



World Bladder Cancer Patient COALITION

# Stigma: The invisible side of bladder cancer

To understand the impact of stigma on people affected by bladder cancer, 312 patients and caregivers from France, Spain, Germany, the United Kingdom and the United States have shared their experiences in a survey and qualitative interviews.



Bladder cancer patients are primarily worried about **disease disadvantage**, followed by **self stigma** and **external stigma**.

## 1. What is disease disadvantage?

### Delayed or misdiagnosis

#### The diagnosis failures are a Systemic Disadvantage

The system seems to be set up to let people down, with multiple delays, misdiagnosis and refusal to take symptoms seriously.



### Lack of bladder cancer knowledge

A natural reluctance to talk about private bodily functions in public. Bladders, urination, incontinence, sex organs are all intensely private.

Men and older patients in particular, want to keep this to themselves – it's not common to talk about such private things.

#### The choice to hide

Some patients want to regain ownership of their lives and their bodies.

They have a desire to portray normality to the world – to protect yourself and also save yourself from the awkwardness of others.



**"No-one likes talking about their bits."**

#### Peer support and information

For some patients and caregivers there's a lack of information about how life will be different afterwards. The value of patient support groups and networks is evident.



**"Why do you have to collapse in the ER before people take you seriously?"**

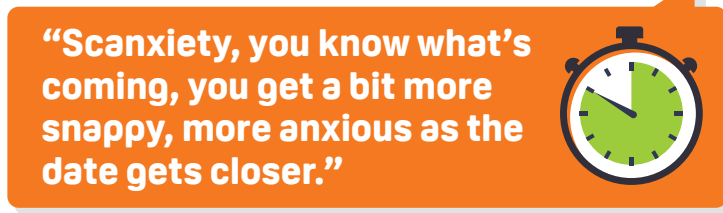
### Life on hold

#### Hamster wheel of treatments

Life is effectively on hold as seemingly endless rounds of treatment, scans and retreatments become a reality. It is often impossible to commit to any plans or live a normal life due to repeated, painful and uncomfortable hospital trips.

#### Scanxiety

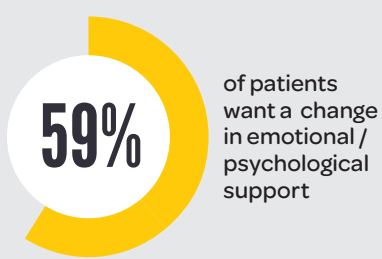
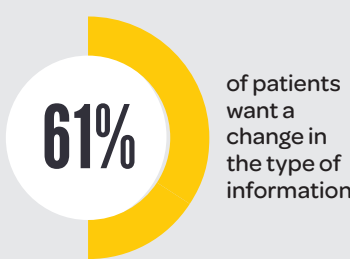
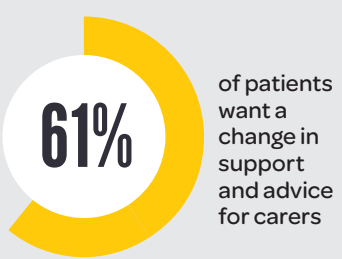
A big part of the trauma of this rollercoaster is the inevitable fear of recurrence – as the time for another scan comes round, patients are fearful and anxious – it's another attack on their mental health, already vulnerable through self stigma.



**43%** of patient respondents say their mental state has negatively impacted the relationship with their partner.

**57%** of patients felt the opportunity to talk to other bladder cancer patients was important.

## Making a difference for patients

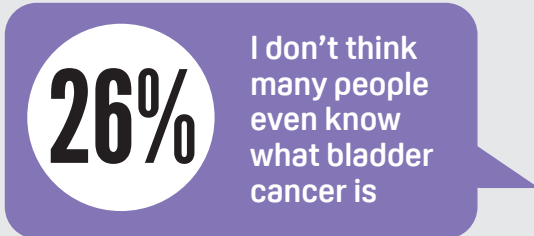


## 2. Experience of internal stigma

### A fear of being judged

**Self-stigma** is a significant issue for patients as they often **anticipate and believe that others will judge them.**

Patients resonated with the following statements:



