



What I need you to know about my pancreatic cancer diagnosis

My pancreatic cancer diagnosis, in my own words

In 2018, Pancreatic Cancer UK, Picker and Oxford Brookes University worked together to measure the experiences and supportive care needs for people with pancreatic cancer.

The survey was completed by 274 people living with and beyond pancreatic cancer. The questions covered all aspects of care and asked about people's physical and emotional support needs, and how well they were being addressed.

Patients were asked about how they received their diagnosis, the treatments they received, management of symptoms and side effects. They shared with us their thoughts on the written information they had been given and the attitudes of the medical professionals who had treated them.

It was the first survey of its kind in the UK, and the findings from it allow us to understand these needs for people living with and beyond pancreatic cancer. The supportive care needs for people with pancreatic cancer in the UK have not been explored until now. We want to thank everybody that helped us to develop the survey, and took part in our research.



Foreword

This research is incredibly important because, in comparison to other common cancers, we know very little about the experiences and supportive care needs of people living with pancreatic cancer in the UK. The National Cancer Patient Experience Survey (NCPES) is distributed within four to six months of diagnosis when many people with pancreatic cancer have already died, or are too unwell to respond.

Due to the poor prognosis of the disease, a diagnosis of pancreatic cancer is devastating to receive. Our results show it is essential that this diagnosis is communicated carefully, in a timely manner and that support is available to help people cope. How a diagnosis is given can have a huge impact on how people feel about the treatment and care they subsequently receive.

Our results demonstrated there are huge unmet psychological needs for people diagnosed with pancreatic cancer, with uncertainty about the future being a major concern. We urgently need to improve the supportive care available to those diagnosed, through raising awareness of these needs.

By ensuring people receive a holistic assessment at diagnosis, finding and sharing best practice, and conducting research to develop effective psychological interventions, we can better support people with pancreatic cancer.

Anna Jewell
Director of Operations, Pancreatic Cancer UK



What we learned about diagnosis

A significant proportion of people with pancreatic cancer expressed a negative experience in terms of how their cancer diagnosis was communicated.

You will hear what it can be like to receive a pancreatic cancer diagnosis from people who have shared their experience with us, in their own words.

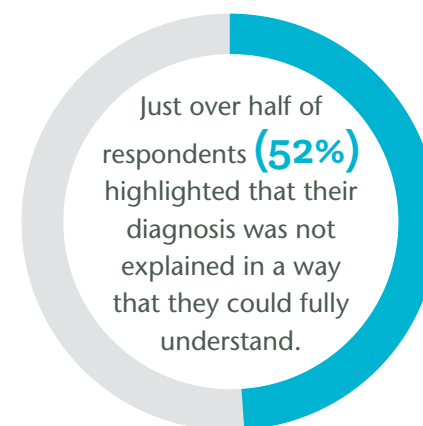


I need my diagnosis to be: **sensitive and knowledgeable**

In our survey we learned that the diagnosis could be given in a more timely, knowledgeable and sensitive way.



“ [I] was told by the consultant that it was up to me whether I was a glass half full or glass half empty type of person, following diagnosis, and to go home and put my affairs in order. ”



“ From what I can remember I was told different explanations from a lot of doctors, quite a lot of them were junior, you don’t get to see the main senior consultant. ”



“ The GP didn’t know much about it only that it was not good and not much chance of survival, nothing positive about treatment ”

I need my diagnosis to be: **supportive of my psychological needs**

Pancreatic cancer patients were asked about their supportive care needs over the last month. Seven of the ten highest needs that had not been met were psychological in nature.

Patients said that they needed help with the following issues but they hadn't received any.



“To feel free of anxiety of dying”

“It would be good to receive psychological support for guilt as a survivor of PC”



My biggest need right now is:

“For people to treat me normally”

“I know every individual person is different in their symptoms but I feel we need more after care. I felt very alone. They listen but put you in a box like everyone else and I refused to talk to anyone apart from my hubby who did not always understand, so hence I get upset and angry, and I don't like feeling this way”



“The feelings I'm having are I've had to now get on with your life, no more just get on with it... I feel empty very lonely”

“I was dealing with a diagnosis of pancreatic cancer 4 years ago now, after an incidental discovery, and would have appreciated support or contact somewhere at that time. I was fit and healthy in every way and to be suddenly dealing with the fact that I may only have months to live and then wait for a huge operation for a number of months knowing my health would then never be the same again was extremely difficult. It was difficult for a very long time afterwards too”



Patients said that their biggest immediate need was:

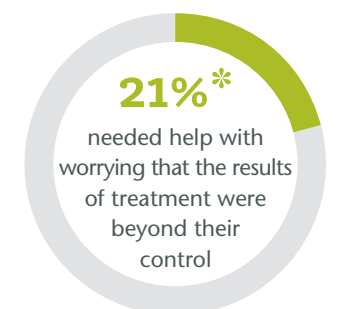
“[I] need to know it has NOT returned”



“I do not know whether I can expect to be seen by a clinician next week, in three weeks or in 2 months (if I am still here). I have a family and a job to juggle, yet everything is in limbo”



“Uncertainty about success of treatment and potential return of cancer or likelihood of secondary cancer”



My biggest need right now is:

“That my children are happy”

“Speaking to my family about my funeral”

“Help with being able to address family members' unwillingness to talk about a possible negative outcome”



I need my diagnosis to be: **timely**

Patients highlighted room for improvement in the speed of receiving their pancreatic cancer diagnosis:



“They knew pancreatic cancer was the diagnosis but waited until my outpatient clinic appointment to tell us some 3 weeks later!”

“Two weeks after diagnosis I still feel completely in the dark as to what is going to happen next and when. I cannot get hold of anybody to talk to.”


What needs to be done

The NICE Quality Standard has identified the key area to improve pancreatic cancer care is effective psychological intervention. Pancreatic Cancer UK will:

- Share these findings with the pancreatic cancer community – clinical and nursing practitioners, NHS healthcare commissioners, the government and providers – to ensure the best care standards as recommended in the NICE Guidelines and as outlined in the Pancreatic Cancer UK Patient Charter.
- Put pressure on the NHS to offer a holistic needs assessment straight after diagnosis. This will generate a publicly available dataset on patient needs and quality of life outcomes. From this we can benchmark, track progress and inform implementation of personalised care.
- Work with clinical specialists and NHS commissioners so that patients have immediate access to early supportive care for physical and psychological needs. This includes, access to diet information and specialists to ensure prescription of Pancreatic Enzyme Replacement Therapy (PERT).
- Ask research bodies (such as the National Institute for Health Research) to prioritise funding for the development of psychological interventions, aligned with the top 10 research priorities of the National Cancer Research Institute.

These steps will help to create strong evidence, that will inform the future development of the NICE Quality Standard on pancreatic cancer.





If you or someone you know has been affected by pancreatic cancer, free confidential advice is available through the Pancreatic Cancer UK Support Line, which is staffed by specialist nurses. Call 080 801 0707 on weekdays 10am-4pm. Or via email: nurse@pancreaticcancer.org.uk

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