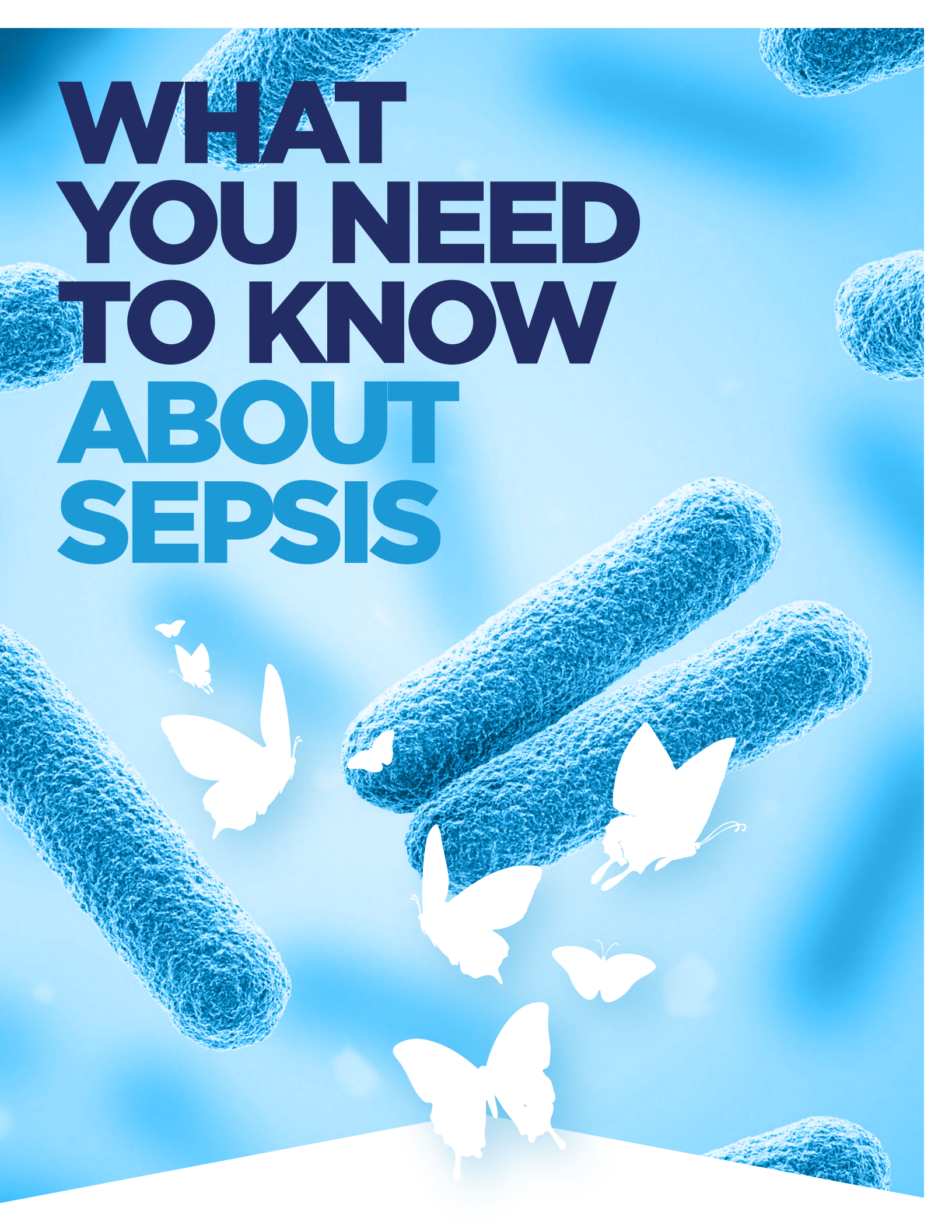


WHAT YOU NEED TO KNOW ABOUT SEPSIS



If you're reading this...





You have been affected by sepsis.

