

Original article

ALK Positive Lung Cancer (UK)

Advice for patients on brain tumours (metastases) and driving

Guidance for patients from the Charity's DVLA advisory panel



Contents

- 1 About this document
- 2 Key points about brain tumours (metastases) and driving
- 3 Introduction
- 4 What happens if you get a brain met?
- 4 How is your fitness to drive assessed?
- 6 When does a driving restriction period start?
- 7 Re-applying for a short-term medical driving licence
- 8 Renewing a short-term medical driving licence
- 8 Tips for dealing with the DVLA
- 10 Can you drive under section 88 of the road traffic act 1988?
- 11 Tips for car insurance
- 12 Why should you follow medical and DVLA advice?
- 13 Online information referred to in this document

Contact details available on the back cover

A digital version of this booklet is also available at
www.alkpositive.org.uk

The content of this ALK Positive Lung Cancer (UK) booklet is for information only and should not be used for the diagnosis or treatment of medical conditions. We are unable to offer specific advice and, if you are worried about any symptoms, please consult your doctor.

Come join us at:



www.alkpositive.org.uk



hello@alkpositive.org.uk



[facebook.com/groups/ALKPositiveUK](https://www.facebook.com/groups/ALKPositiveUK)



[@UKALK1](https://twitter.com/UKALK1)



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



UK ALK Positive Patient Support
and Advocacy Group

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)

Advice for patients on brain tumours (metastases) and driving

About this document

This document is for people with ALK-positive lung cancer who have brain tumours (brain metastases) and their families. It provides:

- Information on the Driver & Vehicle Licensing Agency (DVLA) processes, rules and guidance, if you have a brain tumour (brain metastases).
- Guidance and advice on the DVLA, insurance companies and Section 88 of the Road Traffic Act 1988.

This document has been written by the ALK Positive Lung Cancer (UK) Charity's DVLA Panel. The panel members are Paul Cooper, Ian Cluett and Duncan Edmonstone. All three have ALK-positive lung cancer. They all have experience of losing and regaining their driving licences and are familiar with the DVLA processes, rules and guidance. They have had discussions with the DVLA about how their rules apply to people with ALK-positive lung cancer and brain tumours (brain metastases). Note that the Charity's DVLA panel is not affiliated with or endorsed by the DVLA. If, after reading this document, you still have questions, you can contact the Charity's DVLA Panel by:

- Sending a direct Facebook message to an individual member.
- Emailing hello@alkpositive.org.uk, who will put you in touch with a member.

Panel members can offer advice and guidance but cannot deal with the DVLA on your behalf.

Useful website addresses can be found at the back of this document.

Key points about brain tumours (metastases) and driving

- A 'brain metastasis' or 'brain met' is a tumour in the brain. 'Brain metastases' or 'brain mets' means more than one tumour in the brain.
- If you develop a brain met or mets, you may need to give up (surrender) your driving licence. This can happen even if you do not have any symptoms from the brain mets.
- The 'driving restriction' period or 'time off driving' period is the length of time over which the DVLA say you are not allowed to drive. This period starts when the DVLA says it does, not when you stop driving.
- The DVLA and your medical team use the DVLA's 'Assessing Fitness to Drive' (AFTD) guidance to decide if you must stop driving and for how long. We talk more about the guidance in Section 3. In summary:
 - You must not drive for at least 1 year if:
 - brain mets are found when you are diagnosed or later, and
 - you are given treatment for those mets, as a targeted therapy (TKI) or radiotherapy.
 - You must tell the DVLA, but you may be able to continue to drive if:
 - brain mets are found while you are taking a targeted therapy (TKI), and
 - you do not have any symptoms from the brain mets and
 - you do not start any new treatments or have changes in your treatment for the brain mets.
 - However, the DVLA will make the decision after you have told them.
- In most cases, you can re-apply for a short-term medical driving licence if:
 - your treatment is effective and
 - there is evidence that the brain mets have not grown or have shrunk, and
 - you have no symptoms from the brain mets for 1 year after starting a TKI, or finishing targeted brain radiotherapy.
- We recommend that you re-apply for your licence 8 weeks before the date you would be allowed to start driving again. If you apply earlier than this, the DVLA may reject your application.
- Re-applying for a licence is free. You must complete a DVLA D1 form and medical form BT1 and post them to the DVLA. You cannot re-apply online.
- The DVLA will contact your oncologist about your medical condition and treatments.
- If you get your licence back, it will be a short-term medical driving licence. This will probably be valid for 1 year. You will need to renew this licence when it expires. Renewing a licence is free.

