

# **Employment support for people with epilepsy**

**Qualitative research to identify what good employment support for people with epilepsy should look like**

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# Institute for Employment Studies

IES is an independent, apolitical, international centre of research and consultancy in public employment policy and HR management. It works closely with employers in all sectors, government departments, agencies, professional bodies and associations. IES is a focus of knowledge and practical experience in employment and training policy, the operation of labour markets, and HR planning and development. IES is a not-for-profit organisation.

## Acknowledgements

The authors would like to thank the people with epilepsy, employers and health and wellbeing experts who gave up their time to share their personal experiences and contribute their insights and suggestions.

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IES project code: 01037-5290

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# 1 Executive summary

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## 1.1 Aims

This report presents findings from qualitative research undertaken by the Institute for Employment Studies (IES) on behalf of Epilepsy Action. The limited research into epilepsy and employment in the UK shows that people with epilepsy in the UK are disadvantaged in finding and retaining employment. However, there is a lack of UK-specific evidence for why this is the case and limited understanding of the best strategies to enable people with epilepsy to find and retain employment. The aim of this study was to explore the factors that contribute to people with epilepsy being disadvantaged at work in the UK, and to identify what good employment support for people with epilepsy should look like.

Specifically, Epilepsy Action commissioned this study to investigate the following research questions:

- How is epilepsy different from other conditions, in terms of support into employment?
- What does epilepsy have in common with other long-term conditions, in terms of support into employment?
- What information about epilepsy would reassure an employer?
- What should good employment support for people with epilepsy look like?
- How can charities that support people with epilepsy and other conditions work with and influence employers?
- What impact could be achieved with good employment support?

## 1.2 Context

In the UK, around one in 100 people (600,000) have a diagnosis of epilepsy (Joint Epilepsy Council, 2011). Despite anti-discrimination legislation, people with epilepsy in the UK are more than twice as likely as those without the condition to be unemployed (Baker, 2017). Labour Force Survey data for the period January to March 2018 relating to the economic activity of people in the UK who were disabled showed that, of those who identified themselves as having epilepsy, 53 per cent were classed as economically inactive and a further three per cent were classed as unemployed (Office for National Statistics, 2018). The higher economic inactivity and unemployment rates amongst people with epilepsy incurs productivity losses (Pugliatti et al, 2007) and are likely to reduce quality of life (for example, Lee, 2005). The linked factors that contribute to higher unemployment amongst people with epilepsy include clinical factors (such as uncontrolled seizures), psychological factors (such as perceptions of stigma), socio-economic (such as lower education level) and political factors (such as restrictions on holding a driving

licence) (Wo et al, 2015a). Research suggests that UK employers are wary about recruiting someone with epilepsy. A recent YouGov poll showed that over a quarter of UK employees would be concerned about working with a colleague who had epilepsy (YouGov, 2016). An employer survey indicated that the majority of UK employers would not know how to help a co-worker having a seizure (Epilepsy Society, 2016). People with epilepsy may also experience psychological barriers to employment because of poor mental health (Kimiskidis, 2007), or because they are reluctant to place themselves within pressurised workplaces (Epilepsy Action, 2016).

The research is timely given that UK Government's strategy on work, health and disability points to the need for more support for people with fluctuating, less common and more complex health conditions (Department for Work and Pensions, Department of Health, 2017).

### 1.3 Methodology

To address the aims and research questions, IES designed a qualitative study with four main elements:

- Rapid evidence review of relevant literature.
- Interviews with experts (four<sup>1</sup>).
- Interviews with employers (six).
- Two focus groups with people with epilepsy (eight).

Supplementary data was also submitted online by people with epilepsy who were shortlisted to take part in the two focus groups but were unable to attend (five).

The rapid literature review searched and sifted non-clinical research about epilepsy and employment from OECD nations from 2000 to the present, then shortlisted 22 relevant reports. The findings of the review are incorporated within the body of this report.

The four expert interviews were intended to give an overview of employment support for people with epilepsy and an insight into how epilepsy compares to other health conditions. The experts interviewed were: Professor Stephen Bevan, Head of HR Research Development at IES; a physician and expert in occupational health and epilepsy; a Disability Employment Advisor (DEA) from Jobcentre Plus; and a third sector expert in training and support for people with epilepsy.

The eight employer interviews were intended to reveal what employers know and think about epilepsy and to elicit their views on what information and support would reassure them when employing someone with epilepsy. Employers were recruited from a range of different sized employers from the public, private and third sector, including roles in offices, shops, transport, construction and manufacturing.

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<sup>1</sup> Number of participants

Two focus groups of people with epilepsy took place in London and Yorkshire. The groups were purposively selected to give a diverse demographic profile, and included people with different epilepsy symptoms and employment situations. The focus groups conveyed the lived experience of people with epilepsy, to understand the barriers to employment and to gather views on the kind of employment support that could make it easier to get and keep a job.

## **1.4 How does epilepsy compare with other health conditions, in terms of support into employment?**

According to the experts interviewed, employers have limited knowledge of epilepsy and tend to respond negatively to the idea of employing someone with epilepsy. While employers are often reluctant to hire anyone with a chronic health condition, experts thought they were more averse to recruiting someone with epilepsy, because of safety concerns about epileptic seizures. Since many people with epilepsy also have mental health conditions this could be a further deterrent. Experts thought that 'self-management' and 'self-advocacy' approaches (such as those used in the Individual Placement and Support trials, discussed in detail in section 7.1.7) could help people with epilepsy when talking to employers about their health.

## **1.5 What information about epilepsy would reassure an employer?**

Employers interviewed for this research were usually unfamiliar with different epilepsy symptoms and sometimes did not realise that epilepsy can be well controlled by medication. When they were told about three hypothetical individuals with different epilepsy symptoms, all three individuals were regarded as difficult to accommodate in the workplace. Employers were usually strongly in favour of people with epilepsy disclosing their condition, ideally during recruitment. Employers' main concerns about epilepsy focused on the safety of the person with epilepsy during a seizure. Seizures were also seen to be potentially upsetting for others to witness. Making adjustments to enable a person with epilepsy to work at their organisation was not always feasible, according to employers, because of the predicted costs and logistical challenges. Job roles involving operating machinery, vehicles or working remotely or alone, or while caring for others were usually felt to be out of bounds. However, employers were more prepared to make adjustments for an existing employee who developed epilepsy while in the role. The employers' interview findings suggest that educating employers about epilepsy could allay employers' fears about safety and disruption and show that employing someone with epilepsy is feasible.

