

BLADDER CANCER SURVEY: INSIGHTS FROM PATIENTS AND CAREGIVERS

DISEASE DISADVANTAGE: FACING BLADDER CANCER



Bladder cancer is the

10TH

most commonly diagnosed cancer worldwide¹

From July – September 2021 across, France, UK, Spain, Germany and USA we surveyed²

226  bladder cancer patients

86  caregivers

SUMMARY OF RESEARCH FINDINGS²

People living with bladder cancer feel disadvantaged by their experience of a ‘cruel’ cancer and experience self-stigma:



FEELINGS OF BEING JUDGED AND BLAMED BY FRIENDS AND DOCTORS

“ At times I blame myself in some way for my illness ”

46%

of people immediately after receiving a diagnosis agree with the above statement. This increases to 56% once they have undergone bladder removal surgery.

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

Younger male and female patients feel and express disease disadvantage more intensely



THE STIGMA EXPERIENCE²

“THEY DON’T KNOW HOW TO DEAL WITH IT”

There are two types of stigma experienced by bladder cancer patients:

SELF-STIGMA:



A patient's own feelings of:

- ▶ Embarrassment
- ▶ Disgust
- ▶ Self-blame
- ▶ Fear of feeling judged

22%

of people with bladder cancer blame themselves for their illness

EXTERNAL STIGMA:



Squeamishness & embarrassment from others:

- ▶ Perception of being unclean
- ▶ Incontinence
- ▶ Assumptions around a stoma bag

21%

of people living with bladder cancer believe “society treats people with bladder cancer worse than people with other cancers”

Following their diagnosis, people living with bladder cancer are likely to use the following words to describe themselves:

MORE LIKELY

- Lonely (25%)**
- Isolated (25%)**
- Depressed (24%)**

LESS LIKELY

- Fun (29%)**
- Active in their community (27%)**
- An organiser (27%)**

EXPERIENCES OF CAREGIVERS²

Caregivers shoulder the disadvantage of disease burden meaning their mental health is often affected following a diagnosis of bladder cancer:

42% of caregivers agree with the statement

16%

of patients are affected by depression and anxiety



23%

of caregivers are affected by depression and anxiety



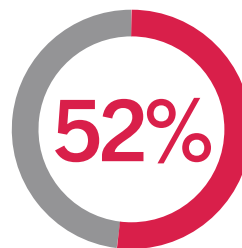
“ We no longer feel like husband and wife, instead we feel like patient and caregiver ”

Caregivers tend to call out **self-blame, feelings of judgements and unfair treatment by others**, given towards people living with bladder cancer

PERSONAL GROWTH²



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 disadvantage



of people living with bladder cancer report that their relationship has grown stronger since the diagnosis

Education and support can help people living with bladder cancer regain control and bolster caregivers' resilience

This research was conducted on behalf of Astellas by The Research Partnership, between July and September 2021. A total of 226 bladder cancer patients and 86 caregivers were surveyed in five markets: France, Germany, Spain, UK, USA.

1. World Bladder Cancer Patient Coalition. GLOBOCAN 2020: Bladder cancer 10th most commonly diagnosed worldwide. Available at: https://worldbladdercancer.org/news_events/globocan-2020-bladder-cancer-10th-most-commonly-diagnosed-worldwide/. Last accessed March 2022 2. Astellas, 2022, Disease Disadvantage: Facing Bladder Cancer Alone. Data on file

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