

All Party Parliamentary Group for Defibrillators

Sudden Cardiac Arrest: Personal Experiences

Date: 22nd February 2023

Time: 10.30 – 11.30 am

Chair: Jonathan Gullis MP

Minutes taken by: Tamsin Melville, DGA (Secretariat)

Members present:

- Jonathan Gullis MP (Chair)
- Lord Aberdare

Speakers

- Ryan Nelson
- Paul Swindell, founder Sudden Cardiac Arrest UK
- Dr Thomas Keeble, Consultant Cardiologist, Essex Cardiothoracic Centre, Associate Professor, Cardiology and Circulatory Health

Audience:

- Esther Kuku, Resuscitation Council
- Marcus Loney-Evans, Resuscitation Council
- Susannah Kerr, Head of Public Affairs British Heart Foundation
- Harry Mahoney Roberts, Jonathan Gullis MP Parliamentary Assistant
- Sam Bellamy, Ruth Edwards MP Parliamentary Assistant
- Tamsin Melville, DGA (Secretariat)
- Sonia Kharaud, DGA (Secretariat)
- Holly Ramsey, DGA (Secretariat)
- Olivia Arnold, DGA (Secretariat)

Minutes

Jonathan Gullis MP opened the meeting and introduced himself and the other members. He then welcomed the external speakers to the second APPG for Defibrillators session on Sudden Cardiac Arrest: Personal Experiences.

He spoke about the reason for the formation of the group and the impact of Sudden Cardiac arrest.

He then asked for the speakers introduce themselves.

Ryan Nelson introduced himself and spoke of his cardiac arrest. He experienced a cardiac arrest at home. It took 14 minutes for the Ambulance to arrive. He received 4 shocks from the defibrillator.

After 26 minutes he received adrenaline and another shock which put him into an induced coma. He currently has an ICD.

He said following the experience he suffered severe memory loss.

Ryan explained that his children have been impacted by the experience with his daughter experiencing panic attacks and she is now receiving counselling.

Ryan has now done local television in regard to defibrillator access. Going forward, he wants defibrillators to be personalised.

Ryan explained that his son did CPR on him when the incidence happened and now Ryan is working closely with Air Ambulance in Northern Ireland.

Jonathan Gullis MP thanked Ryan for his introduction and said that it was very powerful and that he hadn't previously considered the impact on the family. He then asked for Paul Swindell to introduce himself.

Paul Swindell introduced himself.

He said that his story was very similar to Ryan's and said that he has created the Sudden Cardiac arrest UK charity.

He said that he has no memory of his incident but he is particularly focused in survivorship.

Paul experienced an unwitnessed cardiac arrest at home. His wife found him at home and called 999 and started CPR and received a shock

He was put into an induced coma and also received an ICD.

He was told to live life 'as before' by his doctor but he said there was no plan for what to do next. He experienced issues such as fatigue, head aches and problems with his speech.

Paul said he went to see his GP, but he wasn't very helpful as he had never treated someone who has had a sudden cardiac arrest.

Paul said that following his incidence, he did not receive rehab or mental health support.

Following his visit to the GP, he went to see his neurologist .

Paul also mentioned that his wife was suffering and her mental health had deteriorated.

Paul said that families of survivors of sudden cardiac arrest are often termed as a forgotten patient .

He describes his experience as a roller coaster and he had a lack of support by services and that his quality of life had suffered.

Paul has started a peer support group – Sudden Cardiac Arrest UK with over 3k peers.

He said that many people who have joined Sudden Cardiac Arrest UK have had the same sort of experience as himself and Ryan.

Paul spoke of Christian Erikson and how he had a great chain of survival and recovery process, however 25% of people who experience sudden cardiac arrest do not return to work.

He said that many survivors have good outcomes but also experience long term impairment and research has shown that early intervention can improve this situation significantly .

He says that he feels privileged to survive but his recovery was more painful than it should have been.

He believes that care after cardiac arrest should have parity with cancer and stroke.

Jonathan Gullis MP thanked the speakers for the introductions.

Jonathan Gullis was surprised to hear of how there is a lack of support following cardiac arrest and empathised with the witnesses regarding the trauma of sudden cardiac arrest and for families who have witnessed a cardiac arrest and was surprised to hear that support for families wasn't available.

He asked how we can make a smooth system and how we can support cardiac arrest survivors to return back to work following their incident .

He also asked if there are any NHS trust which has a package of support or an individual post SCA and how common is that?

Dr Tom Keeble introduced himself, and said he set up the care clinic which gives SCA survivors information and a leaflet following their incident and they also offer a phone line and sees them within 3 months to ensure that there are no big issues.

He said is working with Resuscitation Council to make sure there is a minimum standard to ensure that recovery isn't a post code lottery.

He said that the issues with SCA survivorship are huge, referencing driving and insurance.

Jonathan Gullis MP agreed and he said that postcode lottery was a key phrase and that it wasn't fair that some areas have better services than others.

Dr Tom Keeble said that the cause of cardiac arrest is what ascertains what recovery you receive.

He stressed that everybody should be allowed to have cardiac rehab.

He said that unless you have a SCA caused by a clot then you are not permitted to have rehab.

The consequences also mean that they are excluded from the DVLA.

Jonathan Gullis MP asked if Lord Aberdare if he had any contributions.

Lord Aberdare thanked Ryan and Paul for their contributions.

He said that one of the most powerful messages he received was that there is a lack of recovery from SCA.

