



FACING

**BLADDER
CANCER**

CONTENTS

MEET THE EXPERT PANEL	3
FOREWORD FROM EXPERT PANEL MEMBER	4
SUMMARY OF IMPORTANT RESEARCH FINDINGS	5
INTRODUCING BLADDER CANCER	6
EPIDEMIOLOGY:	6
RISK FACTORS:	7
DIAGNOSIS:	8
TREATMENT:	9
ABOUT THE RESEARCH	10
IMPORTANT RESEARCH FINDINGS	11
EXPERT PANEL RECOMMENDATIONS	24
SOURCES OF SUPPORT	25
ABOUT ASTELLAS	26
ABOUT THE SAMPLE	27
REFERENCES	29

MEET THE EXPERT PANEL



SUSAN MULLERWORTH

Fight Bladder Cancer



ANITA EIK ROALD

Norwegian Bladder Cancer Society



LAURA MAGENTA

PaLiNUro



ALEX FILICEVAS

World Bladder Cancer Patient Coalition



GLOSSARY OF IMPORTANT ABBREVIATIONS

BCG	Bacillus Calmette-Guerin
ChT	chemotherapy
CT	computed tomography
DNA	deoxyribose nucleic acid
EAU	European Association of Urology
ESMO	European Society for Medical Oncology
HCP	healthcare professional
MIBC	muscle-invasive bladder cancer
NMIBC	non-muscle invasive bladder cancer
TURBT	transurethral resection of bladder tumour

FOREWORD FROM EXPERT PANEL MEMBER

THIS REPORT COMMISSIONED BY ASTELLAS PUTS A MUCH-NEEDED SPOTLIGHT ON THE SIGNS, SYMPTOMS AND PREVALENCE OF BLADDER CANCER, AND MORE IMPORTANTLY HOW PATIENTS AND CAREGIVERS FEEL ABOUT THEIR BLADDER CANCER JOURNEY. WHAT IS CLEAR IS THAT BOTH PATIENTS AND CAREGIVERS FEEL A DISEASE DISADVANTAGE ABOUT THEIR CANCER, COMPARED TO PATIENTS SUFFERING FROM OTHER CANCERS SUCH AS BREAST, OVARIAN OR PROSTATE.

Patients feel a huge mixture of emotions including shame at the disease, self-blame, anguish and injustice, confounded by negative experiences. The report has also highlighted the difference in experiences between patients, in particular older versus younger patients: the average age at diagnosis is 73 but those diagnosed younger than this often feel embarrassed, feeling that bladder cancer is dirty and unhealthy.^{1,2}

Another interesting element highlighted is the mental health impact this disease has not only on patients, but caregivers too. Many of those questioned mentioned mental health issues after their diagnosis with some even going so far as to say that “the physical part is easier than the mental part”. It would sadly seem that the experience of bladder cancer starts off on the worst possible footing – it being negative for every single person interviewed, with heart-breaking stories of misdiagnosis,

delay, confusion and anguish, leading to anger and frustration particularly in younger patients.

The report rightly highlights that the system is not matching patients’ urgency to be diagnosed – seen through first-hand stories of delayed diagnosis, presenting multiple times in pain, sometimes in emergency rooms. The diagnosis experience is against patients which leads to anger and frustration, stress, mental health impact and some patients giving up due to lack of confidence to present again. And what about the relationships with our doctors? Unfortunately patients feel they’ve not been taken seriously; their own knowledge of their bodies has been dismissed; they have had a cruel experience of diagnosis. Although there are patient stories of positive HCP support, the diagnosis experience is a hard act from which to recover, and one which absolutely needs to be addressed.

I am pleased to see a spotlight shone on bladder cancer – this community is now getting the attention it deserves. I look forward to continuing to work with the bladder cancer community to address these unmet needs and challenges, making life a little easier for those diagnosed and living with bladder cancer.

Susan Mullerworth
Fight Bladder Cancer

SUMMARY OF IMPORTANT RESEARCH FINDINGS

01

People living with bladder cancer feel disadvantaged by their experience of cancer. They have a feeling of self-stigma towards their disease, since they have to face their own feelings of embarrassment and self-blame at their disease²

02

Younger male and female patients feel and express a feeling of disease disadvantage more intensely, since bladder cancer has a low public profile and more typically affects older men (the hidden majority) who tend to be more resigned to their disease²

03

People living with bladder cancer feel disease disadvantage for the entire length of their journey, from the often-delayed diagnosis to surgical treatment to palliative care²

04

Disease disadvantage doesn't just affect people living with bladder cancer – their caregivers also experience a significant impact on their persona and daily activities, as well as considerable mental health issues, including depression and anxiety, which affects up to 16% of patients and up to 23% of caregivers²

05

Some people living with bladder cancer use the experience of living with this disease as an opportunity for personal growth i.e. they have a different persona before and after diagnosis and use it to strengthen relationships with significant others, which can help overcome the disease disadvantage²

INTRODUCING BLADDER CANCER

EPIDEMIOLOGY:

In 2020 it was estimated that bladder cancer is the fifth most common cancer in Europe, but these numbers may be even higher.³ Males are three-times more likely to be diagnosed with bladder cancer than females.⁴

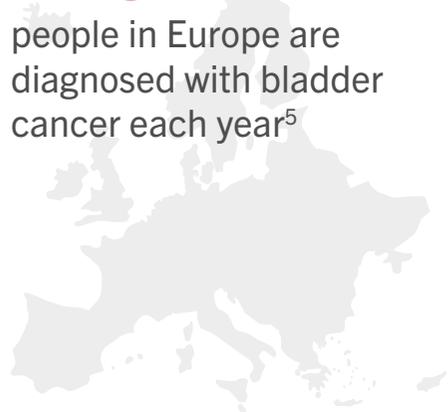
90%



About 90% of people with bladder cancer are over the age of 55 years.¹

151K+

people in Europe are diagnosed with bladder cancer each year⁵



Overall the five-year survival rate for people with bladder cancer is around

77%¹



People whose bladder cancer has not spread beyond the inner layer of the bladder wall (early stage disease) have a five-year survival rate of 96%¹