We understand how scary this time is for your family. You may not have even heard the word “sepsis” before. When Audrey got sick, we hadn’t. It wasn’t until Audrey read her discharge paperwork that we decided to educate ourselves on it. We want to alleviate some of your burden with this comprehensive guide on what sepsis is.

Marc & Audrey

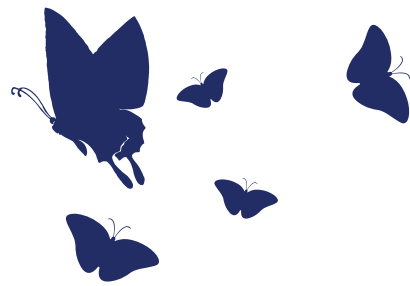
Marc & Audrey Leishman
Founders of Begin Again Foundation



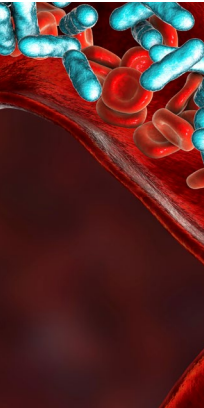
Audrey Leishman
Sepsis Survivor

WHAT YOU NEED TO KNOW ABOUT SEPSIS

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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.





SEPSIS OVERVIEW

What is sepsis?

Who is at risk?

How does it start?

What are the most common causes of sepsis?

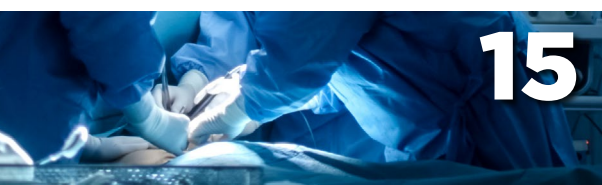
How is it spotted and diagnosed?

What are the stages of sepsis?

Who is on your Care Team?

Should I keep a care journal/diary?

What questions should I ask my care team?

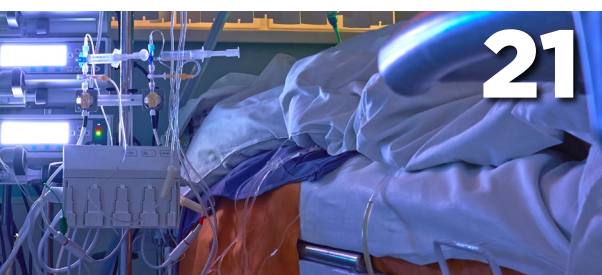


TREATMENT OVERVIEW

How is sepsis treated?

What interventions are used to treat sepsis?

What questions should I ask my care team?



RECOVERY OVERVIEW

What happens when I wake up from a medically induced coma?

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 am in a Step-Down Unit?

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



DISCHARGE OVERVIEW

What happens once I get home?

What is a discharge plan?

What is included in a discharge plan?



AFTERCARE OVERVIEW

What happens once I am home?

Should I continue to keep a care journal?

What else can I do to help my recovery?

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



LONG-TERM CARE OVERVIEW

Should I talk to a counselor or therapist?

What are any long-term effects of sepsis?

What is Post-Sepsis Syndrome?

What questions should I ask my care team?

**WHAT
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**SEPSIS
OVERVIEW**





What is sepsis?

Who is at risk?

How does it start?

What are the most common causes of sepsis?

How is it spotted and diagnosed?

What are the stages of sepsis?

Who is on your Care Team?

Should I keep a care journal/diary?

What questions should I ask my care team?

WHAT IS SEPSIS?

Sepsis is a life-threatening immune response to an infection in the body that quickly leads to tissue damage, organ failure and death.

Alternative names: Septicemia, Sepsis Syndrome

WHO IS AT RISK?

Anyone.

There are higher risk groups that should be especially vigilant and include those:



over the age of 65



with chronic illness



premature, newborn and under one year old

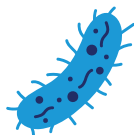


who are immunocompromised or with a weakened immune system

HOW DOES IT START?

