

Cross Party Group on Sepsis

Summary Report

March 2021



This report has been written by Angela Burns MS on behalf of the Cross-Party Group on Sepsis in conjunction with the UK Sepsis Trust.

The report is dedicated to the memory of Jayne Carpenter 1967– 2020 an inspiration to many who led the way in demonstrating how to overcome adversity to effect change.

Sepsis: Surviving and Living Well

Introduction from Angela Burns MS Chair of the Welsh Parliament's Cross-Party Group on Sepsis

This report aims to draw some conclusions from the work undertaken by the Cross-Party Group on Sepsis during the fifth Assembly / Senedd Term.

The report draws together evidence provided to the Cross-Party Group, evidence given to the Senedd's Health and Social Care Committee inquiry into Sepsis and includes personal, first-hand case studies.

The Cross-Party Group was constituted in 2016 with the intention to raise awareness of Sepsis amongst elected members of the Welsh Assembly / Senedd. The Secretariat of the Group was provided by the Sepsis Trust UK and attendees and contributors included medical professionals, sepsis survivors and family members of people who died due to Sepsis.

During the Welsh Parliamentary term, 10 meetings have been held, the group has undertaken two postal surveys to both local authorities and GP practices, interviewed care providers and health professionals, taken evidence from both the Minister for Health and the Deputy Minister for Social Care, and submitted evidence to the Senedd's Health and Social Care Committee's inquiry into Sepsis.

I would like to express my personal thanks to all who took part, to Terence Canning of Sepsis UK for providing the secretariat and above all to the families and survivors of sepsis. Your courage and desire to improve the fortunes of others affected is inspirational.

Jayne Carpenter was the epitome of someone cruelly struck down by the effects of sepsis and her determination to raise awareness of sepsis, to improve outcomes for survivors and to educate health professionals is her legacy. This report is part of her story.

Recommendations

- **Recommendation 1:** The Cross-Party Group calls on the Welsh Government to encourage Public Health Wales (PHW) to make progress with plans to introduce a public awareness campaign into Sepsis.
- **Recommendation 2:** With as many as 80% of sepsis cases originating in non- hospital settings the Cross-Party Group calls on the Welsh Government to undertake a detailed study on how to improve the support and training that is required to reduce the risk of Sepsis.
- **Recommendation 3:** The Cross-Party Group calls on the Welsh Ambulance Service (WAST) to review their position on call handling and to investigate the introduction of Sepsis protocol cards.
- **Recommendation 4:** The Cross-Party Group calls on the government to clarify their message and to ensure that the extra training that they have insisted on takes place.
- **Recommendation 5:** The Cross-Party Group calls for an all-Wales standard to be introduced for the collecting of data.
- **Recommendation 6:** The Cross-Party group calls on the Welsh Government to undertake detailed studies into the mental health effects of surviving sepsis.
- **Recommendation 7:** The Cross-Party Group calls for clear pathways to be established to help support Sepsis survivors in their recovery.

Background:

What is Sepsis?

Sepsis is the body's overreaction to an infection or injury. If not dealt with immediately, sepsis can result in organ failure and death, but with early diagnosis, it can be treated with antibiotics.

Sepsis is responsible for 1 in 5 deaths worldwide, kills 48,000 people out of the 245,000 affected by the condition, in the UK, every year. In Wales this equates to over 2,000 deaths from approximately 8,000 cases.

This is more than breast, bowel and prostate cancer deaths combined. If it is not treated as a medical emergency, it can take someone's life in under 24 hours.

Despite the scale and these stark figures, many people have never heard of sepsis, or if they have, are often confused about what it is and what signs to look out for. Sepsis is indiscriminate and can affect anyone who has acquired an infection, and therefore raising awareness so people can access healthcare in time to be effectively treated is so important.

Sepsis often goes unnoticed amongst those with no real history of ill health as they do not know what to look for and are expecting to recover. This is often compounded if a health professional also fails to suspect sepsis and can sometimes result in preventable community tragedies like the deaths of Rachel Day at 29, 17-year-old Chloe Christopher and Skyla Whiting who was just 4.

