

# Kidderminster & Worcestershire Prostate Cancer Support Group



Aidan Adkins (Chair of Solihull PCSG and Tackle trustee)  
volunteering at the Commonwealth Games in Birmingham

Tackle Making a Difference (pages 12-18)

## SUPPORTER

**September 2022 issue 85**

**[www.kwpcsg.co.uk](http://www.kwpcsg.co.uk)**

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## EDITORIAL



It was great to hear from our acting Chair, **Mary Symons**, that she had come through her knee operation with flying colours and was soon back in action up front and, crucially, behind the scenes, dispensing knowledge and good advice to our members.

Her absence, however temporary, made me reflect on the health of our **KWPCSG committee**. In recent months both **Martin Harrington** and **Eddie Rudge** have stepped down, and health issues are reducing the involvement of two other members. While this is far from unusual, given the root cause of our involvement with the support group and the advanced age profile in many cases, we have a particular challenge.

Over many years we have developed a reputation as a group which offers far more to its members than most PCSGs up and down the country.

Here are just a few reminders of who we are and what we do:

- **One of the largest groups in the country (over 400 members)**
- **One of the first to develop a small group support contact system for all members**
- **South Worcestershire PCSG created as our satellite based in Pershore**
- **Only PCSG to be granted Queen's Award for Voluntary Service (2017)**
- **Major contributor to local PC fundraising projects (e.g. Rory Appeal for Alexandra Hospital, SABR compressors for Worcestershire Royal)**
- **Our own, recently revamped website ([www.kwpcsp.co.uk](http://www.kwpcsp.co.uk))**
- **Our quarterly 24-page printed Supporter magazine posted to all members**
- **6 open meetings per year (attendances between 30-120 members)**
- **Recent introduction of hybrid meetings, allowing members unable to attend having access to the event live via the website or later via YouTube**
- **4 Coffee & Chat mornings across the county each year**
- **The Shed / The Men's Shed providing gardening activities at Leapgate**

These don't just happen. They require members and committee members to devote time and energy to keeping this excellent and forward-thinking charity on the road. In this magazine issue we have articles on 3 key figures who have moved the dial regionally and nationally thanks to their selfless commitment to supporting members with prostate cancer.

We need not just to admire them for their commitment to a great cause but to be inspired by them to step forward and offer our services to the PC community in Worcestershire and beyond. **Our committee needs more women** as we consider occasional partners-only meetings. It needs at least one member of the **Afro-Caribbean community** if we are to engage meaningfully with a group more at risk than other groups. It needs some **younger, newly diagnosed members** to help us to improve the effectiveness of our data base, to expand our social media profile and to provide new ideas which can contribute to both the physical and mental wellbeing of our members. But we also require more foot soldiers willing to distribute leaflets and posters and to improve our profile in underrepresented areas of the county.

Please don't delay. Commit now and either phone Mary on 01299 823166 or write to her at [mandmsymons@talktalk.net](mailto:mandmsymons@talktalk.net)

*Peter Corbishley / [editor@kwpcsg.co.uk](mailto:editor@kwpcsg.co.uk)*

# FUTURE EVENTS



## NICK OWEN GUESTS AT OCTOBER KWPCSG EVENT

We are delighted to confirm that BBC Midlands Today presenter, Nick Owen, will be our guest at our next Kidderminster meeting on Tuesday, October 18<sup>th</sup>. at Kidderminster Town Hall (19.30 but recommend you arrive earlier to secure a seat). Questioning Nick will be his old friend, Peter Tomlinson, also a former TV and radio presenter whom we featured in our September and December 2021 issues.

Nick has been a journalist for more than fifty years, starting in newspapers, moving to radio and then television in 1978, where he has been ever since. Nick was in at the start of breakfast television, broadcasting the sports news on the very first day of TV-am before being promoted to main anchor-man, replacing David Frost, within just eight weeks of the station starting up. He was soon joined by Anne Diamond and their partnership, both at TV-am and a decade later on Good Morning with Anne and Nick for the BBC, has probably been the defining element of his career. He has presented BBC Midlands Today since 1997. Nick has interviewed seven Prime Ministers and a range of celebrities from Paul McCartney to Arnold Schwarzenegger to Eric Morecambe ( his all-time favourite!).



Nick Owen

## STEVE ALLEN RETURNS TO PERSHORE



Dr. Steve Allen

Once again, we are extremely fortunate to have secured the services of Dr. Steve Allen, who will be familiar to many of you who have attended his previous guest appearances in Pershore or Kidderminster. A few months ago, Steve took on the mantle of acting Chair of Tackle (see pages 12-13), so his involvement with PC support groups continues to grow. As both a medic and as someone who continues to receive treatment for PC, Steve is always a most entertaining, engaging and forthright speaker.

**The meeting has been arranged for Wednesday, October 12<sup>th</sup>., starting at 19.00 at the Wychavon Civic Centre, Pershore,**

## COFFEE & CHAT HEADS FOR STUDLEY

Our year of events comes to an end on Tuesday, November 8th when the C&C roadshow moves on to Studley. This involves linking up with the South Warwickshire PCSG. It will be held in the foyer of Studley Village Hall, High Street, Studley B80 7HJ (free car parking to the rear and nearby). Remember the coffee and cake is free for members, partners and even non-members.

## MARY'S CORNER



Four weeks on from my total knee replacement on the 20th July, I am doing really well. I started off with two crutches and now only use one when walking any distance in public but, most of the time, can cope without using it. My physio has told me that I am well in front of my recovery schedule and, while taking me through some exercises yesterday, was surprised to see I could step up on to my operated leg without putting my other leg down on the step.

Sounds like I am showing off, and I don't blame you if you think that. I have, however, followed every instruction given to me by the hospital staff and physio to improve my recovery from this operation. I also feel grateful for the help Di Fox's classes gave me, to strengthen the muscles in my legs pre operation and hope to rejoin her classes soon.

I have been told that the main discomfort will continue for at least three months post op. I am today two weeks away from seeing the Consultant when I should be given the okay to start driving again. It is crucial to my life to get back to normality, as my husband depends on me to drive him everywhere and I cannot attend any events for the group until I can drive.

I was sorry to hear that one of our few Afro-Caribbean members, Logan Walcott, had passed away at the age of 90. His son, Michael, wanted us to know because of the article about Logan in the December 2021 issue of the Supporter. Logan grew up in Jamaica before emigrating to the UK. He settled in Handsworth and remembered shameful signs in windows, stating, "No Irish, No Darkies or Gypsies", and had to face racism when applying for jobs.

