## A sepis survivor's story

Jason

7 March 2018 eta 1 hr

2015 to 2018

A 3 Year journey of....



### **FEAR**



## HELPLESSNESS



## HORROR



## HOPE



## EMOTIONS



## REBUILDING

## 2<sup>nd</sup>-5<sup>th</sup> November 2015

#### Normal week at work, bit stressful

#### Started to feel unwell

#### Went home sick Thursday 5th lunchtime

Friday 6<sup>th</sup> November 2015

**Texted work** 

Went to bed shivering (rigor)

## Saturday 7<sup>th</sup> November 2015

- Woke Toilet floor
- Felt like a hangover
- Stomach pains
- Texted girlfriend
- Unlocked front door
- Bedroom, felt more ill







## SEPSIS IN ADULTS IS A SERIOUS CONDITION

that can initially look like flu, gastroenteritis or a chest infection. Sepsis affects more than 250,000 people every year in the UK.

The UK Sepsis Trust registered charity number (England & Wales) 1158843 Seek medical help urgently if you develop any or one of the following: lurred speech or confusion xtreme shivering or muscle pain assing no urine (in a day) evere breathlessness t feels like you're going to die kin mottled or discoloured

IT'S A SIMPLE QUESTION, BUT IT COULD SAVE A LIFE.

## Saturday 7<sup>th</sup> November 2015

07:25 Ambulance call logged

# **07:31** Ambulance (Single Response Vehicle) on scene

### Saturday 7<sup>th</sup> November 2015

Paramedic (SRV) first on scene

As soon as he saw me, he knew I was in trouble

Called code red, ambulance arrived 8 mins later

He didn't expect me to survive

How do I know all this ... ?



#### February 2018

## "One foot at a time" Saturday 7<sup>th</sup> November 2015

#### 07:40 (at home)

#### Ambulance noted :-

- Vomiting
- Sweating
- Loose stool
- Mottled skin

| Serial Obs 1 |                         |        |                      | Serial Obs 2      |                    |             |  |  |
|--------------|-------------------------|--------|----------------------|-------------------|--------------------|-------------|--|--|
| 0            | 3                       | 0      | C                    | 8                 | 16                 | 3           |  |  |
| Read         | 6 5                     | 8      |                      | Respt             | 5                  | 6           |  |  |
| PO+(94)      | 8                       | 4      | SPO: (N)             |                   | 9                  | 6           |  |  |
| On NO X      | anas                    |        | On Air?              |                   | 000                |             |  |  |
| h Fiow       |                         |        | Pistir Pipu          |                   |                    |             |  |  |
| rt Plake     | 17                      | 7      | Heart Role           | 1                 | 6                  | 3           |  |  |
| Symbic 💽     | 0                       | 2      | BP Systols:          |                   | 9                  | 9           |  |  |
| DARANC       | 6                       | Z      | EP Duarok:           |                   | 6                  | 7           |  |  |
| empral-      | 52                      | 6      | Tomp ("ct            |                   |                    |             |  |  |
| GLCOSE       | 2                       | 9      | Bood Glazase         |                   | 5                  | 5           |  |  |
| Hoctim y     |                         |        | Pupil Heaction       | 4                 | $\overline{n}$     |             |  |  |
|              | + Normal<br>able to Ase |        | id 5 = Slow<br>U = V | N Nic<br>Uniatoio | ernet F<br>to Acro | Fiend       |  |  |
| rolesses -   | 2                       |        | PupilSze             | 1.                | Ft                 |             |  |  |
| ALS.         | in Scale in             | 15     | ] ocs []             |                   | :)[                | VTI<br>Town |  |  |
| 1312         |                         | -lotal | 1                    | 31                | 51                 | 1           |  |  |