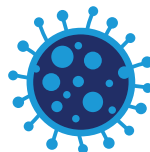
It starts with any infection.

WHAT ARE THE MOST COMMON CAUSES?



Bacterial infections

UTIs, Pneumonia, wound infections, MRSA, Meningitis



Viral infections

Flu, Pneumonia, Herpes Virus, Epstein-Barr



Fungal infections

Candida, Aspergillosis, Pneumonia

Sepsis isn't caused by the infection itself. Instead, it begins with an overreaction in our own immune response.

Our immune system is designed to detect intruders or harmful microbes that cause infection. Throughout our lives, our body's natural defenses fight these intruders effectively without needing additional medical intervention. However, with sepsis, your immune system's release of chemical mediators to combat the infection goes unchecked and triggers an overwhelming inflammatory response.

This 'friendly fire' inflammatory response creates blood clots, leaky blood vessels and reduces blood flow throughout your body. When blood flow is impaired, your limbs and organs don't get the nutrients and oxygen they need. This quickly leads to tissue damage, organ failure and death.

HOW IS IT SPOTTED & DIAGNOSED?

Sepsis can be hard to spot in its early stage because its symptoms can mimic other illnesses – especially the flu or gastrointestinal issues.

Additionally, the medical community, with gains in knowledge about sepsis, continue to debate and modify the definition. Currently, there is no 'gold standard' diagnostic test for sepsis.

Thus, it is important to know the symptoms and seek medical attention when you recognize them in yourself or another and tell a medical professional—I suspect SEPSIS!

Although a single diagnostic test does not exist, many hospitals have protocols in place to alert them to sepsis.

They measure:



Vital signs

Heart rate, respiration rate, body temperature and blood pressure



Lab work

Urine or stool samples, wound culture (taking tissue, skin or fluid from injury site), respiratory secretion testing (taking a sample of saliva, phlegm or mucus) or blood samples to look for markers of an over-reactive immune system



Imaging studies

X-rays, ultrasound scan, Computerized Tomography scan (CT) or Magnetic Resonance Imaging (MRI)

Think S-E-P-S-I-S



Shivering
Fever or Very Cold



Extreme
Pain or Discomfort



Pale
or Discolored Skin



Sleepy,
Difficult to Wake or Confused



I
Feel Like I May Die



Short
of Breath

WHAT ARE THE STAGES OF SEPSIS?

Many clinicians divide sepsis into three stages.



**INFECTION
+ 2 ABNORMAL VITALS**

COMMON ABNORMAL VITALS

>90
BEATS
/MIN



>20
BREATHS
/MIN



▲101°F
▼96.8°F



The first stage is referred to as **Sepsis**. An underlying infection causes overwhelming inflammation in your body. Abnormalities in vital signs will appear - commonly seen are a very low or high white blood cell count, very low or high body temperature, high respiratory rate (shortness of breath), changes to mental alertness (sleepy, difficult to rouse, confused) and severe pain.



SEVERE SEPSIS

**INFECTION
+ ABNORMAL VITALS
+ ORGAN DYSFUNCTION**

The second stage is referred to as **Severe Sepsis**. This means acute organ dysfunction is detected along with low blood pressure and/or decreased blood flow to organs. Organ dysfunction is characterized by decreased urine output, sudden changes in mental state, abnormal heart function and pain (most commonly in the abdomen).



SEPTIC SHOCK

**INFECTION
+ ABNORMAL VITALS
+ ORGAN DYSFUNCTION
+ VERY LOW BLOOD PRESSURE**

The third stage is referred to as **Septic Shock**. Symptoms are similar to severe sepsis but now with a significant drop in blood pressure. This drop in blood pressure can quickly lead to heart failure, stroke, organ failure and impair respiratory function.

WHO IS ON MY CARE TEAM?