-
- If the DVLA delay reviewing your licence re-application or renewal, you may be able to drive while you wait. Section 88 of the Road Traffic Act 1988 outlines this. You must be sure you meet all the criteria outlined within Section 88. See Section 8 for more information.

1. Introduction

Some people with ALK-positive lung cancer develop a brain tumour or tumours. They may be found at diagnosis or develop after treatment has started. A single brain tumour is called a 'brain metastasis' or a 'brain met'. More than one tumour is called 'brain metastases' or 'brain mets'.

If you develop a brain met or brain mets, you may need to give up (surrender) your driving licence to the DVLA. If you are already dealing with an ALK-positive lung cancer diagnosis, the DVLA's approach can seem harsh. Compared to many other countries, the UK has a low number of traffic deaths, per head of population each year. The DVLA guards the reputation for safe roads in Great Britain through strict standards.

The Secretary of State for Transport manages several Honorary Medical Advisory Panels. For brain mets, the 'Honorary Medical Advisory Panel on driving and disorders of the nervous

system' provides guidance. This guidance is used to help the DVLA create rules and make decisions about driving, such as when to remove and renew a driving licence and when a person can re-apply for a licence.

The DVLA use different words and terms in their guidance, and we also use them in this document. It is important that you understand what these mean. They include:

- **Surrender of a licence:** A driver voluntarily gives up their driving licence and hands it over to the DVLA. For people with ALK-positive lung cancer, their oncologist will usually talk to them about when to surrender a licence.
- **Revocation of a licence:** The DVLA cancels (revokes) a driver's licence. This means the person is not legally allowed to drive. This usually happens when the DVLA become aware that a driver is unfit to drive, and the driver has not told the DVLA.
- **Re-applying for a licence:** A driver re-applies for a short-term medical driving licence after their 'driving restriction' period has ended.
- **Renewal of a licence:** A driver applies for a new short-term medical driving licence after it expires.

2. What happens if you get a brain met?

You are most likely to find out if you have a brain met after having an MRI scan of your head. The DVLA guidelines apply when a brain met is found at diagnosis of the cancer or at some point in the future.

You may have a brain met at diagnosis or develop one during treatment. If you are told you have a brain met, your medical team will tell you that you cannot drive unless they decide to monitor the situation at the next MRI scan.

As the driver, you are legally responsible for telling the DVLA about your medical conditions and treatments. If your medical team told you not to drive and believe you have ignored their advice, they must report it to the DVLA.

If a brain met is found at diagnosis of ALK-positive lung cancer, your medical team will almost certainly tell you not to drive. We recommend you contact the DVLA to surrender your driving licence straight away rather than waiting for it to be revoked. There are 2 reasons for this:

- After you have served your time off driving, you may be able to take advantage of Section 88 of the Road Traffic Act 1988 if the DVLA are delayed in processing your application (see Section 8 for more information).

- The length of time you will be unable to drive for may be shorter (see Section 4 for more information).

The DVLA provide guidance on how to surrender your driving licence (See website address 1)

If a brain met is found while you are being treated and you have no symptoms from the brain met, or your scan results are unclear, your medical team may decide to monitor the situation at the next MRI and not change your treatment. You must tell the DVLA about your brain met, that you have no symptoms and that your treatment is unchanged, and they will make the decision about whether you can continue to drive.