He said that the other striking point was that their families have been part of the campaigns .

He asked what access they have to defibrillators and referenced the circuit.

He said that the access to the circuit is limited and you have to be a registered practitioner.

He was also interested in defibrillators in the home.

Lord Aberdare mentioned CellaED and said that it has to get through the NHS. Ryan also agreed about personal defibrillation and CellaED saying that this would be key to helping those access defibrillators in the home.

Lord Aberdare said he was supporter of the Governments decision for defibs 4 schools but one defib per school doesn't seem enough and that you need to know that there is one easily accessible.

He said a key issues is to support families who have experienced .

Paul Swindell said that as part of the package of supplying an AED , he wants those to be accompanied by a debrief with information.

He spoke of the DVLA and how people get their license after experiencing a SCA and an ICD.

Jonathan Gullis MP mentioned that he shares an office with the minister for DVLA.

Dr Thomas Keeble spoke about how people have experienced a cardiac arrest and get their license revoked and said if you have a heart attack you would be able to drive a week later but this is not the case for sudden cardiac arrest survivors and that the DVLA would need medical expertise to differentiate the two.

Paul Swindell agreed and said it's not a simple process and detailed how some people get their license suspended or revoked following a sudden cardiac arrest.

Jonathan Gullis MP asked why the DVLA treat SCA and heart attacks differently?

Paul Swindell said that heart attack is more treatable because you understand what the cause was.

Lord Aberdare asked about training and driving.

He said we need to find a way for people to be trained in CPR.

Dr Thomas Keeble gave the example of Canada and giving CPR training during driving tests.

Jonathan Gullis MP also spoke of a campaign where children had to learn CPR in schools.

Susannah from the British Heart Foundation (BHF) spoke of the nations of life savers campaign which aims to get every child to have training in CPR and said that it's part of the PHSE curriculum.

Jonathan Gullis MP said that prior to being an MP, he was a citizenship teacher. He said that the programme was reliant on the teacher being dedicated to teaching CPR however some just used a powerpoint as a 'tick box' exercise.

Susannah said that the Department for Education is surveying schools to examine how they are implementing the CPR training in schools.

She also spoke of the circuit and how there are 60,000 defibrillators registered and there is also defibfinder.uk.

However she mentioned that it's not mandatory to register the defibrillator on the circuit.

She said that the British Heart Foundation are trying to get the messaging out to ensure people are registering their defibrillators on the circuit.

Jonathan Gullis MP agreed that defibrillator campaigns have a powerful impact.

He asked would the BHF need to get to a point where they make it mandatory to register a defibrillator.

Susannah said that we need to remove the barriers to make people want a defibrillator without admin costs.

Lord Aberdare spoke of the access to defibrillators and the circuit and said that the circuit needs to establish itself.

Susannah said that they are trying to make it *the* place where people find a defibrillator. She said that they need to come together to make sure that there aren't disparities.

Paul Swindell added that the primary thing is to phone 999, who will bring a defibrillator. But also said if there is a defibrillator down the road you can't leave the patient while they're having a sudden cardiac arrest.

He also spoke of children who have been affected badly by witnessing a sudden cardiac arrest or having to use CPR.

He said that he's scared to get children involved in this but there is also not a support option for children who have experienced having to do CPR.

Jonathan Gullis MP said that there should absolutely be packages of support.

Lord Aberdare spoke of his involvement with St John Ambulance in Wales. He said he heard many stories of children saving the lives of parents.

Ryan said that his son called 999 and the guy talking him through it was brilliant however he said he couldn't get his son to go get support for mental health .

He said that something could be triggered and he could have a break down.

Lord Aberdare said that there are a large number of cases where there haven't been good outcomes.

Dr Thomas Keeble spoke about defibrillator density.

He said defibrillator access varies and the defibrillators are all in the wrong place due to mainly being located in affluent areas.

He also spoke about connecting people who have been the life savers of a sudden cardiac arrest victim. He mentioned that there should be capacity to let people know if the person who had a cardiac arrest survived.

He added that defibrillators should be as common as fire extinguishers.

Jonathan Gullis MP said that he sees this being possible with environment standards and he thinks that new buildings should include defibs.

Dr Thomas Keeble said that survivorship and family support are the most important aspects of SCA.

Sam Bellamy (assistant) asked if it would be worth pulling together a best practice of what Dr Thomas Keeble is doing for MPs to lobby the minister.

Jonathan Gullis MP agreed and would like a list of selected questions for MPs to share.

Marcus RSUK – introduced himself and said that they are developing a minimum standard for post SCA recovery care.

Jonathan Gullis MP wants to table written parliamentary questions and speak to multiple different departments.



He asked speakers to feed in questions .

Sam Bellamy (Ruth Edwards MP assistant) said that Ruth Edwards MP is in the whips office and asked to please share briefing.

Lord Aberdare asked if the speakers had any further questions.

Ryan spoke of housing insurance and would like that to be considered in the report.

Dr Thomas Keeble said that there is potential to lobby insurance services.

Paul Swindell added that insurance providers know a lot about the chain of survival and that there is no plan for SCA survivors.

He said that they can't wait another 9 years for progress in this area.

Jonathan Gullis MP thanked the speakers for attending the session and said that the group has heard their message to ask the government of support for sudden cardiac arrest survivors and their families.

He concluded that the secretariat will send the recording to colleagues who weren't able to attend.

Meeting closed.