

# Talking to people about your ALK + NSCLC



Talking to family and friends about your ALK+NSCLC can be difficult. You may worry about you or them losing control of feelings, or becoming overwhelmed by the situation. You may also be wanting to protect close family or friends from becoming upset. However, people who care about you will want to be involved, and talking about your ALK+ NSCLC can help you deal with the situation.

Talking with family and friends can help you to make important decisions, feel more in control, build bonds and, most importantly, get the support you need. Remember, what you feel comfortable talking about, and who you talk about it with, is up to you.

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## Useful tips for conversations

To help aid your conversations, below are some tips to consider:

- Decide whether you'd like to tell people singularly or in groups
- Choose when and where you'd like the conversation to take place. It may be better to tell family or friends in a private space. However, there is no right or wrong way
- Prepare for different reactions as people do not always react in the way you'd expect them to. If their reaction is different to what you had anticipated, remember it does not mean they don't care; it's just their way of coping
- Consider what you want to say to people, and what you'd rather not discuss. If a topic crops up that you find too sensitive, don't be afraid to ask for a change of subject
- Think about what support you need from each person in your life and be clear with your request(s). You may want to ask one person to help out with day-to-day tasks and another to simply listen
- Give thought to whether you'd like to work with external sources, such as a counsellor or social worker, to get extra support



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## Common questions

Similarly to when you were diagnosed, your family and friends are likely to have many questions about your ALK+ NSCLC. To help conversations run as smoothly as possible, we've included some common questions, along with suggested answers or tips, below.

*"Are you okay?!"*

As discussed earlier, different people react in different ways. Asking whether you're alright may seem like a stupid question, but remember this only means that your family member or friend has your emotional well-being in mind.

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## Common questions

Instead of talking about all of your emotions during your first conversation with someone, it may be better to talk about some of your emotions to begin with, and leave talking about others for your next chat. This can help keep the conversation from becoming overwhelming.

*“Is it down to smoking?”*

Some people may look for causes and reasons why; they may ask you if smoking is what caused it. Regardless of whether you smoked or did not smoke, this question can be infuriating. But remember, many people just don't know how to react and definitely do not mean to cause offence.

When answering, you may want to tell them that it doesn't matter why or how you got ALK+ NSCLC or that no one really knows why you have it. You could also tell them that you'd prefer not to focus on this and divert the conversation by talking about what support you need.

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## Talking to children

It can be especially difficult to let your children, or grandchildren, know about your ALK+ NSCLC, and you may consider not sharing the news with them. However, children can usually sense something is going on, and being open and honest can help them avoid misinterpreting the situation. Letting them know will also mean that they can ask any questions, and help them better cope with what's going on. Below are some tips for telling children:

- Think about whether you want to tell them on their own, or with the other parent
- Prepare what you're going to tell them and consider any questions they're likely to ask
- Keep it simple
- Find out what they know and put right any misunderstandings
- If you have young children, it might be good to inform other parents, nursery staff or teachers of the situation. You may also want to get advice from a paediatrician, social worker or psychologist before telling them
- Know that if they ask you any particularly difficult questions, it's fine to say you don't know
- If you have older children that want to help, let them know the ways in which they can offer their support

# Talking to people about your ALK + NSCLC

## Talking to your employer

Talking to your employer about your ALK+ NSCLC may seem scary for a number of reasons. Firstly, it's important to know that your job is secure and that you are protected against discrimination by law, so this should not be a concern of yours.

Talking to your employer will enable them to support you throughout your illness. They can take a number of measures and actions, allowing you to take time off when necessary. They can also inform you of your company's sick pay procedures. Some tips for talking to employers are highlighted below:

- Plan the conversation beforehand, ensuring a private space with enough time for an in-depth discussion. You may also want to note down any key points you want to say / any questions you want to ask
- If you feel nervous, think about whether you'd like to take someone into the meeting with you. This could be a friend or a union representative
- Be realistic when talking about what you'll need / what time you'll need off. It may be good to take a list of any changes to your role or schedule you feel would help e.g. you may want to amend working hours to avoid rush hour etc.
- Decide whether you'd like your employer to share the news with your colleagues, or whether you'd like to tell them. Remember that close colleagues will be willing to support you
- Get in touch with your HR department – they will be able to help you plan and discuss any changes with your employer
- Keep a note of any communication with your manager(s) and HR department

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## Talking to someone you don't know

Sometimes, you may find it helpful talking with someone you don't know. This may be because you don't have to worry about protecting or upsetting loved ones, or because you simply need reassurance from an outside perspective. It may also be beneficial to talk to somebody who knows what you are going through.

Remember that you are never alone, and that there are people out there who are more than willing to help.

You may want to try:

- Calling a support line
- Joining a support group or online community
- Having talking therapy