The focus groups with people with epilepsy revealed the need for people with epilepsy to be supported in their interactions with employers. People with epilepsy were usually reluctant to disclose their epilepsy to an employer until they had been offered a job. They also often felt unable to clearly 'self-advocate' with employers about their health. Sometimes this was because they found it difficult to talk about and define their epilepsy. Others were deterred from being open about epilepsy because they had previously

encountered employer discrimination. People with epilepsy sometimes felt unable to take jobs that made the best use of their abilities, because of concerns about safety. Mental health issues were a common experience which also blocked people from suitable employment. Many participants suspected they had been discriminated against during job applications, after a seizure, or when employers refused to allow adjustments. Employees need support to facilitate conversations with employers about epilepsy, including help to make disclosure easier and to negotiate a seizure 'plan'.

## **1.6 What should good employment support for people with epilepsy look like?**

Supporting positive, open dialogue between employers and employees was clearly identified as a priority. A personalised online toolkit was one option to achieve this, using an online menu to generate a customised print-out for different types of epilepsy that employer and employee would discuss together. Suggested content would include disclosure, a seizure and recovery plan, health and safety risks, employer's liability insurance, reasonable adjustments, communications with colleagues, first aid and discrimination. Including a clinical assessment by the person with epilepsy's healthcare professional would also be welcomed by employers. Using checklists could help assess, for example, employees' 'work ability', the employee's fit with job description tasks, or competency to operate machinery. E-learning packages, building on Epilepsy Action's existing training, could supplement the toolkit with additional education for employers, focusing on epilepsy awareness. Epilepsy Action's local branches could provide face-to-face advocacy for people with epilepsy in their discussions with employers.

## **1.7 How can charities that support people with epilepsy and other conditions work with and influence employers?**

People with epilepsy, employers and experts would like to see Epilepsy Action-led campaigns that change employers' and the general public's attitudes to epilepsy. Publicising case studies of people with epilepsy (including celebrities) in unexpected jobs could help change perceptions. Good practice amongst employers using a person-centred and whole organisation approach to health and wellbeing could also be showcased. Experts suggested that Epilepsy Action could influence clinicians, the NHS, NICE and leading employers and employers' groups to change attitudes and behaviours to promote people with epilepsy in achieving and retaining employment. Epilepsy Action could also seek a role in the local partnerships that are increasingly responsible for delivering employment support services, and provide advice to Jobcentre Plus on the needs of people with epilepsy.



## 1.8 What impact could be achieved with good employment support?

Improved employment support, education and campaigns could help increase employers' awareness of epilepsy and increase their confidence and willingness to recruit someone with epilepsy and to make 'reasonable adjustments' to the workplace and working practices. Giving people with epilepsy the tools to support their conversations with employers would help them to enter employment, negotiate adjustments, retain their jobs and fight discrimination. People with epilepsy hoped that getting work could lead to greater financial security and allow them to find satisfying employment. Raising the employment rate of people with epilepsy would also reduce government expenditure on benefits and increase tax revenue.

## 2 Context

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This chapter sets out the employment situation for people with epilepsy in the UK and more widely, the economic and psychological costs of unemployment for people with epilepsy, the barriers to achieving and maintaining employment and the resultant areas of interest for this study.

In the UK, around 1 in 100 people (600,000) have a diagnosis of epilepsy (Joint Epilepsy Council, 2011). The UK is among other developed countries where epilepsy is recognised as a disability eligible for legal protection and the employment rate for people with epilepsy in the UK is higher than that in some less developed countries (Wo et al, 2015a). The Equality Act 2010 obliges UK employers to make 'reasonable adjustments' such as changes to the workplace and working practices to enable people with disabilities to access work. However, people with epilepsy in the UK remain more than twice as likely as those without the condition to be unemployed (Baker, 2017). Labour Force Survey data for the period January to March 2018 relating to the economic activity of people in the UK who were disabled showed that, of those who identified themselves as having epilepsy (195,566), 53 per cent (103,107) were classed as economically inactive and a further three per cent (5,724) were classed as unemployed (Office for National Statistics, 2018). Under-employment is also expected to be greater amongst people with epilepsy compared with the general UK population (TUC, 2015); globally, adults with epilepsy have consistently been found to experience high levels of under-employment (Bishop and Chiu, 2011)

The economic costs of unemployment and economic inactivity caused by epilepsy in the UK are likely to be considerable. A study based on epidemiologic, health economic, and international population statistics, estimated that cases of epilepsy in the UK incurred productivity losses<sup>2</sup> of €876 million (Pugliatti M et al, 2007). The intangible costs of the psychological impact of unemployment as a result of epilepsy are harder to quantify (ibid.), but the research literature recognises that unemployment is likely to reduce quality of life for people with epilepsy (Lee, 2005).

There appear to be many complex and interacting barriers that influence why people with epilepsy find it more difficult than average to get and keep a job, as evidenced in several global comparative studies (Wo et al, 2015a; Bautista et al, 2014; Smeets et al, 2007). The most recent systematic international review of the effect of epilepsy on employability

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<sup>2</sup> €876 million productivity losses comprised sick leave, early retirement and premature mortality; lost productivity was calculated by multiplying human capital lost work days by the wage rate. Estimated productivity losses excluded direct healthcare costs and indirect costs such as social care (Pugliatti M et al, 2007).

concluded that the negative influences affecting the employability of people with epilepsy included clinical factors (such as uncontrolled seizures), psychological factors (such as perceptions of stigma), socio-economic (such as lower education level) and political factors (such as restrictions on holding a driving licence) (Wo et al, 2015a). However, this global review found that the adjusted employment rate of people with epilepsy who have uncontrolled seizures is comparable to those whose seizures can be controlled with medication, and concluded that the main barriers preventing people with epilepsy from entering employment are more likely to be non-clinical factors, such as discrimination and stigma.

Discrimination and stigma against people with epilepsy in the UK are likely to be factors in their lower than averages rates of employment. A 2016 poll showed that over a quarter of UK employees would be concerned about working with a colleague who had epilepsy (YouGov, 2016). This is in spite of the fact that the changes to the workplace required to facilitate people with epilepsy are often as straightforward as providing a place to rest and relax, maintenance of all lights and machinery that flash or flicker, or training for managers and staff about epilepsy (TUC, 2015). In a survey of employers, 67 per cent indicated that their apprehension was a consequence of having no idea how to help or assist a co-worker having a seizure (Epilepsy Society, 2016). It is perhaps unsurprising then, that many people with epilepsy worry about telling their employer about the condition (TUC, 2015).

The low employment rate amongst people with epilepsy might also be influenced by psychological barriers, although these are under-researched. Psychological factors were identified as a crucial element in predicting successful employment for people with epilepsy in a systematic review of international studies of epilepsy (Wo et al, 2015a). People with epilepsy are more likely than the general population to face depression, anxiety and low mood (Kimiskidis, 2007), conditions proven to affect an individual's success within the labour market (The Work Foundation, 2015). Furthermore, as stress is known to sometimes trigger seizures, people with epilepsy might be reluctant to place themselves within pressurised workplaces (Epilepsy Action, 2016). Psycho-social factors, such as a high self-perceived importance of work and decreased fears of workplace discrimination, are significantly associated with employment in epilepsy patients (Bautista and Wludyka, 2007).