Where bladder cancer is invasive but has not spread beyond the bladder the five-year survival rate is about 70%¹



When bladder cancer has spread to surrounding tissues or nearby lymph nodes or organs the five-year survival rate is about 38%¹

“ This is an old man’s disease that young women and children don’t get. ”

Females tend to be diagnosed with more aggressive bladder cancers than men and show shorter cancer-specific survival.⁶



RISK FACTORS:



Studies have shown that approximately half the cases of bladder cancer (49%) may be preventable.⁶

- ▶ However, a person's risk of developing bladder cancer depends on a number of factors which are not preventable, including age, genetics, workplace exposure (e.g. dye, paint and rubber industries; 6%) and radiation (2%).⁶ However, many legislations are now in place regarding exposure to carcinogens at work.⁷

“ Why me? Why have I got it? I did some research into the chemicals I've used over the years. I've been around aviation fuel since I was 18. I pursued it with the union. Maybe someone needs to be made answerable for it. ”

- ▶ Genetic risk factors contribute to bladder cancer: e.g. about 50% of people living with bladder cancer show high levels of the receptor for epithelial growth factor; p53 and retinoblastoma genes, etc.^{8,9} However, inherited gene mutations are not thought to be a major cause of the disease.¹⁰
- ▶ Other factors thought to increase the risk of developing bladder cancer include: smoking, alcohol consumption, eating red meat and processed meat, which are associated with a 45%, 17% and 10% increased risk of bladder cancer, and obesity, which is associated with a 10% increase in risk.¹¹

SYMPTOMS OF BLADDER CANCER^{12,13}



Blood in the urine (haematuria) which is usually painless



Pain when passing urine (dysuria)



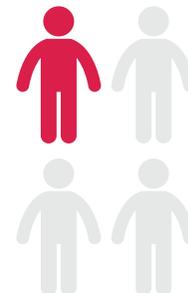
A need to pass urine more frequently



ARE YOU EXPERIENCING ANY OF THESE?

A quarter of people living with bladder cancer present with cancer that has spread to muscles in the bladder wall (muscle-invasive) or other parts of the body (metastases) and need intensive therapy.¹⁴

Anyone experiencing these symptoms should book in to see their GP or ask for a specialist referral



1/4

of people living with bladder cancer present with cancer that has spread to muscles in the bladder wall (muscle-invasive) or other parts of the body (metastases) and need intensive therapy.

DIAGNOSIS:



A number of tests are used to diagnose bladder cancer. Following a patient history and physical examination, tests may be done using imaging e.g. CT urogram, ultrasound and multi-parametric magnetic resonance imaging, along with test for cancer cells in the urine (urinary cytology).¹⁵



A thin tube with a camera and a light at the end (cystoscope) are passed through the urethra (the tube through which urine flows) into the bladder is carried out to confirm the diagnosis.¹⁶

BLADDER CANCER SUBTYPES:

The 2022 EAU guidelines categorise bladder cancer to guide treatment and follow-up: ^{13,17}

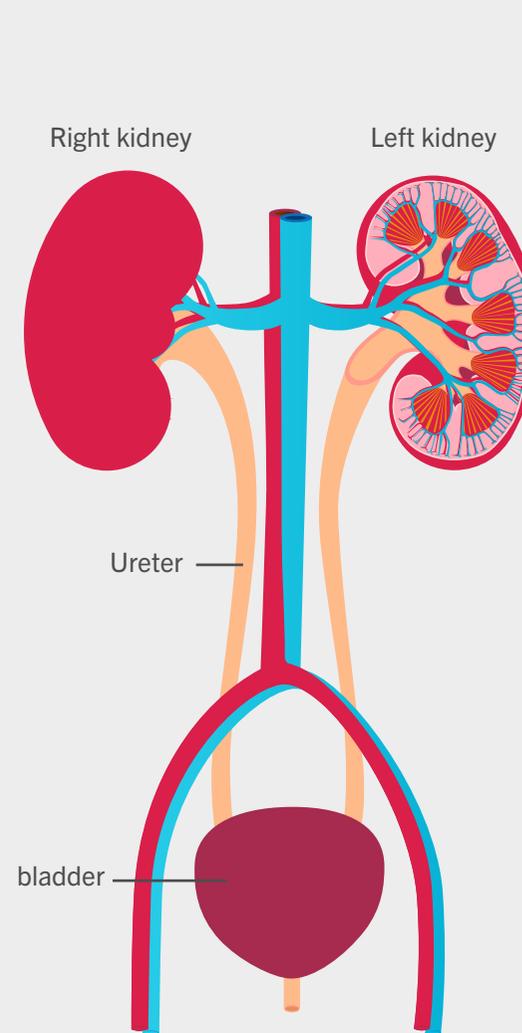
Non-muscle invasive disease:

- ▶ Low risk
- ▶ Intermediate risk
- ▶ high risk
- ▶ Very high risk or BCG (Bacillus Calmette-Guerin) unresponsive

Muscle-invasive disease:

- ▶ Unfit for cisplatin-based ChT
- ▶ Fit for cisplatin-based ChT

BLADDER ANATOMY¹³



The most frequent type of bladder cancer (90%) is

UROTHELIAL BLADDER CANCER



Other types of cancer that can affect the bladder include

SQUAMOUS CELL CARCINOMA & ADENOCARCINOMA



Some other
**RARE FORMS OF
BLADDER CANCER**
also exist

TREATMENT:

TREATMENT OF BLADDER CANCER IS GUIDED BY TYPE (NMIBC OR MIBC) AND RISK CATEGORY.¹⁸

Immunotherapy (i.e. Bacillus Calmette-Guerin – BCG)

- ▶ Non-muscle invasive bladder cancer (NMIBC)
- ▶ Muscle-invasive bladder cancer (MIBC)

Radiotherapy (including radiosensitiser)

- ▶ Early stage
- ▶ After TURBT surgery
- ▶ For those who cannot have chemotherapy

Transurethral laser surgery

- ▶ Non-muscle invasive bladder cancer (NMIBC)
- ▶ Followed by adjuvant intravesical chemotherapy or immunotherapy

Radical cystectomy

- ▶ If the cancer is larger or is in more than one part of the bladder

Surgical removal

- ▶ Muscle invasive bladder cancer

Neoadjuvant and adjuvant chemotherapy

- ▶ Muscle invasive bladder cancer and low-grade non-muscle invasive bladder cancer

PROGNOSIS VARIES DEPENDING IN THE STAGE AT WHICH BLADDER CANCER IS DIAGNOSED:^{19,20}

- ▶ The proportion of people who survive for five years or more after diagnosis ranges from around 80% for people with stage 1 cancer to around 10% for patients with stage 4 cancer.



STAGE 1 means the cancer has started to grow into the connective tissue under the lining of the bladder.



At **STAGE 4** the cancer has spread to other parts of the body such as the wall of the abdomen or pelvis, or the lymph nodes.

“ After TURBT [transurethral resection of a bladder tumour] it’s like peeing shards of glass ”



Patients who are diagnosed early are likely to live longer than those diagnosed later. Some evidence suggests that a three-month delay in diagnosis doubles the risk of death for people with bladder cancer.

ABOUT THE RESEARCH

AN ONLINE 20 MINUTE SURVEY



 **312** PEOPLE


226
PATIENTS


86
CAREGIVERS

...who had been invited to take part was completed in five countries (USA, France, UK, Spain and Germany).*



In addition, 21 in-depth one-hour interviews were conducted during with the following participants:

USA:  4 PATIENTS  3 CARERS

France:  3 PATIENTS  3 CARERS

UK:  4 PATIENTS  4 CARERS

In total there were 5 male and 6 female patients and among caregivers 3 were male and 7 female. The patients were diagnosed 2–4 years previously with the exception of 1 more recently diagnosed.

The reason for conducting the research was to gain insights that will deepen understanding of disadvantage in bladder cancer for patients and their caregivers. Specifically:

Understand if and how this stigma exists within the bladder cancer community



Is our understanding of it mirrored by patients and caregivers or do they talk about it differently?



Understand what stigma is, how it manifests itself, and what different types of stigma there are

Explore how stigma evolves over the course of the disease



Differences, tensions and opportunities in the varying experiences and emotions of patients and families, at these key moments



Similarities and differences across the markets and patient types, where statistically available



Start to explore patients' and caregivers' solutions to stigma and their wish list for change



IMPORTANT RESEARCH FINDINGS

01

People living with bladder cancer feel disadvantaged by their experience of cancer. They have a feeling of self-stigma towards their disease, since they have to face their own feelings embarrassment and self-blame²

People living with bladder cancer are often embarrassed about their disease; they feel dirty and unclean and some dread appearing weak – mainly in the case of incontinence due to surgery. Patients experience trauma in needing to urinate maybe 30 times a day, often painfully and with little notice.²

“ I see myself through the eyes of others and I am somehow smaller. ”

“ She’s more of an enemy to herself, almost punishing herself ”

“ I’ve made excuses in meetings – oh I’ve had too many coffees this morning! – when I’m pitching business people make decisions on prejudices, so I have to keep the focus on business. There’s potency in being a male and impotency from physical problems. ”

- ▶ Internalised views, such as self-blame (reported to be experienced sometimes by 22%), impaired self-esteem (21% said they feel ashamed sometimes and 19% reported feeling their illness sometimes disgusts them) and poor body image, are among the negative experiences that affect how people living with bladder cancer live their lives with 68% saying they had a severe or moderate impact.²

- ▶ Caregivers were more likely to call out more self-blame, feelings of judgement and unfair treatment by others: 30% said that patients sometimes blamed themselves for their illness and 29% said patients feel judged sometimes. It may be that because caregivers are observing they can have a more objective view of the situation patients find themselves in.²



43%

of younger patients:
“immediately after diagnosis I felt the doctor blamed me in some way”



52%

of patients aged 18-39:
“I felt my family, friends or colleagues have been embarrassed by my illness”



95%

of younger patients:
“I unfortunately have mental health issues”

NEGATIVE EXPERIENCES AFFECT HOW MOST PEOPLE LIVING WITH BLADDER CANCER LIVE THEIR LIVES²



CAREGIVERS CALL OUT MORE SELF-BLAME, FEELINGS OF JUDGEMENT AND UNFAIR TREATMENT BY OTHERS – AS OBSERVERS, THEY MAY SEE MORE THAN PEOPLE LIVING WITH BLADDER CANCER²

“ I don’t know how to deal with it ”

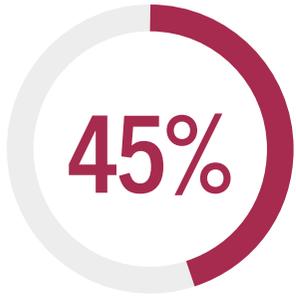
“ Oh look grandpa is wearing nappies ”

“ As neighbours, we used to be really close, but not any more ”



“ Why doesn’t she give up smoking? ”

“ Our sex life is very different ”



of bladder cancer is caused by smoking, but the majority occur in non-smokers with other risk factors.⁶