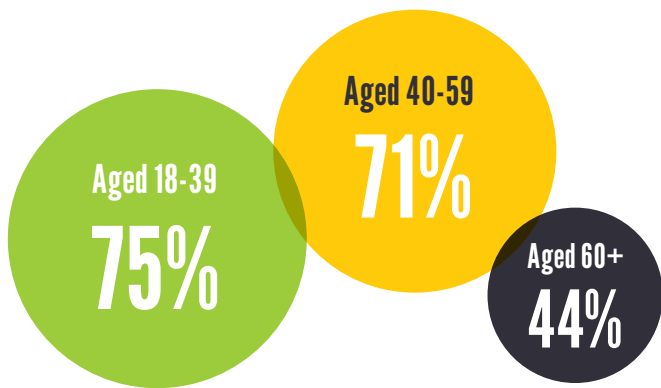
**22%** I sometimes blame myself for my illness

**21%** Sometimes I feel ashamed

**21%** Society treats people with bladder cancer worse than people with other cancers

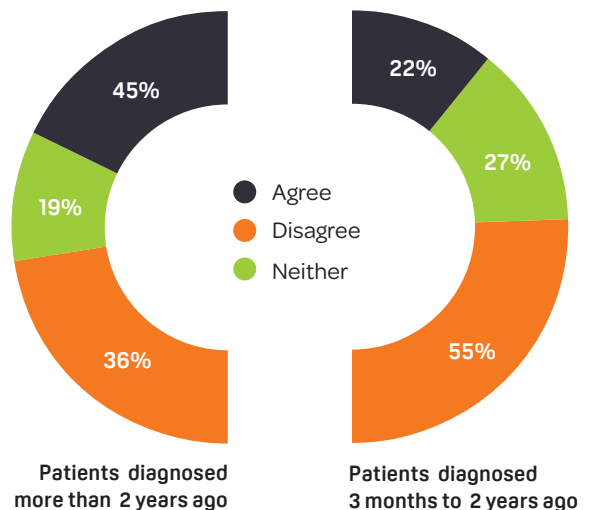
**21%** I feel judged sometimes

Experience of stigma and disease disadvantage have less impact on older patients



Of the patients reported that bladder cancer had a severe or moderate impact on their lives.

The percentage of patients who agree or disagree with the statement that stigma decreases over time



## 3. Experience of external stigma

**45%** of young patients felt blame from their family

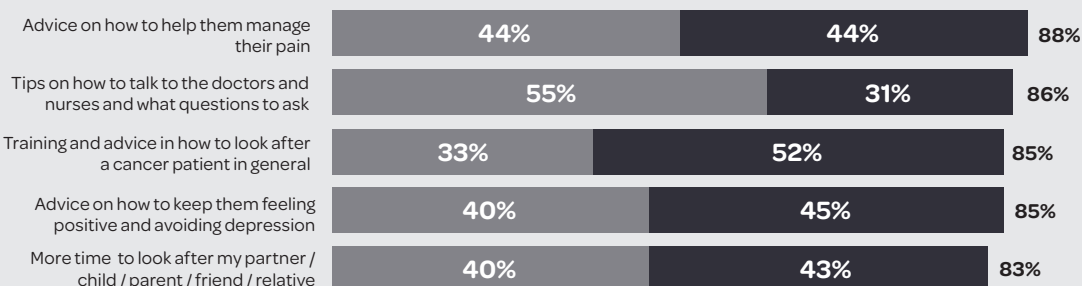
**43%** of young patients felt blamed by the doctor

**31%** of patients feel that they have embarrassed their family, friends or colleagues by their illness

## Making a difference for caregivers

Improving the lives of caregivers:

**23%** of caregivers have been diagnosed with depression or anxiety.



● Slightly agree  
● Strongly agree  
● ALL agree

### DISCLAIMER:

The infographic was developed by the World Bladder Cancer Patient Coalition with the financial support of Astellas Pharma Europe Ltd, using the data from the "Patient and caregiver survey on stigma and disease disadvantage in bladder cancer 2022" developed by Real Sky Thinking for Astellas Pharma Europe Ltd.