This research is timely, as the ten-year UK Government strategy for work, health and disability calls for more attention to be paid to supporting people who have fluctuating, less common and more complex health conditions (Department for Work and Pensions, Department of Health, 2017). Government strategy is underpinned by partnership working which includes charities collaborating with employment services, employers and health services in improving employment outcomes for people with disabilities and health conditions. The emphasis is on supporting employers to becoming more 'inclusive' in their approach. The strategy also anticipates a continued role for charities and people with lived experience in the Work and Health Unit's Expert Advisory Group forum, which advises the Government on health and employment.

This research will probe further into the above areas, addressing the gaps in our knowledge about why and how people with epilepsy in the UK are excluded from the

workforce and to identify the best ways of supporting people with epilepsy to enter and thrive in employment.

## 3 Methodology

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### 3.1 Aims and approach

The aim of the research was to address the following specific research questions:

- How is epilepsy different from other conditions, in terms of support into employment?
- What does epilepsy have in common with other long-term conditions, in terms of support into employment?
- What information about epilepsy would reassure an employer?
- What should good employment support for people with epilepsy look like?
- How can charities that support people with epilepsy and other conditions work with and influence employers?
- What impact could be achieved with good employment support?

IES' study consisted of four strands:

- A rapid literature review.
- Interviews with experts on work, health and wellbeing (four<sup>3</sup>).
- Interviews with employers (six).
- Two focus groups with people with epilepsy (eight). Within this strand, supplementary data was submitted online by people with epilepsy who were shortlisted to take part in the two focus groups but were unable to attend (five individuals).

The research adopted a qualitative approach to explore the issues in depth with a range of individuals: subject matter experts and practitioners, employers and people with epilepsy. This approach enabled the research to cover all six research questions comprehensively, to triangulate the findings, and to highlight good practice where this was evident.

### 3.2 Rapid literature review

The aim of the literature review was to understand the context in which Epilepsy Action was seeking to develop its employment support for people with epilepsy and to clarify what was already known before embarking on data gathering. The review equipped the team to target fieldwork appropriately, building on existing knowledge rather than replicating it.

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<sup>3</sup> Number of participants

To make best use of the available resources, the research team utilised a Rapid Evidence Assessment (REA) (UK Government website, July 2018) to systematically gather and assess the existing evidence on employment support for people with epilepsy. Using the University of Brighton Online Library Search, the team identified relevant articles in academic journals with a focus on epilepsy, disability and occupational health. ‘Grey’ literature sources from government research publications, trade union publications and more informal publications and blogs from epilepsy-focused charities and public health bodies were also consulted.

The search terms used are shown in Table 3.1 below.

**Table 3.1: RAE search terms**

Primary terms		Secondary terms		Tertiary terms (optional, to allow a more targeted search)
Epilepsy	AND	Employment	AND	Adjustment*
		Employer		Prejudic*
		Job*		Stigma*
		Career*		Safety
		Occupational*		“Seizure
		Unemploy*		Medication
				Side Effects

\* denotes free text after word stem to allow for plurals/similar word forms

“” denotes string

This initial search generated 50 documents. These were sifted using the criteria shown in Table 3.2, creating a shortlist of 22 documents for review (the shortlisted documents are shown at Appendix 2).

**Table 3.2: Sift criteria**

Relevance	Methodology
Non-clinical research into epilepsy and employment	Quantitative studies: surveys of 140 participants or more
Publication date: 2000 to present	Qualitative studies: 20 participants or more
Cultural appropriateness: reports in English from OECD nations <sup>4</sup>	

Initially, the sift methodology excluded quantitative studies involving fewer than 500 participants and qualitative studies involving fewer than 50 participants. However, this generated a very small number of relevant studies, so the criteria were revised to include surveys of 140 participants or more and qualitative studies of 20 participants or more.

<sup>4</sup> With the exception of two Malaysian studies (Wo et al, 2015a; Wo et al, 2015b) which were included because they are high quality peer-reviewed studies, published in relevant journals (*Epilepsy Research* and *Epilepsy & Behavior*).

### 3.3 Expert interviews

Interviews took place with four experts from a range of backgrounds to obtain an overview of employment support for people with epilepsy and to inform the research with employers and people with epilepsy:

- **Professor Stephen Bevan:** IES's expert in workforce health and wellbeing and leader of national and international projects focusing on workforce health and the impact of chronic illness on productivity and social inclusion.
- A physician and occupational health adviser from a leading employer organisation, with specialist expertise in epilepsy.
- A **Disability Employment Advisor (DEA)** and Work Coach from Jobcentre Plus, responsible for managing employment support services to assist people with disabilities and health conditions to enter employment.
- A third sector **expert in training and support for people with epilepsy.**

The expert interviews took place concurrently with the literature review and before the employer interviews and focus groups. This enabled insights from the expert interviews and literature review to inform the questions asked of the employers and the people with epilepsy.

The experts were consulted about all six of the research questions, and were also asked to provide insight into how epilepsy compares with other long-term health conditions, in relation to support into employment.

### 3.4 Employer interviews

Eight employers were recruited as a purposive sample, selected from IES's network of employer contacts. Although this was not a representative sample of the UK employers population the sample allowed researchers to elicit opinions from the private, public and third sectors, and from large and small employers. Manual occupations as well as office-based roles were covered to ensure discussions referred to jobs involving different levels of physical activity and cognitive workload.

The sample included:

- Four large, two medium and two small employers.
- Six private sector employers, one from the third sector and one from the public sector.
- Industries included retail, transport, manufacturing, social care, construction and the service industry.
- Interviewees held diverse senior roles as line managers, business owners, HR managers and occupational health managers.

A key aim was to explore the type of information and employment support that would help inform and reassure employers when considering employing someone with epilepsy or continuing to employ someone with epilepsy.

## 3.5 Focus groups with people with epilepsy

The face-to-face focus groups with people were a valuable opportunity to obtain the lived experience perspective of people of working age with epilepsy.

The focus groups were recruited via Epilepsy Action's network of contacts, in order to efficiently and sensitively reach people with epilepsy. Two groups took place in Yorkshire and London, split approximately equally between the two areas, to provide a geographical spread across England, each involving a total of eight participants. Following low attendance at the Yorkshire group, these data were supplemented by online data submitted by five people with epilepsy who were shortlisted to take part in the groups but were unable to attend.

