

THE FBC Manifesto for Bladder Cancer

Without a clear statement of objectives, progress is always going to be hampered, so one of FBC's major new initiatives is to begin the development of a fully integrated manifesto

Fight Bladder Cancer was founded by patients and carers, and their health and well-being is always at the centre of all we do. In the short time we have been around and developing our knowledge of bladder cancer, we have been struck by the lack of a co-ordinated agreement of what is important to patients and what needs to happen to create the improvements we both need and want.

As Roger Wilson argues in his article on page 35, it is essential that patients are involved at the core of cancer research projects. However, until recently, the lack of an organisation like Fight Bladder Cancer has meant that there has

been a huge void in discussions between patients, researchers and clinicians even about essentials, let alone what is desirable.

We are putting this document out for discussion with the whole bladder cancer community – to clinicians, specialist nurses, researchers, policy-makers, patients and carers – and asking for their responses. What have we missed? Where have we gone wrong? Help us refine these fundamental directions of travel that will enable us to achieve the essential improvements we have seen in other, better funded, cancers.

This is just the first step.

We know there will be changes, additions and refinements but without a 'starter for ten', the discussion cannot move ahead, so this is our statement to open the discussion. It is our top 10 lists of wants: the 10 top subjects that we want patients, carers and our professional colleagues to focus on over the next few years.



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This manifesto is our first co-ordinated statement of what we believe are the most important areas for action that will have the greatest impact for the patient and carer community.

We have a long way to go to get the quality of care that we deserve; a quality of care that can be given in other cancers but is missing from bladder cancer.

Where do we start from?

Bladder cancer kills 14 people every day in the UK and the prognosis has hardly changed in the last 40 years.

At present we don't even know accurately how many people are given a bladder cancer diagnosis every year as not all cases are registered in the national cancer registration database. We believe that it is somewhere between the 10,000 being registered and the 17,000 estimated by a representative from Public Health England's Cancer Registration team recently at a bladder cancer working group meeting. At 17,000 this would make it the fifth most common cancer in the UK after breast, prostate, lung and bowel cancers. Certainly, bladder cancer is not a rare cancer.

Prognosis varies wildly depending on how early it is caught (between 80% and 10% survival averages between Stage 1 and Stage 4) and is worse for women than for men. More men get bladder cancer than women and it is still quite rare in the young. Why this is we don't really know.

There is also a hypothesis that, if we screened for bladder cancer in the same way that we do for breast, bowel and prostate cancer, the numbers would be even higher as it could be that there are many people who live with a bladder cancer that does not kill them but remains undiscovered.

What we do know is that bladder cancer has the highest recurrence rate of any cancer and is the most expensive for the NHS to treat on a per patient basis and this high recurrence rate continues because the existing treatments are just not adequately effective.

Research into the causes of bladder cancer and for new and better treatments is pitifully low, currently getting just 0.6% of cancer research spend in the UK. As a contrast,

leukemia gets 17% of research spend and affects a smaller number of patients.

We do know that there are holes in our knowledge about bladder cancer, many of which were identified in the development of the NICE guidelines in 2015, with many others being identified by patients as we travel on our journeys through the pathway.

So, why is bladder cancer such a 'Cinderella' cancer?

The FBC/ECPC Patient Experience Study (see the report on page 20) has shown that the majority of people have never heard of this common cancer and that access to effective treatments is one of the biggest causes of concern. Historically, bladder cancer was known as the 'poor man's' or 'working man's' cancer. This came about because of the links found between certain industrial processes, working practices that didn't take heed of the risk of exposure to carcinogens, and from smoking.

Importantly, many of these causes have now been or are being taken out of the environment but we still do not know why it is that bladder cancer remains so common. Whilst we understand about the huge risks associated with smoking, the research into other causes is limited. Environmental factors are potentially an area where we need to look further, especially with regard to air pollution that the World Health Organisation has indicated could be a cause of bladder cancer. FBC has now produced a report on the current evidence on the environmental risks for bladder cancer (see the report on page 40).

As we write this article, we hear that the MASH actor, David Ogden Stiers, who played the character Major Charles Winchester, has died aged 75 following his battle with bladder

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cancer. He is probably the most famous person internationally who we have seen to have lost their lives to the cancer since the rise of social media, and this one announcement has generated more social media traffic about bladder cancer than any other news item ever. Bladder cancer continues to struggle to get media attention that would help with our campaigns. Cancer in the media is dominated by a small number of cancers and all the others struggle to get a space in the spotlight. The huge, and welcomed, improvements in prognosis and quality of life for those affected by breast or prostate cancer can be directly related to the strength of their campaigning voice in the public domain and with the national policy-makers.

