to you.

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## WHAT IS A DISCHARGE PLAN?

**It is your individualized outline of continued treatments and medicines to ensure a smooth transition home and continued progress in your recovery.**

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## WHAT IS INCLUDED IN A DISCHARGE PLAN?

### Medicines

Your care team will give a list of medicines.

It is important to understand the purpose of each medicine prescribed and the instructions on when and how to take it.

### Home health:

Your care team may set you up with home health care visits – these may help with:

#### Wound care

If you have sutures or wound sites that need continued care, you may receive home health visits, or you will be given instructions on how to clean and care at home.

Make sure to review instructions on how and when to change the dressing on your wound. Make certain to wash your hands before and after changing your dressing.

#### IV medicines

Your care team may send you home with an IV port for continued intravenous delivery of medicine. Make sure you understand how to keep your IV site clean and dry.

## Follow-up visits

Your care team will give you instructions on follow up appointments. These could include appointments with several different disciplines just like in the hospital.

Make sure you understand who you need appointments with and how soon after discharge you should be seen. Often your first follow up appointments will be made for you by hospital staff.

**Make sure you have the names and contact information for the providers you need to follow up with.**

## Therapy

You may be followed by physical, occupational and speech therapies either in home or on an outpatient basis to help with regaining independence, strength and overall wellbeing.

## Home adaptive equipment

Your care team will assess how much help with daily activities you will need assistance with. Be sure to talk with team about the physical needs around your house – stairs, if you have someone who will be available to help you, height of beds, bathroom configuration and more. This will help determine what equipment may be needed to help you. A few you may need include:

- **A raised toilet seat**
- **A wheelchair, walker, crutches or other device to help with mobility**
- **A shower chair**

## Restrictions

Your care team will give you a list of activity restrictions. These could include:

- **Driving**
- **Operating machinery**
- **Putting your full body weight on your feet**
- **Lifting anything over a designated weight**
- **No rigorous exercise**
- **Diet restrictions**

## Complications

Your care team will also give you guidance on what the possible complications are - like new or worsening symptoms and when to seek immediate medical attention.

**If you have any concerns at any time, call your provider or go to your closest emergency department.**

# WHAT QUESTIONS SHOULD I ASK ABOUT MY DISCHARGE PLAN?

**ANY question you have!**

Here a few to consider:

- **Who is my primary point of contact for any concerns about my progress at home?**
- **Do I have all the adaptive equipment that I need to take care of myself? Or for others to care for me at home?**
- **Have we both received instructions on how to use it?**
- **Do I know all the medications I will need at discharge?**
- **Will I be leaving the hospital with my medications, or have they been called into a pharmacy of my choosing?**
- **Do I understand what the medicines are for?**
- **Do I have all of the follow-up appointments that I need?**
- **Do I have any follow-up tests or labs?**
- **Are there any results from previous tests or labs pending?**
- **What do I do if I am struggling at home?**
- **What physical and emotional changes should I report?**
- **Do I need someone with me at all times?**
- **Will I be receiving any home health services?**

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**WHAT TO  
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**ONCE  
AT HOME**







**What happens once I am home?**

**Should I continue to keep a care journal/diary?**

**What else can I do to help my recovery?**

**I am concerned, when should I reach out to my care team?**

**Should I talk to a counselor or therapist?**

## WHAT HAPPENS ONCE I AM HOME?

### Follow your discharge plan.

Make sure you have any medicine and follow up appointments scheduled. Then give yourself time.

## SHOULD I CONTINUE TO KEEP A CARE JOURNAL/DIARY?

### Yes. It is helpful to keep a home journal similar to the one used during your stay at the hospital.

Use it to record how your days/night are going, how you are feeling and questions that come up to ask your care team.

## WHAT ELSE CAN I DO TO HELP MY RECOVERY?

A few suggestions are:



### Practice good hygiene

Bathing, toileting, washing hands, and oral care.



### Allow yourself to rest and rebuild your strength.



### Stay hydrated!

Keep your urine a pale yellow.



### Set small achievable daily and weekly goals

Let any of your therapists help set these goals. Examples: take a shower or bath, dressing yourself, getting up and taking short walks around your home or outside.



