

Stigma: The invisible side of bladder cancer

To understand the impact of stigma on people affected by bladder cancer, 312 patients or caregivers of which 69 from the United Kingdom 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 Systemic Disadvantage

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



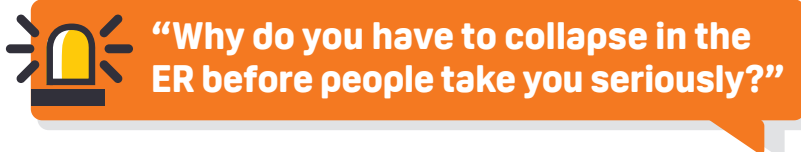
Lack of bladder cancer knowledge

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.



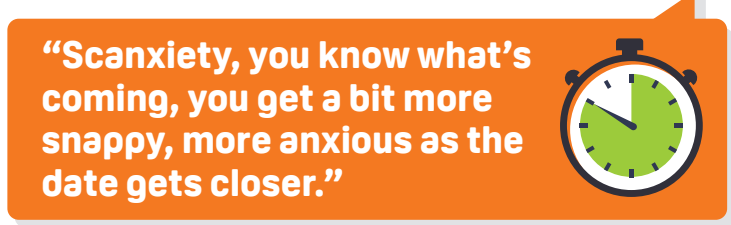
Life on hold

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 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.



Peer support and information

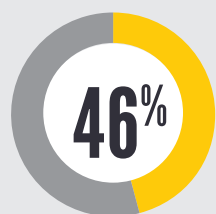
For some patients and caregivers there's a lack of information about how life will be different afterwards. The value of patient support groups and networks is evident.



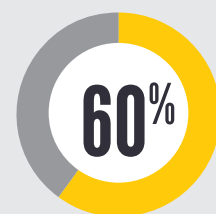
Making a difference for patients in the UK



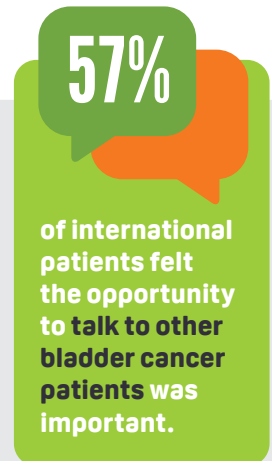
of patients want a change in support and advice for carers



of patients want a change in the type of information



of patients want a change in emotional / psychological support

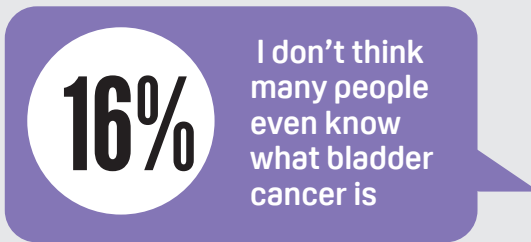


2. Experience of internal stigma

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 in the UK resonated with the following statements:



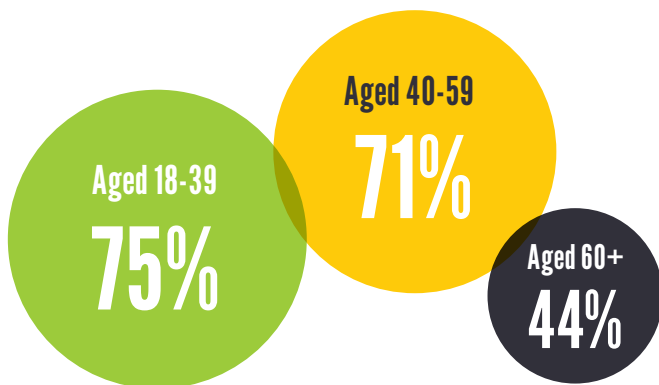
16% I sometimes blame myself for my illness

14% Society treats people with bladder cancer worse than people with other cancers

20% Sometimes I feel ashamed

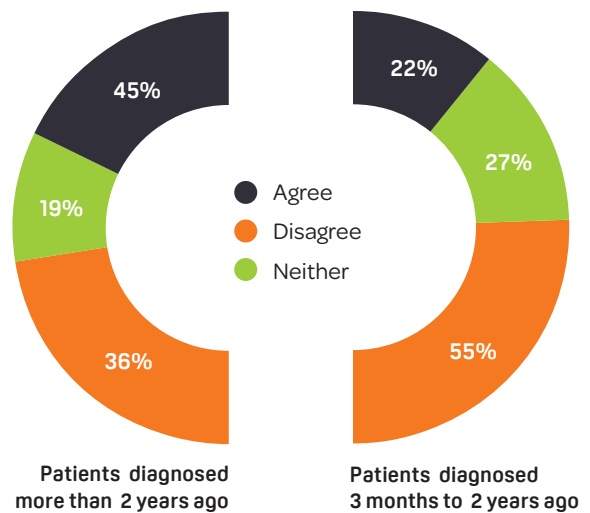
18% I feel judged sometimes

Experience of stigma and disease disadvantage have less impact on older patients across the surveyed countries:



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

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



3. Experience of external stigma

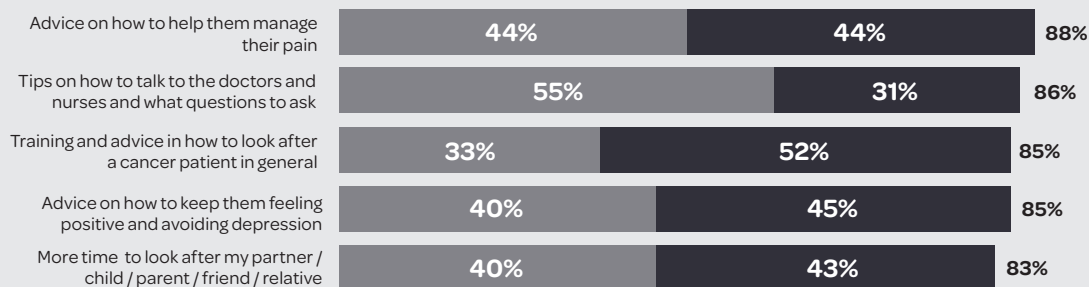
45% of young patients felt blame from their family

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 from the surveyed countries:



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. The survey received a total of 312 replies from bladder cancer patients or caregivers from: France, Germany, Spain, the United Kingdom, the United States of America. Country-specific data is explicitly highlighted.