3. How is your fitness to drive assessed?

The 'Assessing Fitness to Drive' (AFTD) guidance

The DVLA 'Assessing Fitness to Drive' (AFTD) guidance is for medical professionals. It helps them decide whether a person can drive based on their medical condition. If you have ALK-positive lung cancer, you do not need to understand the AFTD guidance. However, knowledge is power. We think some understanding of it can help when you talk to your medical team and the DVLA.

The latest AFTD guidance can be found on the gov.uk website (See website address 2). At the time of writing, the latest AFTD guidance is dated August 2024.

The information in this document only covers group 1 licensing, which includes cars and motorcycles. We do not provide guidance on group 2 licencing, large lorries and buses. However, both groups are included in the AFTD guidance.

How the AFTD guidance applies to ALK-positive lung cancer and brain mets

For most people with ALK-positive lung cancer, the relevant part of the AFTD guidance is 'pages 37 to 46 in 'Chapter 1 - Neurological disorders', which cover 'Brain Tumours'. Section 1 of this chapter classifies types of brain tumour. The classification relevant to people with ALK-positive lung cancer and brain mets is: 'Brain Metastases, Primary and Secondary CNS lymphoma, non-CNS tumours invading intracranially and breaching the dura'.

If you have any other medical conditions, you may need to look at other sections of the AFTD guidance as well.

The table on pages 44 to 46, within 'Section 2 - Medical standards of fitness to drive', breaks down the guidance on driving by how the brain met is managed (treated). If you are having

more than one treatment, the most recent treatment with the longest time without driving will apply.

In most cases, the 'driving restriction' period (the time in which you should not drive) will last for at least 1 year if your treatment is effective. If you have whole-brain radiotherapy that is effective, you will be unable to drive for at least 2 years after the radiotherapy.

In the AFTD guidance where you see the term 'molecular targeted therapy' used, this means the targeted therapy drugs (or TKIs) that ALK-positive lung cancer patients take.

Examples of how the guidance may apply if you have ALK-positive lung cancer and brain mets

- **Example 1:** A patient is diagnosed with ALK-positive lung cancer. An MRI shows brain mets. After talking to their medical team, the patient surrenders their driving licence. The patient begins treatment with a targeted therapy, TKI. Over the next year, follow-up scans show the mets remain stable and the patient has no symptoms from them. The patient would be allowed to drive 1 year after starting TKI treatment.
- **Example 2:** A patient is diagnosed with ALK-positive lung cancer. An MRI shows brain mets. After talking to their medical team, the patient surrenders their driving licence.

The patient begins treatment with a targeted therapy, TKI. They also have targeted radiotherapy to the brain 1 month later. Over the next year, follow-up scans show the mets remain stable and the patient has no symptoms from them. The patient would be allowed to drive 1 year after finishing radiotherapy.

- **Example 3:** A patient with ALK-positive lung cancer has been stable on a targeted therapy, TKI. An MRI shows new brain mets, but the patient is having no symptoms from them. The patient and medical team agree to continue treatment with the same TKI. The patient tells the DVLA about the brain met and treatment plan. They may be able to continue to drive if they do not have any other treatment for the brain met. This will require their medical team's support, but the DVLA will make the decision.
- **Example 4:** An ALK-positive lung cancer patient has been stable on a targeted therapy, TKI. An MRI shows a new brain met. The patient and medical team agree to start treatment with a different TKI to treat the brain met. The patient surrenders their driving licence. Follow-up scans over the next year show the met remains stable and the patient has no symptoms from them. The patient would be allowed to drive 1 year after starting on the new TKI.
- **Example 5:** An ALK-positive lung cancer patient has been stable on

a targeted therapy, TKI. An MRI shows a new brain met, but the patient has no symptoms. The patient and their medical team agree the patient will have targeted radiotherapy to the brain. The patient surrenders their driving licence. Over the next year, follow-up scans show the met remains stable, and the patient has no symptoms from them. The patient would be allowed to drive 1 year after finishing radiotherapy.

