

The impact of brain metastases on people living with ALK+ NSCLC: the patient experience

In 2021, Pfizer partnered with ALK Positive UK to host a virtual advisory board. The group shared stories from their personal journeys and suggested ways in which the lives of people with ALK+ NSCLC could be improved.

8 people with ALK+ NSCLC

4 also had brain metastases

1 Caregiver



Before the diagnosis

Members of the group reported that their early symptoms were sometimes dismissed as they were non-specific to lung cancer. Non-smokers and young people weren't always tested for lung cancer at first, as they were not to be at risk.



Pain Fatigue Seizures Dizziness Vomiting

"I had an 18-month son, I didn't know if I can play with him, interact with him, there was no information on side effects, how to overcome this, I was not provided with enough information to help me understand this."

Getting diagnosed

Several members of the group were only diagnosed after repeat visits to their GP or hospital. Even with diagnosis there was not always enough information about what comes next in terms of general wellbeing. Members of the group felt doctors assumed they had quite a lot of technical knowledge like what "progression" actually means – it may not be clear that this refers to the size and invasiveness of the tumour.

Testing and monitoring

Members of the group found they had to put a lot of energy into self-advocacy and pushing for tests such as MRI scans, which are not always offered. 'Scanxiety' was very distressing; delays in communicating the results of tests contributed to poor mental health.

"[My] oncologist said, 'You have brain mets, what do you expect?' I felt they thought I should be grateful. People are not empathetic, people don't give you time to process the information... Sometimes I feel I'm looked after, other times I feel let down."

Brain metastases

Diagnosis of brain metastases is often delayed as symptoms like headaches are put down to stress or anxiety. Some participants weren't aware of the risk of developing brain metastases until they were diagnosed. This can make the diagnosis an even more traumatic experience.

Receiving treatment

People with ALK+ NSCLC may receive biologic therapy, radiotherapy, chemotherapy or surgery. A few members of the group said there was enough clarity around the different types of treatment, how they differed, and what were the relative benefits and risks. Specialists don't always talk to each other directly, meaning people have to share important information for them.

"People don't understand the condition and treatment- days can vary and symptoms, no one had the answer or support me and generally will say 'I don't know what to do with you'"

Navigating daily life

Some people with ALK+ NSCLC lost their driving license and had difficulty travelling for care, or to see loved ones. The psychological experience can be difficult, with mental health being impacted by the diagnosis, lifestyle changes and treatment side effects. People with ALK+ NSCLC also have lots of practical questions about financial support, employment guidance, and how to live well despite their symptoms.

"Life now looks different. I'm dependent on people to take me around. I'm not working and feel like I've lost my confidence to ever return after three years away. I live by myself, but family stay when needed, which can be a lot in a month. I don't look like me anymore. I am now trying to enjoy what life I have and what brings me joy."

What can be done to improve the lives of those with ALK+ NSCLC?

PSYCHOLOGICAL SUPPORT



- Psychological support for both people with cancer and their families
- Guidance on how to have difficult conversations with loved ones
- Shared stories and experiences from other people in the same situation

INFORMATION FOR PATIENTS



- Information on the different personnel in the healthcare team
- Clear information specific to an ALK+ NSCLC as opposed to other forms of lung cancer
- Cancer terminology and 'translating' the healthcare system

EDUCATION FOR HEALTHCARE PROFESSIONALS



- Educate doctors to recognise ALK+ NSCLC more quickly, and be familiar with the appropriate treatment pathway for these patients
- Improve communication between healthcare teams, particularly in different healthcare settings e.g. GP and hospital
- Reduce the admin burden for people getting treatment

SUPPORT FOR PEOPLE AT RISK OF BRAIN METASTASES



- Manage the anxiety of living with this risk
- Share advice on what would happen should someone be diagnosed
- Provide a checklist of questions to ask if disease progresses