## "One foot at a time" Saturday 7<sup>th</sup> November 2015

#### 08:00 (at home)

#### **Code Yellow Sepsis**



Do Not Delay Transport - Mortality Increases 7.8% Per Hour - TIME IS TISSUE

## Saturday 7<sup>th</sup> November 2015

08:09 ambulance left scene08:15 at hospital, 50 mins after 999 call



## "One foot at a time" Saturday 7<sup>th</sup> November 2015

#### 08:18 Hospital tests

Blood gas values pH

#### Major incident form :-

- o/a peripherally shutdown
- very mottled and cold to touch
- very faint radial pulses
- numbness to both feet

| BL90 EMERGENCY DE<br>ATIENT REPORT                                       | PARTMENT - V<br>Syringe - S ( | VO 1393<br>65uL | 08:18<br>Sampl | e #  | 07/11/20<br>457 |   |
|--|-------------------------------|-----------------|----------------|------|-----------------|---|
| Identifications<br>Patient ID<br>Patient last name<br>Patient first name | 001                           |                 |                |      |                 |   |
| Date of birth<br>Sample type   | Arterial                      |                 |                |      |                 |   |
| Operator   | Chem Path                     |                 |                |      |                 |   |
| Т  | 37.0 °C                       |                 |                |      |                 |   |
| Blood gas values   |                               |                 |                |      |                 |   |
| рН   | (7.132)                       |                 | [              |      | -               | 1 |
| pO2  | 3.75                          | kPa             | [              |      | -               | 1 |
| pCO <sub>2</sub>   | 6.77                          | kPa             |                |      |                 |   |
| Oximetry values  |                               |                 |                |      |                 |   |
| ctHb   | 161                           | g/L             | [              | 100  | - 170           | ] |
| sO2  | 35.4                          | %               | l              |      | -               | 1 |
| FO <sub>2</sub> Hb   | 34.7                          | %               | [              |      | -               | 1 |
| FCOHb  | 1.1                           | %               | [              | 0.0  | - 2.5           | ] |
| FHHb   | 63.4                          | %               | [              |      | -               | 1 |
| FMetHb   | 0.8                           | %               | [              |      | -               | ] |
| Electrolyte values   |                               |                 |                |      |                 |   |
| ↓ cK*  | 3.5                           | mmol/L          | [              | 3.5  | - 5.5           | 1 |
| cNa <sup>+</sup>   | 138                           | mmol/L          | [              | 135  | - 145           | 1 |
| ↓ cCa²⁺  | 1.05                          | mmol/L          | [              | 1.15 | - 1.29          | ] |
| cCl⁻   | 97                            | mmol/L          | ]              | 90   | - 110           | 1 |
| Metabolite values  |                               |                 |                |      |                 |   |
| cGlu   | 47                            | mmol/L          | [              | 3.0  | - 7.0           | ] |
| † cLac   | 11.0                          | mmol/L          | [              | 0.6  | - 2.2           | 1 |
| Temperature-corre  | cted values                   |                 |                |      |                 |   |
| pH(T)  | 7.132                         |                 |                |      | *               |   |
| $pCO_2(T)$   | 6.77                          | kPa             |                |      |                 |   |
| $pO_2(T)$  | 3.75                          | kPa             |                |      |                 |   |
| Oxygen status  |                               |                 |                |      |                 |   |
| ctO <sub>2C</sub>  | 7.9                           | Vol%            |                |      |                 |   |
| <i>p</i> 50 <sub>c</sub>   | 4.71                          | kPa             |                |      |                 |   |
| Acid-base status   | $\bigcap$                     | )               |                |      |                 |   |
| cBase(Ecf)c  | ( -12.2/                      | mmol/l          | -              |      |                 |   |
| cHCO <sub>3</sub> <sup>-</sup> (P,st) <sub>C</sub>                       | (14.3)                        | mmol/l          | -              |      |                 |   |

## Saturday 7<sup>th</sup> November 2015

#### 08:40 sepsis pathway B.U.F.A.L.O

#### Antibiotics within 1 hour

| History or signs of new infection + NEWS S<br>THIS PATIENT NEEDS TO FOLLOW SEVERE S<br>RESUSCITATE: WITHIN ONE HOUR         | 경험감감감   |       | eter.     |
|---|---|-------|-----------|
| TIME 0540 DATE: 711/15 .  | the second s  | Time  | Signature |
| B - Blood cultures taken  | 80  | 830   | Surger    |
| U - Urine output measurements<br>commenced  |   |       |           |
| F - IV Fluid resuscitation commenced  |   | OFFIC |           |
| A - Antibiotics prescribed and given  | ORCARD  | 0640  | S         |
| L - Hb and Lactate taken  | W.  |       |           |
| O - High flow Oxygen  | 0   |       |           |
| Senior DR REVIEW within one hour.<br>Hypotension unresponsive to fluid challen<br>Escalate immediately to Outreach and/or I | Constraints of the second s<br>Second second s<br>Second second se | ocx   |           |

