

# Meningococcal: how a life can change in 12 hours

Sarah Joyce

2023

The Beginning:  
Presenting to ED  
with a high  
fever, headache  
and vomiting.



**Please be  
aware that you  
may find the  
following  
images  
confronting**



**12 hours later: Life support with a less than 5% chance of survival**



**My family  
were told to  
say goodbye  
to me  
multiple  
times**

















Waking up  
after 9 days.  
The damage  
done, but  
the fight to  
live was far  
from over...





Health warning after third case of meningococcal confirmed on Central Coast in 2016. It comes after 30-year-old Sarah Joyce (pictured) was struck down by the disease six weeks ago.



Health warning over meningococcal  
dailytelegraph.com.au

WEDNESDAY, SEPTEMBER 7, 2016 EXPRESS ADVOCATE

COASTWIDE

# Sarah shows amazing courage under fire



**Denise Barnes**

JUST over four weeks ago 30-year-old Sarah Joyce was rushed to Gosford Hospital with extreme flu symptoms. In a matter of 12 hours, her body had shut down. Her family was told she might not make it and called into her room at each critical point in case it was the last time they would see her. After five days the family was given the diagnosis - meningococcal, just the second case on the Central Coast this year.

That week Sarah was one of five across the state diagnosed with the deadly virus. "Luckily when Sarah was first admitted she was given the right antibiotic to treat meningococcal and the teams at Gosford Hospital worked rapidly to assist her," sister Karly Joyce said. After eight days on life support, Sarah woke up, amazing everyone around her. She is off life support and has undergone a number of amputations that have affected her right hand and will soon undergo more surgery on her toes.

When she is strong enough, she will need to have her spleen removed and a kidney transplant down the track.

While it was a shock for everyone who knew Sarah, who just a short time ago celebrated her 30th birthday,

with friends and family including her mum and dad, Karen and Garry, of Wamberal, her brave attitude continues to amaze everyone. "She's had nurses and doctors in tears, shocked and relieved at her progress and how she's fought with everything she has - barely a complaint," Karly said. "She's extremely strong-willed and is the toughest girl we know. We will probably never know how she contracted the virus, it was most likely airborne, through a cough or sneeze."

Sarah and her family are keen to raise awareness of the virus saying people need to act quickly if they suspect they may have contracted it. "If you don't act quickly, it can be too late," Karly said.

Sarah has a long road ahead of her, including dialysis three times a week while waiting for a transplant, and it is only just starting to sink in. "She will need to slowly learn to stand and walk again and is now building strength with physio each day," Karly said.

A GoFundMe page has been set up to help Sarah with the financial realities she will face in the future. "We've had so many people offering support," Karly said.

You can help by visiting [gofundme.com/](http://gofundme.com/)

**Dr Peter Lewis.**

## Disease numbers on the decline

**Denise Barnes**

THE number of people diagnosed with meningococcal disease on the Central Coast has fallen dramatically over the past 30 years from an average of about 15 cases a year down to less than five. This is in stark contrast to the early 80s when the Central Coast was considered a meningococcal hot-spot following the death of two children from the disease, seven-year-old Stephen Samia in 1980 and seven-year-old Rebecca Calverly in 1982.

Central Coast Local Health District's public health director Dr Peter Lewis said there had been two cases on the Coast in 2015 and four in 2014, while so far this year there had been two cases, one in July and one in August.

In NSW, there have been 81 cases so far this year, with 46 of those in Sydney.

**Sarah Joyce in Gosford Hospital following surgeries to amputate parts of her fingers after she was struck down by the meningococcal disease. Inset: Sarah before she was struck by the virus.**

PRIDE OF AUSTRALIA 2016

WEDNESDAY, SEPTEMBER 7, 2016

Central Coast Gosford

# Express Advocate

news local

## Brave battle to overcome deadly meningococcal virus

# SARAH'S STRENGTH



Sarah Joyce spent eight days on life support after contracting meningococcal. Now the 30 year old has woken up and is amazing everyone around her with her will to live.

Full story page 9

Sarah Joyce at her 30th birthday celebrations before she was struck down with the meningococcal disease last month. Inset: Sarah on life support in Gosford Hospital.











