

ALK Positive UK

Financial hardship experienced by ALK-positive lung cancer patients



If you have ALK-positive lung cancer, you may wish to share this booklet with any doctor or other healthcare professional who may not be familiar with ALK-positive Lung Cancer.

Come join us at:



www.alkpositive.org.uk



hello@alkpositive.org.uk



ALK Positive Lung Cancer – UK



@UKALK1



[alkpositivelungcanceruk](https://www.instagram.com/alkpositivelungcanceruk)



ALK Positive Lung Cancer UK

A registered charity in England and Wales, registration number 1181171. A registered charity in Scotland, registration number SC053692.

Your feedback on this guidance is welcome. Please email: hello@alkpositive.org.uk

ALK Positive Lung Cancer (UK)

Financial hardship experienced by ALK-positive lung cancer patients.

Introduction

ALK-positive lung cancer is a rare form of lung cancer occurring in about 5% of non-small cell lung cancer. Patients are likely to be younger than other lung cancer patients and to have never smoked or been only light smokers. About 90% of patients are likely to be diagnosed at Stage 4 when there is no cure, although modern drugs can often prolong lives for many years.

About half of patients are likely to be under 50 years of age when diagnosed and may have young families. Many are in the middle of their working lives.

Financial hardship survey

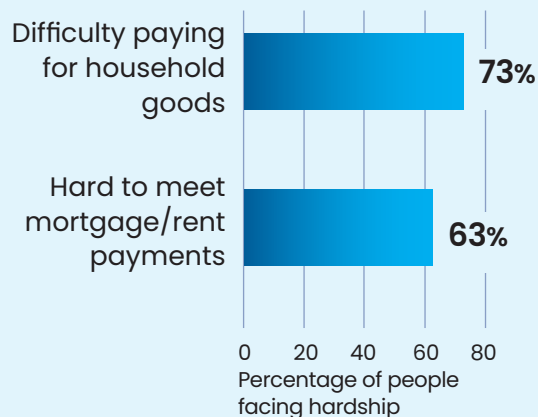
In 2023, Lung Cancer Europe conducted a survey to ascertain the level of financial hardship experienced by patients as a result of living with lung cancer and 84 ALK-positive patients living in the UK took part in the survey.

This report records the responses of those 84 patients, of whom 71% were women.

Results

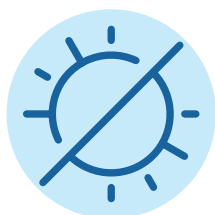
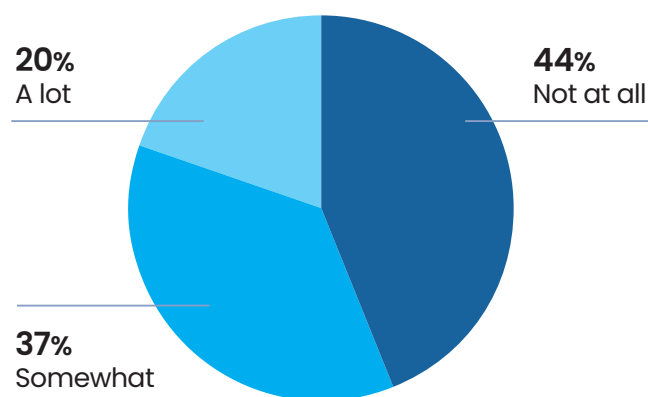
Over half of patients reported experiencing some level of financial hardship as a result of the disease and had to reduce their household expenditure.

The financial hardship breakdown



My husband and myself took early retirement. I couldn't work due to extreme fatigue. My husband retired early to look after me but also to spend as much time together while we could.

To what extent have you experienced financial difficulties as a result of lung cancer (n=82)

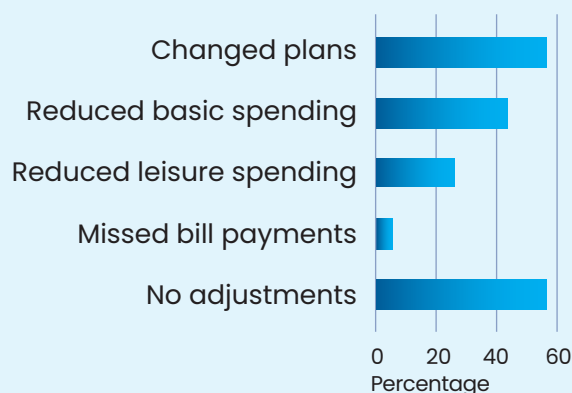


1 in 3 patients had reduced their expenditure on basic household items and **1 in 5** had cut back on leisure spending.

