**Benefits consultation**

The government are going to make changes to how health-related benefits are provided, and how they support people with health conditions into work. We believe these changes could have a serious impact on people affected by epilepsy, and we want the government to hear your thoughts on the consultation questions.

The government are interested in responses from anyone living in the UK, but are particularly interested in responses from disabled people and people living with health conditions.

The changes the government will make that are informed by this consultation will apply to England, Wales and Scotland. Responses from people in Northern Ireland will be shared with the Department for Communities in Northern Ireland.

The consultation questions ask about changes proposed in the green paper titled ‘Pathways to Work: Reforming Benefits and Support to Get Britain Working’, and the ‘Spring Statement 2025 health and disability reforms’. You can find those consultation documents, and more information about the consultation, here: [Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper - GOV.UK](https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper)

There are two ways to respond to this consultation. You can either:

* Respond online here: [Pathways to Work: Reforming Benefits and Support to Get Britain Working](https://forms.office.com/pages/responsepage.aspx?id=6fbxllcQF0GsKIDN_ob4w8sPhcBFC_lLibLhGndbUv9UN0Y4UTYzNUVVM0lFUThFWFM3VVEwSFJPMCQlQCN0PWcu&route=shorturl)
* Or respond by email to Consultation.pathwaystowork@dwp.gov.uk

The deadline for responses is **Monday 30th June 2025**.

Alongside these questions, there will also be virtual and face to face events as part of the consultation. You can find details for these events here: [Pathways to Work: Reforming Benefits and Support to Get Britain Working Green Paper - GOV.UK](https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper)

To help you think about how the changes may impact people with epilepsy and their families, we have created some response prompts and guidance. You can use this document to help you think about your responses. **The most important things to include are your own thoughts and experiences**. The government needs to hear how **you** think the changes will affect **you** and **the people you care about**, and how you think changes can be made that will help rather than harm people with epilepsy.

**Questions:**

**Chapter 2: Reforming the structure of the health and disability benefits system**

**1. What further steps could the Department for Work and Pensions take to make sure the benefit system supports people to try work without the worry that it may affect their benefit entitlement?**

* Do not means test any health-related benefits. These benefits are vital to reduce the financial barriers faced by people with health conditions. These benefits should put them on an even footing with people who don’t have health conditions, to reduce the inequalities between these groups. People with health conditions or disabilities should not be penalised if they are able to work or have savings, as they will still face a higher cost of living due to health related costs.
* Do not begin means-testing of benefits until the probation period of a new job has passed, and do not ask for back-payments once means testing commences.
* Implement a gradual reduction of benefits rather than an abrupt cut-off to avoid the "benefits cliff", when means testing begins.
* Provide support for all of the additional costs that come with a disability. For people with epilepsy this can include transport, seizure alarms, bed monitors, carers, and adaptations to make bathing and cooking safer, among many other things. These things are vital to keep people with epilepsy safe, to maintain a good quality of life, and to allow them to access public life and the workplace. The financial inequalities faced by disabled people can be reduced by reducing the amount they need to spend on these vital items and services. The costs should be covered either by a benefit or by providing all necessary items and services through the NHS or social care, without implementing postcode lotteries or rejecting claims for items that support quality of life.
* Provide financial support for adaptations needed during the job application process and when starting a new job. For example, people with epilepsy may need a taxi to take them to an interview if they are unable to drive and there aren’t good public transport options in their area. They may also need a fall monitor, camera, or seizure alarm if they will be working alone. Funding for support like this is vital to ensure people with epilepsy can access work safely and in the same way everybody else can.
* Offer temporary and partial disability awards: Provide financial support to individuals whose health conditions or disabilities allow them to work only part-time or intermittently. Temporary awards would help cover living expenses and other costs during periods when their health condition worsens and they cannot work. Partial awards would offer ongoing support to those who can work part-time, ensuring they receive adequate assistance while still being encouraged to participate in the workforce to the extent their health allows.

**2. What support do you think we could provide for those who will lose their Personal Independence Payment entitlement as a result of a new additional requirement to score at least four points on one daily living activity?**