The interview participants did not constitute a representative sample of the UK population of people with epilepsy, but were purposively selected via screening calls to create focus groups with a mixture of different profiles and experiences. The resultant sample of 15 people comprised:

- About half female (7), half male (8).
- Two thirds white (10) one third BAME (5).
- A mix of ages: 21-30 (5), 31-40 (1), 41-50 (5), 51-60 (4).
- Two thirds were employed - either full time (4), part time (3) or self-employed (3); two participants were unable to work because of their health condition; a further three were unemployed and looking for work.
- People predominantly described their seizures as 'tonic-clonic'; a smaller number of participants had absence, focal or other forms of seizure.
- For a third of people, their seizures were fully controlled by medication; less than two thirds had seizures that were partially controlled; one participant had seizures that were not controlled at all.
- About a third of the participants had had a seizure over a year ago, the remainder had had seizures at least once in the past year, and over a third had at least one seizure a month.

The focus group approach offered the advantages of allowing those involved to share experiences in a supportive environment, helping them to feel comfortable and talk freely, and to exchange ideas about the types of employment support that they would like to see. The people with epilepsy were able to address most of the research questions, and in particular offered insight into what good employment support for people with epilepsy should look like and what impact could be achieved with good employment support.

## 3.6 Analysis and report structure

The remainder of the report synthesises findings from the desk review, focus groups and interviews, based on a thematic analysis of the data.



The report structure is as follows:

- Chapter 4 examines how epilepsy compares to other health conditions and the possible implications for employment support.
- Chapter 5 considers the findings from the employers' interviews, with particular reference to what information about epilepsy would reassure an employer.
- Chapter 6 covers the barriers that people with epilepsy encounter in their dealings with employers and the support needs that might result.
- Chapter 7 draws conclusions about what employment support for people with epilepsy should look like, and how charities that support people with epilepsy and other conditions might best work with and influence employers.
- Chapter 8 looks at the impact that participants thought could be achieved with good employment support.
- Chapter 9 presents the conclusions.

## 4 How epilepsy compares to other health conditions

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The research aimed to establish what might make epilepsy intrinsically different from other health conditions, as well as how it might be seen as similar to other health conditions. Communicating how epilepsy is different from other health conditions is likely to be important in designing and publicising employment support for people with epilepsy and their employers.

The literature identified during the desk review had little to say about how epilepsy compared with other health conditions, but fieldwork findings were more informative. The experts who were interviewed were well placed to draw interesting parallels between epilepsy and other conditions, as their experience across occupational health, applied and academic research, and employment support, covered both epilepsy and many other health conditions. Based on academic research and their own experience, experts were able to shed light on how attitudes towards epilepsy compared with other health conditions. They were also able to consider how epilepsy might affect people's entry into various types of employment, and compare this with the experience of people with similar or contrasting conditions.

The differences and similarities between epilepsy and other health conditions can be a difficult topic to draw conclusions about, because of the diversity of epilepsy itself, and the variety of other health conditions that exist. However, common themes emerged from the experts' opinions. They agreed that, like other health conditions, epilepsy is a 'red flag' for employers because of employers' productivity concerns. Nevertheless, they thought that epilepsy 'stood out' from other health conditions as it represented 'more of an issue' for employers, most notably because of employers' safety concerns. Several other linked aspects appeared to influence why epilepsy might be seen as more difficult to accommodate in the workplace than other conditions; these aspects are set out below.

### 4.1 Awareness

The research team explored what experts thought about knowledge and preparedness about epilepsy from the perspective of employers and the general public, compared with other health conditions. One expert described the 'ignorance' surrounding epilepsy as 'staggering'. Other experts agreed that epilepsy is seen as 'more of an issue' than some other health conditions, because of the general lack of awareness, and the stigma surrounding epilepsy. There was a feeling that the multitude of different types of epilepsy and the individual way it affects people were part of the reason for this. This highlights a general need for improved education and communications about epilepsy, a theme that is explored throughout this report.

To illustrate the lack of understanding about epilepsy, one expert compared it with asthma and diabetes, conditions that can lead to a physical collapse at work. He thought that the reaction of members of the public to an epileptic seizure was likely to be less informed and less helpful:

### Case study: expert opinion on people's attitudes to and preparedness for epilepsy seizures

A physician and occupational health expert thought it was more likely that someone witnessing an epileptic seizure would be more worried and unsure what to do, than if they saw someone with diabetes having a hypoglycaemic attack. He believed that the general public were better informed about diabetes and had a more 'matter-of-fact' attitude towards it: in the event of someone with diabetes collapsing, a member of the public might, he thought, respond in a practical and helpful way – *'just get [them] some sugar and everything will be fine'*. An epileptic seizure, on the other hand, might result in a more fearful and less informed response.

These suggestions echo the findings of several earlier studies of employers' and employees' awareness of epilepsy. A survey of employees found that familiarity with a person with epilepsy led to a higher level of knowledge and a more positive perception of someone with epilepsy as a possible future colleague; the researchers concluded that employees at all levels should be educated about epilepsy in order to improve the employability of people with epilepsy (Dorota et al, 2014). Another study noted that negative attitudes towards the employment of people with epilepsy often stemmed from employers' ignorance about the condition (Baker, 2017). Findings from a UK survey of employers showed that employers' main concerns about employing someone with epilepsy centred on fears of extra costs and disruption (Jacoby et al, 2005). Employers' specific worries were:

- That it could make other employees uncomfortable if they witnessed a seizure (73 per cent)
- That it could increase employer liability insurance costs (42 per cent)
- That it could disrupt work flow (38 per cent)
- That it could reduce other employees' concentration levels (22 per cent)
- That it could undermine company efficiency (14 per cent)
- That it could cause other employees to refuse job assignments (12 per cent).

That survey was completed 13 years ago. Our interviews with employers, reported in the next chapter, show that such concerns are still commonplace. Perceptions around productivity are explored further in the next section.

## 4.2 Productivity concerns

Experts thought that epilepsy resembles other health conditions in that it immediately raises concerns for employers about the potential loss of productivity, due to doubts about the reliability and attendance record of someone with epilepsy. This is despite the fact that (as experts pointed out) an individual's condition might be stable and well controlled by

medication. There was also a view that employers might expect someone with epilepsy to take more days off for sickness absence than the average. These could be because of a seizure, to recover from a seizure, to attend health appointments, to undertake tasks in a different way, or for other reasons related to their epilepsy. Experts were aware too of employers' concerns about 'presenteeism': someone with epilepsy attending work but being less productive than normal, for example because of feeling drowsy while on anti-epilepsy medication, or feeling tired because of insomnia or when recovering from a seizure. This highlights potential misperceptions that could be addressed with information targeted at employers.

### 4.3 Unpredictability

Unlike some easier to manage health conditions, epilepsy was perceived to be unpredictable. Experts drew parallels between epilepsy and other health conditions that are variable and irregular, such as multiple sclerosis, rheumatoid arthritis, psoriasis and irritable bowel syndrome (IBS). The erratic nature of epilepsy and other similar conditions was noted to be difficult for employers to manage when planning staff resourcing and supplying products and services.