He became a bus conductor with Birmingham City Council and his wife Ethel was a midwife. They moved to Kidderminster when Ethel was offered a midwifery post at Kidderminster hospital. They became regular worshippers at St. Mary's Church in Kidderminster.

Logan was diagnosed with prostate cancer in 1998 when I first met him at the hospital but did not need treatment immediately. He finally had treatment in 2002 when he had radiotherapy at Wolverhampton and joined the support group. He was a lovely man, and our thoughts are with his family.

Finally, Nicky Langford has contacted us to say that both abdominal compressors, purchased through the fundraising project launched by her unit at WRH last August, have now been installed at the Alexandra Hospital and are ready for action.

### KWPCSG COMMITTEE 2022

Mary Symons	Acting Chair / Secretary	01299 823166
Paul Markall	Treasurer	01562 751355
Dick Langley	Publicity / Website	07861 233930
Derek Scully	Support Contact Co-ordinator	01886 833236
David Underhill	Tackle Representative	07817 518201
Mark Hall	Minute Secretary	01299 879953
Peter Corbishley	Editor Supporter Magazine	01386 556434
Dick Herbert	Trustee	01299 250598
Val Markall	Co-opted Member	01562 751355
Nicky Langford	WAHT Fund Raiser	07590 624426
Peter Spencer	Co-opted Member	01562 914797

**Please contact us if you need support or advice**





## RECENT EVENTS

### PERSHORE HYBRID EVENT A GREAT SUCCESS

In June the South Worcestershire PCSG organised not only its first panel meeting but had it streamed online via its website so that those unable to attend the event could still watch it live. The panel of former Pershore GP, Dr. Chris Perks, WAHT oncologist, Dr. Lisa Capaldi, and Simeon Greene from the West Midlands Cancer Alliance Forum was chaired by SWPCSG Chairman, Gordon Kingston, with a good level of participation, too, from members of the audience.



*Chris Parsons (ex-Pershore Mayor) gives details of the fund he has created to support those locally with prostate cancer*

There was an excellent turn-out of 48 on the night, with more than 30 watching online. In the 2 weeks after the event over 180 people viewed the meeting via YouTube. Our grateful

thanks go to Daniel Cook, our own tech guru, him or us down. You are a star, Daniel.

### TACKLE CHAIR AT KIDDERMINSTER MEETING



*Gordon Kingston (SWPCSG Chair), Mary Symons (KWPCSG Acting Chair) and Dr. Steve Allen*

Although he had been one of our Zoom guests during lockdown, this was Dr. Steve Allen's first and most welcome return to Kidderminster in July. Record temperatures that day and stubbornly high Covid rates had an effect on audience numbers, but those who attended were treated to an enthusiastic updating of the current direction of travel in diagnosis and treatment of prostate cancer. Steve explained in detail which new advancements were coming on stream.

### FIRST COFFEE & CHAT IN DROITWICH

Like the old Radio 1 roadshow the SWPCSG Coffee & Chat (C&C) turned up in Droitwich for the first time in June – and what a success it was! A record (for C&Cs) 35 members, prospective members and partners turned up at the Gaudet Luce Golf Club on a beautiful Friday morning. Although the room was on the first floor of the club house, bifold doors gave access onto an extensive terrace overlooking the golf course.

For the first time one of our C&Cs included a guest speaker. Aidan Adkins, the chair of the Solihull PCSG and a trustee of Tackle (see the article on pages 15 and 16), gave a very personal talk about his diagnosis when he was only 53 and about his determination to do all he can to improve the support given to those living with PC and their families.

Special thanks are due to Chris Marsh, a relatively new member who organised the event and helped with the advertising, Harriet Horton (club events organiser) and John Hawkes (club owner). We hope Chris' involvement will encourage others to come forward with ideas for C&Cs in their town.



# COMMUNITY



## SIMEON - A CHALLENGING LIFE



Simeon Greene

I met Simeon Greene at Tackle's first regional conference at Hopwood, near Birmingham. His contributions from the floor impressed us so much that we invited him to represent patients' interest on our panel at Pershore in June. After the event he joined us at the nearby Pickled Plum for a drink and a chat with some of the SWPCSG and several of my Pershore Tennis Club friends. Several days later we received the email from him (below) which, on the one hand, made us feel proud that Simeon had felt very at ease that night but, on the other hand, quite ashamed and shocked that his life is still blighted by racism. This is his story.

Hi Gordon and Peter,

I put myself forward to be a patient advocate and, like with everything I do in life, I attempt to do it to the best of my ability. I see too many people in similar roles, who I feel are there either for something to fill their time or for some sort of self-aggrandisement. I see my role in this as being an amplifier for the voices of unheard patients and their families. So I accepted the invitation from the South Worcestershire PCSG, partly from a sense of duty and partly because I'd never been to your part of the Midlands and wondered how it would feel.

As a Black man living in Britain today, I'm always on edge. It's not always about the overtly obvious demonstration of racist behaviour that is the most upsetting, it's some of the micro-aggressions: somebody crossing the road to avoid you; a woman clutching her handbag just that little bit tighter; someone in the supermarket stopping in their tracks, turning on their heels, going in the opposite direction to avoid you; overhearing someone reprimand a toddler for smiling at you. I can experience all of that very close to home, even on the street where I live. So I'm always a little bit apprehensive when I go to somewhere new. While I refuse to succumb to such fears, it was with this state of slight anxiety that I arrived in Pershore.

However, from the moment I arrived, I started to feel at ease. There were none of the looks I often encounter - a kind of moment where it feels (at least to me) that everything stops at the indignation of my presence. I felt none of that. I felt I was received as an equal and treated with dignity and respect by every single person I met, both at the meeting and in the Pickled Plum. I've travelled all around the UK and have never felt more at ease anywhere (not even on the street where I live). I've been pondering this since, wondering why. What comes to mind is that you all seemed very much at ease with yourselves and that reflects in how you receive others (either that or the local plums are drugged).

Please pass this on my thanks to those who attended the meeting and to the guys in the pub. I'm not blowing smoke, there was something genuinely special about all the people I met before, during and after the Pershore panel meeting..