* Reverse that change! People who have conditions that impact them to a lesser extent but those impacts affect many areas of their life also need support with the additional costs those conditions bring. For example, epilepsy can impact someone’s ability to use an oven or hob to prepare food, memory for taking medication, safety when bathing and dressing, and often co-exists with conditions like dyslexia, autism and learning disabilities which can affect someone’s ability to communicate. These impacts may not score 4 or more in one area, but will still have wide-ranging impacts on the individual’s life and ability to function in their home and work lives. Those impacts will have cost implications, and removing PIP from these people will make it harder for them to afford to pay for the support they need to keep themselves safe, to access work, and to have a good quality of life.
* Create a new non-means-tested benefit to support people with long term conditions which impact their life in a significant way, but do not meet the new threshold for PIP.
* Improve access to support through health and social care routes. For example, provide high-quality, well trained carers who are available 24/7 and as needed for everyone who requires them, for free, through the NHS or social care system. Provide universal free access to supportive technologies, such as seizure monitors, bed monitors, and fall alarms, through the NHS or social care. Currently there is a postcode lottery as to whether such technologies are available or not, who provides them, and how easy they are to access. These options are not available in many areas. Often even when they are available, people with epilepsy are not made aware, and the barriers to qualify to receive one are very high, the application process is complicated and lengthy, and there are long waits once approved.
* Provide good quality epilepsy training to all staff working for statutory organisations. This would greatly improve the safety of people with epilepsy when they are accessing services and reduce some of the need for carers to be present. It would also help to tackle the stigma people with epilepsy face when trying to gain employment, by normalising the condition.
* Provide comprehensive job coaching and placement services to help individuals find suitable employment and navigate the job market more effectively.
* Enhance workplace accommodations by ensuring employers are supported and incentivised to provide necessary accommodations for employees with disabilities.
* Implement tax incentives for employers who hire and retain employees with disabilities to encourage more businesses to create inclusive workplaces.

**3. How could we improve the experience of the health and care system for people who are claiming Personal Independence Payment who would lose entitlement?**

* All health and care staff should have high-quality and thorough epilepsy training as standard, which is repeated and updated every two years. Epilepsy affects 1 in 100 people in the UK, and all staff in health and care roles will support people with epilepsy regularly. However we know that staff often don’t understand epilepsy, including those with a high level of medical training. Improving knowledge of epilepsy will improve safety, contribute towards preventative care and better screening, and improve access to health and social care.
* Improve access to carers, supportive technologies, and advocates.
* Provide more services closer to home, to reduce the reliance on poor public transport infrastructure for people with epilepsy who are unable to drive
* Improve access to services outside of business hours. Everyone should be able to get an appointment on an evening or weekend with any service they need to attend, including with their own named GP, regular dentist, and normal social worker.

**4. How could we introduce a new Unemployment Insurance, how long should it last for and what support should be provided during this time to support people to adjust to changes in their life and get back into work?**

* Unemployment insurance should cover all of the time someone is unemployed but able to look for work. Other benefits should cover people who are unemployed and unable to look for work.
* Financial support should be provided to ensure everyone out of work is able to maintain a good standard of living. Additional support should be provided for people who have extra costs due to health conditions and disabilities. This support should address all of the additional costs they face.
* Support with job applications should be provided as standard to everyone, with adjustments made for those who need them due to health conditions or disabilities.
* Support in finding jobs that suit each individual’s skills, needs and preferences should be offered, without forcing people to apply for jobs that they do not want.
* Support should include finding jobs, writing applications, job interviews and recruitment processes. Support should continue post-recruitment to cover changes that employment brings, such as changes to childcare and transport.

**5. What practical steps could we take to improve our current approach to safeguarding people who use our services?**

* Provide enhanced training to all staff on safeguarding and on supporting people with disabilities and health conditions, with the inclusion of epilepsy and all seizure types.

**Chapter 3: Supporting people to thrive**

**6. How should the support conversation be designed and delivered so that it is welcomed by individuals and is effective?**

* Focus the conversation on the barriers that people face and the support that is available to address these, rather than assessing against a strict criteria that doesn’t apply to everyone.
* Accept the goals and aspirations of the respondents and do not force them to prioritise work over their own health and quality of life.
* Take into account medical evidence and weigh the input of specialists and professionals who know the applicant above the opinions of the assessor.
* Discuss what adjustments, if any, could help to support the applicant. Ask what they would need to be able to thrive. Be open to their feedback and avoid trying to force pre-designed solutions that may not be useful for individuals.
* Allow carers, supporters and advocates to accompany applicants in these conversations.
* Provide pre-conversations tools to help applicants plan what they would like to say.
* Consider the impact that employment may have on their ability to carry out everyday tasks. For example, someone with epilepsy may be able to function fairly well in their daily life, but if they have a comorbid anxiety condition (which is very common), the added stress of working may trigger many more seizures, reducing both their quality of life, ability to function in their everyday life, and their ability to be employed.
* Allow conversations to happen virtually or in a location close to the person’s home, depending on their preference and needs.
* Provide a full range of adaptations for communication to meet everyone’s needs and abilities.

**7. How should we design and deliver conversations to people who currently receive no or little contact, so that they are most effective?**

* If they have previously been assessed as unlikely to have a change in their ability to work, they should have a one-off conversation about their goals and needs, and should be provided support to meet those goals and needs. This conversation should not include employment if they have previously been considered unable to work. It should instead be a way to access other support for daily activities and wellbeing.
* For example, someone with refractory epilepsy who is experiencing many seizures a day should not be asked about their ability to work. They should instead be offered support with their safety, ways to reduce isolation, and ways to improve wellbeing, relevant to their unique circumstances.