### 4.4 Safety and the law

Experts felt that safety would be a key area of concern for employers in relation to epilepsy, more so than for other health conditions. These concerns would be likely to centre on firstly, the safety of the individual with epilepsy during a seizure and secondly, the impact that could have on colleagues. Experts thought that employers' concerns would focus on the most disruptive forms of seizure, and that they would anticipate potential knock-on effects on teams' productivity, such as needing to take other staff away from their duties, or the need for a trained first aider.

Experts were sympathetic to employers' safety focus which was seen as '*understandable concern*'. They felt this would be more of an issue in industries like manufacturing, and in relation to employees engaged in physical and mechanical tasks. This was borne out in the interviews with employers set out in the next chapter.

It was felt that a 'safety-first' approach could be problematic since some employers might use this to justify not hiring someone with epilepsy, or as a reason to dismiss them, as argued in the case study below. The UK legal system was seen as generally very favourable towards the rights of people with health conditions and disabilities. An expert in training and support for people with epilepsy pointed out that people in the UK were encouraged to disclose their epilepsy during job applications. However, he thought that early disclosure could give an employer the opportunity to turn down a job application from someone with epilepsy. Note that chapters 5 and 6 illustrate this point, with examples from people with epilepsy who have encountered a 'safety-first' argument as a barrier to their employment.

### Expert believed employers use ‘safety’ to justify discriminatory practices

Professor Stephen Bevan, IES’s expert in workforce health and wellbeing, commented on employers’ concerns about epilepsy, safety and employment. His opinion was that employers often *‘instrumentalise’* their concerns about health and safety as a means of justifying not employing people with health conditions such as epilepsy. Research on health and wellbeing at work showed, he said, that in many cases such concerns were groundless. He suspected that employers might use ‘health and safety’ as a reason to not hire someone with epilepsy, even in situations where the epilepsy is well controlled, because they saw having an employee with epilepsy as *‘too much hassle’*.

Another expert in the area of employment support for people with disabilities and health conditions provided examples of employers justifying their reluctance to hire someone with epilepsy. Common ‘excuses’ included citing ‘health and safety’ policies and procedures, claiming their employer liability costs would be higher if they employed someone with epilepsy, or that they would be sued if someone with epilepsy had a seizure and sustained an injury.

By using these and other safety-related concerns as justification to not hire someone, or to dismiss someone, experts pointed out that employers might be in contravention of the Equality Act 2010, the UK’s anti-discrimination legislation. This highlights the limitations of relying on legal guidelines alone to change people’s attitudes to health conditions; this is discussed further under chapter 7.

The association between epilepsy and safety concerns is arguably a consequence of stigmatisation, which is described in more detail below.

## 4.5 Stigma

Experts perceived that employers tend to ‘stigmatise’ epilepsy and, by association, people with the condition, making them reluctant to employ people with epilepsy or support them to progress their career. While this was true of people’s attitudes towards other health conditions, experts thought that prejudices about epilepsy were particularly profound in this respect. Experts described employers as *‘fearful’* and *‘ultra-cautious’*. They suspected employers were influenced by worries that seizures were dangerous for the person with epilepsy and problematic for their employers and colleagues. Experts described the fearful reaction to epilepsy as similar to that shown towards serious mental health conditions, of which schizophrenia was one example.

Evidence about stigma in the literature included a survey of 204 UK companies (Jacoby et al, 2005). This data showed that employers were particularly concerned about employing someone with a disability or health condition when it is ‘invisible’. Experts echoed this finding: they agreed that employers and employees tend to be less sympathetic towards, and more likely to stigmatise, people with epilepsy and other conditions such as mental illnesses that are not immediately physically obvious. It was suggested that this was because epilepsy is less visible, less easy to define and less easy to understand. With such an unclear picture, employers might be likely to assume the worst. The Jobcentre

Plus Work Coach expert noted that employers typically worry that someone with epilepsy *'won't fit in'* or will *'be a bit odd'* and *'the team won't cope'*.

#### 4.5.1 Less stigma towards existing employees?

Experts thought employers would show more enthusiasm for and flexibility in finding solutions to allow an existing employee who developed epilepsy to remain in their job, than they would if recruiting someone with epilepsy who was unknown to them. The Equalities Act 2010 was noted to be a 'safety belt' that incentivises employers to retain existing staff. This suggests there is need to provide support to employers with particular attention to getting people into work, as well as enabling them to remain in and progress in their roles.

#### 4.5.2 Mental health and 'self-stigma'

Mild to moderate mental health conditions are often 'co-morbid' with other chronic health conditions. Therefore, experts expected that many people with epilepsy were likely to have mental health conditions, typically anxiety and depression. This could result in low self-esteem and lack of confidence, potentially leading those affected to set lower career goals and rule themselves out of fulfilling employment opportunities that might seem out of reach. Some experts suggested that poor mental health and self-limiting behaviour around employment were often apparent from an early age in people who had epilepsy in childhood. This could be negatively influenced by school experiences, as well as families and other carers being overly protective. This shielding attitude of family and friends could continue into adult life:

*'It really starts quite early on about what you can and can't do. Families can actually stifle [...] what the kid, the adolescent or the teenager with epilepsy goes on to do.'*

Epilepsy expert

The Jobcentre Plus Work Coach expert recognised that it could take a long time for employment support professionals to address low mood in an individual with epilepsy and to help them build confidence to look for work that truly matched their abilities. Anxiety and depression and feelings of self-stigma were seen as very hard to shift. She described late onset epilepsy as being particularly difficult for people to manage at work, since it involves a change of lifestyle and potentially self-image that can be hard to adjust to.

The above views mirror the findings of academic studies that have looked at the effect of self-stigma. Bautista and Wludyka found that the psychosocial factors that were significantly associated with employment in epilepsy patients included decreased fears of workplace discrimination (Bautista and Wludyka, 2007). A Malaysian study based on interviews with 21 people with uncontrolled seizures, found that individuals who were employed tended to have a positive perception of their own working ability despite their epilepsy and were not *'ashamed of having seizures'* (Wo et al, 2015b). These findings highlight the need for people with epilepsy to receive support to overcome self-stigma and to raise their confidence in pursuing career goals.



## 4.6 Self-management and positive disclosure

Several experts talked about the need for people with any kind of chronic health condition to 'self-advocate' or 'self-manage' their condition. Academic and applied research across a range of health conditions has shown that providing people with chronic health conditions with tools to 'self-manage' and 'self-advocate' can enhance their chances of successful employment. According to the experts participating in the current study, the concept of encouraging people to be active in managing their health condition is relatively new. It is interesting to note that there is academic evidence from the Netherlands suggesting that training interventions to improve self-efficacy and coping skills can equip people with epilepsy with more confidence to apply for suitable employment (Smeets et al, 2007). Similarly, a small study carried out by an American specialist in rehabilitation counselling recommended 'impression management' as a valuable tool to 'empower' people with epilepsy to combat stigma, and offset any negative perceptions that employers may have (Sung et al, 2017). These findings suggest that employment support that targets people's ability to 'self-advocate' and 'self-manage' may improve people with epilepsy's employment experience.