# The Long, Hard Road to Recovery continued...





**Dad slept on the floor of ICU for two months!**







# Many ups and downs – to leave ICU after over 80 days





FINALLY HOME! But not for long...





The next  
chapter  
begins.....

# 7 years of constant fight, this is my story



In August 2016, I began to feel unwell with flu like symptoms.



Symptoms and progression of symptoms.



Emergency Department experience.



Strain of Meningococcal identified 4 days into coma.



Immunisation? – the most common question I am asked.

- In ICU my heart was failing, and my lungs filled with 3L of fluid.
- Everyday, something new presented.
- I was put back on life support a further 5 times.
- Operations began whilst in ICU and have continued up to September this year – 7 years on.
- A total of 70 surgeries/procedures.



# Surgeries

Removal of Spleen, gallbladder & large bowel

Formation of ileostomy plus reversal

Initial Finger and toe amputations - plus revisions and further amputations.

5 Laparotomy surgeries due to bowel obstructions – 2 of which occurred this year

Kidney Transplant in 2020

Multiple insertions of feeding and peg/pej tubes in abdomen.

Insertion and removal of failed catheters for attempting Peritoneal Dialysis.

Multiple Central lines – at least 30

Formation of AV Fistula for dialysis – revised 7 times.

Dialysis CVAD – multiple

Vascular surgery to ligate AV fistula and thrombosis x2.

Venoplasty

Multiple scopes

# Dialysis: My kidneys failed completely during the early onset of Meningococcal and would never recover



Haemo Dialysis – 3  
days a week.



Five hours a session to  
stay alive for four  
years.



The mental health  
impact.



# Life Saving Kidney Transplant

- **1<sup>st</sup> August 2020 I received THE call**
- **Proudly named Little Ripper**
- **Immune suppressant medications**
- **No more dialysis!!**



**Hospital  
Admissions:  
Approx. 250.**





# TPN & IV Life



Intestinal failure  
& gastroparesis



Unable to sustain  
life through oral  
nutrition



TPN for 4 years



IV Fluids



IV antiemetics  
every 4 hours



Limitations



# ADVOCACY



Sharing my recovery so publicly in the hopes of saving others from this cruel disease



Billboard & buses outside Parliament House



Social media



Advocating for change – ACWY



# Advocacy



Sarah thought she had the flu. Within 12 hours doctors were telling her family to say goodbye.



BELINDA JEPSEN  
Senior Content Producer  
July 26, 2018

[REAL LIFE]



NSW Health  
@NSWHealth

Today is #WorldMeningitisDay. Meningitis is a rare but serious and sometimes fatal infection. Find out more in our factsheets for meningococcal disease, Hib disease and pneumococcal disease:  
[health.nsw.gov.au/Infectious/fac...](http://health.nsw.gov.au/Infectious/fac...)

Meningitis can affect people of any age.



Symptoms of meningitis often appear suddenly and can get worse very quickly

👁️ Early identification and treatment is key

🧠 If you think you or someone you know could have meningitis, seek urgent medical advice - don't wait!

Learn about signs, symptoms and prevention on our website



**Australia:** Sarah Joyce sent CoMO's call to action letter to a MP to ask him to support the campaign. He sent her a supportive letter back, attended her High Tea event and NSW Health recognised the day for the first time ever!

# NSW Parliament

- Meningococcal B Advocacy with my mother, Karen the CEO of Meningitis Centre Australia and Stacey who lost her son to MenB last November.
- Spent 2 days in September with positive discussions with MP's from all parties regarding the need to prevent deaths and disabilities.
- The importance of adding MenB to NSW State Immunisation Plan funded for infants & teens.
- B The Change For Brayden



# Where to from here:

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- Living on TPN permanently
- Severely immunocompromised
- Recurrent hospital admissions
- Anti-rejection medications for kidney transplant
- Continue studying Bachelor of Public Health
- Campaigns & projects

Connect & Follow my ongoing  
journey via:

Instagram: @iamsarahjoyce\_

[www.facebook.com/sarahsrecovery2016](https://www.facebook.com/sarahsrecovery2016)

[www.championhealthagency.com.au](http://www.championhealthagency.com.au)

