

## ABC UK – OUR WORK: UPDATE NOVEMBER 2023

---

**ABC UK's current work priorities and exciting plans for 2024.**

### **ABC UK PATIENT SUPPORT SERVICES**

One of the most vital areas of our activity is our work in supporting patients.

Receiving a bladder cancer diagnosis can be a difficult and challenging time – both for the patient themselves and also for their families and close friends.

ABC UK are here to help. Many patients (or relatives) come to us when they are first diagnosed, or when first being sent for tests – to seek information, to find help in understanding a diagnosis, sometimes to be able to absorb information in a quieter moment, or to find a friendly and informed voice. Many also come to us when faced with a treatment decision, when about to start a new treatment, or when coping with treatment or surgery. We help patients in different ways ...

### **Patient Information**

We provide information about bladder cancer for patients. Our website has a lot of information about bladder cancer, we also have a range of patient information materials. Our materials are available online on our website and also in print. Sometimes patients prefer print copies and hospitals like to hand these to patients at an appropriate time eg diagnosis/testing, at a treatment decision, pre-surgery etc.



Our leaflets and information sheets cover a range of topics and are both authoritative and accessible, and all our materials are produced with both patients and expert clinicians.

We are continually extending the range of our information – and have new materials planned for 2024.

We are developing our patient information area of our website – improving accessibility of materials, editing and updating areas of specific information regarding bladder cancer and its treatments, new illustrations, improved flow of information for different patient treatment pathways.

## Direct Patient Support

We have built a network of Patient Advisors who are able to provide direct support for patients either by phone or email, many patients find it of great help to be able to talk through their concerns with someone who has already experienced the same issues. We are working to expand this network and train new advisors. We are also developing a nurse-led service.

## Patient Stories

It can sometimes be immensely helpful for patients, and family members, to hear other patients tell of their own experiences in their own words. We support patients to tell their stories and many of these are on the ABC UK website.

**PERSONAL STORY – PHIL KELLY**



Let's start with the good news first – I have recently passed the important cancer survival timescale of 5 years post initial diagnosis. I'm alive – and well! So that's all Good!!

True – I no longer have a bladder (nor a prostate and various other 'bits and pieces'), in one wee into a urine bag on my abdomen (a urostomy pouch). But then, I had the most aggressive form of bladder cancer: most people with bladder cancer don't and will not need radical treatment. For me, some things have changed – but I am leading a full and very active life, doing most of what I used to do before, enjoying various UK, European and some long haul holidays, spending as much time as we can manage with our grandchildren, going to music gigs and continuing to partake in a sensible level of social drinking. When I talk about my experience of having bladder cancer, I usually describe myself as being one of the lucky 'unlucky ones' – it had been a bit of a roller coaster experience, especially during the first couple of years. But – and it's a big 'but' – I might not have been here – and I am. You could probably say that I am now 'cured' – though I don't like to use that word – not wanting to tempt providence ...


Enough! I'm getting ahead of myself – let's go back to the start of my bladder cancer story

**Caroline's Story**

We are very grateful to everyone who has shared their story with us on this website. We know that many people find reading the story of other patients very helpful when trying to make sense of their diagnosis or cancer journey. We also know that these stories can be very powerful in helping to raise awareness of bladder cancer and highlight the urgent need for new treatments, research and support for those with bladder cancer.

If you would like to tell your story please do get in touch with us by email at [group@actionbladdercanceruk.org](mailto:group@actionbladdercanceruk.org)

We can arrange for one of our Patient Support Officers to get in touch to help you tell your story, if that would be helpful, and we also have a 'hints and tips' sheet to give you more ideas about what to write.



Caroline Raw, 51, was diagnosed with bladder cancer after noticing small amounts of blood in her urine. Caroline has two grown-up children and now helps care for her partner Jonny's teenage son, tells her story.

I first noticed something in the middle of May this year. There were two tiny spots of blood, the size of a pin head, on the paper. I'd had an operation to remove the lining of my womb two years before, so I just thought it might be related to that and didn't think anything more of it.

A couple of weeks later, when I was out with friends during the Bank Holiday weekend, I went to the toilet and noticed blood on the paper again, along with a streak of blood in my urine.

The sharing of direct experience is of particular help at key points in a patient journey – understanding a diagnosis, helping to understand what a particular treatment may mean and what happens, support in making a difficult treatment choice, and providing

reassurance. We support patients who are willing to tell their story, creating a bank of relevant personal experiences to help other patients.