### Use your care journal

Record some basic information like— what you ate, your temperature, your energy level, and how you are sleeping.



### Talk to your family and friends about your feelings.

Include these thoughts in your care journal.



### Record the contact information of everyone involved in your care

Names and phone numbers. And have it easily accessible.



### Keep track of updates to your treatment and ask questions

If possible, have someone with you at your appointments to help you.

# I AM CONCERNED. WHEN SHOULD I REACH OUT TO MY CARE TEAM?

**Anytime! If you have a concern, share it with your care team.**

Here are some things you should communicate to your primary physician:

**If you or others observe:**

- You are talking/communicating less.
- You require more help with daily activities.
- You have new or worsening pain.
- You have a decrease in appetite and/or drinking less fluid.
- You have a decline in bowel and urine output.
- You become more agitated or nervous.
- You have changes in skin color or condition.
- You notice any worrying effects of prescribe medicines.



If you experience any  
of the following  
**get help right away!**



difficulty breathing



rapid or slow heart rate



change in mental  
status (confusion or  
hallucinations)



fever or low body  
temperature



an infection doesn't  
appear to be improving  
or is becoming worse



no bowel movements in  
three days or diarrhea



have thoughts about  
hurting yourself or others

# SHOULD I TALK TO A COUNSELOR OR THERAPIST?

**Yes. Your emotional health is just as vital as your physical health.**

Talking with a professional can help you process the medical and emotional trauma you experienced. Look for a trauma informed therapist. These therapists are trained at treating all the symptoms and conditions resulting from trauma. They have insight on the impact trauma has on your physical and emotional health and recognize that parts of your recovery can be retraumatizing for both you and your loved ones. You can ask your hospital care team for a referral or search for you own at the **Trauma Therapist Network**.

## Trauma Therapist Network

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

It is very common to experience many emotions and to be unsure of yourself. You don't have to work through them alone.

You may also experience:

- **Wanting to be alone and avoiding friends and family.**
- **Feeling anxious out in public spaces.**
- **Depression, anger and unmotivated.**
- **Frustration with yourself and the progress of your recovery.**

## Psychology Today

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

## Good Therapy

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

## Find Treatment

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

## 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

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



## 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 |**



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**LONG LASTING  
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**What is Post-Sepsis Syndrome?**

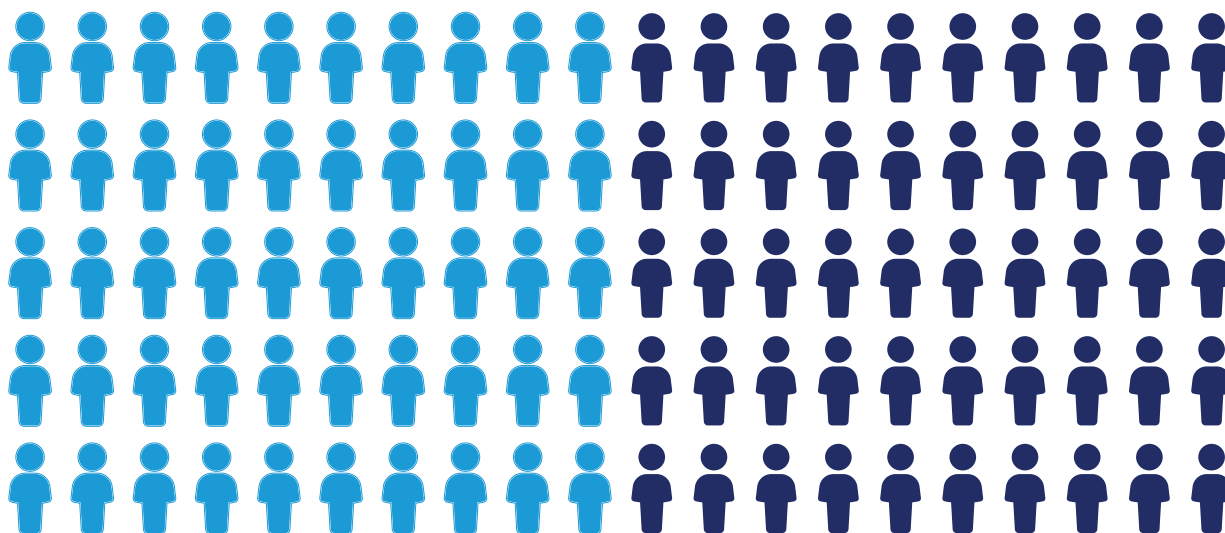
**What are the symptoms of Post-Sepsis Syndrome?**