Whilst the emotional cost to each family is incalculable, we know 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. We know that earlier treatment will minimise deterioration and the need for critical care, and ultimately reduce the burden of long-term health problems for survivors. In turn 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.

Jayne Carpenter's Story

At 9am on May 1, 2016, Jayne decided to visit her GP out of hours adjacent to Prince Charles Hospital after feeling unwell for a couple of days. Jayne was a nurse at the time and thought she was

coming down with a cold or maybe chest infection. Following blood tests, she was diagnosed with community acquired pneumonia and probable neutropenic sepsis and given oral antibiotics. But within hours things went from bad to worse when she was found to have severe sepsis and transferred to intensive care.

By midnight Jayne had gone into respiratory failure - in which not enough oxygen passes from the lungs into the blood - and suffered multiple organ failure shortly afterwards.

Jayne remained critically and gravely ill, and after three days was placed in a medically induced coma. As gangrene had set into many of her limbs, the decision was made to amputate both of her legs from the knee down, her left arm from the elbow down and four fingers from her right hand and her life had changed beyond measure forever.

As Jane said:

"The emotions I have felt can be equated to a grieving process. I have grieved not only the loss of my limbs, but also for the life I once had and the ease and ability to do so many things that we all take for granted. Living life as a quadruple amputee is so incredibly hard and staying strong is frequently harder than you can imagine."

The effect sepsis had on survivors like Jayne can be visible, but survivors often take years to recover even though they appear physically well. This can be very difficult to deal with both at home and in the workplace, when others will have the same expectations as they used to have of those who have survived serious sepsis.

Public and professional awareness of sepsis.

As a Cross Party Group, we have made repeated calls for a public awareness campaign to be launched to highlight the signs of Sepsis.

An NHS Health Development Agency report entitled "The effectiveness of Public Health Campaigns" identifies providing basic, accurate information through clear, unambiguous messages as being a key element for success in changing behaviour.

To date the Cross-Party Group has found both Public Health Wales and the Minister for Health and Social Service quite averse to a public awareness campaign.

The Cross-Party group has been given two key reasons for not having a Sepsis awareness campaign.

- 1. It is complex and important to strike the right balance with messages about the appropriate use of antibiotics and the risk of creating public anxiety.**

There is consensus that there is an intrinsic interrelationship between the three pillars of infection management: infection prevention, rapid treatment of time-critical infection and antimicrobial stewardship. It is essential that none be considered in isolation from the others. Just as it would be inappropriate to consider strategies to improve outcomes from sepsis without due consideration to Antimicrobial resistance (AMR), so it would be inappropriate to fight AMR without considering its potential impact on patients with sepsis. We are facing an existential problem.

As such, all activities driving improvements in the way we recognise and manage sepsis need to be mindful of adverse consequence. Programs should evaluate the impact on total antimicrobial consumption, and the way in which the geography of antimicrobial prescribing is altered. Such considerations need to address the whole system rather than an individual location of care, as the interrelationship is likely to impact in unpredictable ways.

An example can be seen in data from the Royal Pharmaceutical Society around antibiotic usage following the introduction of NHS England's CQUIN commissioning incentive on sepsis. Whilst antibiotic consumption in Emergency Departments doubled in a few short years, total consumption across English hospitals remained largely static: it appeared that the result was that we were front-loading antibiotics without adverse consequence when considered across the system. We need to continue to monitor this situation closely if we are to get the balance right.

Best practice would be that clinicians administer antibiotics where it is felt appropriate whilst investigations are ongoing and then reviewing them with a senior clinician later. Just because you start a course of antibiotics you do not need to finish it if it is deemed unnecessary on review.

With regards to creating public anxiety, we think we are possibly being too quick to judge and dismiss how the public will react to information around sepsis especially given that 70% of all sepsis cases are community acquired. We are the experts on our own lives and have a huge part to play in making the right decisions about accessing healthcare and I think there is a danger we are not given enough consideration to this.

