

BACKGROUND - ABOUT BLADDER CANCER

Bladder Cancer is not a rare cancer.

It is one of the ten most common cancers in the UK - with one of the highest mortality rates. Over 20,300 people in the UK are diagnosed each year* – half of these will die. Bladder cancer has the highest recurrence rate of any known cancer, ranging from 30% to 70%, with rates of progression as high as 10% to 30% for high-risk tumours. There are few available treatments, low awareness in the public, a need for better understanding by health professionals and little support available for patients.

***Note: Statistics given by CRUK quote 10,300 people diagnosed each year in the UK, however this does not include early-stage urothelial cancers which ABC UK argues should be included within these statistics.**

THE KEY ISSUES

There is an urgent need for earlier diagnosis – bladder cancer can often be diagnosed late, particularly in women. This can be due to a combination of reasons - a lack of symptoms awareness, a hesitancy in seeking medical advice, low GP awareness of when to refer for further examination and a lack of accurate and widely available testing for use at an early stage. A significantly high proportion of bladder cancer patients are diagnosed upon an emergency admission when compared to other cancers (24% of women, 16% of men). Late diagnosis of bladder cancer impacts significantly on survival - early detection saves lives.

About 50% of those diagnosed with bladder cancer will die – this is very high mortality rate for a UK cancer. Survival rates for bladder cancer have also not significantly improved in recent years, in contrast to the general trend across all cancers. This can be clearly demonstrated by looking at survival rates when compared with a cancer such as prostate cancer. Survival rates for prostate cancer show significant improvements, moving from survival rates in the 1970's of 31% (5-year survival) to 84.8% (1996-2000). Whereas outcomes for bladder cancer patients have only improved by c1% in a similar timeframe.

There is a notable lack of research investment - bladder cancer is one of the most expensive malignancies to manage on a per patient basis from diagnosis to death, costing £65million annually, yet it only got 0.6% research investment (in 2013-2014).

This lack of research investment has a direct impact on many aspects of treating bladder cancer – and new, accurate testing or improving the patient treatment pathway and experience. Treatment pathways can be long and often complex, and the high recurrence rate means a patient may often have repeat treatments and surgical procedures. A startling fact is that there have been no significant new treatments come into use for treating bladder cancer in the past 40 years - leaving the patient (and the health professionals treating them) with few options or choices. There has been some recent movement in the development of new immunotherapy treatments, however most of these are in the early clinical trial stage, are expensive and none are yet widely available.

There is a necessity for better understanding within primary care. The lack of research investment means there is no reliable test which could be used on a wide scale in a national screening programme or within primary care. The need to improve early diagnosis is an urgent issue for women, among whom survival outcomes are significantly worse - partly due to women being

more likely to be treated for gynaecological conditions or urinary infections rather than referred for investigations to whether bladder cancer is the cause of the symptoms.

There is a necessity to improve understanding amongst health professionals – there is a need to offer urology cancer nursing specialists further training and learning opportunities about bladder cancer, and there is an argument that a bladder cancer specialism should be embedded within all urological services (bladder cancer specialist knowledge can vary considerably across the UK).

Bladder cancer also has an issue of poor awareness. Amongst the general public there is very little awareness of what symptoms to look out for - many patients say the first they heard of bladder cancer was upon their own diagnosis. There is little understanding of the key issues amongst decision makers within health service provision and commissioning and in Government.

Bladder cancer often has a significant and lasting impact on patient quality of life. Any cancer patient will face challenges once diagnosed with the disease – but those with bladder cancer can face particular, and long-lasting, challenges. These include a complex, prolonged care pathway and life changing surgery (with radical cystectomy to remove the bladder, often the only choice for high-risk forms of the disease), and the high recurrence rates will also frequently require intensive surveillance over the lifetime of the patient.

ABC UK is often told by bladder cancer patients and their families that they are angry, feel overlooked, and question why such a serious and common condition is so neglected – bladder cancer has not performed well in the annual National Cancer Patient Experience Surveys since they started. Patients tell us that they find it difficult to get information about their condition, sometimes have trouble accessing best treatment or services, and are shocked by the lack of treatment choices and sources of support available to them and their families.

If bladder cancer was given the investment and attention demanded by incidence and prevalence, we feel strongly that improvements in outcomes (and streamlining of treatment pathways and related expense) could emulate that of other cancers.

Bladder cancer is therefore common, expensive to treat, has experienced little improvement in outcomes, has a persistent pattern of poor experiences for patients across the UK and significant challenges for both patients and health professionals – bladder cancer is a forgotten or “Cinderella” cancer. These facts are what drive our work at Action Bladder Cancer UK.