## Saturday 7<sup>th</sup> November 2015

#### Casualty card ...

- Temp lower than 37
- BP dropping, Lowest 68/47



## "One foot at a time" Saturday 7<sup>th</sup> November 2015

Ambulance crew thought "cold sepsis"

#### 09:50

#### Where was the infection source ?

- ? Perforated peptic ulcer
  - ? AAA
  - ? Acute pancreatitis

## <u>"One foot at a time"</u> Saturday 7<sup>th</sup> November 2015

Initially I said I didn't want my parents to know

Now I was critical, they were contacted.

Taken to a relatives' room, they were told I might not survive the weekend.

## "One foot at a time" Saturday 7<sup>th</sup> November 2015 11:00 In septic shock, abdo slightly distended and soft ICU consultant visits me in A&E Moved to ICU





"One foot at a time" Sunday 8<sup>th</sup> November 2015

> 12:46 Diagnosis from microbiology....

Meningococcal Septicaemia

## "One foot at a time" Meanwhile.....



## Flashbacks !!!!

- Heard things around me, tried to make sense of it
- Finding answers helps....
- No patient diaries
- - Mum's diary, medical records, my memories
- Counselling helps

## Night terrors

- Explosions, loud bangs.
- Doctors shouting at other patients in the night
- Police shot another patient in my room

## 19<sup>th</sup> November 2015










#### 21<sup>st</sup> November 2015

• CPAP hood, flashbacks !!



# 24<sup>th</sup> ,25<sup>th</sup> November 2015

- Tracheostomy done
- 2<sup>nd</sup> dialysis
- Lower legs, ? Amputation
- May lose fingers
- Hands, plastics to liase



## 26<sup>th</sup> November 2015













- Heart tachycardia x 2, I thought I would die
- I was very scared !
- Pysch liaison review. PTSD diagnosed.
- Sertraline prescribed

"One foot at a time" 14<sup>th</sup> December 2015 (+38 days)

# Transferred to Brighton ICU (blue light)

Transfer notes :-

- Meningococcal Septicaemia
- MOF (kidneys, liver, heart, marrow)
- DIC
- Cardiogenic shock
- 10 units of blood, 10 units platelets

## 15<sup>th</sup> December 2015

#### **Debridement operation**

- Sub clavicle central line
- Right leg BKA likely, not sure about left leg

## 22<sup>nd</sup> December 2015

After .....

47 days / 7 weeks / 2 different hospitals I left ICU !!

- In the "naughty bed"
- Curtains around me
- Can't see out window
- More people !
- Is life a dream ?
- Phone, stylus, friends visit !

- No muscle strength.
- Skin on arms fragile
- Weight & muscle loss
- Speech therapy
- Physio on fingers as curled
- Toes tapping at end of bed
- Drug effects fading

# QUESTION

Why do nurses <u>wake</u> <u>everyone up at 6am</u> to check their blood pressure ?!

## 24<sup>th</sup> December 2015

Discussion with consultant Mr B about my legs





# "One foot at a time" 27<sup>th</sup> December 2015



# **Cone foot at a time** 29<sup>th</sup> December 2015 Day before op



## 30<sup>th</sup> December 2015

- Right BK amputation
- 5 hour operation
- Hope for recovery next year

# Physios

- Chunky cutlery
- Finger straightening
- Foot drop left foot
- Speech therapy exercises