The treatment of sepsis can involve many disciplines, including but not limited to:

- infectious disease
- cardiology (heart)
- pulmonology (lung)
- gastroenterology (digestive tract)
- surgery
- physical/occupational/speech therapy
- wound care
- respiratory therapy
- nursing



This can quickly become overwhelming for the patient, family and loved ones. The care team is there to help you and those you designate, understand your diagnosis and treatment.

Have questions? Don't be afraid to ask!

**WHAT
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ABOUT
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**TREATMENT
OVERVIEW**





How is sepsis treated?

What interventions are used to treat sepsis?

What questions should I ask my care team?

HOW IS SEPSIS TREATED?

The care team will individualize a treatment plan for you.

Depending on how advanced the case of sepsis is (Stage 1, 2 or 3), the treatment may occur in the Intensive Care Unit (ICU) where the care team will monitor you closely and respond quickly to any changes in your status. This unit is where patients are treated when they require support for their major organs.

WHAT INTERVENTIONS ARE USED TO TREAT SEPSIS?

Medications

Antibiotics

Although any infection can turn into sepsis, the most common cause is bacteria. Initially a broad-spectrum antibiotic may be started and then switched to a more targeted antibiotic once testing confirms source and type of infection. These are most often administered intravenously (directly to a vein)

Antifungals

In the case of fungal infection, the care team may administer antifungals to combat the underlying infection. These are most often administered intravenously (directly into a vein).

Antiviral

In the case of viral infection, the care team may administer antivirals to combat the underlying infection. These are most often administered intravenously (directly into a vein).

Other medications

- **Insulin** for blood sugar levels
- **Painkillers** for pain management
- **Corticosteroids** for inflammation

Fluids

Medications alone may not be enough to combat sepsis, especially its impact on a patient's blood pressure. Intravenous fluids are often given. Fluids help to increase blood volume and prevent dehydration. Both help keep blood pressure stable and help support organ function.

Supportive Care

- **Oxygen through nasal cannula, mask or with a mechanical ventilator**

This therapy helps raise the amount of oxygen the lungs receive and in turn is delivered to your blood supply and organs.

- **Blood transfusions**

This can be employed to help if there is a low red blood cell count (anemia).

- **Dialysis**

This supports kidney function.

- **Feeding tube**

To help maintain proper nutrition.

Vasopressors

Vasopressors are used to treat life-threatening, dangerously low blood pressure. Low blood pressure makes it harder for your blood to carry oxygen and nutrients throughout the body and especially to vital organs. Vasopressors help increase blood pressure by narrowing blood vessels. This helps organs get the nutrients and oxygen they need to continue working. The use of vasopressors may affect the blood supply to a patient's limbs. In severe cases this can lead to fingers, toes or whole limbs becoming irreversibly necrotic (dead) and amputation may be required.

Sedation

Varied levels of sedation may be used to help treat sepsis. They may be used to assist with pain management and anxiety or if the patient is disoriented and exhibiting behavior that could cause further injury. If mechanical ventilation with a breathing tube is required, the patient will most likely be placed in an induced coma using sedation. This helps minimize vital body functions so the body can rest and heal.

Surgery

Surgery may be required during treatment. Two common reasons for surgery are to remove sources of infection like an abscess (a pocket of puss inside your body) or to repair a hole (gastric perforation) in the gastrointestinal tract.

**WHAT
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RECOVERY OVERVIEW





**What happens when I wake up
from a medically induced comma?**

Why am I being discharged from of the ICU?

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

What is a Step-Down Unit?

What happens while I am in a Step-Down Unit?

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

WHAT HAPPENS WHEN I WAKE UP FROM A MEDICALLY INDUCED COMMA?

Remember you are coming out of a medical trauma and your recovery, like your treatment, is a process. Being brought out of a medically induced coma is a gradual process. Your sedatives are very strong, and they will be reduced slowly as your care team monitors your response. You will regain consciousness slowly. The effects of these drugs will take time to dissipate. Many patients experience Post-Intensive Care Syndrome (PICS).