We want to change this. ABC UK is working to turn the spotlight on bladder cancer – for it to receive the urgent attention it requires - for bladder cancer to be recognised as a common cancer and to receive the acknowledgement, level of public awareness, improvements in treatments and medical research investment which it merits - and which those with bladder cancer deserve. Recent developments in treatments are welcome, but so much more needs to be done. We want bladder cancer patients to have a voice and the support that they, and their families, need.

ACTION BLADDER CANCER UK – our organisation and our work

Background

Action Bladder Cancer UK was set up in 2009 by a group of patients and clinicians who were deeply concerned about the low profile of bladder cancer as a serious disease and felt that something needed to be done urgently to provide both support and reliable, accurate, information for those with bladder cancer and their families.

In April 2016, we relaunched with our new name - Action Bladder Cancer UK, which better reflects our role as a UK-wide, pro-active, charity - and our new website www.actionbladdercanceruk.org. Since then, we have grown, and are continuing to grow, expanding our activity to reach as many patients as possible. Reinforced by significant strategic planning, we have launched new projects and programmes - with exciting plans for the future. Our Trustee board and executive is a unique mix of bladder cancer patients and leading medical and research specialists. Our medical trustees represent specialists within urology, research, cancer nursing and general practice. Our patient trustees provide the insight of direct personal experience, and are also leading members of advisory panels, patient support groups and regional cancer networks.

We have a Chief Executive and a highly committed core staff. Other project work is carried out by patient volunteers and specialist project staff. Our wonderful volunteers (all bladder cancer patients) help deliver our projects and plan our work – also giving invaluable input to help guide our work and provide support to other patients. Our administration and finance central office is based in Gloucestershire – our team is based across the UK.

ABC UK Trustees

Professor Roger Kockelbergh – Chair (from Oct 2021): Honorary Professor of Urology (Cancer Studies) Univ of Leicester, Consultant Urologist/lead clinician Uro-oncology, Leicester General Hospital; Allen Knight – (Chair to Oct 2021): bladder cancer patient; Jeremy Crew - Vice Chair & Treasurer: Consultant urologist & honorary senior lecturer, Oxford University Foundation Hospital Trust; Paula Allchorne: Senior Cancer Nursing Specialist; Richard T Bryan: Senior Research Fellow, The Institute of Cancer & Genomic Sciences, University of Birmingham; Peter Harper: Oncologist, founder London Oncology Centre; Kevin Gorman: Bladder cancer patient; Mark Page: Bladder cancer patient; Caroline Raw; Bladder cancer patient.

OUR WORK

ABC UK's driving aim is to make life better for bladder cancer patients and to provide a voice for those with bladder cancer, and their families. Our work has four strands:

- Raising Awareness
- Supporting Patients
- Improving outcomes
- Funding and encouraging research into bladder cancer

The charity has created exciting new programmes of patient support, directly improving outcomes and research, as well as educating the medical profession and the public about bladder cancer and the symptoms and the importance of early diagnosis. There is a great need for our work, and a

strong desire amongst patients for a charity which can not only provide information and support but can drive improvements and new programmes of work. We have grown rapidly and our programmes are demonstrating strong beneficial impacts for bladder cancer patients. Like many charities, the last two years have been challenging, however we have been delighted with how our team has responded - and our plans for 2022 and onwards are exciting and ambitious.

Patient Support

The treatment pathway for those with bladder cancer can often be complicated, and long. We believe that effective support needs to be offered at varying points along that pathway, and in varying forms to meet the needs of patients. Patients need to be able to access relevant and accurate information at different times and at different stages of their treatment journey. This is a summary of some of the ways we work to help those with bladder cancer.

Information and Resources

Any cancer patient faces a difficult journey – undergoing treatment or surgery, facing difficult decisions, as well as the emotional impact of a diagnosis on themselves and their loved ones. Living with cancer raises many issues for patients, both emotional and practical. Bladder cancer patients can face particular challenges. Finding the right kind of support and information can help enormously. Providing information for those with bladder cancer, and their families, is one of our core activities.

In addition to extensive information on our website, we produce a range of patient leaflets and information sheets. ABC UK prides itself on the accessible and authoritative style of our resources and they are developed to a high standard, working with both clinicians and patients. We provide these materials direct to hospitals, support groups and individual patients and they are all available both online and in printed form. We continue to add further information and resources to expand our impact and meet the needs of patients and health professionals – information includes materials on types of bladder cancer and treatments, and also living with bladder cancer. We are currently developing a new range of materials, including patient information films, to provide appropriate support along key points of the patient treatment pathway.