4. When does a driving restriction period start?

The 'driving restriction' period, or 'time off driving' period is the length of time over which the DVLA says you are not allowed to drive. It starts when the DVLA says it does, not when you stop driving. You should tell the DVLA and surrender your driving licence as soon as your medical team tell you that you should not drive. The sooner you tell them, the better. It can take some time for the DVLA to review your case and confirm when your driving restriction period will officially start and end.

If you wait to have your driving licence revoked:

- You will delay the start of the driving restriction period.
- You will increase the length of the driving restriction period if you are having a treatment with no specific end date, such as a TKI.

This sometimes catches patients out. In the stress and worry of diagnosis or progression, speaking to the DVLA may not seem like a priority. However, it is better in the long-run to contact the DVLA as soon as possible.

The charity is aware of some patients who surrendered their driving licence several months after their medical team told them not to drive. They made successful appeals to the DVLA. The start of their driving restriction period was changed to when their targeted therapy treatment began rather than when they surrendered their licence. This may not happen in every case.

5. Re-applying for a short-term medical driving licence

When to re-apply for a driving licence

You can re-apply for a new short-term medical driving licence as you get close to the end of your driving restriction period. If you re-apply more than 8 weeks before you think your restriction period is due to end, the DVLA will not consider your re-application.

Talking to your medical team

We recommend that you always talk to your oncologist and medical team about re-applying. Without their support, you are unlikely to get a new licence. The DVLA will contact your oncologist for details of your current

medical situation. This will include treatment plans and scan results. They will use this information to assess your medical fitness to drive and your re-application.

Medical professionals are generally supportive in most cases. However, if you feel your medical team is not being reasonable, please contact a member of the charity's DVLA Panel. They can support and guide you in re-applying.

How to re-apply for a driving licence

Re-applying for a licence is free. To re-apply, you must complete a DVLA D1 form. You can only get this form at a Post Office.

You must provide proof of identity for your D1 form. The easiest way is to provide a passport number if you have one. Full details on proving identity are available on the gov.uk website (See website address 3). If you had a UK photo driving licence, you should not need to provide a new photograph.

You also need to complete any relevant medical forms. In almost every case, the only medical form a person with ALK-positive lung cancer and brain mets must complete is form BT1. The form is available to print from the gov.uk website (See website address 4).

All the DVLA medical forms will ask for details of your GP and consultant. The consultant will be your oncologist. We advise including a short letter with your re-application to explain:

-
- That many ALK-positive lung cancer patients have GPs who know little or nothing about their condition. This means it would be better for them to contact your oncologist instead.
 - Any details of your medical history that are not mentioned on the medical form.

Make sure your oncologist knows you have sent your re-application to the DVLA, as the DVLA will write to your oncologist with forms for them to complete. You may need to remind your oncologist to complete and return the forms so it does not delay your re-application. When the DVLA receives the forms, they will consider your re-application. The DVLA will write to you to confirm that a licence is being issued or to explain why it is not being issued.

You will receive your new short-term medical driving licence in a separate letter. It will only be valid for a short period of time, usually 1 year.

6. Renewing a short-term medical driving licence

You will need to renew your short-term medical driving licence if it is going to expire. The DVLA will write to you about 10 weeks before your licence expires and invite you to renew it. They will include all the forms you need to complete. Renewing your licence is

free. You do not need to provide proof of ID or return your expired short-term medical driving licence to the DVLA.

Let your oncologist know that you are planning to renew your licence, as the DVLA will again contact them to ask questions about your medical condition. Everything should be straight forward if the cancer has remained stable since you last re-applied for, or renewed your licence.

The DVLA usually issues 1-year renewals for the 3 years after a medically related driving restriction period ends. If a person remains stable and without symptoms for those 3 years, the DVLA will then consider issuing a licence that lasts for 3 years.