- ▶ Unfortunately, partly due to smoking and other preventable risk factors, most people living with bladder cancer feel that other people blame them for their illness; this feeling extends to their significant other, for example 16% said their immediate family were embarrassed by their illness.²

“Smoking just seems to be a scapegoat because it’s so socially unacceptable now”



“I was told it was because I smoked. My doctor immediately said ‘you smoke and that’s why you have bladder cancer’”



- ▶ Expressions of self-stigma, such as feelings of being judged and blame by friends and doctors, can emerge soon after diagnosis and increase slightly as the bladder cancer journey progresses²



of patients agreed with the statement “At times I blame myself in some way for my illness”. However, these feelings were expressed more frequently by younger patients with 59% agreeing that they felt in some way to blame.²

- ▶ Looking at specific dimensions of self-stigma it appears that some aspects did improve over time after diagnosis. For example:²

Those who agree they had good self-esteem increased from 60% immediately after diagnosis to 68%

For patients aged 18-39 years 59% felt positive about how their body looked immediately after diagnosis, which rose to 71% over time

People who had a cystectomy had a particularly bad experience but around three-quarters felt that now they had good self-esteem (75%) and felt positive about how their body looked (71%) compared with immediately after diagnosis (64% and 60% respectively).



After diagnosis, some people (31%) living with bladder cancer perceive family and friends apportioning blame and not expressing any more sympathy than doctors.²

“After diagnosis, I have perceived family and friends apportioning blame and not expressing any more sympathy than doctors”



“Why doesn't she give up smoking? I said it myself to someone with bowel cancer. How very judgmental of me!”

“It's not like it's hereditary”



MOST PEOPLE LIVING WITH BLADDER CANCER SAY THE FOLLOWING INFLUENCE THEIR REDUCED INVOLVEMENT IN ACTIVITIES:²



Pre-planning



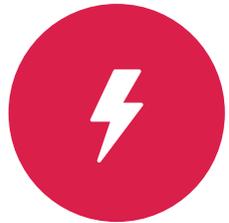
Incontinence



Tiredness



Pain



- ▶ In general, people living with bladder cancer can rely on strong levels of sympathy throughout their journey. Nevertheless, people living with bladder cancer aged 60 years and older report a drop in the sympathy they feel from those around them; immediately after diagnosis 98% agreed that they felt people around them were sympathetic but that fell to 85% over time.²



“At the beginning the friends said 'we're here for you' but they don't ask how he is and in the end it becomes radio silence”

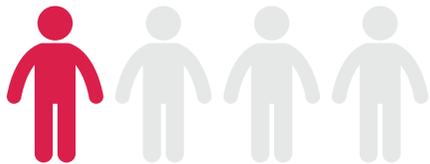
02

Younger men and female patients feel and express disease disadvantage more intensely, since bladder cancer has a low public profile and more typically affects older men (the hidden majority) who tend to be more resigned to their disease²

Some younger and female patients are angry and are devastated by what's happened – this group experience more disease disadvantage.²

“ This is an old man’s disease that young women and children don’t get. ”

A DIAGNOSIS OF BLADDER CANCER ALSO IMPACTS ON HOW PEOPLE DESCRIBE THEMSELVES:²



Around a quarter of respondents were more likely to describe themselves as lonely (25%), isolated (25%) or depressed (24%) after diagnosis compared with before they were diagnosed.



Between a quarter and a third of patients were less likely to describe themselves as fun (29%), active in my community (27%) or as an organiser (27%).

Lack of awareness (e.g. little public discourse) of bladder cancer contributes to poor understanding and people living with bladder cancer’s experiences of isolation.²



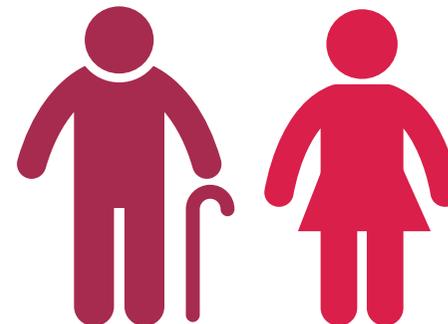
The typical bladder cancer patient is diagnosed at 73 years.¹ Although they are ‘the bulk of the iceberg’, they are less likely to be in public and social situations and remain relatively hidden.



“ Now we don’t go out so much, but that was already changing anyway. ”

“ I don’t think it’s unusual. It happens frequently in older people. ”

DISEASE DISADVANTAGE



Older people living with bladder cancer are less likely than younger people to report that disease disadvantage affected how they live their lives: 75% of those aged 18–39 years compared with 44% of those over the age of 60 years saying negative experiences had a moderate or severe impact on how they lived their lives.

03

Many people living with bladder cancer feel disease disadvantage for the entire length of their journey, from the often delayed diagnosis to surgical treatment to palliative care

People living with bladder cancer often report significant diagnostic delays, which may cause avoidable disease progression:²

- ▶ People with early bladder cancer are at a disadvantage from the ambiguous initial symptoms, which may be misdiagnosed as urinary tract infections or inappropriately referred (e.g. to a gynaecologist).
- ▶ Delayed or missed diagnoses can undermine the ‘alliance’ between people living with bladder cancer and HCPs (nurses, GPs, urologists).

“ Keep going to your GP / Primary Care Provider. You have to shout loud. ”

Definitive (potentially curative) treatment (e.g. radical cystectomy) can be life-altering and distressing and leave people living with bladder cancer facing potential embarrassing consequences (e.g. leaking stoma bag)



91%

of people living with bladder cancer say bladder surgery influenced reduced involvement in activities



Uncertainty about recurrence can leave people living with bladder cancer and their caregivers facing anxiety, which can disadvantage their ability to take part in activities.²



53% of patients say they cannot mentally bring themselves to do activities that involve seeing colleagues socially any more compared with 38% who say they cannot physically undertake such activities.²



Some people living with bladder cancer feel that disease management tends to be focused on surgery, with less interest shown in the practical and psychological disadvantages associated with the operation.²

Cystectomy can affect other organs, including those associated with sexual activity and identity (e.g. penile shortening following radical cystoprostatectomy and a hysterectomy - removal of the uterus, ovaries and part of the vagina)²³. This can have emotional as well as physical after-effects:²

58%

of those who had had bladder removal surgery agreed their sex life had reduced significantly since diagnosis compared with 47% of those with bladder cancer who had not had surgery.