**8. How we should determine who is subject to a requirement only to participate in conversations, or work preparation activity rather than the stronger requirements placed on people in the Intensive Work Search regime?**

* This should be decided in collaboration with the applicant, and with input from medical and social care professionals who know the applicant personally. The opinions of professionals should be trusted and not overruled by assessors.

**9. Should we require most people to participate in a support conversation as a condition of receipt of their full benefit award or of the health element in Universal Credit?**

* Support conversations which are conducted in a beneficial way and have genuinely useful outcomes **for applicants** should be offered to all applicants, if they wish to have one. However, this should not be required to receive the health element of Universal Credit or their full benefit award.

**10. How should we determine which individuals or groups of individuals should be exempt from requirements?**

* For individuals, this should be decided in collaboration with the applicant, and with input from medical and social care professionals who know the applicant personally. The opinions of professionals should be trusted and not overruled by assessors.
* For groups, this should be based on high-quality evidence from specialists, healthcare professionals, researchers, and third sector organisations with expertise in those specific conditions/groups.

**11. Should we delay access to the health element of Universal Credit within the reformed system until someone is aged 22?**

* No. This punishes disabled young people and young people with health conditions and will not make them more likely to go into employment. Instead, it raises many barriers for employment, as the young person will have less resources to support job applications and interviews.
* Additionally, this will create an even greater financial disparity between families that include people with health conditions and disabilities, and families who do not. This will require parents of disabled young people to provide extra support and cover more costs, compared to their peers whose children are not disabled. This is further exacerbated when those parents themselves have health conditions or disabilities, and are already facing the additional financial burden posed by their own health related costs. This change will only increase financial inequality for people with health conditions or disabilities.

**12. Do you think 18 is the right age for young people to start claiming the adult disability benefit, Personal Independence Payment? If not, what age do you think it should be?**

* PIP or an equivalent should be available to support people of any age who needs it.

**Chapter 4: Supporting employers and making work accessible**

**13. How can we support and ensure employers, including Small and Medium Sized Enterprises, to know what workplace adjustments they can make to help employees with a disability or health condition?**

* Provide thorough training and resources to support employers in this, including epilepsy-specific training. This training and resources should be created by experts who understand the conditions being discussed and the impact they can have in the workplace, and should be co-produced by people living with the conditions.
* Provide easy and quick access to Access to Work and similar support.
* For people who have had a ‘support conversation’, this should include relevant information about which workplace adjustments would be helpful and how a new employer can implement them. This should be available in a document that the employer can be given during the recruitment process or upon appointment, so that adjustments can be made quickly before the new employee starts work.

**14. What should DWP directly fund for both employers and individuals to maximise the impact of a future Access to Work and reach as many people as possible?**

* Technology and equipment that can support employees to access work and perform to their best ability, and to remain employed for as long as possible.
* Training for managers and colleagues to improve understanding of health conditions a new employee may have, provided before the employee begins work, or at the time of diagnosis for existing employees.
* General awareness training about a range of common health conditions, including epilepsy.

**15. What do you think the future role and design of Access to Work should be?**

* To provide access to any items, technologies, training or other resources that employees may need to remove barriers they face at work due to their disability/ies or health condition/s, which can’t be provided directly by the employer.
* To improve workplace inclusion of all employers by providing resources and training to employers.

**16. How can we better define and utilise the various roles of Access to Work, the Health and Safety Executive, Advisory, Conciliation and Arbitration Service and the Equalities and Human Rights Commission to achieve a cultural shift in employer awareness and action on workplace adjustments?**

* Define the remit for each organisation and remove overlapping goals:
	+ Access to Work- provide support for employers and employees to remove barriers faced due to health conditions and disabilities.
	+ Health and Safety Executive- provide information to employers and organisations regarding health and safety.
	+ Advisory, Conciliation, and Arbitration Service- resolve disputes between employers and employees
	+ Equalities and Human Rights Commission- enforce legislation on human rights and equalities and investigate breaches.

**17. What should be the future delivery model for the future of Access to Work?**

* A centrally-managed scheme which supports both employers and employees with information, funding and access to support.
* Available to provide support before a new employee begins work, and at the time of diagnosis for current employees with new conditions or disabilities
* Available in a timely manner, and introducing no delays in starting employment or returning to work after a new diagnosis.

**Other**

**18. Which of the following best describes how you are responding to this consultation. Are you responding:**

As a member of the public

As or on behalf of an individual business

As or on behalf of an employer/ business representative organisation

As or on behalf of an interested charity or other representative organisation

**19. Do you consider yourself to have a health condition or a disability?**

Yes

No

Prefer not to say

**20. Do you live in:**

England

Northern Ireland

Scotland

Wales

Prefer not to say