*Regards Simeon*

## SIMEON'S UNCEASING BATTLES

I walk into the Evoke café in Penn on the southern edge of Wolverhampton and there's that smile again, the one we were treated to in June when Simeon Green was one of our panel of three for the South Worcestershire PCSG meeting in Pershore. Almost 3 hours later I leave the café and return to Pershore, my head buzzing with all that Simeon had told me about his life since moving from Jamaica to the West Midlands at the aged 5.

Doing justice to Simeon's life and unceasing battles in one article would be doing him a disservice, so I hope in future issues we can return to his recollections of life in the UK. His first article devoted to his childhood begins on page 8.



*Simeon at the Tackle West Midlands Regional Conference in May*

Simeon was born in Spanish Town, Jamaica's second-largest city, in 1965, the youngest of a family of 5 children. Three years later his father moved to the UK in response to adverts for jobs in factories in the West Midlands. To save enough money to support his family in Jamaica, including his own parents, and to purchase airline tickets for his wife and Simeon to follow him to the UK 18 months later, his father worked an 8-hour shift in an engineering factory, then jumped over the fence to start another 8-hour shift at the factory next door before returning to share a single room in the notorious Whitmore Reans area of Wolverhampton with two other workers from the West Indies.

Simeon read out to me his first experiences of life in the UK and his early years at school

(see article on page 8). Was the blatant racism and discrimination all happening in plain sight only 50 years ago in this country? Our membership is of an age to know that, yes, it was. Those experiences at school shaped Simeon's deep-rooted conviction that things had to change.

His parents had moved out into short-term rented accommodation in Penn Fields. His mother worked full-time as a press operator in the motor trade, then in light assembly in the Morphy Richards factory and finally as a chef in the Bernie Inns chain. In other words, his was not a family that fitted the prejudice of the right-wing press of those years that most immigrant families were benefit scroungers.

Although he was joined over the years by all 4 siblings who came over to the UK and worked here for a number of years, all chose to return over time to the West Indies 'to thrive', as Simeon put it, 'rather than just survive.' But Simeon stayed, leaving school at 16 and completing his O Levels at college. He was passionate about sport – hockey, cycling, karate, middle-distance running – but, most of all, it was football where his talents lay, culminating in the offer of an apprenticeship with Crystal Palace. Sadly, this ended prematurely with a double leg fracture and a return to Wolverhampton. He secured work on the Race Equality Council which guided him towards higher education (a Combined Studies course at Wolverhampton Polytechnic) and a career in improving the lives of those without a voice. At the end of the 3-year course he was offered an administrative post at the Polytechnic, which became the University of Wolverhampton in 1992. Became branch secretary of Unison and joined the Labour Party. Ironically, he couldn't attend one of his first meetings in Bilston as the venue operated a colour bar.

His next move was to a post in the Racial Equality unit in Dudley. Once the contract ended 3 years later, he was offered a position with Wolverhampton Council as their Racial Harassment Co-ordinator. It was during his time there that an act of maladministration

*continued on next page*

20 years earlier by the Home Office began to seriously impact on his life. In short, he and many of the so-called Windrush generation going back to 1948 had to prove they had a right to be citizens of the UK after the Home Office had destroyed many of the documents required over that period.

By 2009 an employer could be fined for employing someone without such documents. This meant a zealous head of HR made him redundant and the post disappeared. Now began a 10-year, debilitating struggle, battling against the threat of deportation from the very Home Office for whom he had once worked. Anyone who has read Kafka's 'The Castle' or 'The Trial' will have some appreciation of how those years must have been for Simeon.

This battle came to a successful conclusion in 2019, but another one developed – a battle which is still ongoing against prostate cancer. He is determined that he can put his experiences to good use as a patient representative on the Cancer Alliance board in the West Midlands and on national panels. He is the man I would choose to press for better treatment, better after-care and support and, ultimately, better outcomes for prostate cancer patients.

Simeon will always be a welcome visitor to Worcestershire, to SWPCSG and to KWPCSG. I am sure that his efforts on our behalf will be appreciated and rewarded over the next few years.

*Peter Corbishley*

## A CHILDHOOD IN A NEW COUNTRY

### Arrival in the UK

I came to the UK from Jamaica at the age of 5.

As was often the case, my father had travelled to the UK around 18 months earlier, to find work and pave the way for our arrival. As the youngest child, I travelled with my mother, the intention was to 'send for' my siblings to join us when finances permitted. Until then they would live with our maternal grandmother.

We arrived in the UK on a cold Friday night in November and were met by my dad and a friend of his (with a van) who he hired to drive him to the airport to meet us and to take us to our new home.

Along the way I peered through the window, looking at the long row of factories with smoke coming out of chimneys. I had heard of lots of other men from back in Jamaica who had come to England to find work and thought there was clearly lots of work, given the number of factories.

I must have fallen asleep, because I was being woken up by my mother, who was telling me, "We're home". I looked out of the window and saw that home was one of the many terraced houses I had mistaken for factories - you see, Jamaica didn't have houses built that way.

We had arrived in the Whitmore Reans area of Wolverhampton with about 6 inches of snow on the ground, that, while travelling, I had mistaken for white painted streets. I'd heard the word 'snow' but hadn't got a clue about it until now. I hated it!

My parents (as with many Jamaicans of that generation) were very religious, and the following Sunday we went to the local Church of England church 'to give thanks to God' for mine and my mother's safe arrival. At the end of the service the vicar took my mother and father to one side for a chat. I later found out that he had told them not to come back, because the



*Simeon Greene aged 5*

congregation didn't want them there. I was 5 years old, it was only my second day in the UK and I was already being subjected to overt racism.

The next Sunday my parents dressed in their Sunday best and worshiped in our living room. As time went by, family friends joined us each week. Eventually, the numbers attending became too many for the space and they hired bigger and bigger rooms in a local school, until eventually they raised the funds to purchase their own building. So started a branch of the Church of God of Prophecy, one of the largest Black-led churches in Wolverhampton.

## School

My first day of school was around 2 weeks after arriving in the country. Being the new boy in the school (the school year having already started in September), my class teacher sat me next to another (white) boy who was to be my buddy, to aid my orientation.

After morning break, we had no sooner resumed our seats when the door was thrown open and I was pulled up out of my seat by the mother of my allotted buddy. She was angry that I was in such close proximity to her son because I was "uncivilised". Was she worried that whatever she disliked or objected to about me was catching and that I might infect her son? It turned out that this boy's mother was also a teacher in the school and was to be my form teacher the next academic year!