Improving 'self-management' and 'self-advocacy' may also have a bearing on how confident people with epilepsy feel about disclosing their condition to employers. While expert interviewees were keen to encourage people with epilepsy to disclose their condition confidently and 'positively' to employers, they recognised that many would dislike discussing their condition openly. They expected poor mental health and a possible tendency to 'self-stigmatise' to affect individuals' readiness and ability to disclose their epilepsy to an employer and to educate an employer about their condition. Young people were noted to be more likely to be nervous or embarrassed about approaching employers with their needs. It was suggested that there might also be a drop-off in support as young people transition from education into employment, and in the move from medical care for children into adult care.

The psychological factors that affect people with epilepsy's employability and employment status have also been discussed in the research literature. Wo and colleagues' small scale qualitative study found that those people with epilepsy who were employed tended to work towards a future goal and were motivated by self-satisfaction, while those who were unemployed tended to lack intention to work (Wo et al, 2015b). The themes of openness about disclosing and discussing epilepsy, and managing epilepsy at work were very prevalent in the focus group conversations and are discussed further in chapter 6.

## 4.7 Summary

Across the expert interviews, there was a clear consensus that some employers react negatively to the idea of working with someone with a health condition, often centring on concerns about productivity. Experts thought employers might be even more averse to employing someone with epilepsy. They ascribed this to employers' lack of awareness about epilepsy, employers' concerns (which experts thought were often exaggerated or misinformed) about safety, and about the unpredictability of the condition – all of which

could contribute to a tendency to stigmatise epilepsy. Experts also expected that the common occurrence of mental health conditions alongside epilepsy would be further barriers to people with epilepsy being welcomed into the workforce. Experts thought that the concepts of 'self-management' and 'self-advocacy' were likely to be effective in helping people with epilepsy to succeed in employment (this is discussed further in chapter 7). The next two chapters substantiate these findings, drawing from the direct experiences of employers and people with epilepsy.



## 5 What information about epilepsy would reassure an employer?

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This chapter considers findings from the employers' interviews, with a focus on the type of information about epilepsy that would reassure an employer. Employers were encouraged to speak candidly about:

- What they knew about epilepsy, including their personal experiences.
- How they perceived people with epilepsy.
- How confident they felt about hiring and working with people with epilepsy.
- How they might approach recruiting and managing someone with epilepsy.
- Where they would seek help or advice.
- What information or guidance would reassure them and make it more likely that they would consider hiring someone with epilepsy in the future.

During the employer interviews, employers were also asked how they would feel about hiring and working with three hypothetical individuals with different epilepsy symptoms (the descriptions that were shared with employers are included in Appendix 1), to gauge how employers' would react to varied epilepsy symptoms, differences in seizure frequency and duration, differences in seizure recovery period and how effectively the condition was controlled by medication.

While an expert warned us that employers might give us a more positive and 'theoretical' picture of their attitudes and behaviours than was the 'reality' - employers did appear to voice their concerns frankly. From their responses it is possible to discern some areas where Epilepsy Action could make a contribution to reassuring employers and filling in gaps in their knowledge.

### 5.1 Employers' awareness of epilepsy

Personal experience of epilepsy was quite limited among participating employers: although a small number had previously known or worked with someone with epilepsy and one had had epilepsy as a child.

At the start of the interviews, most employers described themselves as having some general knowledge about epilepsy. While all thought that epilepsy involved a seizure, these were usually assumed to involve the person falling to the floor and losing consciousness (what are classified medically as 'tonic-clonic' seizures). Employers were usually less familiar with other less visible types of seizures, such as absence seizures. There was uncertainty about the triggers that might result in a seizure; for example,

several thought that the majority of people with epilepsy would be 'photosensitive', having seizures triggered by flashing lights or flickering computer screens, although this is relatively uncommon (Epilepsy Action website, 2018). Employers also lacked awareness of the fact that about half of people with epilepsy are seizure-free (Epilepsy Action website, 2018).

During the discussion of the three hypothetical individuals with different epilepsy symptoms (Appendix 1), it was noticeable that employers' initial reaction towards the person with 'absence' seizure was not markedly more positive than their reaction towards the individuals who had 'tonic-clonic' seizures. Employers tended to take a blanket attitude of finding epilepsy off-putting. The researchers often needed to prompt the employers, by highlighting the implications of each individual's symptoms in detail, before they began to recognise that less disruptive symptoms, or symptoms that were well controlled by medication, would be easier to accommodate in the workplace than they had first assumed. This can be seen in the following case study.

### Paul starts to question his assumptions about employing someone with epilepsy

Paul, the owner-manager of a family-run retail business, had no direct experience of epilepsy<sup>5</sup>. He was aware that it involved *'fits, every now and again'*. During the discussion of the three individuals with epilepsy (Appendix 1), it was interesting to see how his attitude softened, once he had heard more about epilepsy and after he had reflected further. Paul's initial reaction was that it *'would not be ideal'* for someone with epilepsy to work in his business because his employees handle knives and other sharp tools and work in close proximity to one another. He was also worried that his customers would not know how to react if an employee had a seizure. However, it came as a surprise to him that epilepsy can often be well controlled by medication and he was interested to learn that not all seizures would involve someone falling to the floor. The interviewer prompted him to think about the fact that the three individuals could be ideal employees, with the knowledge, skills and experience to work in his business. Towards the end of the interview Paul wondered if it might be a matter of keeping an open mind: meeting the prospective employee, hearing in detail about their health condition then, if their epilepsy was well controlled by medication, he might *'see what develops'*.

Employers' lack of awareness of epilepsy strongly suggests an education need amongst employers, and this is discussed at greater length in chapters 6 and 7. Employers also expected an employee with epilepsy would be able to explain their condition to them, and to suggest suitable adjustments. As will be seen in chapter 6, people with epilepsy might not always be in a position to do this.

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<sup>5</sup> Names have been changed.

## 5.2 Employers' concerns

### 5.2.1 Safety

In line with findings in the previous chapter, safety appeared to be employers' principal concern when considering hiring or working with someone with epilepsy and was the first thing they mentioned when asked how they would feel about the three hypothetical individuals with epilepsy (Appendix 1). Their safety concerns centred on a number of areas, influenced by the types of workplaces and work activities they carried out. Operating machinery of any kind, but particularly driving vehicles and using machines with blades, was a central concern. Working alone, particularly when away from the main work premises or with a client, was raised as a potential issue. Putting too much pressure on the person with epilepsy was also a worry, whether this was caused by stressful situations, long working hours, shift working or testing deadlines. Some contrasting examples of the safety issues that employers identified in different workplaces are given in the following case studies.