Direct patient support

We are contacted by many patients, or family members, asking for advice and support, which they have been unable to find elsewhere. We provide a one to one support service by both phone and email, and will be significantly expanding this service in 2022-2023.

Bladder Cancer Patient Support Groups

Attending a support group can be of great help, both emotionally and practically, to patients. ABC UK carried out research in 2015 and found only 10 groups offering support for bladder cancer patients across the whole of the UK. Since then, we have worked pro-actively with major hospitals and patients to initiate groups and provide on-going encouragement and guidance. We're very proud of our achievements in creating local, direct, support for those with bladder cancer and it continues to be one of our key priorities. Support groups had to stop meeting with the COVID restrictions which began in March 2020, and most groups have only met on occasion since then. We helped the situation by providing free Zoom licences to any group who wanted one, and helped them initiate virtual support, also running regular online sessions for

support group leaders to share experiences. Groups are beginning to meet face to face again, and we are delighted to be working again to set up new groups.

ABC UK Events

ABC UK were to launch a new national programme of ABC UK events for bladder cancer patients in the summer of 2020 – however, this programme was postponed due to the pandemic, the related restrictions on face to face meetings and understandable concerns about patient safety. We are now planning to launch this programme later in 2022 – we know that the interest and need is there.

However, the same restrictions did encourage us to push on with our plans to start new online events for patients and we have been delighted with the response to the ABC UK Zoom events we ran in 2021 and in 2022, and have now embedded online events into our longer term plans. The team are currently working on further events for 2022 and beyond – the response to these first events from both patients and nurses has made us feel that a mix of online and face to face events would give us scope to reach a wider audience and would offer patients more choice.

We also attend well being events and events for cancer patients and health professionals across the UK – taking our ABC UK information and resources where they are needed. We participate and speak at major conferences, workshops and meetings – face to face and online.

Awareness

Raising awareness of the symptoms of bladder cancer is one of our core priorities and we are constantly working to get the message home and also to highlight the issues surrounding bladder cancer, such as the fact that bladder cancer is neglected and under-funded despite being one of the ten most common cancers in the UK.

We also run awareness raising events – and have delivered some particularly successful workforce sessions online in 2020 and 2021. We are pleased to be a founding partner in the Public Health England Be Aware: Blood in Pee campaign, which ran again in July 2018.

ABC UK Research

Lack of research investment for bladder cancer is a serious problem. Despite the levels of incidence, bladder cancer receives a very low level of research funding, having a direct impact on poor patient outcomes and poor patient experience. We launched IOPP in November 2016 to encourage standalone projects which directly improve outcomes for patients and we now run an annual grant funding programme. This is, as far as we know, the only bladder cancer specific grants programme in the UK. The response to this programme has been terrific, with submissions from researchers, urologists and nurses and we shall be expanding this programme in future years.

We are in the process of developing our new strategy to expand our own programme of ABC UK research.

Supporting Health Professionals

ABC UK works closely with many health professionals. For example, we work with nurses to set up and sustain support groups for bladder cancer patients; we speak at training days and provide information materials and advice; we work with nurses, other clinicians and patients to develop new materials to support patients. We are developing study days/workshops for health professional to learn about bladder cancer.

Primary Care

Bladder cancer can be diagnosed late and working to improve GP awareness of symptoms and when to 'think bladder cancer' is a priority. We are pleased we have been able to fund research projects within our IOP Programme which look at improving diagnosis and anticipate more submissions to this grant programme relating to the area of bladder cancer diagnostics. We are also currently working on producing learning resources for GPs and practice staff to improve early diagnosis.

Putting the Patient Perspective

We regularly attend conferences, seminars and sturdy days for health professionals – such as urologists, cancer and urology nursing specialists and researchers – where we work to raise awareness and present the patient perspective.

We also provide patient input to clinical trials and consultations and provide patient briefing and viewpoint to many within the bladder cancer sector.

Policy

We are regular contributors to NICE consultations relating to bladder cancer and lobby on bladder cancer issues. We work to raise the profile of bladder cancer with decision makers and contribute to cancer patient consortiums, conferences and roundtables, both UK and EU. We are a founding partner of the NHS PHE Blood in Pee Campaign and the World Bladder Cancer Patient Consortium. There is a much more to be done to improve the position for those with bladder cancer and to address some of the underlying issues behind late diagnosis and poor outcomes, to raise public awareness.

If you'd like to find out more about ABC UK or about bladder cancer

E mail: info@actionbladdercanceruk.org Call: 0300 302 0085