When leaving school to go home on that first day, I looked across the yard and spotted my mother with the other parents waiting just outside of the school gate for their children.

A woman broke ranks and entered the school yard, walked straight up to me, felt between my legs and around my buttocks and shouted to other parents, in a surprised voice,

"No, he doesn't have a tail."

The next academic year my parents moved house to enable me to attend a different school, where there were other Black children

These were my earliest experiences of racism, and I've been living with it ever since.

Less than a week ago a van drove at me through a red light on a pedestrian crossing and shouted, 'Nigger!'

While not every incident is as overt as those, I have experienced racism pretty much every day in the more than 50 years I've lived in this country. Most incidents are imperceptible to White people, even when they witness it themselves. On witnessing some blatantly racist incidents, I've been advised by White teachers, employers, friends to rise above it.

I remember watching a football match between Real Zaragoza and FC Barcelona on TV, at the time Cameroonian Samuel Eto'o was probably the hottest striker in the world. During the game Eto'o, who had been a victim of constant racist abuse, decided he would not take it anymore and proceeded to walk off the pitch. His entire team, half of Zaragoza's team and even the referee blocked his way in an attempt to persuade him to stay on the pitch and continue playing. I can imagine him being told to "rise above it", being told that "sticks and stones will break your bones, but names will never hurt you." People were able to lip-read Eto'o respond in Spanish, "No más, no más", (No more, no more).

Speaking for myself I'm tired of the drip, drip, drip, the water torture that is racism.

*Simeon Greene*





## Robot assisted surgery in Worcestershire takes another step forward

Plans to bring state-of-the-art robot assisted surgery to Worcestershire have taken another significant step forward with work making an operating theatre at the Alexandra Hospital (Redditch) robot-ready.

Contractors have almost completed an upgrade and refurbishment of an operating theatre so that it can be used for robotic assisted surgery when the service goes live later this year.

The work, which will have taken around six weeks to complete, included reinforcing the theatre floor to take the weight of the robot as well as upgrading the ventilation system, general refurbishment and redecoration.

Worcestershire Acute Hospitals NHS Trust, which runs the Alexandra as well as Kidderminster Hospital and Treatment Centre and Worcestershire Royal Hospital, is investing more than £3.5 million in the new service. Thanks to the generosity of local supporters, a fundraising appeal in aid of robotic surgery had already raised around £500,000, before plans for the development were paused during the Covid-19 pandemic.

Surgeon Mr Terng Chen, the Trust's clinical service lead for Urology, said in July: "After working for many years to bring robot assisted surgery to Worcestershire, to see work actually starting on the operating theatre where it will be carried out is another very positive step forward which is great news for our patients and our service."

The first procedure to be offered by the new service will be robot-assisted prostate surgery for men with prostate cancer. For those patients who are able to have it, Robotic-Assisted Radical Prostatectomy (RARP) can offer equivalent or better outcomes, less pain, shorter stays in hospital and quicker recovery for patients with prostate cancer, which is the most common form of cancer in men.



*Contractors are now on site at the Alexandra Hospital to upgrade and refurbish an operating theatre so that it can be used for robotic assisted surgery*

Currently, any prostate cancer patient from Worcestershire who wants this type of surgery as part of their treatment has to travel out of the county for it. That means around 80 patients a year having to travel away from Worcestershire for their operation.

Mr Stephen Goodyear, the Trust's Divisional Director for Surgery, adds: "As well as offering state of the art care for our patients, this new facility will also help to make our Trust an even more attractive place to work or train for clinical staff from a wide range of roles and specialties including surgeons and theatre practitioners."

"I would like to thank colleagues who have worked so hard to get us to this stage, as well as to the teams at the Alexandra and Kidderminster who have helped us efficiently deliver planned surgery within other theatres across those two sites to ensure that we can avoid any disruption to this activity while the work is carried out."



**Worcestershire  
Acute Hospitals**  
NHS Trust

## Droitwich Coffee & Chat (see page 5)



# TACKLE MAKING A DIFFERENCE

Tackle Prostate Cancer (The National Federation of Prostate Cancer Support Group) became a charity in 2008, however the history of our federation started with our pioneering support groups in the mid-1990s.

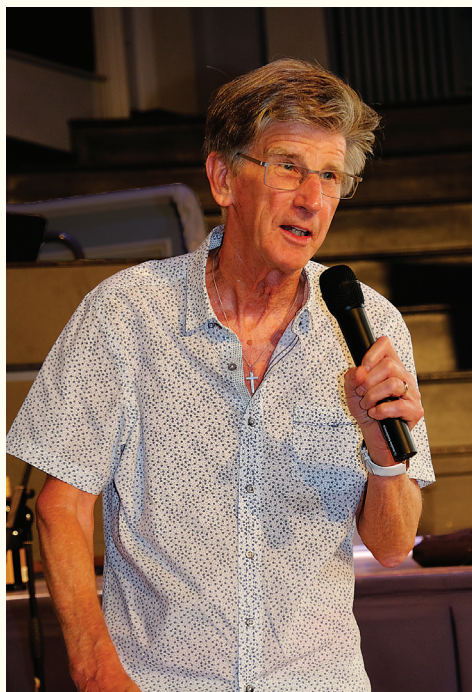
One of the first recorded peer-led Prostate Cancer Support Groups was set up in London in 1995 by Angus Earnshaw, who was diagnosed with prostate cancer while he was living in Holland. On his return to the UK, he discovered that there were no support groups for men with prostate cancer in this country. He wanted to create somewhere where men, who had just been diagnosed, could ring and talk to someone on the other end of the phone. He understood how powerless it can feel being diagnosed with prostate cancer, and how it is often difficult for men to deal with strong emotions.

Later, in 1996 two men, Roy Nixon and Ray Dalton, met to discuss their prostate cancer at a local pub in Cheadle Hulme near Manchester, where conversations led to them developing a plan to set up a local peer support group. In 1999, the group set up by Angus Earnshaw developed into the Prostate Cancer Support Association (PCSA aka PSA). Several regional groups affiliated with PSA, including the Northwest group. It was agreed that 'one voice' would be beneficial going forward, both to encourage as much local initiative as possible, and combine the voices of people living with and affected by Prostate Cancer nationally.

TODAY, our federation brings together over ninety-five prostate cancer support groups across England and Wales under 3 broad aims: support, awareness, and campaigning.