We cannot underestimate the potential value of the public. We are the experts on our 'normal selves' and the 'normal selves' of the people close to us and can play a huge role in helping the health professional make a diagnosis and care decision. With sensible education on the symptoms of sepsis should result in:

- The sick person or carer of sick person, at the very least, being able to recognise something is not normal. A recognition of being abnormally or unusually unwell for that

person and being communicated that to a health professional can be incredibly useful. Even more so if they can additionally indicate concern around infection.

- The first health professional spoken too is then the most important person and they, in turn, need to:
 - Listen for key signs.
 - Ask key questions to elicit key signs e.g. 'Are they confused?', 'When did they last go to toilet. Can you find out?' Together they can think about sepsis and ask the important question 'Could this be sepsis?' so that it can be ruled out.

Currently we are asking for a healthier Wales and for communities to take responsibility but, in terms of sepsis, we are not empowering them to do so.

2. There is no evidence to suggest campaigns lead to improvement to justify the public money required to fund the campaign.

As a starting point, if we had asked members of the public 5 years ago very few of them would have heard of sepsis. In most cases those who were aware, only knew because they had been affected by it in some way. This has changed considerably more recently. Many more people have heard of sepsis now for a variety of reasons ...News coverage, Social Media, Radio and even storylines in soap operas such as Coronation Street. We can say with some confidence that the word 'sepsis' is recognised more now. However, there is a big difference between having heard of 'sepsis' and knowing how to recognise the signs and understanding what the best course of action is.

This is clearly not a campaign that would have cost a lot of money and while it is not perfect it does deliver a very simple message in very simple language. As mentioned earlier the public do not know about NEWS, have no relationship with it and will not be using it as reference point to access healthcare. The process we need is for the sick / deteriorating patient to present to healthcare where the health professional then uses NEWS as a reference point for diagnosis and treatment or escalation if required. If the patient was not severely unwell at this stage IE well enough to go home and self-monitor or be monitored by parent or guardian then maybe this is the stage to introduce the basics of NEWS to the patient/public. This would be the 'safety net' as we know that some patients who ultimately end up in septic shock were not triggering on NEWS when they first accessed healthcare, for example, at the GP surgery. It is often the deterioration that is missed because people are not aware enough to act. They wait.

Two examples of where public health campaigns have been effective in Wales can be seen in the Organ Donation Campaign and the FAST Campaign.

The FAST campaign raised awareness of symptoms of stroke has 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 because 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.

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.

If an education and awareness campaign has been successful for stroke, then why would it not be similarly successful for sepsis?

The Welsh Government's Building a Healthier Wales document published in March 2019 stated that 'Prevention is at the heart of a healthy Wales'.

It went on to say:

"To make our services work as a single system, we need everyone to work together and pull in the same direction. We think we can do this in a small country like Wales, especially if we as a government provide stronger national leadership, and make sure we keep talking – and listening – to the people who deliver and use our health and social care services".

A final important point to consider with regards campaigns is while there are individual campaigns which raise local awareness and are responsible there are concerns over some of the campaigns run

by media outlets. A media driven campaign which throws out a horror story a month is potentially more of a risk than delivering a targeted sensitive and responsible Government and Healthcare led campaign.

There are always reasons to not to do something. We must establish a route which will allow concerns to be mitigated, find alternative ways of doing something, rather than allowing the hurdles to trip us up.

Recommendation 1: The group calls on the Welsh Government to encourage PHW to make progress with plans to introduce a public awareness campaign into Sepsis.

Professional Awareness:

The Cross-Party Group undertook two investigations to gather couple of investigations into how well Sepsis is understood within a different field.

We sent out a short questionnaire to every GP surgery in Wales, around 450. We received 11 responses. The data obtained from this project was minimal, but the key messages back from the GPs was that they could not identify Sepsis champions within their Health Board nor a specific rehabilitation team with their Health Board. They also said they would welcome more support in identifying sepsis and there was a mixed view in terms of a tool kit being available.

A similar questionnaire was issued to Social Services departments at Welsh Local Authorities – Again the response was poor and highlighted the haphazard approach to identifying Sepsis in Council run care homes and the lack of clarity when it came to treatment pathways.

