

Work and epilepsy — employees



Epilepsy Action – together we can change lives

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

- Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
- Run local events and support groups, so that fewer people have to face epilepsy alone
- Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

It's only your support that can make this life-changing work possible.

Please donate today.

You can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at epilepsy.org.uk/donate
You can also stay up-to-date with all the latest epilepsy news and information by joining Epilepsy Action. Membership starts from just £1 a month - join today by calling 0113 210 8800 or sign up online at epilepsy.org.uk/join

Thank you.



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Epilepsy Action
Information you can trust

Find out more
[epilepsy.org.uk/trust](https://www.epilepsy.org.uk/trust)



Am I considered to be disabled if I have epilepsy?

If you have epilepsy that has a substantial effect on your day-to-day activities or would have a substantial effect if you weren't taking your epilepsy medicine, you are considered to be disabled under the Equality Act.

You may also be protected by the equality laws if your epilepsy isn't causing any problems and doesn't need any treatment but could be triggered by specific things. Some common triggers for epileptic seizures are:

- Feeling tired
- Not getting enough sleep
- Stress
- Forgetting to take epilepsy medicines

You can read more about seizure triggers at epilepsy.org.uk/triggers

The equality laws are called the Equality Act in England, Scotland and Wales and the Disability Discrimination Act in Northern Ireland. They apply to you whether or not you take epilepsy medicine.

The equality laws cover:

- Application forms
- Interview arrangements
- Aptitude or proficiency tests
- Job offers
- Terms of employment, including pay
- Promotion, transfer and training opportunities
- Dismissal or redundancy
- Discipline and grievances



What type of work can I do?

It depends on your skills, experience and how epilepsy affects your daily life. Most jobs should be open to you as employers can only refuse you a job if they have very good reason. For example, you could be refused a role because:

- There are health and safety risks to you or somebody else. For example, if you are still having seizures, they could refuse to give you a job where climbing ladders is a substantial part of the job
- You don't have the right type of driving licence for the job. For example, if you have epilepsy, you're not legally allowed to drive heavy goods vehicles, even if your seizures are controlled by medicine
- You apply for the Armed Forces. The Armed Forces aren't covered by the equality laws. This means they can refuse to employ you because you have epilepsy or a history of epilepsy

Can I be asked questions about my health before I'm offered a job?

Employers aren't allowed to ask you questions about your health before they offer you the job, unless they have a good reason to. This includes questions about your previous sickness absence. They also can't refer you to an occupational health adviser or ask you to fill in a questionnaire provided by an occupational health adviser, at this stage of the recruitment process. It would be classed as discrimination for an employer to ask you about your health before offering you a job, without a good reason.

An example of a good reason for asking questions before a job offer might be to make a reasonable adjustment for your job interview, such as giving you extra time to do a test.

Application forms

Employers should only ask you questions about your health that are relevant to the essential duties of the job before making a job offer. For example, they could ask if there is anything stopping you from lifting, if the job involves lifting. If health questions are asked before an offer is made, and you don't feel this is relevant, you can choose to ignore them.



Job interviews

During an interview, an employer is only allowed to ask questions about your health if they are directly linked to an essential aspect of the job you are applying for. For example, they could ask how your epilepsy could affect your ability to do that job safely.

If your epilepsy would not affect your ability to do the job safely and effectively, you don't need to mention it. This might be if you only have seizures when you are asleep, or your seizures are well controlled.



Sources of help and support when looking for work

Jobcentre Plus work coaches

A work coach can help you in your search for work, or to gain new skills. They can also tell you about disability-friendly employers in your area. To have an appointment with a work coach, you need to be already receiving certain benefits, or be disabled.

For more information contact your JobcentrePlus online. If you live in Scotland, you can also get help from Fair Start Scotland.

You can read more about Jobcentre plus and Fair Start Scotland at gov.uk/contact-jobcentre-plus mygov.scot/help-find-job/



Disability Confident

When you're looking for work, look for the disability confident logo on adverts and application forms. The

logo means the employer is committed to employing disabled people. If a job advert displays the logo, you'll be guaranteed an interview if you meet the essential conditions for the job.

Website: gov.uk/government/publications/disability-confident-service-providers

Work programmes and clubs

The Work and Health Programme

If you live in England or Wales, the Work and Health Programme can help you find and keep a job if you're out of work. This is a general programme for people having difficulty finding or keeping work.

Website: gov.uk/work-health-programme

Intensive Personalised Employment Support

This is one-to-one support and training to help you into work if you have a disability or health condition. You must be unemployed and live in England or Wales to get Intensive Personalised Employment Support. You also need to be between school leaving age and State Pension age.