We need to strengthen the orange voice for bladder cancer patients to aid us in our campaigning for improvements.

It has always been difficult for us to generate a list of celebrities who have been affected by bladder cancer, as there is this deadly silence about the subject. It can't be that celebrity status means that you are less likely to get bladder cancer, so why is it that we just simply do not hear of examples as we do with breast and prostate cancer? Is this silence something we can change?

Our manifesto PLEDGES

What is the current patient experience?

Every year the NHS carries out a cancer patients' experience survey. And in every year that it has been produced, bladder cancer has been at the bottom of the satisfaction table, indicating that something is wrong with how our patients are being looked after and treated. Of course, the lack of research and effective treatments must come into play with this, but it is across the whole experience that bladder cancer care seems not to be up to the standard of other cancers.

At FBC, we interact with thousands of patients each year and we know that the quality of care varies across the country and across the globe. From almost perfect early diagnosis, through good-quality information, support, treatment, after care and quality-of-life issues, we also see examples of delays, poor guidance, an almost total lack of support, and problems with access to the best treatment. We expect to see variations between countries due to different economic pressures, but the variations within a country are just not acceptable.

So while we may start from an improving landscape of care and treatment, we have a long way to go to get the quality of care that we deserve; a quality of care that can be given in other cancers but is missing from bladder cancer. This is why we need this manifesto: we need to turn the spotlight on bladder cancer. **And it is also why we are asking you to join us in this campaign that we are launching as part of this year's Bladder Cancer Awareness Month in May.**

One major problem is that bladder cancer is simply not on the radar. Most people understand very little about it, or the risks they face as they get older. There is also, unfortunately, a very real legacy of neglect to overcome within healthcare and research. Reliable tests for diagnosing bladder cancer at a GP level just don't exist and the general public does not know the symptoms. The many different potential symptoms need to be fully understood at a primary care level. Your GP will know about blood in your wee but how many know about the other symptoms?

Prevention is better than cure so we need to ensure that the general public understands the known causes and symptoms of bladder cancer. To achieve this, we need to work together to gain the required media coverage of bladder cancer in order that the general public understands this subject. We then have to identify the other causes to establish whether there are different ways of prevention by changes in lifestyle, work practices or environmental factors.

For breast cancer and prostate cancer, significant improvements in prognosis and quality of life have been achieved in the last 20 years and we know that a lot of this has been because of the strength of the patient voice. Pink power and Movember have made a substantial difference and we want the same for bladder cancer.

Manifesto pledge 1

GROWING THE PATIENT VOICE

We will campaign for dedicated and robust awareness of this common and deadly cancer. This will include a call-out for celebrities affected by bladder cancer to 'come out' and join us in talking about the disease. Silence is deadly.

But what do we want if we get the attention for bladder cancer that it deserves? Prevention is so crucial and is where we must start. There is great ignorance about the causes of bladder cancer and we still have restricted knowledge of all the causes. What do we know? About 30–50% of bladder cancers are due to smoking and then about 10% are due to industrial processes, such as exposure to specific chemicals and dyes. But for about half the cases, we just don't know why the patient has developed this cancer.

There is growing evidence of some environment factors (see article on page 40) but we need significant research to identify all the causes that can be removed from our lives. Imagine if we could take away 50% of all cases of bladder cancer every year; how much more significant than a new drug giving a 3–4% improvement.

Manifesto pledge 2

RESEARCH INTO THE CAUSES OF BLADDER CANCER

We need investment to discover the causes of bladder cancer. Only then will we be able to prevent people getting it in the first place. This essential evidence will also help us identify those who are at risk and thus we will be able to be more accurate in the risk analysis of symptoms presenting at a GP level.

Diagnosis is still fundamentally the same as it was in the 1890s, with the physician looking into the bladder with a cystoscope and using his naked eye to see if a tumour is present. Yes, we have recently seen techniques added – such as blue light or narrow band imaging – to improve how good this visual inspection can be, but a less invasive test still seems a long way away.



Whilst we stick to this method of deciding whether someone has bladder cancer, it will always mean that late diagnosis will be common. If, for a GP, the only route forward is for an expensive hospital admission, there will always be pressure to restrict referral unless the symptoms are unambiguous. We need an economical non-invasive test that can be used at a GP level for anyone who shows symptoms that could be a bladder cancer – regardless of age or gender.