*Sarah Gray*

## DR. STEVE ALLEN, TACKLE ACTING CHAIR



*Photo courtesy of Ray Rogers*

### Steve Allen interviews Steve Allen

**You recently became Chair of Tackle. Are congratulations due?**

Ten years ago, if you had said to me that, one day, I would find myself being chairman of Tackle Prostate Cancer, I would have just laughed.

Whilst I normally attended most AGMs as a representative of my local support group, I was one of the many who sat at the back, asked the odd question but basically kept my head down, particularly when it came to electing people to serve on the organising committee. During those early days it was virtually unknown to need to hold a contested ballot to get people to help run the charity. It seemed that the majority of people on the Board were there because of a personal invitation by other Board members. New members would merely be ratified by a show of hands at the AGM. Maybe readers can recognise that within their own group?

## **So, what changed? Why do you now find yourself in exactly the position you had never considered?**

Four or five years ago I was asked by the then chairman, Roger Wotton, to become a patient representative for Tackle. The 'job' was deemed not too arduous and merely required some intermittent work with a couple of national committees such as NICE. Given my medical background this role appealed to me. With the rapid advance over recent years in treatments for prostate cancer, this has developed into a fascinating but quite busy role. I am proud to say that, through my activity, Tackle has become recognised as an organisation whose opinions and input are respected by many clinicians, pharmaceutical companies and national committees.

## **And then along came Covid.**

One of the many positives that arose was being able to be present remotely at meetings of Support Groups anywhere. I have always enjoyed teaching and giving presentations (some even say I'm quite good at it!) but Zoom now allowed me to interact with many more groups and get to know their members. I was then invited to become part of a strategy group that was being set-up by the Tackle Board, a team that was striving to do their best for their membership.

## **Yes, but you were a busy man and wouldn't have the time to join the Board.**

True, but my thoughts changed, and I began to realise that, in order to be as effective as I could be, I should put myself up for election to the Board.

## **What happened next?**

The traumatic events of our annual general meeting in December 2021 led to a rerun in February when the process of voting members to the Board actually took place. I do not think that it is helpful to go over those events in detail. At our first full Board

meeting in March I was asked to take on the role of Acting Chairman. I only agreed to do so because I felt that Tackle needed to go through a period of calm and restoration. That certainly does not mean that we have not had disagreements and a frank exchange of views on some topics. The important thing, however, is that, when majority decisions are made, all those involved should agree them and work with them. I believe this is a very healthy sign of being able to work in a collaborative fashion.

## **Why 'acting' chair?**

This is at the request of the Board members. The current Articles of Tackle state that the Chairman is permanently elected *not* by the Board, but by the *membership*. The bottom line is that the ongoing role of chairman will be decided at our next AGM.

## **And what about the membership?**

Any group of people will go through periods of change and evolution. Tackle is not immune to that – nor should it be. We must improve our methods of communication. Email and the internet have transformed communication, Zoom can often be a suitable alternative to a face-to-face meeting, social media platforms are becoming more widely accepted. Economically this can be a two-edged sword. Whilst electronic communication can be very much cheaper than a more physical from, it often needs specialist expertise. This comes at a cost – something which needs to be carefully considered.



*An audience who appeared to want to hear about Incontinence from yours truly at the Oncology conference.*



## What are your hopes for the future of Tackle?

That the organisation always reflects the views of its members and has opinions and a reputation that are valued, not only by patients but by such people as opinion leaders, policy makers and decision makers at both national and local levels. Often this may need collaboration with other like-minded organisations – Prostate Cancer UK and Prostate Cancer Research come to mind. A united voice representing many people is more effective than many individual small voices.

There are many things the Board and its chairperson cannot do: we cannot directly



Social activities are an important part of any PCSG

increase your membership for instance, but, by facilitating opportunities for groups to come together to share ideas and experience, new ideas and energy can be infused where they may be waning

## Are you optimistic about the future of prostate cancer treatment?

The future for prostate cancer is changing almost by the day as new investigations and treatments come on stream. But there is still so much more that we can do – from campaigning that appropriate prostate cancer screening becomes the norm so that patients are treated earlier and before their cancer has spread to ensuring the best possible treatment is made available to those with advanced prostate cancer. There is no room for complacency. This has been dramatically demonstrated by those affected by breast cancer – we are still years behind them in public awareness.

## What inscription would you like on your gravestone?

*“He did his very best”.* No-one can ask for more.

*Steve Allen*

## CURRICULUM VITAE

**Born:** 1948, Sidcup (Kent)

**Education:** Chislehurst & Sidcup Grammar School for Boys

**Higher education:** Medical training at Westminster Medical School, London. Then multiple training posts in Reading, London, Cardiff, Melbourne (Australia)

**Career:** Consultant in Anaesthetics and Chronic Pain Management (from 1981) at Royal Berkshire Hospital, Reading

**Prostate Cancer work Reading PCSG:** Volunteer Speaker and Educator with Prostate Cancer UK: Tackle (Patient Rep, Acting Chair)

**Family:** Married Sylvia 49 years ago. Two sons – Richard (German and Business Studies at Bath Uni, Mercedes in Stuttgart, still living there) and Simon (professional jazz saxophonist and music teacher, head of Jazz at the Purcell School of Music in London). Steve and Sylvia now have 2 English and 2 German grandchildren,

**Interests Music.** Never learnt an instrument but used to sing, including the chapel choir in Kings College, London. Talent for writing rude words to well-known songs (including a show where Postman Pat was sent to the VD Clinic!) Now closely involved with his local church (responsible for bringing young people together for some pretty dramatic Rock Mass services).

**Ambitions** ‘You only get out of life what you have put into it!! My aim is to break the mould of the Allen family where, for over 100 years, no male Allen has lived to see his 83<sup>rd</sup> birthday!’

**Dislikes:** ‘Politics and confrontation of any sort – so why on earth do I find myself as a Chair of this Charity??’



## AIDAN ADKINS, TACKLE TRUSTEE

In 2015 Aidan Adkins was working for the engineering giant, GKN, travelling the world in his senior managerial role. The company had more than 300 autonomous plants across the globe. He was, therefore, used to dealing with independent organisations and persuading them to share best practice – a mantra which he has carried through to his new role with Tackle.