A GP from Hywel Dda Health Board area stated that “I have noticed that Sepsis recognition has gained more airtime in post graduate medical education in the last year or so.” He goes on to say that “there appears to be more teaching and pointers on sepsis recognition including the use of computer tools and checklist”. However, he expresses concerns that there is a need to undertake more detailed training to better identify paediatric cases. The GP concludes his observations by stating “The importance of sepsis and in particular public education of the warning signs cannot be overstated”.

From evidence heard from a range of organisations and individuals training into how to recognise signs of sepsis appears to be haphazard and inconsistent. There appears to be no focus on how best

to deliver it regularly and no centralised approach, passing the responsibility back to Health Boards to devise and manage their own schemes.

Angela Burns highlighted this issue during the H&SC Committee enquiry

“They all have multiple levels of training, and there is no clear protocol or step system. We have care homes that do not even practice septic techniques, let alone spot sepsis. It is not just a gap, but a gulf”.

Sepsis often appears to be the poor relation of conditions. It is surprising that training modules on sepsis are not already mandatory for some professional groups, conditions such as heart disease or strokes would not have optional modules, they would be compulsory, so why isn't sepsis?

Things are improving though. The RCGP undertook a study in 2015 finding that only 60% of GPs felt familiar with the presentations of sepsis. A study around a year later, following the College undertaking training work established that this figure had increased to 73%. But there is still further to go.

Recommendation 2: With as many as 80% of sepsis cases originating in no hospital settings the Group calls on the Welsh Government to undertake a detailed study on the how we can better provide the support and training that is required to reduce the risk of Sepsis.

Welsh Ambulance Service:

We took evidence from the Welsh Ambulance Service and from key Sepsis leads within hospital A&E/CDU. Given the chameleon nature of sepsis and the multiplicity of similar symptoms similar to symptoms of other illnesses we recognise how difficult it can be for call handlers to discern a Sepsis call.

Awareness training is therefore vital for both call handlers and paramedics. Additionally the Cross Party Group, supported by Intensivists, have called for Sepsis protocol cards to be issued for call handlers to enable them to recognise the signs of potential Sepsis when 999 calls are being made.

The Welsh Ambulance Service expressed concern that any introduction of additional protocol cards may impact on other diseases being missed or going unrecognised. The Group evidenced that diseases such as cancer or stroke already have clearly defined pathways and identifying signs, something which Sepsis is still lacking.

Recommendation 3: This report calls on the Welsh Ambulance Service to look again at this issue and to investigate the introduction of Sepsis protocol cards.

Care Homes:

A significant number of out of hospital Sepsis cases start in residential care settings. Sepsis often starts as a Urinary Tract Infection, a condition older, more immobile individuals unable or disinclined to drink sufficient quantities of water are more prone too. Despite our inquiries of Care homes and County Council commissioners we were unable to draw a clear picture of the levels of understanding and awareness of Sepsis in Care Homes. However anecdotal evidence from GPs and hospital doctors indicates that residents of Care Homes are a significant proportion of those not admitted for Sepsis via A&E.

Furthermore In 2011 health care providers were asked to ensure that all staff were to undertake ANTT training (Aseptic Non-Touch Technique). This entails an E learning programme (videos and a multi choice assessment) followed by a clinical tuition session and a clinical based assessment. Staff must obtain 80% in the written assessment before they can go any further. The Cross-Party Group were concerned to learn that aseptic technique is no longer taught at the start of their training.

In 2016 Public Health Wales found that ANTT had not being widely adopted and issued another request to health care providers that it was. Now the Welsh Government is insisting on 'all' staff

having this training'. The message here is very muddled and certainly not being enacted on. It is important that monitoring is undertaken to ensure that we have the checks required to ensure ANTT training is happening.

As in every setting early recognition and early treatment is key to best chance of the best outcomes.

The Cross Party Group supports the rolling out of NEWS and sepsis screening into community healthcare settings. Evidence indicates that NEWS works well at identifying sick people but more importantly is vital as a standardised communication tool.

NEWS is a common language of risk and is supported by a commitment of all health boards and trusts who aim to implement NEWS in all 160 Welsh district nursing teams by September 2020.