Symptoms of PICS include:

Pain

While under you were pain free, as you wake up there may be pain and discomfort – especially in the joints. The care team will continue to help address your pain.

Memory loss

You may have no memories or only small snippets of memories that are jumbled and hazy. As you heal, some memories may return, or you may never recall parts of your hospital stay.

Confusion and Hallucinations

Delirium, especially in the first week(s) of coming out of a medically induced coma is very common. Patients may hallucinate, be very agitated and experience nightmares.

Difficulty sleeping

The body's ability to sleep has been greatly impacted. The confusion, anxiety, agitation, possible nightmares and hospital monitoring schedule and environment – often make sleep difficult.

Weakness and Fatigue

Your strength and stamina have been working to recover from sepsis. It will take time, patience and most 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.

Appetite

The care team may be weening 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.

Cognitive

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.

Hair Loss

Many patients experience significant hair loss and changes to hair texture as a response to the medical trauma the body has come through.

Emotional

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

WHY AM I BEING DISCHARGED FROM OF 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.

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 Unity in the hospital.

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, therapy will help you safely regain your strength and endurance.

**WHAT
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DISCHARGE OVERVIEW





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.

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.

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?

Again - 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 I need to take care of myself?
- Has everyone involved with my home care received instruction on how to use it?
- Do I know all 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 I need?
- Do I have any follow-up tests or labs?
- Are there any results of previous test 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?

**WHAT
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AFTERCARE OVERVIEW

What happens once I am home?

Should I continue to keep a care journal?

What else can I do to help my recovery?

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

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

**WHAT
YOU NEED
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SEPSIS**



LONG-TERM CARE OVERVIEW





Should I talk to a counselor or therapist?

What are any long-term effects of sepsis?

What are the symptoms of Post-Sepsis Syndrome?

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

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

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

Good Therapy

www.goodtherapy.org

Find Treatment

findtreatment.gov
findtreatment.gov/state-agencies

SAMHSA

Substance Abuse and Mental
Health Services Administration

www.samhsa.gov/find-support

National Helpline
1-800-662-HELP

HRSA

Health Resources &
Services Administration

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?

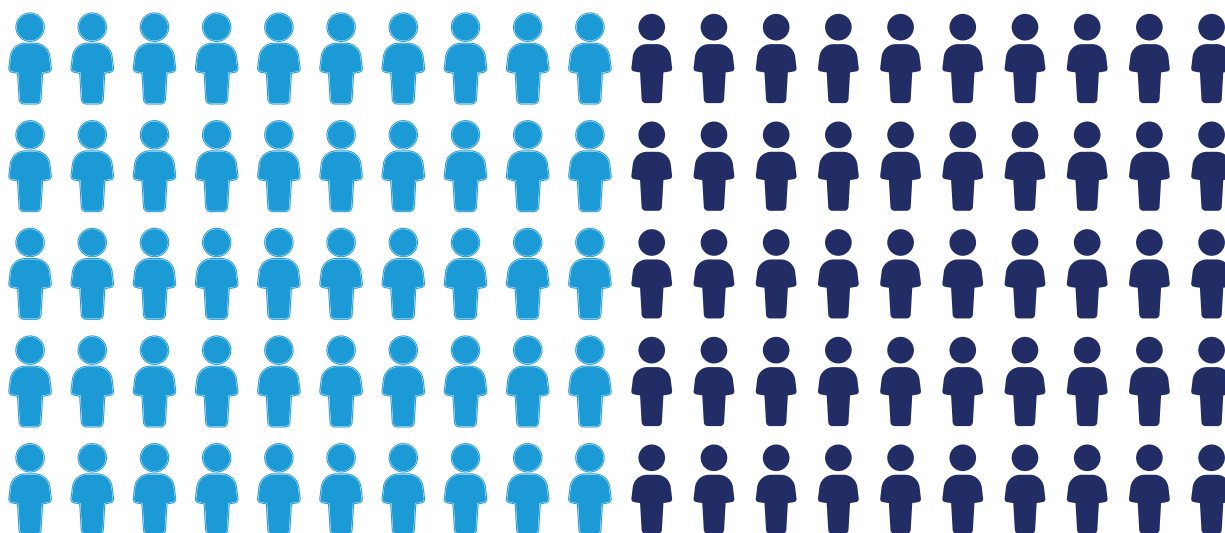
Text HOME to 741741
to connect with a
volunteer Crisis
Counselor