Manifesto pledge 3

A NON-INVASIVE TEST FOR BLADDER CANCER

We will campaign for and support research into the development of a non-invasive test for bladder cancer that can be used at a GP level and for the regular required check-ups following treatment, that reaches or better the accuracy of a cystoscope.

As the same technique is used at all the check-ups that the patient has to endure for this cancer, this is probably one of the main reasons that there is such a huge cost per patient for the diagnosis, treatment and management of bladder cancer, exacerbated by the fact that it has one of the highest recurrence rates of any cancer.

Establishing a new diagnostic technique would allow us to reduce the cost of diagnosis and check-ups, remove the invasive nature of the current technique and improve on the speed of diagnosis, thereby improving prognosis for patients as well as their quality of life.

As we mentioned earlier, we don't actually record all cases of bladder cancer here in the UK. So, if you go onto the Cancer Research UK website you will see a figure of just over 10,000 people being diagnosed with bladder cancer in a year. But these are just the cases where it has been registered in the national registration databases.

We know that this is a false figure but it is the one that sits behind an enormous amount of decision-making as far as resources and profile. If the figure is really something like 17,000 a year, then it makes bladder cancer the fifth most common cancer in the UK. This wouldn't surprise us as the current records shows it as the fifth most common cancer in the Western world.

So we need to find the truth. How many people are diagnosed with bladder cancer every year? How many people do we need to treat every year and what resources of doctors, nurses and specialists do we really need? Surely this is fundamental in any decision-making?

Manifesto pledge 4

CLARITY ON THE BLADDER CANCER BURDEN

We will work with the cancer registration services across the UK, the professional bodies and individual clinical teams to establish the most realistic figure for bladder cancer diagnosis in the UK per annum.

The current clinical pathway for the diagnosis and management of bladder cancer was reviewed and set down by NICE in a guideline document issued in February 2015. This document identified what should be the pathway, based on the evidence that was available. The guideline group noted that there were significant gaps in our knowledge that meant that the pathway recommendations were not as robust as they should be.

However, three years later, the reports we get from patients and clinicians is that there are still variances in the reality of the patient pathway. In order to understand what the adherence to the guidelines actually is, we need a comprehensive audit of the patient experience.

In addition to adherence to the NICE guidelines, it is important that we identify those places where the clinical teams have developed systems and procedures that improve the bladder cancer patient experience. These exemplars of service should be showcased and shared so that we can improve the patient experience for all, no matter where you live.

Manifesto pledge 5

ELIMINATE THE INEQUALITIES OF THE PATIENT EXPERIENCE

We will work with BAUN and BAUS to identify the adherence to the NICE guidelines and to identify and showcase exemplars of good practice.

Essential to the delivery of the guidelines for bladder cancer is the resourcing of clinical nurse specialists (CNS) as identified key workers for every patient.

Unfortunately, the workload of the urology CNS appears to be much greater and the skills required more extensive than CNSs for any other discipline. This could be as a result of the non-registration of many of the patients diagnosed with bladder cancer or the lack of resources for the condition due to its Cinderella status with the funding bodies.

A urology CNS will, most often, have to cover the whole range of urology cancers that include prostate, bladder, testicular and penile cancers. With this wide brief, the urology CNS has a far greater workload than others and also requires a much wider skill set than that required for a singular cancer.

Whatever the cause, this situation must contribute to the fact that bladder cancer comes at the bottom of the NHS annual cancer patient experience survey. It certainly is a subject that comes up repeatedly within our support forums. Linked with the lack of structured support for many patients and the lack of signposting to FBC, bladder cancer is often a very lonely diagnosis.

Manifesto pledge 6

ADDRESS THE UNDER-RESOURCING OF CNSs

We will campaign to strengthen the role of the bladder cancer CNS. This will include working with BAUN to develop specific training and resources for specialist nurses in this role and to campaign for adequate funding together with acceptance of the skills that the CNS can bring to the multi-disciplinary team and in supporting the patient.

Research into new and better treatments for bladder cancer will always be an ongoing strategy for Fight Bladder Cancer. However, we believe that this should be targeted where it can have the greatest impact.

In our manifesto pledge 2, we called for more basic research into the causes of bladder cancer on the basis that prevention is where it should always start.

In this next pledge, we are calling for greater and

improved research for all parts of the treatment pathway but especially focused on two areas of an alternative to BCG for high-risk non-muscle-invasive bladder cancer and an RCT between surgery and chemo-radiotherapy for muscle-invasive bladder cancer.

These are the two areas where patients currently have the most concerns over treatment from a prognostic point of view.