Recommendation 4: The Cross-Party Group calls on the government to clarify their message and to ensure that the extra training that they have insisted on takes place.

Hospitals:

In Hospital settings the National Early Warning Score (NEWS) system is used to assess potential Sepsis cases. This is an aggregate score made up of six physiological parameters, with the aim of improving detection and response to clinical deterioration in acutely unwell patients. The system appears to be well understood and is made regular use of, not only in Primary Care but also secondary care settings. One Welsh Nursing home stated that having employed NEWS they saw a 30% reduction in Hospital admissions.

Last year a new Out of Acute Hospital News Observation chart was launched for testing to support healthcare professionals working in community settings to identify early signs of sepsis. It is in acute settings that progress appears to have been made, albeit slowly. Many A&E departments have Sepsis 6 trolleys which have the tools to identify and treat Sepsis on discovery as well as offering a reminder to staff to consider it when making a diagnosis.

A problem does remain in the Triage area of A&E where patients may present with another problem and the signs of Sepsis may be ignored. The cross-party group have heard from Sepsis survivors who have been discharged from Triage without a Sepsis diagnosis only to be rushed back into A&E later the same day when Sepsis has struck. The challenge is to identify Sepsis at the earliest stage.

ITU Specialists for A&E

The CPG also recognises that the best place to identify sepsis to ensure prompt treatment is at the 'front door' when patients present at A&E. One of the issues here is that often the clinicians most experienced in sepsis care tend not to be deployed in A&E but in ITU. The Cross Party Group would like Health Boards to explore a rapid escalation process whereby more experienced Sepsis clinicians can be asked to review patients where there is a suspicion of sepsis during diagnosis.

Data Collection Issues

To further develop our understanding of Sepsis we must improve data collection. It is commonly agreed that the way data is collected and recorded across the UK is not ideal and this is especially true in Wales.

There is no consistency as to how data is recorded and collated, some is recorded on paper, some electronically, leading to difficulties with collation and analysis. Furthermore there is clear evidence that there is no clear route between primary and secondary care providers when it comes to Sepsis patients. Messages are not passed on or are lost in the system.

The Cross Party Group calls on the Welsh Government to find a standardised approach to data collection and analysis in order to ensure consistency, veracity and affirm confidence in subsequent scrutiny. Without this we will never be able to fully understand the true extent of Sepsis.

Recommendation 5: The Report calls for an all-Wales standard to be introduced for the collecting of data.

Better Support for Sepsis Survivors:

Some individuals develop sepsis so severely they go into septic shock. Many will require ITU or HDU intervention. The positive outcome is that up to 80% of patients survive sepsis and many will return to a normal or a 'near normal' life within 18 months of being ill. However, more than 25% of the 80% will suffer long term consequences such as amputations or memory disfunction.

These long-term problems can be divided into physical and psychological, and often start during the acute phase of Sepsis. Collectively, they are known as Post Sepsis Syndrome (PSS).

Post Sepsis Syndrome

The table below lists some, only some, of the more well recognised consequences of Sepsis.

PHYSICAL LONG-TERM PROBLEMS	PSYCHOLOGICAL LONG-TERM PROBLEMS
Associated problems of amputations Poor mobility Breathlessness / chest pain Fatigue Loss of appetite Taste changes Dry skin Brittle nails and 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) Poor kidney function (which may need dialysis) Repeated infections	Anxiety 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 Survivors guilt

When there is a delay in recognition and treatment of Sepsis, even for those who survive, that survival can come at a personal cost.

Whilst some of the obvious physical consequences can be understood there is more to PSS that is unexplained and needs to be researched, such as the disabling fatigue and chronic pain that many survivors experience. Others complain of seemingly unrelated problems, like unexplained hair loss and crumbling teeth that may occur weeks, months and years after their discharge from the hospital.

Post Sepsis Syndrome is real but it is not yet fully understood and is often overlooked or discounted.