#### **Different working environments raise a variety of safety concerns for employers**

Vincent manages occupational health services for construction companies. He listed the many hazards in the constantly changing construction site environment, including working at height, operating machinery and the dusty atmosphere. When recruiting employees, Vincent asks searching questions of people's mental and physical health and seeks medical advice before employees are cleared to work on site. If a prospective employee did not have a full driving licence that would indicate to him that they had a medical issue that would prevent them being eligible to work for a construction company. He predicted that most people with epilepsy would not be medically cleared for employment in construction. In addition, if someone developed epilepsy while in employment, Vincent expected that most construction companies would dismiss them, as he has seen happen with other workers with comparable health conditions.

Sandra works in HR for a charity that provides support services to vulnerable adults. The majority of employees worked remotely in support roles, often lone working while caring for their clients, driving to see clients or doing night shifts in residential roles. Although everyone at the organisation was *'good hearted'*, Sandra said she could not envisage how anyone with uncontrolled epilepsy could work in support roles since a seizure could leave a vulnerable client unprotected and would also mean the person with epilepsy might be at risk. Sandra thought the only adjustment that would enable someone with epilepsy to work in a support role was if an additional member of staff accompanied the person with epilepsy, but the organisation could not afford this without government help.

In many cases, anticipated safety issues led employers to say they would exclude the possibility of recruiting someone with epilepsy at the outset. This suggests that (as people with epilepsy concluded too) addressing concerns about safety is likely to be key to changing the mindset of many employers about recruiting someone with epilepsy.

## 5.2.2 Productivity, costs and adjustments

The previous chapter suggested that employers - as reported by experts and evidenced in the research literature - are likely to be concerned about the costs and disruption that might ensue from hiring someone with epilepsy. Likewise, employers involved in the current research were hesitant about making adjustments to allow the person with epilepsy to fit into their workplace and activities. They expected this to present costs and logistical challenges and wondered if it would be feasible. For instance, most said they did not have space on their premises where an employee could go to recover after a seizure. They were unsure whether they could afford for other staff to leave their duties to care for someone with epilepsy in the event of a seizure, or cover for someone while they went to hospital or returned home to recover. They were also concerned that hiring a person with epilepsy could increase their employer liability insurance costs. In many cases there was an overall sense that employers wanted to support people with epilepsy, but expected adjustments to be beyond the scope of what they could offer because of the nature of their workplace and its main activities.

## 5.2.3 Reactions of employees and clients

Another key concern for employers was how colleagues would react to seeing a seizure. Those participating in this study anticipated that this would be distressing and that employees would not know what to do, unless they had received prior training. This is consistent with the findings of a poll of 2,043 adults in the UK which showed that, of those (over a quarter of respondents) who expressed concerns about working with a colleague with epilepsy, 63 per cent stated that this was because they had no idea about what to do to help a co-worker suffering a seizure (YouGov, 2016).

Where employers worked with clients or partners, fears about seizures were compounded because they could not expect clients or external organisations to know how to respond. An illustrative example was the store manager for a supermarket.

### **James had concerns about witnessing an epilepsy seizure and how staff would cope**

James is a store manager for a supermarket chain. He was concerned that an employee with epilepsy might pose a risk to customers and other employees as well as to themselves, and that their seizures could distress others. He considered what would happen if an employee with epilepsy had a seizure while carrying something. What would happen if something dropped and injured someone? If the person having the seizure lost bowel control, would the people around them know what to do? If the person with epilepsy had to go home to recover, how would he cover their shift? James expected the situation would distress his employees, many of whom are young. As staff turnover is high James thought it would be difficult to make sure everyone understood the situation and was able to deal with it. James himself would need to make sure that people remained calm. Since health and safety policies and procedures were set by the supermarket's head office, James doubted that he had the scope to make the necessary adjustments to allow someone with epilepsy to work at the store.

Addressing employers' fears and assumptions about epilepsy, and those of their employees and clients, should form an important part of employment support and education about epilepsy. Further findings from the focus groups with people with epilepsy on this point are shown in section 6.2.

#### **5.2.4 More tolerance towards existing employees**

As experts had predicted, employers appeared more open to the idea of making adjustments for an existing employee than they were to recruiting a new member of staff with epilepsy. This suggests that employment support should pay particular attention to getting people with epilepsy into work, as well as enabling people in employment to remain in work and progress.

### **5.3 Open communications**

All of the employers participating in this study said they would expect job candidates with epilepsy to declare their health condition at application, either via the application form, at interview, or immediately after they started their new job. Their reasons were twofold: first to enable the employer to inform anyone responsible for the safety of that person, such as a first aider, their line manager or an occupational health adviser; and second, to enable a conversation about what adjustments needed to be made. Almost all those interviewed said they would take a dim view of someone with epilepsy not revealing their condition if it subsequently emerged, for example by them having a seizure. This emphatic preference for full disclosure of epilepsy at an early stage is in marked contrast to the situation people with epilepsy said they would prefer, as reported in chapter 6.

### **5.4 Summary**

The overriding message from the employers' interviews was that it is important not only to educate employers about different types of epilepsy and how to manage it at work, but to provide reassurance about a range of issues. Employers need to feel confident that someone with epilepsy will be safe in the workplace, will not inconvenience, distress or endanger others, or negatively affect productivity. They also want someone with epilepsy to disclose their condition during the job application, or soon after starting a new job.

## 6 What information about epilepsy would support people with epilepsy in their interactions with employers?

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The research questions for this study did not include examining what information and support would help people with epilepsy in their interactions with employers or colleagues. However, in discussions with people with epilepsy and with employers, this emerged as an overarching need. Earlier research has also identified this as a priority. For example, a US study of 146 adults with epilepsy concluded that people with epilepsy would benefit from education and ‘vocational counselling’ to help them to communicate more effectively with colleagues, both when disclosing their epilepsy and to prepare colleagues to respond to a seizure (Bishop, 2004). A focus on helping people to communicate about health and work is also an important component of recent UK Government strategy. *Improving Lives* set out plans for frontline Jobcentre Plus staff (Work Coaches) to hold ‘Health and Work Conversations’ with people with disabilities and health conditions (Department for Work and Pensions, Department of Health, 2017). These involve the Work Coaches discussing with people who are claiming Employment Support Allowance (ESA) and Universal Credit (UC) their health condition and employment plans. The emphasis is on assisting people to ‘*respond resiliently to challenges*’ and to ‘*overcome [people’s] fixed beliefs*’ about their own abilities.

The information that follows in this chapter illustrates the barriers that people with epilepsy encounter in their dealings with employers and the support and information needs that then result.