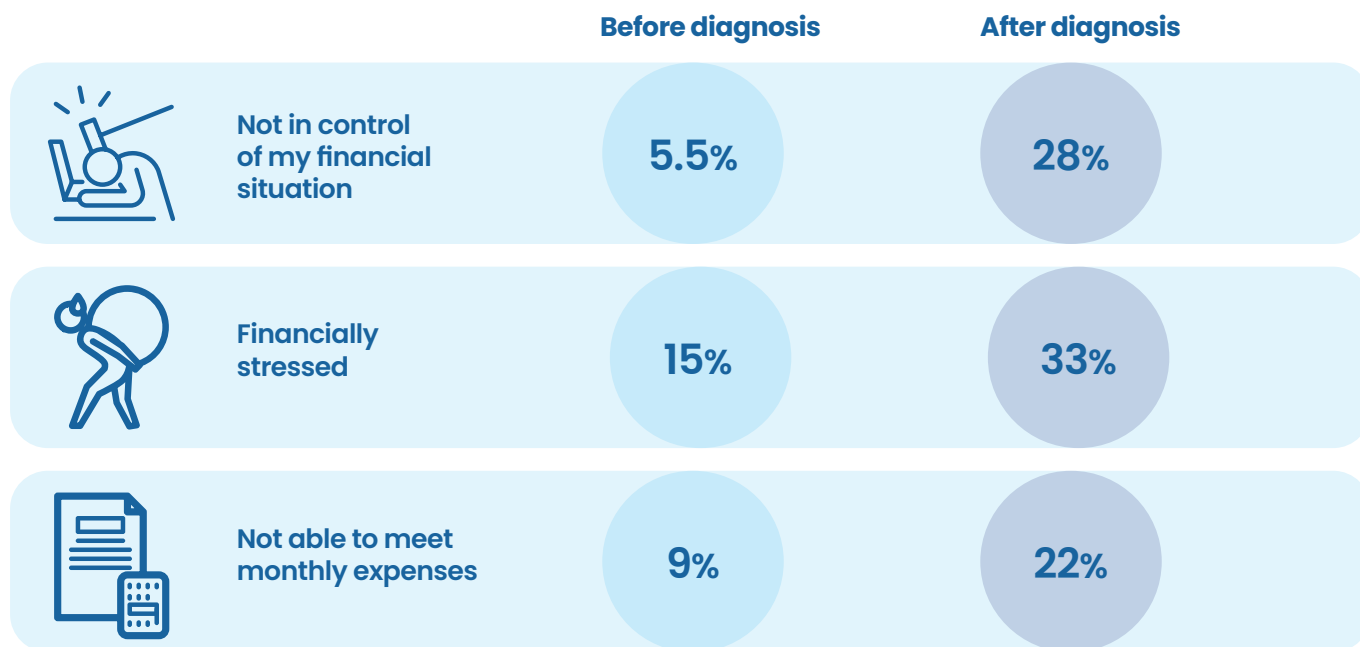


Almost half had changed their plans, e.g. retirement, career development, new car.

Have you made any financial adjustments after the lung cancer diagnosis? (n=84)



Increased financial instability following diagnosis



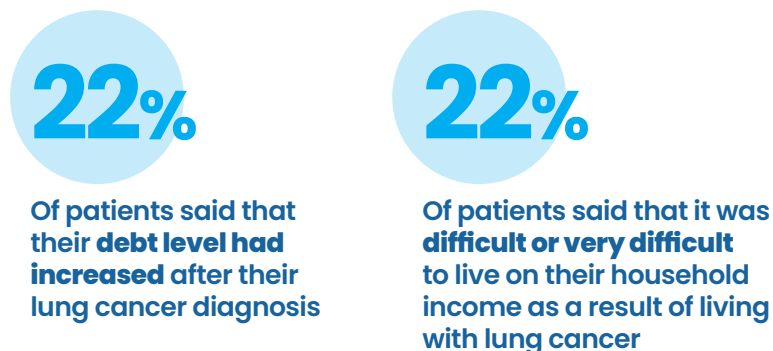
Some patients also made other adjustments in response to their new circumstances:



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Petrol is an added cost as we do many trips to the hospital. We travel 2-3 hours each way to ensure we see a specialist in ALK.

Some patients reported having difficulty managing on their household income



Nearly, 60% of patients said that their household income had fallen due to:



**Reduction in
working hours**
18%



**Inability
to work**
17%



**Retirement
due to illness**
11%



**Absence
from work**
10%



**Many patients
experience an
increase in financial
instability.**



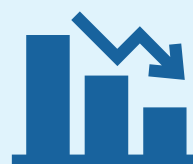
*My work situation and income has been
hugely impacted by my diagnosis.*

Only
12%



of patients had had a
significant discussion with
their healthcare team about
their financial situation.

43%



of patients said that their
household income had
fallen by at least 20%.

Conclusions



Financial hardship is a **significant** and often hidden **consequence** for many patients living with lung cancer.



Financial hardship should be **discussed** as a matter of routine between patients and their healthcare teams.



A diagnosis of lung cancer brings **stress and anxiety** and financial hardship adds another layer.



Healthcare teams should establish clear referral pathways to agencies that can give financial advice and support.

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Not able to work lessened money for children, grandchildren, holidays, social activities feeling less active bringing on lethargy and depression.



If you would like further information about the financial support that is available for patients and their families visit Macmillan Cancer Support

www.macmillan.org.uk/cancer-information-and-support/get-help



This booklet has been produced by

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For further information, please visit www.alkpositive.org.uk