64%

of men who had had bladder removal surgery agreed they experienced erectile dysfunction far more than before their diagnosis compared with 45% who had not had surgery.

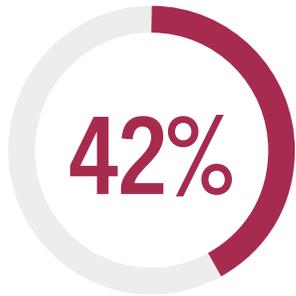
61%

However, on a positive note, 61% of those who had had bladder removal surgery agreed that their relationship had grown stronger since diagnosis compared with 47% of those who had not had surgery.

04

Disease disadvantage doesn't just affect people living with bladder cancer – their caregivers experience a significant impact on their persona and activities as well as considerable mental health issues, including depression and anxiety which affects up to 16% of patients and up to 23% of caregivers.²

Caregivers find themselves in a surprising situation that means they are typically unprepared for the changes in life following a bladder cancer diagnosis.²



of caregivers describe themselves as feeling lonelier now than before the diagnosis, compared with 25% of people living with bladder cancer.²



of caregivers agree that they resent the impact the disease has had on their lives. The figure rises to 50% among younger caregivers.²

CAREGIVERS SHOULD THE DISADVANTAGE OF A LARGELY HIDDEN BURDEN OF THEIR MENTAL HEALTH ISSUES THAT FOLLOW OR ARE EXACERBATED BY A DIAGNOSIS OF BLADDER CANCER AND EXTRA RESOURCES ARE NEEDED TO SUPPORT CAREGIVERS.

“ I’m mindful of the toll it’s taken on me too ”

“ It was tough on me too. My employer couldn’t understand why I also had to take time off for all the appointments ”



MENTAL BARRIERS ARE MORE LIKELY TO LIMIT SOCIAL,
OUT OF HOME ACTIVITIES BUT ALSO LIMIT LONE PURSUITS

PATIENT

“ I feel like a hamster on a wheel. No end in sight ”

“ I sometimes blame myself for my illness ”



“ The physical part is easier than the mental part ”

“ Sometimes I feel ashamed ”

“ I had an absolute breakdown ”

CAREGIVER

“ I wish there was a way for her to talk to other people like her; to get some psychological support for her and her family ”

“ It breaks my heart. She was so upset, beside herself. I said I can change the bed, you don't need to apologise. She's always apologising. ”



“ It's very degrading for her ”

“ Some days he couldn't even leave the bedroom... Mentally I had to help him, he almost gave up ”

Caregivers said there were things that would have a positive impact, especially training and advice. For example:²



Advice on how to help them manage their pain – 88% agreed



Tips on how to talk to doctors and nurses and what question to ask – 86% agreed



Training and advice on how to look after a cancer patient in general – 85% agreed



Advice on how to keep them feeling positive and avoiding depression – 85% agreed



84% of caregivers (74% of patients) see emotional or psychological support from family as very important or extremely important



72% of caregivers rated emotional or psychological support from friends as very or extremely important



73% of caregivers (69% of patients) think that practical support from family is very or extremely important²

THE HIDDEN MENTAL HEALTH BURDEN AMONG PEOPLE LIVING WITH BLADDER CANCER CAN AFFECT PROGNOSIS: ANXIETY AND DEPRESSION IN PEOPLE LIVING WITH BLADDER CANCER SEEMS TO BE ASSOCIATED WITH SHORTER SURVIVAL.²⁴



“ He started having panic attacks if he wasn’t near a loo ”



“ I’m in therapy. That helps tremendously. When I was first diagnosed, I got extremely depressed ”



SUBSTANTIAL SELF-STIGMA HAS A HUGE IMPACT ON MENTAL HEALTH, FREQUENTLY LEADING TO OR BEING COMBINED WITH DEPRESSION AND ANXIETY, MEANING MANY PATIENTS DO NOT WANT TO PARTICIPATE IN EVERYDAY ACTIVITIES.²

“ I wish there was a way for her to talk to other people like her; to get some psychological support for her and for her family ”

“ More than half of us (57%) want the chance to talk to other patients – I think this is extremely important ”

“ I think most of us (61%) feel that the opportunity to talk to other people living with bladder cancer is extremely important ”

“ I also would really like access to emotional or psychological support at the time and after my cystectomy ”



CAREGIVERS MAY FACE THE ‘HIDDEN DISADVANTAGE’ OF BEING CONTINUOUSLY VIGILANT FOR SIGNS OF RECURRENCE.²



Caregivers may recognise changes that the person with bladder cancer either does not recognise or want to discuss.²



of caregivers are less likely to do one or more activities than before diagnosis and more caregivers than people living with bladder cancer feel lonely and isolated²



are less likely to go out in the evening and 77% are less likely to leave their home for a few days²

In particular, they were less likely to take part in activities that involved: moderate to strenuous activity (61%); leaving home for several days (77%), or getting changed (77%)

CAREGIVER QUOTES

“ I have recognised changes in the person I care for, but he/she does not recognise these changes and does not want to discuss them ”

“ I do believe that many of us caregivers suffer from mental health issues ”

“ I am much less likely to do the activities I was doing before the diagnosis ”

“ I find it uncomfortable to deal with – it’s so personal ”