Post-Traumatic Stress Disorder

A well recognised disorder from ICU survivors and now many sepsis survivors also report symptoms of PTSD. Researchers have already recognized that ICU stays is a trigger for PTSD, which can last for years. It can be partially explained because of inflammation caused by sepsis. This inflammation may lead to a breakdown in the blood-brain barrier, which alters the impact on the brain of narcotics, sedatives and other drugs prescribed in the ICU.

No matter how ill someone is after having sepsis, survivors have described it as: “You never feel safe. Every time some little thing happens you think, “Do I need to go to the hospital or is this nothing?”

There remains a fear of repetition, for example a patient who contracted Sepsis having had dental work may go on associating Sepsis with such procedures and avoid obtaining treatment. This fear can also be seen by Sepsis survivors and their close family being hyper vigilant when it comes to their health with any ache, pain or tiredness being considered a sign of Sepsis returning. Mothers who have experienced Sepsis whilst pregnant can worry that if they give birth again, Sepsis may follow.

Sometimes PTSD has in the past being mislabeled as ‘simply’ depression or anxiety when in fact it is much more.

In their evidence to the H&SC committee Public Health Wales said about post sepsis support

“Yes, I think there are gaps, probably a chasm. Within the literature there is a real lack of evidence in terms of post sepsis support. It is probably incredibly tough for people to make sense of what has just happened to them in the way they have been through an intensive care unit and had all those interventions, or whether it has been managed on a ward- there will be significant challenges.

“I think there is a real opportunity for us as a healthcare profession and caring professions to actually be more effective in how we share information, and I think there is opportunity for us to be more effective in how we bring groups together who have suffered with sepsis and how they share some of those experiences.

Recommendation 6: Calls on the Welsh Government to undertake detail studies into the mental health effects of surviving sepsis.

Pathways to Recovery:

Formal support for survivors of sepsis and their families is non-existent. Many leave hospitals without an explanation of what they have suffered, potential impact or signposting. UK Sepsis Trust runs quarterly support groups in North and South Wales; 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 similar people has helped their recovery and understanding of Sepsis.

"Myself and my husband had absolutely no idea of the effect sepsis could have on someone or how long the recovery period was. The UKST and support line and group has been a lifeline to my husband and I over the years as it is a place where we can be sad but have a laugh and feel normal while talking of our experiences" Joy ***James – wife of sepsis survivor John James.***

There is a lack of clear communication between Hospitals and GPs when it comes to patients who are discharged. Sepsis is often not recorded, and it is left to Sepsis survivors to alert GPs about their Sepsis history.

One of the GP responses states that they "would be in favour of enhanced local primary care access to rehabilitation services for those affected by sepsis particularly simple physiotherapy and mental health support."

One of the members of the Cross-Party Group, a former health care professional, had three limbs amputated due to Sepsis and was left to struggle to obtain multidisciplinary assistance in making the life changes that they needed to so they could continue to live independently. There is a lack of joined up thinking between agencies which can cause difficulty and delay in getting home adaptations undertaken and obtaining mental health and physical health support.

Other illnesses such as Cancer see the NHS working in close collaboration with charities such as Tenovus and Macmillan.

The Sepsis lead for Adult Critical Care is leading in developing a sepsis registry for Wales to get reliable data on the incidence and mortality from sepsis and to see what data we can gather on sepsis morbidity to be able to target NHS resources appropriately with the aim of being able to recognise and treat sepsis early to reduce the incidence and severity of post-sepsis syndrome.

The reality is that mental and physical health are intertwined.

The Physical & Mental Health Impact - John James Sepsis Journey

John was a physically fit recently retired police officer who contracted an infection which led to septic shock after a prostate biopsy. John experienced multiple organ failure and ultimately a cardiac arrest. It took 28 minutes to restart John's heart resulting in a spending a month in hospital including 10 days in intensive care where his family were told his chances of survival was slim. This brings its own traumas for family members. The survivor's recovery also places stress on the whole family unit. In John's own words:

"Life post Sepsis was very difficult for myself and my family. On discharge no medical professional explained to my family or myself how long and how difficult the recovery would be from Sepsis. You tend to think when you are discharged as a patient you only need rest, good food and things will be back to normal, however this was not the case.