## Patient Support Groups

Some patients find attending a bladder cancer support group helpful, and ABC UK has initiated the great majority of UK bladder cancer groups. It's great to see groups running face to face meetings again after COVID, but we also continue to give free zoom licences to groups who wish to run online meetings. Our support team attend many groups, help publicise the meetings and give advice and tips. We also provide small grants to help groups set up (refreshments, room hire, equipment etc).

We are focusing on areas and NHS Trusts where there are no support groups within easy travelling distance. Within the past few months, we have already helped to start up 3 new groups, with interest from a 8 further Trusts. Building on our experience of running online groups during COVID, we are also setting up a regular online patient support group for those who do not live near an active group or may prefer to join an online group.



## ABC UK EDUCATION PROGRAMME

### SPECIALIST NURSE EDUCATION

Bladder cancer can have a complicated treatment pathway, affecting everyday life.

The person a patient can see most often is a specialist urology or cancer nurse – for treatment, check-ups or other issues, or for other support. Learning opportunities about bladder cancer for nurses are very limited - a neglected area of health professional education. Working closely with nurses, we have developed what is now a highly successful ABC UK programme, with enormous potential.

**ABC UK Nurses' Education Day:** the first major event in Sept 2022 was a great success, with c100 urology or specialist cancer nurses attending from across the UK. The positive reaction and great enthusiasm confirmed the need and gave valuable insights for our 2024 planning. The **2<sup>nd</sup> Annual Nurse Education Day** (Sept 2023, again c100 attendees) was even more successful. We've also run **1/2 day topic-specific events** - again very popular, with c50 attendees taking part in workshops and discussions. **Webinars:** we are launching a programme in late 2023, to provide online learning for nurses, with shorter, focused learning events to fit around a busy, working day. **Regional events:** after requests we are also exploring regional events.

**Feedback:** Some examples of comments from specialist nurses on our events:

- All really valuable information, helped gain knowledge transferrable to current role.
- Very useful to hear other Trusts' processes. Patient experience great to hear. Excellent event.
- Very interesting to hear other's ideas - learnt a lot and already thinking of things to implement change in my Trust, to improve patient outcomes.
- Very well organised. Speakers were fantastic. Nice to speak to others from different hospitals.
- Fantastic opportunity for nurses to get together and share good practice and discuss practice with colleagues. I will be back next year.
- Event informative, relevant and useful. Lovely day and useful sessions. Extremely comprehensive.

### EARLY DIAGNOSIS - PRIMARY CARE

Bladder cancer can often be diagnosed late. There is a real need for education for GPs – to raise awareness of symptoms, risk factors and when to refer for testing.

As part of our Education Programme, ABC UK is providing learning opportunities for those within primary care. Working with a delivery partner, we have run our first online learning event for GPs on bladder cancer, which is also available online, to date c900 GPs have viewed this. We are now developing an online CPD learning module for GPs.

## ABC UK RESEARCH

Despite the rate of incidence and the high levels of recurrence and mortality, bladder cancer has long been overlooked in terms of research spending. It has lagged behind other cancers, and advances in new treatments have been few over the past forty years with little improvement in survival rates. Other, less common cancers, have received support and resources and consequently have demonstrated a significant improvement in outcomes for patients - we want the same for bladder cancer patients. Funding and supporting research into bladder cancer is one of our core aims as a charity. As well as participating in and supporting research such as clinical trials, we also fund research into bladder cancer.

### ABC UK Grants Programmes



Our annual grants programme, ABC UK IOPP, opens for applications in Autumn and is the only grants programme in the UK dedicated to bladder cancer.

There is little research investment for bladder cancer - our aim with this programme is to actively encourage work which will have an impact and also act as a catalyst to encourage other projects. IOPP is aimed at encouraging work relating to bladder cancer by those in primary care, urologists, oncologists, cancer specialists, researchers and others. We have already funded some innovative work since launching in 2016 and look forward to this programme, and its impact, growing each year.



Specialist nurses make a huge contribution to improving both patient experience and their treatment pathway, and we wish to encourage and enable more nurses to apply for project funding.

This category of grants gives Grants to nurse led projects and work, to encourage and fund small projects which directly benefit bladder cancer patients - projects which will facilitate change, share best practice, explore different approaches or improve knowledge and, most importantly, improve outcomes for patients or their experience.