7. Tips for dealing with the DVLA

Like many large government organisations, the DVLA can sometimes be challenging to deal with. We have put together the following tips that may help:

- DVLA call handlers are generally knowledgeable and helpful, but they deal with all medical conditions that may affect driving. They will not be an expert in brain mets and lung cancer and may never have heard of ALK-positive lung cancer. If you believe the call handler is giving you incorrect or inaccurate information,

you can ask them to consult with a DVLA doctor. If you do not feel confident to do this, please contact a member of the charity's DVLA Panel. They can guide you in how best to engage with the DVLA.

- Keep a diary of all contact you have with the DVLA, including phone calls, emails and letters. Keep details of what is said, sent and when. Photocopy, scan or photograph pages of forms before you post them. It is useful to have a record of these, so you can refer to them when you need to renew your licence.
- If you send letters or documents to the DVLA via post, use Royal Mail Signed For. This means you can get a proof of delivery receipt.
- The DVLA has a special department for medical conditions. You can contact them:
 - By post at:
Drivers' Medical Enquiries
DVLA, Swansea SA99 1TU
 - By calling 0300 790 6806. The line is open 8am to 7pm Monday to Friday and 8am to 2pm on Saturday. You may have to wait a while before you speak with someone. Make sure your mobile phone is well charged and you have a comfortable seat and a drink. The best time to call is mid-afternoon on a weekday.
- By web form: Go to the gov.uk 'Drivers Enquiries' (See website address 5). Select 'Drivers Medical' from the list. Next, choose the reason for your enquiry. This will bring up a web form to fill out. You will get an email response after submitting the web form.
- There is a DVLA medical email address that only medical professionals can use. If your oncologist is questioning a decision on your behalf, they can use this email address. They are likely to get a quicker response than if you use the contact options above.
- **Making a complaint:**
 - If you need to make a complaint to the DVLA you must have tried to resolve the situation through the usual channels. This means with the Drivers' Medical Enquiries team.
 - Details on the complaints process are on the gov.uk website (See website address 6).
 - Complaints raised via the DVLA website form are usually responded to quicker than those sent via post.

8. Can you drive under section 88 of the road traffic act 1988?

You may not get your new driving licence from the DVLA by the date you expect to be allowed to drive again, or your existing licence expires. Section 88 of the Road Traffic Act 1988 may help by allowing you to drive while you wait to receive your new licence.

The DVLA has a leaflet on their website called 'Can I drive while my application is with DVLA?' (See website address 7). It explains Section 88 of the Road Traffic Act 1988. We have listed key points from the leaflet, below:

- **When renewing a short-term medical licence**, all the following must be true to drive under Section 88:
 - Your current short-term medical licence has expired.
 - Your medical team have confirmed you are fit to drive.
 - The DVLA have confirmed they are working on your renewal application, there are no errors, and nothing is missing from it.
 - You submitted your renewal application less than 1 year ago.
- **When re-applying for a licence following the end of your driving restriction period**, all the following must be true to drive under Section 88:
 - You surrendered your licence rather than having it revoked.
 - Your driving restriction period has ended.
 - Your medical team have confirmed you are fit to drive.
 - The DVLA have confirmed they are working on your application, there are no errors and nothing is missing from it.
 - You submitted your application less than 1 year ago.
- **If you can drive under Section 88, it is important that you know:**
 - You are driving without a licence. You will not have a physical licence and your record on the DVLA system will state you do not have a licence to drive.
 - It is useful to have a letter from your medical team 'to whom it may concern' confirming that you are currently fit to drive. You can show it if you are stopped by traffic police. While traffic police are aware of the law in Section 88, the system will show you do not have a licence.