On discharge I was given an appointment to attend an INR clinic on Friday. I soon realised that there was no way I could get to the hospital clinic, so my wife rang them, and they said to take him to the GP to see a nurse. The 20 min journey to the GP was very difficult and walking from the car to the waiting room was nearly impossible. When we got to the nurse, she said no way should we have come to the surgery and said that the district nurses should come to the house. They did for four weeks. This just highlights how Drs and nurses do not realise what life post Sepsis is like especially at home.

Life post Sepsis has been very difficult with Fatigue, dealing with losing 10 days memory, difficulty with speech, aches, and pains, being very emotional, lack of appetite, depression. If it had not been for the full support of my wife and children, I honestly feel I would not have recovered. At times, my memory is so bad that my wife has to complete sentences for me.

Recovery was a long process and took 2 years in which the only support I had was from Sepsis Trust Wales. 6 years ago, there was no outpatient clinic for Sepsis, you tell the GP about your symptoms and although they listened, they can only refer you to separate clinics like physiotherapy, speech therapy and this took months. We needed something quicker.

I used to get very depressed, I was always fit and healthy did not rely on anyone to doing things for me, yet for the best part of a year I was unable to complete simple tasks. 9 months after I had Sepsis, I still could not put shopping into the boot of our car.

Family celebrations, gatherings and Christmas still are very emotional as I think how lucky I am to be here and still be part of my family's lives. It is a mixture of sheer relief and survivor guilt as I know other families I've met were not so 'lucky'.

Six years ago, I had never heard of the word Sepsis and most certainly never realised how serious this illness was. If I had been given the appropriate antibiotics on arrival or during the four hours period before my cardiac arrest, perhaps Sepsis would not have had such a serious impact on my life. I feel that prior to my discharge I should have been made fully aware of how serious the effect of Sepsis has on one's body. Also, it should have been explained how difficult the recovery journey would be for my family and myself. If it had not been for me attending and intensive non-NHS physiotherapy course with counselling this would have also made my recovery even more difficult. There is still a lot of work to be done within the NHS to identify and treat Sepsis quickly and I personally believe there should be a public awareness programme in Wales”.

Recommendation 7: Pathways to be established to help support Sepsis survivors in their recovery.

Conclusion.

This Cross-Party Group report builds on the evidence provided to the Cross Party Group over the Senedd Term, on interviews with Sepsis leads within the Health and Care professions and on evidence provided to the H&SC committee.

We recognise that over the past Senedd term Sepsis and the consequences of Sepsis have become more widely spoken of and that awareness has grown within the Public and Professional spheres.

We also welcome the improvements to Sepsis diagnosis driven by the Welsh Government and we want to gratefully acknowledge the work of Sepsis champions across Wales from the community to secondary care. We have met and worked with a great many dedicated professionals and would like to thank Ministers and NHS Wales for their input.

Whilst this renewed traction in dealing with one of the threats to life faced by people is welcome we are acutely aware that in a space with many competing requests for attention, for funding, for action, that traction could be lost.

We must continue to review and improve current understanding and awareness around Sepsis for health professionals and the public.

We must improve and standardise the collection of data on Sepsis across all health settings.

We must to improve our provision of both mental health and physical health support for Sepsis survivors.

We must recognise that there is a huge gap in the provision of post sepsis care and support with people often being discharged back into the community with little or no information or signposting advice given.

Follow up services are often non-existent, or patients are left to work out what is the best recovery path with their GP's. This often results in a vicious circle where patients with little information on their condition are trying to come up with solutions with GP's who also have little information on the condition. This would not be the case with cardiac, stroke or cancer treatment which have well established follow up clinics. Sepsis affects as many people each year as these conditions but has no established follow through mechanism.

There is a requirement for a more holistic approach towards sepsis after care where departments communicate and collaborate on a patient's recovery plan.

The better we get at diagnosing Sepsis, the more survivors we are going to have.

We are calling on the Welsh Government to commit to building on the good work they have already undertaken in Wales.

This report calls for the Welsh Government to recognise the concerns contained within this report and to implement the recommendations made.

Above all we must believe that it is not enough that people survive Sepsis but that they survive well.