Website: gov.uk/intensive-personalised-employment-support

To apply for the Work and Health Programme or Intensive Personalised Employment Support ask your work coach. If you don't have a work coach, you can ask to speak to one at your local Jobcentre Plus.

Work Clubs

Anyone who's unemployed can join a Work Club. They're run by local organisations like employers and community groups, and give you the chance to share knowledge, experience and job hunting tips. Put **work club** and your location into a search engine for information about clubs near you.

For more sources of support and information see page 30.

Do I have to tell an employer about my epilepsy?

You don't automatically have to tell your employer about your epilepsy, after a job offer, if you don't believe it will affect your ability to do your job safely and effectively. An example could be that your epilepsy is well controlled, or you only ever have sleep seizures.

If you don't tell your employer about your epilepsy and it does affect your ability to do your job safely, your employer may be able to dismiss you. To do this, they would have to prove that:

- You have been given the opportunity to tell them how your epilepsy could affect your job **and**
- You haven't given them this information

If you're not sure whether to tell your employer about your epilepsy, here are some things to think about:

Reasonable adjustment

If your employer doesn't know about your epilepsy, they can't make any reasonable adjustments to help you.

Health and Safety at Work Act

The Health and Safety at Work Act (1974) is a law that says that all employers must provide a safe workplace.

To do this, they must protect all their employees from any possible danger to their health while they are at work. As an employee, you also have a responsibility to take reasonable care of your own and other people's health and safety at work. If your epilepsy could cause a health or safety risk to you or anybody else, you must tell your employer about it. This is the law.

Employer's insurance

Your employer's insurance may pay you compensation if you are injured at work, or if you become ill because of your work. If you don't tell them about your epilepsy, you won't be fully covered by their insurance. So, you might not receive any compensation if you have an accident related to your epilepsy.

However, you are protected by the equality laws from the time you tell your employers you have a disability. So, if your seizures have previously been controlled, but start again, you can tell your employer then, and ask them to do a health and safety risk assessment.

More information about the Health and Safety at Work Act and employer's insurance is available from the Health and Safety Executive (HSE) for England, Scotland and Wales

Website: [hse.gov.uk/pubns/hse40.pdf](https://www.hse.gov.uk/pubns/hse40.pdf)

and Northern Ireland

Website: [hseni.gov.uk](https://www.hseni.gov.uk)

When is it a good time to tell people about my epilepsy?

Your employer

If you decide to tell your employer about your epilepsy, it's a good idea to do it before you start the job. This gives them time to make any reasonable adjustments you need. If you don't tell them about your epilepsy before you start a job, you can change your mind and tell them at any time. As soon as your employer knows about your epilepsy, they should look to put in place reasonable adjustments that would reduce or remove any disadvantage caused by your disability.



The people you work with

It's your decision, whether you tell the people you work with about your epilepsy. But if you do, they may feel more confident about helping you if you have a seizure.

For information about epilepsy awareness training see
Website: epilepsy.org.uk/awarenesstraining

Can my employer tell other people about my epilepsy?

Yes, if you give them permission, and sign a consent form. But they can't tell other people about your epilepsy without your permission. This is to comply with the Data Protection Act.



Do I need a care plan for seizures at work?

If there's a chance you'll have seizures at work, it's a good idea to draw up a care plan with your employer. This can include what happens when you have a seizure and how people can help you during and afterwards. The information from your health and safety risk assessment can be used to do this.

Here are some more suggestions:

- If you usually recover quickly after a seizure, you might be able to get straight back to work. Or you might just need a quiet place to rest, before going back to work. Your care plan should say where you need to rest
- If you normally take a long time to recover from a seizure, you might need to go home. Your care plan should show how you will get home, and who will travel with you, if need be. This should be in line with company policies and procedures for anyone who becomes unwell at work

What is a health and safety risk assessment?

It's an assessment your employer must do to make sure you can carry out your work safely. Some questions that might come up during your health and safety risk assessment are:

- Are your seizures controlled?
- How often do they happen?
- What happens to you when you have a seizure?
- Do you get a warning before a seizure?
- How long do they last?
- How do you feel afterwards?
- Do they happen at a particular time of day?
- Do they happen when you are awake, asleep, or both?
- Is there anything that makes your seizures more likely, such as lack of sleep, tiredness, stress, hormonal changes, flashing or flickering lights or patterns?
- How long does it take you to recover?
- Do you need any first aid/specific care during/following a seizure?

What is a reasonable adjustment?