CRISIS TEXT LINE |

WHAT ARE ANY LONG-TERM EFFECTS OF SEPSIS?

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 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.

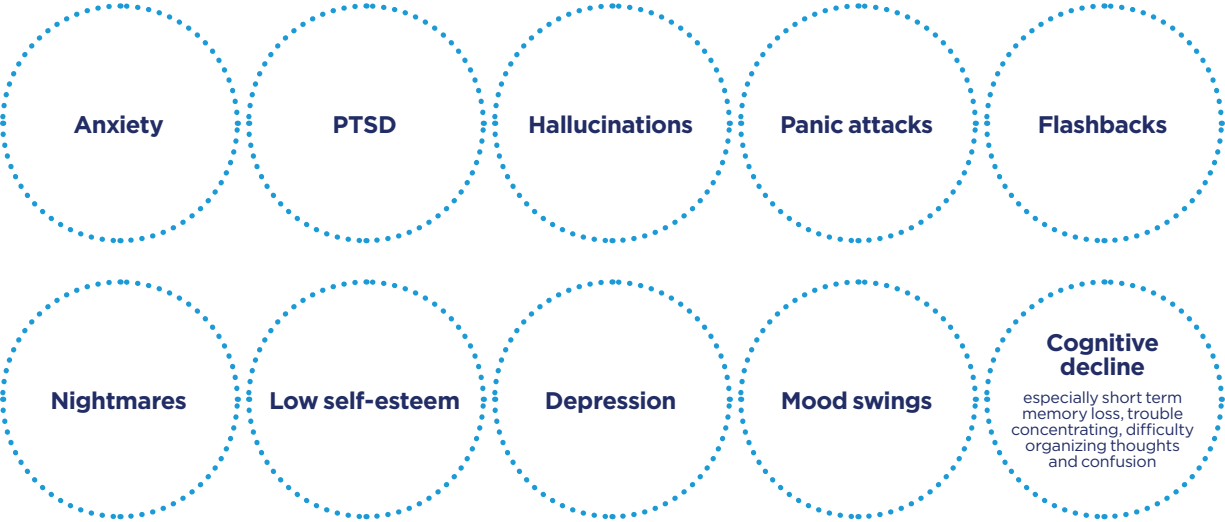
- Use your care journal to document your symptoms.
- Report all symptoms to your care team to discuss any needed medical interventions.
- Find a trauma informed therapist if you are not already being seen by a mental health professional.
- Find/join a support group.

