S 13
Ymchwiliad i Sepsis
Inquiry into Sepsis
Ymateb gan Unigolyn
Response from Unigolyn

Across Wales and the rest of the UK, despite the efforts of charities such as the UK Sepsis Trust and events such as World Sepsis Day, people are still dying or being left with life-changing physical and psychological damage from an illness they've either never heard of or are unaware of the need for a rapid diagnosis and treatment.

Necessity for a campaign

Case Study – Sepsis Survivor Helen [redacted]

'Following a major operation In December 2016 I was discharged from Cardiff Hospital and sent home to recover, however, 3 days later it was clear to my husband that my condition was declining, and my husband took me to see my GP who immediately recognised referred me straight to my local hospital (Neville Hall, Abergavenny). – ***So far, so good.***

On arriving at the hospital, I provided a full history and was triaged by a nurse. The nurse first informed us that they had no ability to admit me, following which she then eventually examined me and told me to wait for the Doctor. On his arrival the Doctor re-examined me and discharged me with anti-nausea medication. – ***Failure one:*** *I was now 96 hours post major Op and clearly showing symptoms of Sepsis, but was sent home, in part I believe because my diagnosis and treatment came second to what hospital treatment was available****. Greater public awareness of Sepsis at this stage*** *would have enabled either myself or my husband to have raised the possibility.*

Having received the diagnosis on the Monday, my husband left for work, in the belief that the medication prescribed by the Doctor should be beginning to take effect. However, soon afterwards I began to feel worse, my father came to see me, and I then put myself to bed. ***A clear opportunity missed –*** *With myself and my husband so close to the situation,* ***had my father been made aware of the signs and symptoms, perhaps he would have either encouraged us to constructively challenge the Doctors diagnosis, or sought medical help at that point.***

I awoke a few hours later and found myself struggling to breath. I felt as if I was dying, but somehow managed to dial 999. Despite being violently sick in front of the paramedic, he initially did not want to take me to hospital. ***Failure two*** *and another* *opportunity missed. Again, my history and signs and symptoms should have been ringing alarm bells in the paramedics' mind and could have presented another opportunity for my family to raise a concern. Thankfully this failure was short lived, because although I have little recollection of the event my condition deteriorated again and I was admitted into Neville Hall Accident and Emergency.*

Following admission, I remained in A & E for a number of hours whilst they ran some tests, but with minimal explanation of what was happening or what the medical teams' concerns might be. ***Failure Three*** *and by context further evidence that* ***Sepsis was not considered*** *during my triage.*

It was at this point that my husband (who was a patrol medic in the military) challenged the medical staff and raised concerns about my oxygen levels, but he was politely offered an explanation that although he wasn't happy with, he decided to defer to the medical Team. ***Failure Four.*** *By this stage I had been triaged three times, had seen a minimum of 10 health care professionals, all of whom had* ***failed to identify the clear signs and symptoms of sepsis****, and the concerns raised by my husband had been dismissed.*

It was at this point that my luck changed however, but not a result of an awareness of Sepsis. It was because a bed had now become available on a ward and although I was assessed to have no surgical issues I was admitted for observation. By now many of the hospital's lights had been dimmed, but on arrival at the ward the Doctor who had sent me home earlier in the week was on duty and as I was being moved on to a ward bed he intervened (by chance) and requested that I was placed in an examination room, - presumably so that he could take a few minutes to understand his patient's needs. – ***This action saved my life.***

Here things happened very quickly as under normal lighting it was obvious that my abdomen had become bloated and that my skin had begun to change colour. In fact, I had gone into kidney failure, and the Senior Consultants who were summoned and arrived shortly afterwards informed my husband that my other major organs were also beginning to shut down, as a result of Sepsis. The emergency surgical team were immediately called in to and I went into theatre at approx. 0200 the following morning.

I awoke a number of days later in ITU, having had life changing surgery (I now have a Stoma), but fortunately oblivious to everything that had happened, and at that point naive to what lay ahead.

Two years on I am still living with the consequences of the lack of awareness and missed opportunities to provide a correct diagnosis. Through the Sepsis Trust I regularly speak to people who have either survived or lost loved ones more recently than my experience which evidences a continued lack need for action. ***So, given the significant numbers affected by Sepsis each year what could change that? To me and the other Sepsis survivors the answer is obvious – A public awareness campaign.***

Through my involvement with the Sepsis Trust I regularly volunteer to speak to groups of health care professionals about my experience, whilst also sharing my story with colleagues and acquaintances - I am proud to say that I've been informed of three diagnosis that came about as a result of those people remembering my story. However, myself and my fellow survivors cannot speak to the entire population of Wales and remembering that Health professionals are also members of the public I believe that it's safe to say that if a campaign had increased awareness in the minds of the health professionals who treated me and my family and friends who supported me after my operation that a conversation would have been had before life changing surgery became the only option.

Additionally, there needs to be significant improvements to the support for sepsis survivors. There are specialist nurses of support for many different health conditions, but nothing for sepsis. The UK Sepsis trust provides invaluable support, however this is all by volunteers - there needs to be investment into support for survivors, as the impact of their physical and psychological health is significant.