It's something that your employer could do to help you at work, such as:

- Providing training or mentoring
- Making changes to their building
- Making sure they provide information in a format you can use
- Changing or using different equipment
- Allowing you extra time to do selection 'tests'
- Reducing targets
- Making sure you don't work alone, or there is a 'regular check in' process for you
- Allowing you to take a period of disability leave

Flexible working

You could also ask for flexible working as a reasonable adjustment. This means making changes to your working patterns. An example might be working part-time or adjusting your start and finish times. Alternatively, it might mean working a particular shift pattern, or working longer hours on some days with time off on others.

Reasonable adjustments have to be reasonable to the employer and to you. Many reasonable adjustments involve little or no cost. If there are costs involved, funding might be available from Access to Work.

Website: [gov.uk/access-to-work](https://www.gov.uk/access-to-work)

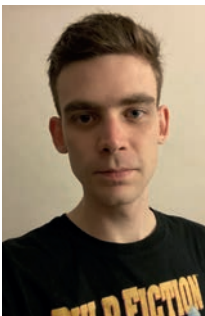
What people have told us about their experiences at work



Ben's story

Ben, who works at Blackburn with Darwen Council, has received fantastic support from his managers. This has helped him and other colleagues with epilepsy to thrive. Here is Ben's story: *"When I was diagnosed, my head of service and senior management made every effort to make reasonable adjustments to help me manage my condition. They did the same with Holly (a colleague who also has epilepsy). The aftercare for me when I had my last tonic-clonic seizure in 2016 was brilliant, including a message of support from the chief executive. As my role involved a lot of travelling, they put a lot of measures in place so that I could continue working in that role."*

Luke's story



After he lost his job in London, Luke was interviewed for a new job. But he had the difficult experience of having a seizure during his interview for a role at a telecoms company: *"I had to apply for the job twice. I was still out of it from a cluster of seizures when I went in to the first interview and, lo and behold, I had a focal seizure in the interview itself. I don't remember much of the interview, but I was rejected for the job."*

He decided to try again and was able to arrange another interview with the company.

“I sent an email asking for feedback. I heard nothing. So, I sent one again, this time quoting a few laws about employment discrimination. Within an hour, I got a phone call telling me I should please apply again because they’d love me to interview once more. I applied, got an interview (this time I was fit and well!) and I got the job.”

Following his interview, Luke started work but it was still far from plain sailing. Despite being aware of his epilepsy, his manager and colleagues didn’t fully understand the extent of his condition. Luke reflects:

“My team manager was new and incredibly keen on good statistics and customer surveys. But as part of this, he took disciplinary action against me because I had higher than usual absences. Apparently, it is company procedure, but upon speaking to his manager, it seems my health information was never actually submitted. It seems he was concerned having someone with epilepsy on his team would count against him.

One day, I had a focal seizure and drooled over my keyboard, breaking it in the process. Only then did the other managers actually realise I have epilepsy. My employers have since been very supportive of me, my appointments and of my upcoming surgery.”

Luke's employers have now created a document to help staff whose circumstances could have an impact on their ability to work. Together with Luke, they have completed a care plan for him. He has been able to list exactly how his epilepsy affects him, his seizure types, how to treat him and who to call in the event of a seizure at work. He also lists his medications, first aid and any adjustments that could help support him.

"It makes a lot of difference knowing people know how to help me. Now my epilepsy is out in the open, I feel I can relax a lot more. But epilepsy is clearly a condition that scares employers."



Erin's story

Erin, who has had tonic-clonic seizures since 2007, currently has a very supportive working environment. However, like many others, her experience of employment hasn't always been positive. *"I once felt told off by a business-owner for having a seizure, which meant the cafe I worked at had to close early. He was very angry, and I don't think I'd have been taken on had he known before. I couldn't shake the feeling of being unwelcome and resigned as soon as I could.*

I now work in Belfast for a charity. I can't fault the organisation for how attentive they've been. My seizures are mostly caused by tiredness, so I'm allowed to take micro-breaks.

I'd say the way epilepsy affects my memory has the biggest impact on my working life. Part of me is paranoid about asking the same questions and seeming like a bit of an airhead to anyone that isn't aware. Each person's experience of epilepsy is unique but for me, one of the defining factors can be feeling vulnerable. I don't like to think of how I might look, especially to someone who's never witnessed a seizure before.

This can be a worry, but at times when I've had seizures at work, my colleagues have helped me see the funnier side. I know as well as anybody that there's nothing funny about seizures, but being able to laugh at those things, for me, is like a little bit of light in the dark.

Aside from educating themselves on the facts, I'd say the most important thing employers can do is to get to know your employee and their individual needs. Seizures can be frightening but less so if you know what to do."

What if I don't need any reasonable adjustments?