-
- You may want to talk to your car insurance company about your situation. However, you do not legally have to. See Section 9 for more information about this.
 - You can drive your own car and any other car you are currently insured for. However, you cannot rent a car. This is because you do not have a licence for the rental company to check.
 - You cannot drive abroad, in your car or a rented one.
 - You cannot drive under Section 88 for longer than 1 year. We are not aware of any ALK-positive patient cases taking longer than 1 year, except when they have challenged AFTD guidance.

9. Tips for car insurance

The following is useful to know when dealing with your car insurance company during or after a driving restriction period.

- If you can no longer drive, think about cancelling or changing your insurance cover. This may save you some money. If you are the only driver and you cancel your insurance, the car must be kept off the public highway. You should think about insurance for damage, fire or theft of the car if you keep it.
- You may want to tell your car insurer if you are driving under Section 88 of the Road Traffic Act 1988, but you do not legally have to.
- Insurers cannot refuse your coverage, increase premiums, or increase excesses because of your health. This right is protected under the Equalities Act 2010. Insurers can request evidence and information about your medical condition. They can increase premiums if they believe your chances of causing an accident have increased. However, they must inform you of their reasons.
- If you have a spouse or partner, it may be easier if they are the insurance policy holder and you are a named driver on the policy. In general, insurers do fewer checks on named drivers than on policy holders. If you are a named driver and lose your licence again, you will not need to cancel the policy and set up a new one for your spouse or partner to continue driving your car.

10. Why should you follow medical and DVLA advice?

It is important that you follow advice from your medical team and the DVLA. The rules may seem strict and you may feel frustrated at the medical team and DVLA's decisions. However, the rules are designed to keep people safe on the roads.

We sometimes hear patients say....
"I can't cope without driving. I have responsibilities and live somewhere without good public transport. I've never had a seizure, I will be fine. I'm going to continue driving."

Our response is always that....
It is a criminal offence not to tell the DVLA about your medical condition. You may be fined or prosecuted if you do not tell them about a medical condition.

Seizures can happen. They can be distressing, and dangerous and happen with little or no warning. If you had a seizure while driving, there is a chance you may kill or seriously injure yourself, a passenger or another road user. If you killed someone, you could face a prison sentence.

If you are in an accident and your car insurance company knows that you were driving against medical advice, they will not pay out and will cancel your insurance. This will be marked in data shared between insurers via

the Motor Insurers Bureau. This means it would be expensive or impossible for you to get car insurance in the future.

If you still have questions you can contact the Charity's DVLA Panel by emailing hello@alkpositive.org.uk, who will put you in touch with a member. Panel members can offer advice and guidance but cannot deal with the DVLA on your behalf.

Online information referred to in this document

Section 1. Website address 1. Voluntarily surrendering your driving licence	www.gov.uk/giving-up-your-driving-licence
Section 2. Website address 2. Assessing fitness to drive: a guide for medical professionals	www.gov.uk/government/publications/assessing-fitness-to-drive-a-guide-for-medical-professionals
Section 5. Website address 3. Identity documents needed for a driving licence application	www.gov.uk/id-for-driving-licence
Section 5. Website address 4. Confidential medical information. Form BT1	https://assets.publishing.service.gov.uk/media/67362f882469c5b71dbc7bb4/bt1-confidential-medical-information.pdf
Section 7. Website address 5. Drivers enquiries	https://contact.dvla.gov.uk/driver/capture-transaction-type
Section 7. Website address 6. Complaints procedure	www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency/about/complaints-procedure
Section 8. Website address 7. Can I drive while my application is with DVLA?	https://assets.publishing.service.gov.uk/media/64edcf3a13ae1500116e2f5d/inf1886-can-i-drive-while-my-application-is-with-dvla.pdf

ALK Positive Lung Cancer (UK) are not responsible for the content on third party websites.



ALK Positive Lung Cancer (UK)

1 Ethley Drive

Raglan

Monmouthshire NP15 2FD

Telephone: 07975 623515

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

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

Published: January 2025. Next review date January 2028.

©ALK Positive Lung Cancer (UK)