“ Am I interfering? I don’t want to appear patronising. It’s maintaining the balance ”



05

Some people living with bladder cancer use the experience of living with bladder cancer as an opportunity for personal growth and to strengthen relationships with significant others, which can help overcome the disease disadvantage²

Education and support can help people living with bladder cancer regain control and bolster theirs and caregivers’ resilience.²

- ▶ Information could help people living with bladder cancer take part in discussions and reduce physical needs after cystectomy (e.g. dealing with urinary diversion, fatigue and bowel problems)²⁵

PATIENTS AND CAREGIVERS RATED CHANGES IN SUPPORT AS EXTREMELY OR VERY IMPORTANT AND WOULD LIKE TO SEE THE FOLLOWING:²

	 PATIENTS	 CAREGIVERS
Support and advice for caregivers (e.g. how to care for patients after surgery)	61%	78%
Type of information (e.g. patient-friendly language, etc)	61%	63%
Emotional / psychological support (e.g. counselling after surgery)	59%	77%
Information access (e.g. how to understand the stage of bladder cancer)	58%	66%
Advice services (e.g. where to join a patient forum)	57%	65%

CAREGIVERS WANT TRAINING AND ADVICE ABOUT LOOKING AFTER PEOPLE LIVING WITH BLADDER CANCER (E.G. MANAGING PAIN) AND LOOKING AFTER THEMSELVES (E.G. STAYING POSITIVE).²

CAREGIVER QUOTES

“ I was very unprepared in every sense for the debilitating life change ”

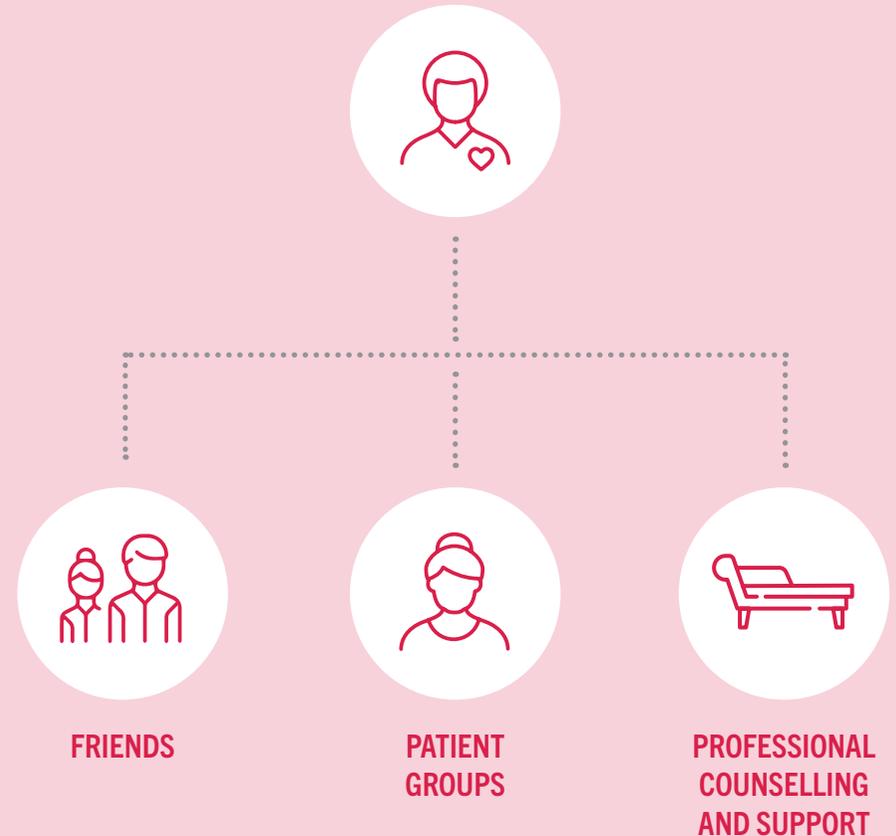
“ I didn't sign up for this and feel isolated and alone ”



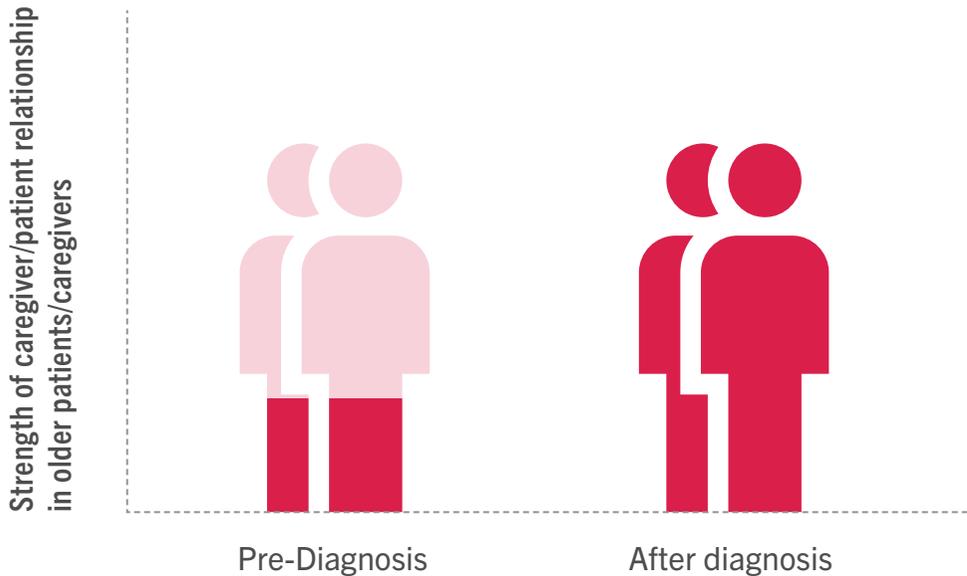
“ The person I care for turns to me for support and advice and answers, but I don't have them ”