It may be that you won't need any adjustments to be made in the workplace. This could be if you're completely seizure free, or neither you, or other people would come to any harm if you had a seizure at work.

Am I entitled to sick leave and sick pay?

It depends on your terms and conditions. But you shouldn't be treated less favourably than other people without epilepsy, as that would be discrimination. This is particularly important if your work's policies are flexible. An example would be when the company are making individual decisions about stopping sick pay or sickness reviews.

Can my employer count disability-related absence as sick absence?

While some employer's separate disability-related absence from other sickness absence, this is not an automatic requirement under the Equality Act. Employers can decide how much sickness absence they will allow before your absence due to epilepsy is considered excessive. They might consider these changes to be a reasonable adjustment.

Saleem's experience



This is what Saleem says about his work: *“I need regular hospital appointments during my usual working hours. My work does their best to accommodate them. They also log my epilepsy sickness separately from sickness for other reasons. This means it doesn't look too bad on my sickness record.”*

Will I get Statutory Sick Pay (SSP)?

If you are sick and unable to work, you may qualify for SSP, which is the government sick pay. It's paid by your employer for up to 28 weeks and you are eligible if you have been off work sick for 4 or more days in a row.

See [gov.uk/statutory-sick-pay](https://www.gov.uk/statutory-sick-pay) for more information about SSP

Contractual sick pay

Some employers also pay contractual sick pay (CSP). The length of sick pay varies but you should be able to see whether your employer pays CSP from your terms and conditions. If you are eligible for CSP, your employer tops up your SSP so that it amounts to your normal pay.



Am I allowed time off for medical appointments?

You are allowed time off for medical appointments in the same way as other people you work with. But it depends on your terms and conditions whether you get paid for these absences. If you also need to have limited time off work to go to medical appointments related to your epilepsy, it could be considered a reasonable adjustment to count these separately. You will have to agree with your employer how much time is acceptable before any sickness reviews are needed.



What can I do if I feel I have been treated unfairly at work?

Talk to people

Talk to the people involved. They might be your colleagues, your line manager or your employer. If you're a member of a union, you could ask them to be with you at any work meetings. If not, you could ask to bring a colleague or friend with you to meetings when you are discussing your work situation.

Keep notes

Keep notes of any actions or comments made that concern you. Also, keep a note of how you've tried to sort the situation out. This can be useful information if you decide later to take more formal action, such as raising a grievance or getting legal advice.

Know your rights

Check your contract, in particular the terms and conditions and the grievance procedure. If your employer wants information from your doctor, they can only get this with your consent. They should only ask for information that is relevant to your epilepsy.

How do I take legal action against someone who has treated me unfairly at work?

Seek advice as soon as possible, as there are strict time limits for bringing cases to Employment Tribunals and courts. You can get advice from different organisations, including Citizen's Advice, ACAS, or your trade union. If you are a member of a trade union, they may also support you at an Employment Tribunal.

You can also take legal advice from a solicitor, but this could be expensive. You might consider opting for legal expenses insurance cover, for example when taking out house contents insurance. This usually doesn't cost a lot and can be valuable if you have problems at work.

If you decide to employ a solicitor, it's important to check at the beginning how much it will cost.

I want to keep my job, but I'm having problems

If you are having problems at work because of your epilepsy, here are some things you could do that might help.

- Keep your employer up-to-date with any changes to your health that could affect your work
- Make a note of your discussions and of any changes to your working conditions that are made as a result. This would be useful if your work situation became difficult and you needed to raise a grievance

- If your epilepsy has changed, you could ask your employer to arrange a new risk assessment for you
- If you are off sick because of your epilepsy, keep them up-to-date with your situation

If your employer doesn't make reasonable adjustments to help you, this could be illegal, unless they have significant justification. But sometimes it might not be possible to make a job safe, even with adjustments, if you have uncontrolled seizures. Not making reasonable adjustments in this instance may not be illegal.

If you have fewer, or more seizures than usual, you could ask your employer to do a new risk assessment for you. This could mean you can do a bigger range of work within your organisation. If you're allowed to drive a car there are few jobs you can't do.

Epilepsy awareness training

For information about epilepsy awareness training see
Website: [epilepsy.org.uk/awarenesstraining](https://www.epilepsy.org.uk/awarenesstraining)

Sources of further advice and information

Equality Advisory and Support Service (EASS) (England, Scotland and Wales)

The Equality Advisory Support service gives free advice, information and guidance to individuals on equality, discrimination and human rights issues.

Tel. 0808 800 0082

Website: equalityadvisoryservice.com

Equality and Human Rights Commission (England, Scotland and Wales)

The Equality and Human Rights Commission (EHRC) provides advice and guidance on rights, responsibilities, and good practice, based on equality law and human rights.