One of the perks of the GKN job was a company-financed comprehensive medical check. Everything fine, bar one set of data. Aidan's PSA level was 27. Aged only 53 at the time, being very fit and healthy, showing no symptoms and not having had a family history of prostate cancer, Aidan at first found it difficult to come to terms with the results, the subsequent confirmation that he had prostate cancer and, with a Gleason score of 4 + 5, that action would be urgently required.

Struggling to find the necessary peer support, he turned to his local Solihull PCSG based just a mile away at the British Legion club. Not knowing anyone at the meeting he began to feel this just was not for him, but he came away with a different feeling, having been warmly received by the members. This was the start of Aidan's involvement as a member of a support group, going on to become the chairman of that group and in 2022 being elected as a trustee of Tackle, the umbrella organisation for PC support groups in England.

Aidan opted for a radical prostatectomy, with a need for residual radiotherapy (33 sessions at the QE in Birmingham). Unfortunately, a rising PSA level in 2020 meant more investigation was required in the form of PSMA (Prostate-Specific Membrane Antigen) PET-CT scan, which allows medics to track down hard-to-find cancer cells and to plan better treatment and targeted care.

This led to 3 sessions of SABR (stereotactic ablative radiotherapy) treatment which successfully targeted 2 tumours on a nearby lymph node but only to identify 10 other tumours, so he moved onto hormone therapy and chemotherapy. Aidan was now appreciating the scale of his battle against an aggressive cancer.

2018 had brought another major challenge. GKN was taken over by the Melrose Group who announced within days that all those at the corporate HQ would be made redundant. At 58 he decided to retire and to devote much of his time to helping others with prostate cancer. One of the first challenges had been, as chair of the Solihull PCSG, to rescue the smaller Sutton Coldfield PCSG which was in imminent danger of folding. Monthly Solihull meetings with outside speakers were replicated in Sutton Coldfield whose support group gradually began to return to a sounder footing.

Being aware of the huge benefits a well-organised PC support group can offer its members, Aidan decided on a return to academic life, signing up for an MA at Oxford Brookes University and focusing his research on budding systems in charitable organisations. Having completed his dissertation and gained his master's he was now qualified to train others keen to act as



*On holiday in Cornwall 2022*

buddies. His first commission was to train 8 members of the Solihull group over a two-day period in 2020, a training scheme which he would have liked to roll out across the sector but which the pandemic interrupted.

Aidan is passionate about improving the skills and the focus of those running support groups, but he also feels that there must be an improvement across the NHS so that clinicians are duty bound to provide PC patients with signposts to the full range of support available to them. He is also a patient advocate on the West Midlands Cancer Alliance Urology Expert Advisory Group where he provides a voice for men in the region by raising issues such as this.



*Solihull 5 km Park Run (November 2021)*

Aidan's philosophy is shaped by the acute depression suffered by his father, who was in Bomber Command in the war, in the final 6 years of his life. This experience triggered a professional interest in positive psychology. 'What can we learn from people enjoying life?' was a question he posed. 'If people are happy to come to work, this benefits the company.' Gratitude, kindness and understanding are all key elements in this area. 'It comes down to what you want to achieve in life.' One final tip: 'Don't worry about things you can't control.'

Tackle is fortunate to have someone on its board without a medical background but with analytical skills honed over many years in engineering. Born in Solihull Aidan attended Tudor Grange Grammar School before going on to study Mechanical Engineering at Birmingham University. His studies were sponsored by Lucas Aerospace, for whom he worked for the next 25 years.

During his time at university, he joined up with the Territorial Army, serving mainly in the Intelligence Corps. Married to his wife, Laura, with a 25 year-old daughter and still living in the Solihull area, Aidan has always sought to maintain a high level of physical fitness, as exemplified by his completing the Coast-to-Coast walk (192 miles) in 2018.

Another of Aidan's mantras is, 'You've got to have a graph.' In other words, once you know your enemy (in this case, prostate cancer), you gather as much data as you can and eventually get some sense of control despite the underlying uncertainty. His research took him to Nick James, now Professor for Clinical Oncology at the Institute of Cancer Research at the Royal Marsden Hospital in London, whose work has led to advances in the treatment of PC. Aidan is following with great interest Professor James' work on the ground-breaking Stampede trials which seek to evaluate 10 different procedures.

Having such a determined and optimistic member from the West Midlands on the Tackle board gives us all hope that PCSGs up and down the country will only get better. The broader battle against our enemy is not yet won and there is absolutely no room for complacency, particularly after 2 years of disruption and longer waiting lists, but, with concerted action, we'll get there. In Aidan's words, 'We can travel fast when alone but further when together.'

*Peter Corbishley*



*Buddy training for buddies from 3 Midlands support groups (Birmingham, June 2022)*

# SARAH GRAY, TACKLE'S NATIONAL SUPPORT AND DEVELOPMENT MANAGER

My role is funded through the National Lottery for three years and I came into post in September 2020. Having spent the majority of my career managing health and social care services, I moved to the charity sector almost 20 years ago. I have worked both regionally (across the Midlands) and nationally for charities including Parkinson's UK, British Lung Foundation, Macmillan Cancer Support, Prostate Cancer UK and now Tackle.

Many of my roles have been about collaborating with clinical teams and commissioners to improve treatments, services and support for people living with life-limiting and long-term conditions. Raising the voice of people living with and affected by prostate cancer is a cause close to my heart. My father was diagnosed over 20 years ago and was living with advanced prostate cancer when he passed away late last year.

My role as National Support and Development Manager is very much to support our network to grow. We are able to harness the views of our members to use in partnership with other charities to campaign for better services, treatments, care and support

Initially the expectation was that the role would work with health care professionals across the country to set up new groups. Covid, however, fundamentally changed the way healthcare was being delivered for the first 18 months of my role. Much of the focus of the role has moved to working with our existing network of groups. So now my role looks to support group leaders to reach people not accessing peer support, as well as collaborating with them to develop tools to support them run their groups.

Since September 2020, I have met with around 60% of our member groups, initially on Zoom, due to COVID restrictions. In recent months, however, I have visited many groups from Ipswich to Llangollen, and from Somerset to Burnley and many places in between! Meeting people face to face and hearing people's experiences is what feeds my passion for my role and drives me to

do my best. There is a sense of shared understanding and fellowship in the groups I visit. One man described his group to me as a 'Band of Brothers'

We now run a Monthly Support Group Leaders Network meeting, as well as sending out monthly briefings to group leaders. Additionally, we are starting to bring groups together in regional networks to share good practice and raise awareness of the importance of early diagnosis. The first of these events was held in the West Midlands, where there was great representation from KWPCSG.