The Burden of Sepsis

A public awareness campaign by Welsh Government will help people to understand what sepsis is and the need for early, rapid screening, diagnosis and treatment. The **annual cost** to the UK economy of sepsis care is currently estimated at between **£10.5**

billion and £15.5 billion. The costs and risk of adding to the workload of front-line clinicians will be more than offset by earlier treatment, which will prevent deterioration and the need for critical care, and ultimately reduce the burden of long-term health problems for survivors. This will reduce the need for support service and primary care health services for sepsis survivors, helping them to return to work and contribute to the economy.

Further details can be found here : http://allcatsrgrey.org.uk/wp/download/health_economics/YHEC-Sepsis-Report-17.02.17-FINAL.pdf

Campaigns (1) – Do they work?

Case Study – Stroke: The FAST Campaign

On **Friday 29 January 2016** Welsh Gov released a news report with the headline “**More people in Wales surviving stroke shows new report”**

In essence the report shows that more people are surviving and fewer people are now dying from stroke. The report also highlights how awareness campaigns and better prevention have helped to reduce the number of people having strokes, while faster interventions have increased people’s chances of surviving and returning to independence as quickly as possible.

Amongst the key findings it is stated that:

- For strokes time matters.
- There is an improved awareness of the symptoms of stroke as a result of campaigns such as FAST or Lower Your Risk of Stroke. These are supporting people to recognise when they are having a stroke and take appropriate action quickly

Dr Andrew Goodall CEO NHS Wales

“*I want to pay tribute to the NHS staff who have played a vital role in making continued and sustained improvements to services.*

*“Our annual report shows that by focusing on a number of areas and through prevention, **awareness-raising and education; effective and timely treatment**; research and supporting those living and dying from a stroke, we are delivering quality care for people. We will continue to build on this progress*.”

Like Stroke, Sepsis is also **time critical** illness with risk of mortality increasing by 8% for each hour that a septic patient does receive antibiotics. **Lack of sepsis awareness** in the communities often means sick individuals are **slow to access health care** which causes delays in diagnosis and treatment which can be fatal or result in life changing outcomes. It should be highlighted that, for all the brilliant work that NHS Wales and PHW have undertaken in the care setting, 70% of sepsis cases are community acquired.

For stroke an estimated 7,000 people will have a stroke each year in Wales and there are more than 65,000 stroke survivors living in Wales.

For Sepsis and estimated 8,000 people will have sepsis each year in Wales and there are more than 2,000 deaths.

The question is ….if an education and awareness campaign has been successful for stroke then why would it not be similarly successful for sepsis?

Full report on improvements in stroke can be found here:

https://gov.wales/newsroom/health-and-social-services/2016/160129stroke-report/?lang=en

Campaigns – Does WAG support campaigns?

We have covered the successful FAST campaign above and given that just yesterday Public Health Wales announced their #loveyourcervix campaign you would have to conclude that they do. Like the Minister for Health and Social Services we also believe in building a healthier Wales. We also believe that prevention is at the heart of a healthy Wales but to able be prevent anything happening you must be aware of the possibility that it may happen in the first place. Otherwise, therefore, you do nothing and the worst thing you can do with sepsis is to do nothing at all.

‘***Prevention is at the heart of a healthy Wales***” - Vaughan Gething (Building a Healthier Wales (12/3/2019)

Better Support for Sepsis Survivors

Some individuals develop sepsis so severe that they can become desperately ill very quickly and might need treatment in an ITU / HDU. Up to 80% of patients survive sepsis. Most patients who experience this critical illness will return to a normal or a ‘near normal’ life within 18 months of being ill. However, some survivors will have long term problems, occasionally having life changing effects which might impact on both them and their family.

These long-term problems can be divided into physical and psychological, and often start during the acute phase of your illness. Collectively, they are known as Post Sepsis Syndrome (PSS). Post Sepsis Syndrome is more common in people who have needed to be cared for in a Critical Care Unit, particularly if their stay was over four days.

PHYSICAL LONG-TERM PROBLEMS	PSYCHOLOGICAL LONG-TERM PROBLEMS
Poor mobility Breathlessness / chest pain	Anxiety

Fatigue Loss of appetite Taste changes Dry skin Brittle nails Brittle teeth Hair loss Oedema (excessive fluid in the tissues, which look swollen) Joint stiffness or pain Muscle wasting Changes of sensation in limbs (tingling, numbness, pain) Reduced libido (loss of sex drive) Poor kidney function (which may need dialysis) Repeated infections	Insomnia (difficulty sleeping which can also be a result of pain or breathlessness) Flashbacks, panic attacks and nightmares Depression PTSD (Post Traumatic Stress Disorder) Poor concentration Short term memory loss

Support for survivors of sepsis and their families is ad hoc and many leave hospitals without an explanation of what they have suffered, what the impact is or where they can find support. UK Sepsis Trust runs quarterly support groups in Cardiff and Wrexham, however, these are dependent on fundraising income. There is no funding from WAG although the support groups and telephone support helpline are staffed with former consultant nurses. In Cardiff, volunteers also run monthly 'well-being' walks and participants have advised that meeting people who have been impacted by Sepsis has helped their recovery and understanding of Sepsis. We are calling for a timescale for the Sepsis registry that the Health Minister announced on World Sepsis Day 2018 and a Wales wide strategy for survivors and families impacted by Sepsis.