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

UNINSURED MEDICAL EXPENSES OR CASE MANAGEMENT ISSUES

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

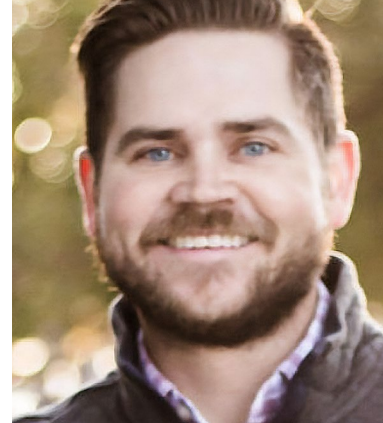
beginagainfoundation.com/leishline

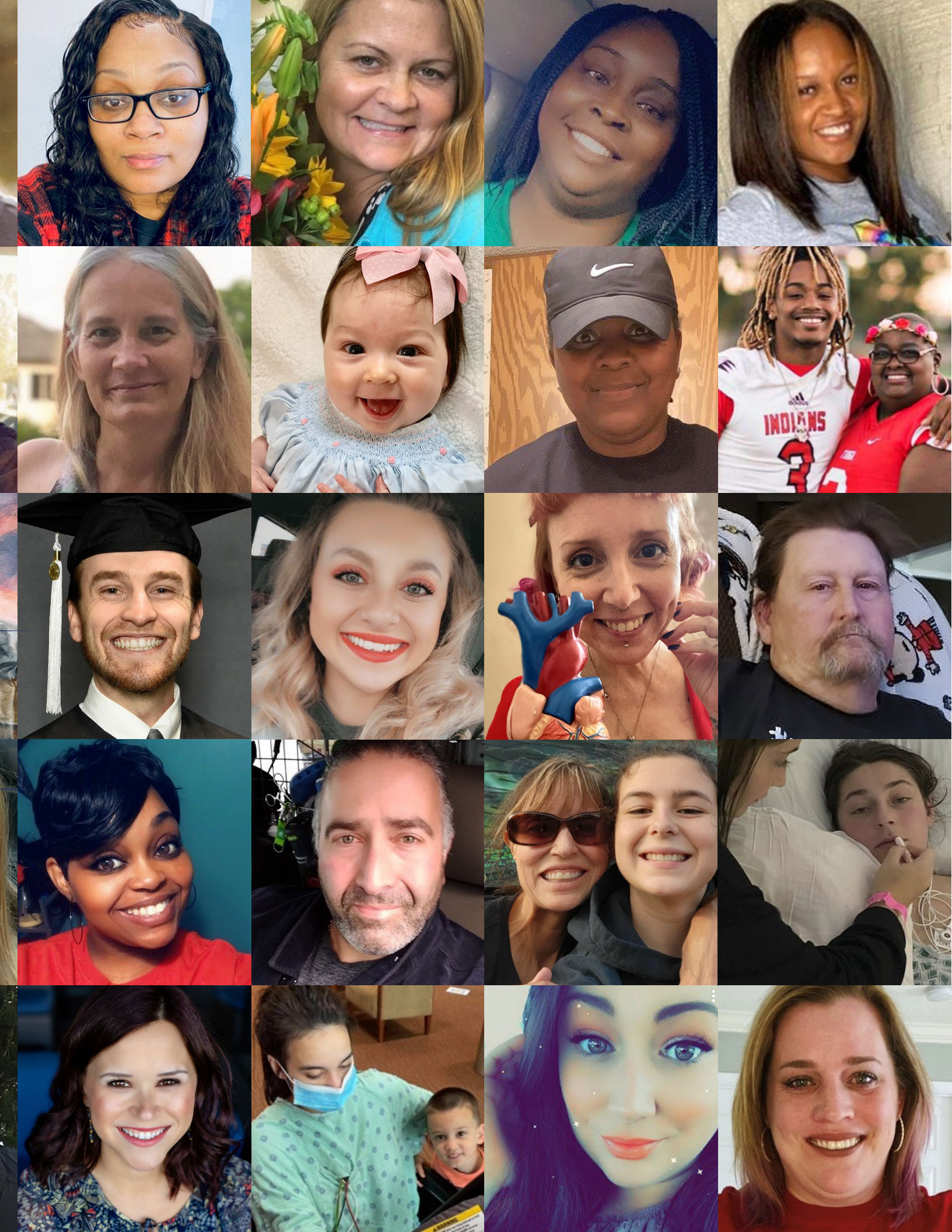
GENERAL INFORMATION

info@beginagainfoundation.com

www.beginagainfoundation.com

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







BEGIN AGAIN FOUNDATION

Saving lives. Supporting survivors.