Website: equalityhumanrights.com

The Equality Commission (Northern Ireland)

The Equality Commission provides advice and information about the Disability Discrimination Act in Northern Ireland.

Tel: 028 90 500 600

Website: equalityni.org

Law Centres (England, Scotland and Wales)

Law Centres provide free legal advice and representation to disadvantaged people.

Tel: See your local Phone Book

Website: lawcentres.org.uk

ACAS (Advisory, Conciliation and Arbitration Service) (England, Scotland and Wales)

ACAS aims to improve organisations and working life through better employment relations. They offer free advice about employment rights. Tel: 0300 123 1100

Website: acas.org.uk

Disability Law Services

Disability Law Services offer advice and information about employment law to disabled people.

Tel: 020 7791 9800

Website: dls.org.uk

Fair Start Scotland

Fair Start Scotland is an employment support service which helps people living in Scotland to find work.

Website: mygov.scot/help-find-job

Fit for Work

Fit for Work offers free expert and impartial advice to anyone looking for help with issues around health and work.

Website: support.fitforwork.org/app/home

Jobcentre Plus

Tel: See your local Phone Book

Website: direct.gov.uk (search for Jobcentre Plus)

The Health and Safety Executive (HSE)

HSE can provide general information and guidance for employers about work-related health and safety issues.

Website: hse.gov.uk



About this publication

This booklet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything else you would like to say about this booklet, please contact us.

To find out why you can trust Epilepsy Action's information, please contact us or visit epilepsy.org.uk/trust

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Liam Kinealy has declared no conflict of interest.

Disclaimer

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor.

Do...

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person on their side (in the recovery position) when the seizure has finished (see picture)
- Stay with them until recovery is complete
- Be calmly reassuring



Don't...

- Restrain the person's movements
- Put anything in their mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure **or**
- The seizure continues for more than five minutes **or**
- One seizure follows another without the person regaining consciousness between seizures **or**
- The person is injured **or**
- You believe the person needs urgent medical attention

First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

Do...

- Guide the person away from danger
- Stay with the person until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

Don't...

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure **or**
- The seizure continues for more than five minutes **or**
- The person is injured **or**
- You believe the person needs urgent medical attention

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.

Epilepsy Action's support services



helpline

Our friendly helpline team offer confidential advice and information to anyone affected by epilepsy:

Freephone 0808 800 5050

Staff are text relay trained and able to offer advice and information in 150 languages, via an interpreting service.

Live chat

Visit epilepsy.org.uk to chat with a member of the helpline team. We usually reply to chat requests within 5 minutes.

Email helpline@epilepsy.org.uk

Send us your question about epilepsy. We aim to reply within 48 hours (on workdays).

To see our opening hours and find out more about the support we offer visit: epilepsy.org.uk/helpline



talk and support

Our Talk and Support groups offer an opportunity to connect with others affected by epilepsy. You can join a group which meets face-to-face or online.



befriending

Our befriending service links people who are affected by epilepsy to a volunteer befriender. Your befriender can listen if you are going through a difficult time and could also help you take steps towards positive change.

Continued on page 39

Work and epilepsy

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

Yes	No	
		I feel more informed about issues to do with epilepsy
		I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don't apply)
		I have talked to my employer/colleague/teacher/family/ other (cross out those that don't apply) and they have improved how well they support me
		I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline or support groups

Please tell us how you think we can improve this information

Please return the completed form to:

**FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action,
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY**

You can also give us feedback online. Visit [epilepsy.org.uk/feedback](https://www.epilepsy.org.uk/feedback)

Thank you.

epilepsy *action*

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Registered charity in England and Wales (No. 234343)



counselling

Our counselling service is available to adults living in Northern Ireland and Wales who are affected by epilepsy, caring for someone affected by epilepsy, or the parent of someone affected by epilepsy.



**family support
Northern Ireland**

Our family support services offer support to families and carers of people affected by epilepsy in Northern Ireland and Wales.

**To find out more about the services we offer, including ways to get in touch and how to apply, visit:
epilepsy.org.uk/support-for-you.**

Information about epilepsy

Epilepsy Action has a wide range of information on our website about many different aspects of epilepsy. You can also download our information as a factsheet.

If you would like our information printed in large text, you can order this by contacting the Epilepsy Action Helpline.

Epilepsy Action Helpline:

freephone 0808 800 5050
epilepsy.org.uk



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Epilepsy Action Information you can trust
Find out more epilepsy.org.uk/trust

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Environmental statement

All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.