Manifesto pledge 7

IMPACTFUL RESEARCH FOR PATIENT CHOICE

Research needs to be targeted where it will have the most impact. It is essential that we find alternatives to BCG for the treatment of high-risk non-invasive bladder cancer and carry out research that establishes the situations where either bladder-sparing treatments or bladder removal should be chosen by patients for best prognosis and quality of life.

Alongside the significant lack of research into new and better treatments for bladder cancer, the quality of life issues around treatment and survivorship for bladder cancer patients is a neglected subject. At most points in the current pathway, the clinical team can only offer limited advice to their patients, as there is simply no robust data about the reality of the patient experience.

Quality of life during and after treatments can be more important than extension of life. QoL information is always crucial to understand at any point in the bladder cancer pathway. Not only does this information prepare you for the reality of the treatment, it is essential to understand when there are treatment choices to be made.

We need to establish, in greater detail, the real world side-effects of bladder cancer treatments for patients of all ages, genders and with other common comorbidities. We then need to develop guidance for patients to manage or mitigate these side-effects and to ensure that this support is readily available for all.

With any research work, we need to improve the extent and the quality of the patient reported outcomes (PROs) by working to make sure that we capture the relevant data. To this end we need to work towards an improved suite of validated questionnaires specific for the different treatment points along the pathway.



Manifesto pledge 8

IMPROVE QUALITY OF LIFE DURING & AFTER TREATMENT

QoL data is as essential as treatment effectiveness so we will campaign that robust data should be collected throughout clinical trials and post trials in order to fully understand the real world side-effects. Alongside this, is the need to develop a bladder cancer specific set of validated questionnaires that have had significant patient advocacy group input.

In some ways, these final manifesto pledges are the most critical to gain the greatest impact for all bladder cancer patients in the shortest time. They are the 'low-hanging fruit' for bladder cancer that are currently often missing from the patient experience and, if acted upon, will see a great improvement at zero cost to the NHS.

Communication must be improved. From the earliest symptoms through diagnosis and on to treatment, the world for a bladder cancer patient is all about waiting. Unlike in many other cancer pathways, understanding the importance of speedy and accurate information is often lacking.

The time to a detailed diagnosis, the time to receiving a treatment plan, the time to treatment, the time to see if the treatment has been effective and the time to the next check-up is a continuous emotional rollercoaster as you wait and worry. And the worry increases when the timescales lengthen without reason or explanation. Bladder cancer is a lonely diagnosis, as we know with most people never hearing of the illness before diagnosis and then not being able to find support and information from others who have travelled this path before. We must tighten up on the waiting periods when possible as we know that time to definitive treatment is often much longer than it needs to be.

A clear and unambiguous timescale target should be identified for all the steps in the pathway and should be part of all guidelines for the treatment and management of bladder cancer.

This guideline time target should be provided to every patient alongside the treatment plan. We have to have both so that we can understand and plan our lives. And when a time period says something like six weeks, then we want to be told if that has to extend for any reason. We accept that problems do happen and some things might need to be moved but please make sure the patient is spoken to and things explained.

If you have been told that you will hear your results in two weeks and four weeks go by and you hear nothing, you worry. You worry a lot. A simple phone call, email or text explaining a delay will make all the difference if delays cannot be helped.

Manifesto pledge 9

COMMUNICATION

All bladder cancer guidelines have to be updated to include target timescales for all points on the treatment pathway. These targets are to be given to all patients alongside their treatment plans and clinical teams must set up procedures that proactively inform patients of any situations when these targets will not be met.

And finally, the easiest and most effective action we are calling on for implementation: signposting of patients to good-quality, patient friendly information and to support services provided locally and nationally.

At Fight Bladder Cancer we understand that the service provisions possible from a underfunded NHS will mean that the information, advice and support that the clinical teams can provide will be limited by resources available. This is why we exist. We are here to supplement what the healthcare services can do. As patients ourselves we can provide good-quality information that is reviewed by our expert medical advisory panel. We can also provide peer-to-peer support and guidance for all patients no matter where they live or what treatment they are going through. Our online confidential support forum runs 24/7 and is supplemented by our national one-to-one Bladder Buddy service, our local Fight clubs providing a place to meet and chat with other patients and carers, plus our telephone/email helpline service.

So our final pledge is simple.

Manifesto pledge 10

SIGNPOSTING TO FIGHT BLADDER CANCER

We will continue to work to build links with all clinical teams to explain our information and support services and to grow these services so that we can get to a stage when every patient knows that they can make contact with us to supplement the work of their medical teams. We will work to ensure that nobody feels alone with his or her bladder cancer.