We are currently funding some exercise classes, including one in Worcester, as well as a Music therapy group for Black men in South London, a facilitated support group in a hospice and some groups specifically for partners, friends and family who provide care and support for men diagnosed with prostate cancer.

Tackle Prostate Cancer is our community. In my role, your voices and experiences bring my role to life. Please get in touch with me at [sarah.gray@tackleprostate.org](mailto:sarah.gray@tackleprostate.org) and tell me your story, let me know the value of attending your group, give me some ideas of other alternative offers of support we should consider developing.

*Sarah Gray*



*Sarah Gray*

## GORDON KINGSTON, KWPCSG TACKLE REPRESENTATIVE



The world of Tackle provides efficient support through collaborative working together. So, what are the benefits and what do we really want from our Tackle involvement?

When at our most vulnerable, being able to share experience with someone in a similar position can be incredibly valuable. What do Peer Support Groups like KWPCSG have in common?

Well, they help us to talk about our feelings and experience, and, let's face it, men are not always good at sharing their feelings!

Reassurance that we are not the only person who feels like this and introducing ideas and new approaches has been found to help. Shared suggestions on coping mechanisms, come better from "mates" who understand.

Groups in Tackle use a variety of methods to spread the word and deliver Peer Group Support: small informal or open public meetings; online information and support; and one-to-one buddy support, face to face or on the telephone.

Tackle has been re-invigorated with new trustees, a development manager, new website and regional meetings. This has helped your own KWPCSG committee to look at how we function and provide the help needed by prostate patients and families in Worcestershire.

Look what we have already received in help from Tackle. Its current chair, Steve Allen, who is providing clear leadership and clinical clarity to a revitalised charity, has already spoken three times in the county, and is due to speak again in Pershore in October.

Attendance at a West Midland Groups workshop in June gave us ideas and encouragement to revamp our own services to members and to share views with neighbouring groups on spreading awareness and reaching new members.

We have benefited from a terrific contribution from Aidan Adkins (Regional Tackle Trustee) at our Droitwich Coffee & Chat. He not only gave us his thoughtful personal story but made a number of suggestions for our group and gave lots of constructive answers in the question-time period.

In the past year, Mary, Peter, Chris Marsh and I have all attended Tackle events, but we could benefit even further if a few more colleagues were able to join in some of the Tackle offers of help. If you have a few hours to spare, we would love to hear from you and provide background information on the ways we could all help our own and other support groups. Just contact me at [gkingston@btinternet.com](mailto:gkingston@btinternet.com)

*Gordon Kingston*





## New procedure at Alexandra Hospital makes diagnosing prostate cancer easier and safer

Men in Worcestershire with suspected prostate cancer are benefiting from a safer and more accurate diagnostic procedure now being performed at Worcestershire Acute Hospitals NHS Trust.

The Urology Department at Alexandra Hospital in Redditch is now able to perform Local Anaesthetic Transperineal Prostate (LATP) biopsies following an extensive staff training programme. The LATP technique has been shown to offer more accurate detection of prostate as well as improved safety by significantly reducing the risk of infection for patients.

Studies have found the diagnostic procedure to be less uncomfortable for patients than alternative techniques, with no need for a prolonged course of antibiotics afterwards. The technique is much quicker to complete than previous procedures and is easier to target specific areas of concern.

The Urology team underwent extensive training on the new technique in collaboration with Guy's and St Thomas' Hospitals in London and the West Midlands Cancer Alliance. The department has also recruited a new Urology Consultant to the team, Mr Will Gallagher, who has previous experience with LATP.

For patients who are able to have it, Robotic Assisted Radical Prostatectomy (RARP) can offer improved outcomes, less pain, shorter stays in hospital and quicker recovery time.. Clinicians aim to begin providing robotic surgery at the Alexandra Hospital later this year. The surgical robot

will be a further addition to the range of high-quality surgical services already provided at the hospital for patients from across Worcestershire and beyond.

Consultant Urological Surgeon, Mr Paul Rajjyabun said: "This new addition to our diagnostic portfolio will ensure that we maintain our position as one of the leading centres in the UK for the diagnosis and management of Urological disease."

"Developing new services through the challenges of the Covid pandemic has meant that we had to re-double our efforts to make LATP available for our patients. But with the implementation of this revolutionary biopsy technique and the imminent arrival of Robotic Assisted Prostatectomy at the Alexandra Hospital, we are in a position to offer state-of-the-art 'end-to-end' care for men with prostate cancer."



LATP Urology Team



# I NEVER SAW THAT COMING!

## IS IT ME?

The last few months have been difficult. My PSA has been rising since the start of the year. In September, as you are reading the magazine, it is likely that my doctor will be offering another course of treatment.

I thought I would cheer myself up by going to Blackpool, visiting my younger brother and taking him out for dinner on his birthday. It was worth the trip just to see my brother's reaction when the staff turned up singing happy birthday and carrying a cake, two numbered candles indicating "62."



*Mark at the top of Blackpool Tower*

I have been visiting Blackpool for nearly twenty years but going up the tower was one of those things that I was always going to do next time. The 25th June 2022 was when Mark finally climbed Blackpool Tower, (within the safety of an electric lift,) and reached the viewing platform. The view was spectacular. My brother and family had all declined as they don't like heights. Standing on the glass floor and looking down gave the impression of floating in space as the pavement was the next thing in view.

A trip to the Sandcastle Water Park on Blackpool Promenade saw the old Mark finally restored as I raced around like an eight-year-old attempting to get to the next water slide, my niece, her partner and two children trying to keep up with me. It was so refreshing to shout out in near

terror as I was launched into oblivion sat on what looked like an old lorry tyre inner tube.

There was one moment during the trip which could have caused some conflict, I asked my brother was he still getting a regular PSA test. He replied he had not had one yet. I felt rather let down as I had advised my brothers to get tested as they were now in a high-risk group due to my diagnosis, a 1 in 4 risk of PC as opposed to the standard 1 in 8 for the general population. I have now made a point of reminding all three of my brothers, apart from standing in the room when they have a blood test there is not really a lot I can do - just provide regular reminders. I just wish someone had spoken to me about



*Looking down (very briefly)*



*Cleaning the carriages at Toddington*

PSA testing 4 or 5 years ago!)