#### Institutionalisation

- Home seems so far away
- Outside seems a different world



# 9<sup>th</sup> Jan 2016

#### First time sitting up in bed Physios happy !



## 9<sup>th</sup> Jan 2016

#### Stump shrinker



#### Night time brace



#### Infected left index Finger

#### (Stay tuned ....)



- TWOC v2
- Hoisted into wheelchair, first time out of ward.
- Couldn't sit for long (no bottom !)
- Fortisip for weight gain

# PTSD

- Asked to see chaplain in ICU, but never saw him
- Didn't think of asking for counsellor
- Saw chaplain later in ward. Had a cry :\*(

# Medically ready for discharge

- How can I go home ?!
- Rehab. So close to home ...
- Last day on ward 19<sup>th</sup> January

# 19<sup>th</sup> January 2016 Casting for prosthetic







# 19<sup>th</sup> January 2016



# Rehab.....

- Moved to rehab 74 days after admission
- My own room, free TV
- First view outside since admission
- MRSA





# "One foot at a time" February 2016




February to March 2016

- 18 days later, prosthetic leg arrived
- Bandage foot
- Progressed from bars, to frame



• Crutches 36 days into rehab

#### HOME!!!!!!

- Discharged home 17<sup>th</sup> March 2016
- Bandaging, smell of gangrene. Outside flies
- Orange bag & coffee granules
- Foot started to debride (picking !)
- Mr B waiting for toe demarcation

#### <u>"One foot at a time"</u>

#### I was as high as a .....



- 2,600 mg gabby & fentanyl patch
- Slept most of the day, time flew



# March 2016



#### April 2016



#### "One foot at a time" Left index finger after nail came off



- More therapy on fingers.
- East Grinstead gave me night splint
- Counselling for flashbacks helping
- Mr B decided toes now de-marked



#### 7<sup>th</sup> July 2016 Fore-foot Amputation









#### 8<sup>th</sup> July 2016

#### Recovery pain 10/10





#### 8<sup>th</sup> July 2016



#### VAC dressing (TNP)



#### Op + 16 Home



#### Community nurses visit for vac



#### <u>"One foot at a time"</u>

#### September 2016

- Weaned off pills
- Visited GP 3x a week for bandaging
- New car, automatic, adapted, blue badge
- Returned to work 1<sup>st</sup> October 2016, 11 months after illness

#### "One foot at a time" November 2016 Infection, TVN advised



## November 2016 Visited Mr B

- Swab & probe
- Xray Osteomyelitis
- MRI Dead bone side big toe, heal, end long bone
- Started antibiotics (Clyndamicin)



## "One foot at a time" February 2017





- Saw GP
- Saw Mr B

#### "One foot at a time" 15<sup>th</sup> June 2017 Removal 5<sup>th</sup> Metatarsal

Op + 2



- Rifampicin
- Orange urine
- Reflux
- Regular bloods
- Vac dressing !

#### <u>"One foot at a time"</u> 19<sup>th</sup> June 2017



#### "One foot at a time" 30<sup>th</sup> June 2017







#### "One foot at a time" September 2017



#### September 2017

#### "One foot at a time" September 2017

Blisters





#### "One foot at a time" November 2017

March 2018

New prosthetic Foot drop correction

#### March 2018

## Decision time

- Spoke to family, friends, councillor
- Foot drop
- Dead bone
- Bone infection
- Antibiotics since Nov 16
- Ulcer not healing
- Pain levels
- Mobility & life quality
- Conclusion.....

#### "One foot at a time" 13<sup>th</sup> June 2<u>018</u>



#### Leg amputation #2

- Recovery pain 11/10
- Ketamine didn't work
- Given epidural
- Asked Mr B to do "post mortem" on foot
- He said "crumbly bone"

#### June 2018

# Op + 2 weeks

#### Rehab, again ! PAM aid





#### **Cone foot at a time** 7 August 2018 (op + 8 weeks) 1<sup>st</sup> Left Leg



#### September 2018

MDT with consultant :-

- "No more bits to chop off"
- Should we have amputated sooner ?

# The end, or beginning .....

- Returned to work 15<sup>th</sup> October
- Joined a gym
- Beach walks 2.5 miles
- Doing talks
- Enjoying life



#### WWW.JASONAMPUTEE.COM