“ As caregivers we don't get any advice or training on how to be a caregiver. Where's the handbook? ”

IMPROVED CAREGIVER SUPPORT IS THE CHANGE THAT MOST PATIENTS (61%) AND CAREGIVERS (78%) WOULD LIKE TO SEE. AND WHEN CAREGIVERS ARE LUCKY ENOUGH TO FIND SUPPORT IT COMES IN THREE FORMS.²



52% OF PEOPLE LIVING WITH BLADDER CANCER REPORT THAT THEIR RELATIONSHIP HAS GROWN STRONGER SINCE THE DIAGNOSIS.²



“ I do feel a change in the balance of our relationship but also a strengthening of our bond ”
OLDER PATIENT



“ I feel that my caregiver resents the impact this has had on their lives. I've seen a negative change in the dynamic of our relationship. ”
YOUNGER PATIENT



Improved teamwork (the standard of care in many other cancers) between the people living with bladder cancer and the HCPs (nurse, GP, urologist, oncologist) could improve the person's experience.



of patients said that a change in how the medical profession treats people with bladder cancer would be very or extremely important to them. The figure was even higher among caregivers at 67%.²



There were regional differences with 72% of patients in the USA and 69% of patients in Spain saying they would like to see a change in how the medical profession treats people with bladder cancer rating it as very or extremely important. In France the proportion was 47%.²

“ It's made my life more rich. I've got a bigger circle of friends that I would've never had. I'm more open to people now. You've got to live your life. ”

“ It's a hello, goodbye, see you in 3 months . It wasn't what we expected. My advice to a urologist ? Be more human, cancer isn't flu. We had a bad feeling, bad explanations, bad dialogue. ”

“ The worst part for me was the attitude of the doctor. I dreaded going to that office. ”

EXPERT PANEL RECOMMENDATIONS

Those surveyed were the patients and the caregivers living with bladder cancer, allowing us to gain true insights into their experiences and their journey and as such these findings are of high relevance to those currently living with bladder cancer whether they are a patient or a caregiver.

Patients and caregivers clearly feel disadvantaged by their bladder cancer in terms of the impact on them physically and mentally. More needs to be made available to patients in the form of information and psychological support to help them combat feelings of shame, being judged or blamed, and the feeling that friends and family might be embarrassed by the cancer. This is particularly the case for younger patients.

Caregivers must not be forgotten when managing patients with bladder cancer. A diagnosis has a significant impact on the physical and mental wellbeing of caregivers, who also seem to observe more

acutely the effect of the diagnosis on the people they are caring for.

While most patients and caregivers thought healthcare professionals were broadly sympathetic there is still work to be done to improve their relationship with patients and caregivers, particularly in terms of support and advice provided. For example, patients and caregivers would value counselling after diagnosis, advice on how to use and care for a stoma/ostomy bag, emotional or psychological support at the time and after a cystectomy.

Support from the point of diagnosis through the entire treatment journey is absolutely key and could be a way to overcome disease disadvantage. This support must come from doctors, nurses, friends, family and peers, but all these groups need the education and training to understand how best to provide this support.

Professional counselling, including easy access and education around this is something desperately

needed by both patients and caregivers and this may in turn help these two groups with the mental health impact bladder cancer seems to have on many patients and caregivers.

Improving access to tools to help patients and caregivers understand their treatment journey and what the future may hold is fundamental to improving the treatment journey and the experience. Hopefully through urgent interventions, the provision of support from the outset and education to all groups, patients and caregivers will feel encouraged to take part in the activities of everyday life that the rest of us take for granted.

“ SUPPORT FROM THE POINT OF DIAGNOSIS THROUGH THE ENTIRE TREATMENT JOURNEY IS ABSOLUTELY KEY AND COULD BE A WAY TO OVERCOME DISEASE DISADVANTAGE ”

SOURCES OF SUPPORT

Fight Bladder Cancer, UK: www.fightbladdercancer.co.uk/

PAzienti Liberi dalle Neoplasie UROteliali (PaLiNUro), Italy: www.associazionepalinuro.com

World Bladder Cancer Patient Coalition, Belgium: worldbladdercancer.org

Norwegian Bladder Cancer Society, Norway: blaerekreft.no/

Living with Bladder Cancer, The Netherlands: <https://www.blaasofnierkanker.nl/>

Bladder Cancer Self-Help Group, Germany: <https://www.blasenkrebs-shb.de/>

Danish Bladder Cancer Society, Denmark: <https://www.blaerekraefftforeningen.dk/>

The Spanish Group of Cancer Patients, Spain: <http://www.gepac.es/que-es-gepac/>

Bladder cancer symptoms and causes: <http://www.mayoclinic.org/diseases-conditions/bladder-cancer/symptoms-causes/syc-20356104>

ABOUT ASTELLAS

Astellas Pharma Inc. is a pharmaceutical company conducting business in more than 70 countries around the world. We are promoting the Focus Area Approach that is designed to identify opportunities for the continuous creation of new drugs to address diseases with high unmet medical needs by focusing on Biology and Modality. Furthermore, we are also looking beyond our foundational Rx focus to create Rx+® healthcare solutions that combine our expertise and knowledge with cutting-edge technology in different fields of external partners. Through these efforts, Astellas stands on the forefront of healthcare change to turn innovative science into value for patients. For more information, please visit our website at <https://www.astellas.com/en>.