The weekend brought me to one of those, 'Is it just me?' moments. Visiting a popular local coffee shop and listening to the orders, I found myself longing for the old days when the options for coffee were with milk or without milk. The person in front of me ordered a decaf latte with lactose free milk, I found myself thinking, just go for a glass of tap water, probably more taste and benefit, hopefully much cheaper. The following day in another popular coffee chain I watched the barista create a masterpiece with ice, cream, flavoured syrups and toppings, but no coffee. Again my mind shouted, It's a coffee shop. Is it me?

I have been keeping myself busy. Along with my regular exercise and volunteer work at the Gloucestershire Warwickshire Steam Railway and Spetchley Gardens, now finding it hard to fit in new things. The cathedrals challenge is complete, but I have started visiting some of the old Abbey or Priory churches. Before Henry VIII had his run in with the Vatican there were over 900 Abbeys, Priors and Monasteries. Many survive as parish churches, such as Bath, Pershore, Tewkesbury and Great Malvern.

I have certainly become more emotional over the last three years. Things which had no impact years ago can now "set me off." The recent passing of Deborah James, also known as Bowel Babe, saw me having to avoid news programmes for a few days for fear of upsetting myself. It's strange, I am normally able to talk very openly about my own cancer, but some things are taboo, the passing of Dame Deborah was one of those subjects.

As I mentioned at the start, my PSA has started to climb again, rising from 3.8 to 7.7 in 8 weeks which caught me completely unawares, I had expected a slight rise to maybe 4 or 5, but 7.7 really knocked the wind out of my sails. Coming to my rescue was Emma, one of the nurses working in the chemotherapy unit on the day of my visit. She sat with me, calmed me down and then went to find one of my medical team to see if any action needed to be taken.

I have already been through Plan A, basic hormone therapy, Plan B, first line Docetaxel chemotherapy, Plan C, radiotherapy and Plan D, second line hormone therapy. I am told that Plan E is more chemotherapy, this time 10 cycles of Cabazitaxel over 7 months. I am really hoping there is a Plan F, as the cupboard is looking decidedly empty after Plan E. Needless to say, having already had chemo, I am not looking forward to a second course, but this time, should I decide to proceed, I will be prepared, I know what to expect and have a good idea on managing the side effects.

*Mark Howard*




*Watering the plants at Spetchley Gardens*



## THE SHED TAKES TO THE WATER

Trevor Albutt, one of our regular Shed members who is currently receiving treatment at the Worcestershire Royal, explained that his wife, Wendy, is the booking co-ordinator for the Worcester, Birmingham & Droitwich Canals Society. The Society receives money from the Lottery Fund in order to provide canal barge trips that are free of charge to groups who would benefit from a pleasant and relaxing trip on one of our inland waterways. On this occasion the trip was from Alvechurch to Hopwood. Due to insurance constraints the barge can only take 12 passengers, plus a crew of 3, therefore at present trips are restricted to regular members and their partners who attend Shed meetings at Leapgate Farm.

We had lunch at Hopwood House, a pub situated on the canal bank offering a good menu in very pleasant surroundings. After lunch we made our way back to the boat, then meandered back to Alvechurch. The feedback from participants indicated that they had thoroughly enjoyed the experience.



### Allan Morris

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## BACK ON LAND

The attached photos by Ray Rogers show the crops that the team planted earlier in the year are now due to be harvested from our Leapgate allotment. We had an excellent crop of new potatoes, and the main crop will be lifted in mid September. I believe the animals shown in Ray's photos welcome our activities at the farm, as they benefit from the produce and greenery that we can't use. The allotment provides a venue where members of our Group can come together and enjoy a fulfilling activity in the fresh air. The banter on the allotment is something else, but it does raise spirits.

Just a reminder that The Shed at Leapgate is the Support Group's social off-shoot which is free of charge and open to all members and their partners. Just come along to the farm as we are there every Monday. Call me on 01562 751355 for more information.

Paul Markall



*Despite the dry conditions an excellent harvest is expected this month at the support group's Leapgate base*



*Some of the animals at Leapgate Farm cared for by the Activities Centre regulars*

# CALENDAR OF EVENTS 2022

## KIDDERMINSTER COFFEE & CHAT

Café adjoining Kidderminster Town Hall, Vicar Street, Kidderminster DY10 1DB

Friday 16th September 2022 (10.30-12.00)

Free coffee and cake to all members, non-members and partners

The perfect opportunity to get to know others who are being treated for or who have recovered from prostate cancer

## SOUTH WORCESTERSHIRE PCSG

Wychavon Civic Centre, Queen Elizabeth Drive, Pershore WR10 1PT

Wednesday, 12th. October (doors open 6.30 pm for 7.00 start)

### DR. STEVE ALLEN

Retired anaesthetist and Acting Chairman of Tackle

Subject: Current Treatment Pathway

A very popular speaker to our group with a vast knowledge and a wonderful sense of humour (see interview on pages 12-13)

Hybrid event (can be accessed live via Zoom / visit website for more details)

## KIDDERMINSTER & WORCESTERSHIRE PCSG

Kidderminster Town Hall, Vicar Street, Kidderminster DY10 1DB

Tuesday 18th October 2022 (doors open at 7.00 p.m. for 7.30 p.m. start)

### NICK OWEN

TV Presenter and KWPCSG Patron

A fascinating evening is guaranteed – and early arrival is recommended – with stories of

Nick's years in TV and the guests he has interviewed as the TV-AM frontman,

Good Morning Britain host and BBC Midlands News anchor-man.

Peter Tomlinson (former ITV presenter) will be asking the questions

## FITNESS WITH DI FOX (VIA ZOOM)

EVERY MONDAY MORNING (09.30-10.30)

Go to [www.kwpcsg.co.uk](http://www.kwpcsg.co.uk) for login details

## STUDLEY COFFEE & CHAT

Studley Village Hall, High Street, Studley B80 7HJ

Tuesday, 8th. November (10.45-12.30)

We will be sharing the morning with our colleagues in the South Warwickshire PCSG.

Free coffee and cake to all members, non-members and partners

The perfect opportunity to get to know others who are being treated for or who have recovered from prostate cancer

**Keep in touch with us via: / Tel. 01299 832166**

**[www.kwpcsg.co.uk](http://www.kwpcsg.co.uk) / [contact@kwpcsg.co.uk](mailto:contact@kwpcsg.co.uk)**