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

## WHAT IS POST-SEPSIS SYNDROME?

Many people have a full recovery from sepsis and their lives continue as they did before sepsis. However, up to half of sepsis patients continue to have long-term effects. The intensity and duration of these effects varies for everyone. This is known as Post-Sepsis Syndrome. There are services and interventions to help with Post-Sepsis Syndrome.

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



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

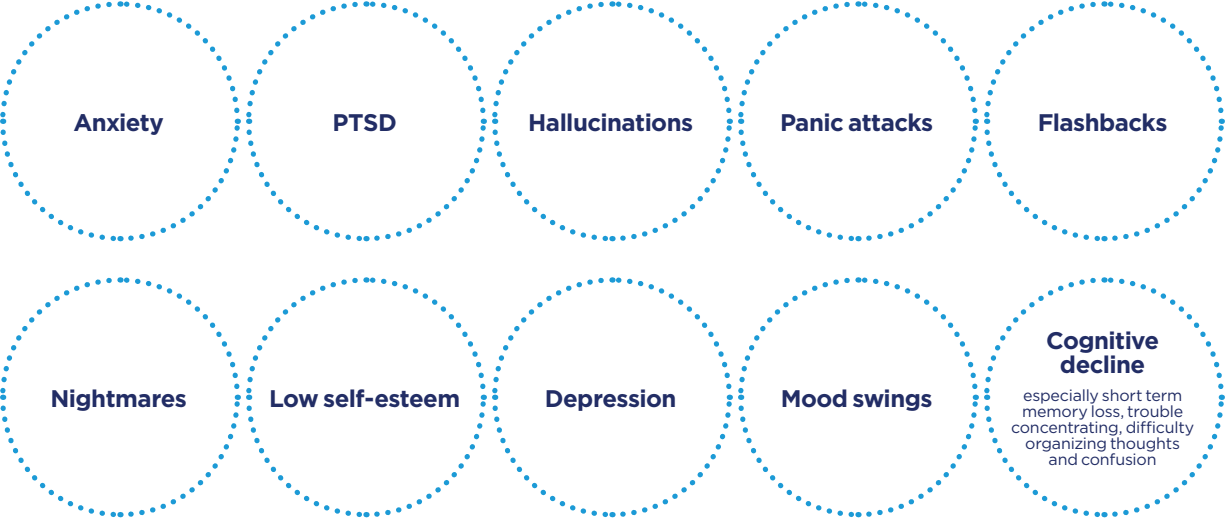
- Use your care journal to document your symptoms.
- Report all symptoms to your care team to discuss any needed medical interventions.
- Find a trauma informed therapist if you are not already being seen by a mental health professional.
- Find/join a support group.

# WHAT ARE THE SYMPTOMS OF POST-SEPSIS SYNDROME?

## Physical



## Psychological/emotional



# 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](http://beginagainfoundation.com/resource-library)

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

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

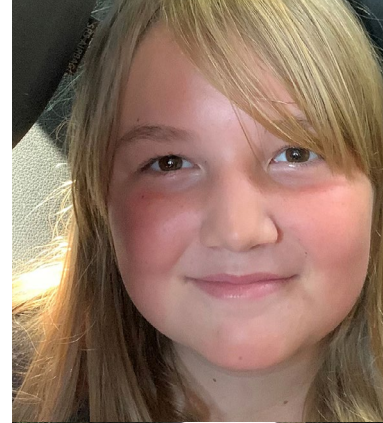
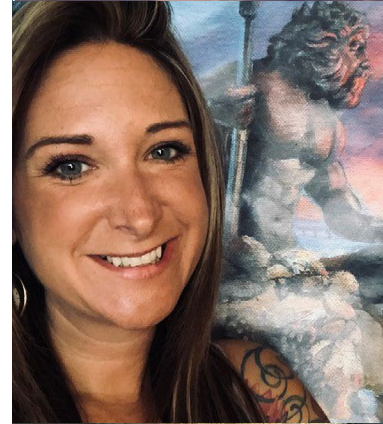
[beginagainfoundation.com/leishline](http://beginagainfoundation.com/leishline)