ABOUT THE SAMPLE

*The sample in detail²

- ▶ An online 20-minute survey of 312 people – 226 patients and 86 caregivers – who had been invited to take part was completed in five countries (USA, France, UK, Spain and Germany).
 - ▶ USA: 43 patients, 19 caregivers
 - ▶ France: 30 patients, 8 caregivers
 - ▶ UK: 50 patients, 19 caregivers
 - ▶ Spain: 52 patients, 21 caregivers
 - ▶ Germany: 51 patients, 19 caregivers.
- ▶ In addition, 21 in-depth one-hour interviews were conducted during with the following participants:
 - ▶ USA: 4 patients, 3 caregivers
 - ▶ France: 3 patients, 3 caregivers
 - ▶ UK: 4 patients, 4 caregivers
 - ▶ In total there were 5 male and 6 female patients among caregivers 3 were male and 7 female. The patients were diagnosed 2–4 years previously with the exception of 1 more recently diagnosed.

REFERENCES

1. Cancer.net. Bladder Cancer: Statistics. Available at: www.cancer.net/cancer-types/bladder-cancer/statistics Accessed April 2022.
2. Astellas. 2022. Disease Disadvantage: Facing Bladder Cancer. Data on file
3. European Commission. JRC Publications Repository. Available at: [https://publications.jrc.ec.europa.eu/repository/handle/JRC101380#:~:text=In%20the%20European%20Union%20\(EU,of%20all%20the%20incident%20cases](https://publications.jrc.ec.europa.eu/repository/handle/JRC101380#:~:text=In%20the%20European%20Union%20(EU,of%20all%20the%20incident%20cases). Accessed April 2022.
4. Hyldgaard JM and Jensen JB. The inequality of females in bladder cancer. *Apmis* 2021;129:694-699.
5. European Cancer Patient Coalition. Urological Cancer Prostate Cancer. Available at: <https://ecpc.org/news-events/bladder-cancer> Accessed April 2022.
6. Cancer Research UK. Bladder cancer statistics. Available at <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/bladder-cancer>. Accessed April 2022.
7. European Agency for Safety and Health at Work. Directive 2004/37/EC -carcinogens or mutagens at work. Available at: <https://osha.europa.eu/en/legislation/directive/directive-200437ec-carcinogens-or-mutagens-work> Accessed April 2022.
8. Maluf FC, Cordon-Cardo C, Verbel DA, Satagopan JM, Boyle MG, Herr H, Bajorin DF. Assessing interactions between mdm-2, p53, and bcl-2 as prognostic variables in muscle-invasive bladder cancer treated with neo-adjuvant chemotherapy followed by locoregional surgical treatment. *Ann Oncol*. 2006 Nov;17(11):1677-86. doi: 10.1093/annonc/mdl289. Epub 2006 Sep 19.
9. Su H, Jiang H, Tao T et al. Hope and challenge: Precision medicine in bladder cancer. *Cancer medicine* 2019;8:1806-1816.
10. American Cancer Society. Inherited gene mutations. Available at: <https://www.cancer.org/cancer/bladder-cancer/causes-risks-prevention/what-causes.html#:~:text=Some%20people%20inherit%20gene%20changes,major%20cause%20of%20this%20disease>. Accessed April 2022.
11. Saginala K, Barsouk A, Aluru JS, et al. Epidemiology of Bladder Cancer. *Med Sci (Basel)* 2020;8(1):15.
12. Action Bladder Cancer UK. Symptoms of Bladder Cancer. Available at: <https://actionbladdercanceruk.org/symptoms/>. Accessed April 2022.
13. European Association of Urology. 2021. Guidelines on non-Muscle-invasive and Metastatic Bladder Cancer.
14. Ghandour R, Singla N, and Lotan Y. Treatment options and outcomes in nonmetastatic muscle invasive bladder cancer. *Trends in Cancer* 2019;5:426-439.
15. American Cancer Society. Tests for Bladder Cancer. Available at: <https://www.cancer.org/cancer/bladder-cancer/detection-diagnosis-staging/how-diagnosed.html> Accessed April 2022.
16. Cancer Research UK: Trans urethral removal of bladder tumour (TURBT). Available at: <https://www.cancerresearchuk.org/about-cancer/bladder-cancer/treatment/early/trans-urethral-removal-tumour>. Accessed April 2022
17. European Association of Urology. 2021. Guidelines on Muscle-invasive and Metastatic Bladder Cancer.
18. Cancer.net. Bladder Cancer: Types of Treatment. Available at: <https://www.cancer.net/cancer-types/bladder-cancer/types-treatment> Accessed April 2022.
19. Cancer Research UK. Survival. Available at: <https://www.cancerresearchuk.org/about-cancer/bladder-cancer/survival> Accessed April 2022.
20. Hollenbeck BK, Dunn RL, Ye Z, et al. Delays in diagnosis and bladder cancer mortality. *Cancer* 2010;116(22):5235-5242.
21. American Cancer Society. Key Statistics for Bladder Cancer. Available at: <https://www.cancer.org/cancer/bladder-cancer/about/key-statistics.html> Accessed April 2022.
22. Cx Bladder. Can Recurrent UTI Symptoms Be a Sign of Cancer?. Available at: <https://www.cxbladder.com/us/blog/can-recurrent-uti-symptoms-be-a-sign-of-cancer/>. Accessed April 2022.
23. Memorial Sloan Kettering Cancer Center. About Your Bladder Surgery With an Ileal Conduit (Urostomy). Available at: <https://www.mskcc.org/cancer-care/patient-education/about-your-bladder-surgery-ileal-conduit-urostomy>. Accessed April 2022.
24. Pham H, Torres H and Sharma P. Mental health implications in bladder cancer patients: A review. *Urologic Oncology: Seminars and Original Investigations*. 2019.
25. De Nunzio C, Giannatempo P, Passalacqua R, Fiorini E, Luccarini I, Brigido A. Epidemiology and unmet needs of bladder cancer in Italy: a critical review. *Minerva Urol Nefrol*. 2020 Feb;72(1):1-12. doi: 10.23736/S0393-2249.19.03498-2.