## **GENERAL INFORMATION**

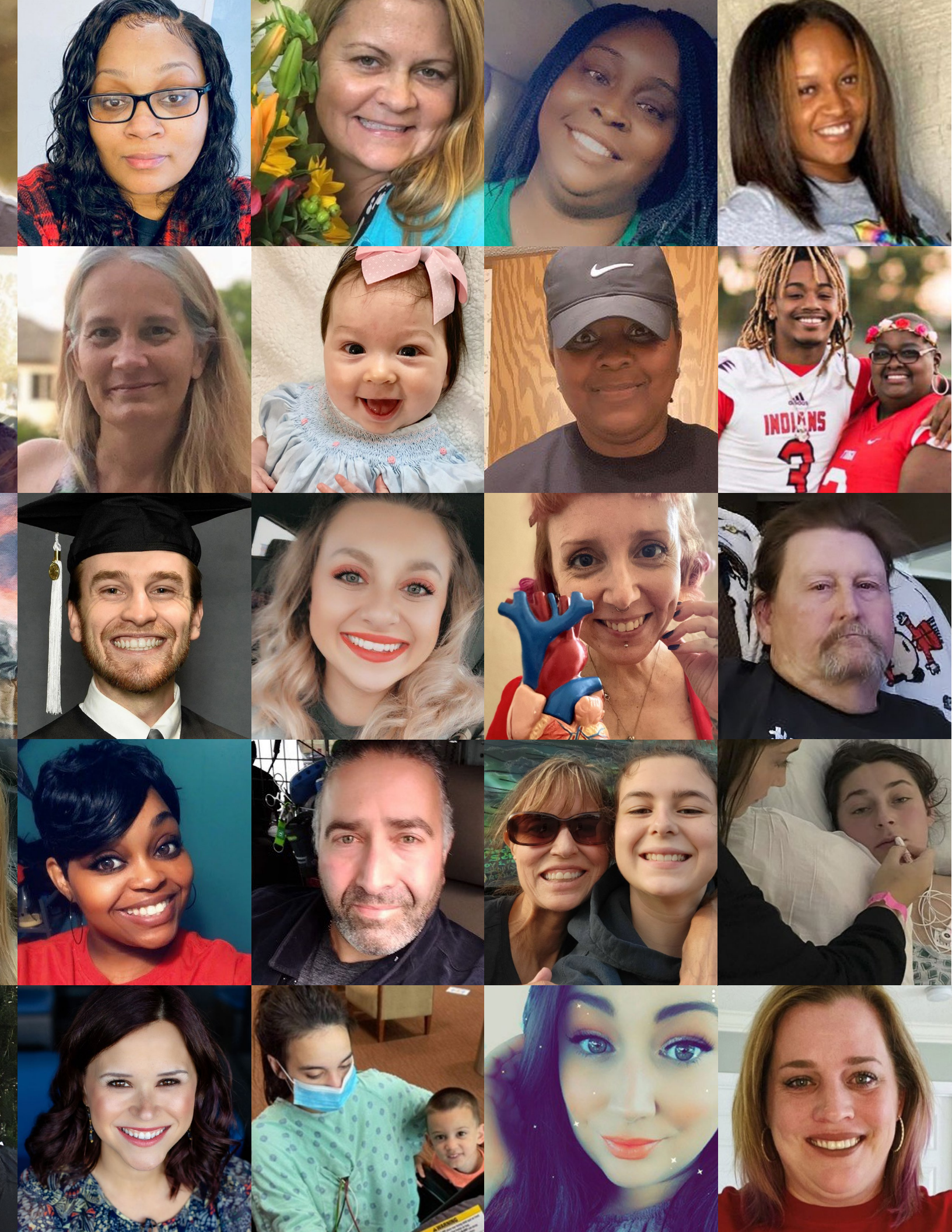
[info@beginagainfoundation.com](mailto:info@beginagainfoundation.com)

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

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











**BEGIN AGAIN FOUNDATION**

Saving lives. Supporting survivors.