### 6.1 Concerns of people with epilepsy

#### 6.1.1 Fluctuating health conditions are hard to understand or describe

The findings in the previous chapter showed that employers wanted people with epilepsy to take the lead in telling them about their condition and the adjustments they needed. Furthermore experts thought that self-management could be a useful approach to empowering individuals to do this. However, as the quotes below illustrate, it was striking that many of the people with epilepsy who took part in this research felt they did not fully understand their own condition, could not define it easily and would not feel comfortable educating an employer about it. For example, some noted that they were unsure what their specific ‘triggers’ were, others did not know if their medication would reliably control the epilepsy in the future. The fact that their condition fluctuated made it hard to describe it clearly and with conviction.



## People with epilepsy find it difficult to explain their fluctuating condition clearly to employers

*'Everyone just thinks a flash of lights [is] going to go off and I'm going to go crazy! [...] Nobody really knows what it is... I had to explain it all and I don't know tons about it myself so it's a bit of a strange one.'*

*'Every employer that I've ever had to be honest has been lovely and really understanding and everything like that, but there's just this feeling that they don't know what it is, and I'm not the person to tell them what it is because I don't understand it fully myself either.'*

*'Explaining it to people – like if I get this job at [organisation] – I don't even know where to start with trying to explain it. Even the first one [type of epilepsy] that I was diagnosed with, I still don't understand it myself.'*

*'I've had it 24 years and I don't fully understand it myself.'*

*'[The issue is] recovery, understanding that you might not be the same every single day.'*

*'It can vary hour to hour how you're feeling. I can go to work fine one morning, but by lunchtime I could be feeling really crap.'*

*'I would expect HR to know about this [epilepsy and seizures], I wouldn't expect someone to come to me and say, "can you tell me about your condition please?"'*

People with epilepsy

Due to the difficulty of understanding and defining their own variable health condition, most people with epilepsy concluded that they would not feel confident and comfortable about clearly describing it to an employer, or educating colleagues about how to handle their condition at work. This could make it more difficult for people with epilepsy to negotiate adjustments to the physical environment and workplace activities and to agree with colleagues what to do in the event of a seizure. It could also make it harder for people with epilepsy to challenge employer discrimination. Providing a solution to this need could be fruitful for Epilepsy Action to explore, and suggestions are shown in the next chapter.

### 6.1.2 Safety is main concern

Employees with epilepsy were concerned to assure their own safety and that of colleagues, but found the conversations with employers about this awkward and stressful. Sometimes people with epilepsy appeared to take a short cut to being safe in the workplace by ruling themselves out of certain jobs, as in Karen's case below. This carries the risk that the person with epilepsy might limit themselves to jobs that are physically safe, but below their capabilities.

#### Karen considered her safety and that of others when selecting a job

*'Safety, of myself and others that might be around'* was a key consideration for Karen when selecting a job. Her epilepsy causes one side of her body to jerk and she monitors her work environment carefully to ensure that this does not endanger herself and others around her.

She ruled out working at one office because the only toilets were accessed by a spiral staircase. At another workplace, the kitchen was downstairs, so she relied on colleagues to help her carry drinks. Lights triggered bad headaches, so she had to negotiate with colleagues to agree to her having lights off in her area of office; if visitors were unaware of this it could lead to misunderstandings. Karen took care to ensure she was never in the building on her own. Attending external events was too risky because she could not control the physical environment outside her office, and this led to her missing out on learning opportunities such as team-building days.

Karen was considering her next job move: choosing between a job with a familiar employer and a promising new job with an unknown employer. She thought that the new role would be a good opportunity, but *'all the stress of starting from scratch again'* in a new environment deterred her.

Helping people with epilepsy to discuss safety and adjustments with their employers in a clear and constructive way is another area where Epilepsy Action provides useful guidance. Suggestions to develop this further are discussed in the next chapter.

### 6.1.3 Mental health issues can also be present

As the experts had predicted, poor mental health was reported by many of the people with epilepsy who took part in this research. Stress, depression, low mood and anxiety were all raised as issues. People emphasised that their mental health conditions were not a direct result of their epilepsy but resulted from the emotional toll of coping with epilepsy and its life-changing consequences. Treating both epilepsy and a mental health condition simultaneously sometimes meant people were taking several types of medication; this could result in side effects that affected work performance, such as drowsiness or insomnia. Often, people were reluctant to speak to employers about their mental health for fear of *'adding another issue'* to their roster, as described in Amanda's example below.

#### Adult onset epilepsy led to mental health issues for Amanda

Amanda echoed the feelings of many people in this research when she described *'the deep-rooted feeling of anxiety and low self-esteem which have insidiously affected my mental health'*.

Having developed epilepsy in early adulthood as the result of an injury, Amanda's mental health had declined. She described her epilepsy as giving her the sense that she was facing death on a daily basis. At work, Amanda felt that her employer perceived her epilepsy to be a nuisance. Conversations about her epilepsy with her line manager were often difficult and on one occasion, she was warned not to *'play the disability card'*. Despite being aware that her poor mental health was having a negative effect on her ability to work, Amanda did not seek assistance from her line manager or from human resources. Given her employer's complaints about her epilepsy, Amanda did not feel comfortable telling her employer about the additional impact that epilepsy has on her mental health.

The co-morbidity of mental health conditions and epilepsy in many cases suggests that it would be worthwhile educating employers and people with epilepsy about the likelihood of both types of conditions being present. This would also necessitate equipping some employers with better mental health awareness.



### 6.1.4 How epilepsy and medication affect ways of thinking

People with epilepsy often talked about how their condition affected their style of thinking. Sometimes epilepsy, or the medication they were on, made it more difficult to carry out tasks in the way that line managers and other colleagues expected them to. The fluctuating nature of the condition could mean that people found they were thinking less clearly on certain days, particularly during the recovery period after a seizure, or when adjusting to new medication that might leave them with muddled thinking. People talked about having insomnia or memory loss that made it hard to concentrate and ‘*keep track of things*’ at work. They used techniques to help their memory and processing, such as writing lists, printing emails or labelling items.

However, differences in their way of thinking and processing led to conflict if line managers refused to adjust ways of working or measured their performance using strict competency-based criteria. Disagreements with employers sometimes created a vicious circle of tension between employer and employee, leading to the person with epilepsy having poorer mental health and increasing the likelihood of work disputes and dismissal or resignation from work.

Giving people with epilepsy hints and tips to assist with memory and loss of concentration could be useful. Supporting people with epilepsy to negotiate alternative ways of working and performance measurement could also help to avert work disputes.

### 6.1.5 Confusion about discrimination

The people with epilepsy who took part in this research were unclear about what constitutes discrimination against people with disabilities in employment. This meant that they were reluctant to challenge behaviours and practices that they felt to be discriminatory, because they were unsure if this was supported by legislation. Comments and suggestions made about their ability to take on work and progress with in the organisation were often felt to sit in a ‘grey area’.

*‘The lack of understanding what my rights are in the workplace around epilepsy and disability really prevents me from knowing what they’re doing wrong and how it ought to be according to disability law.’*

*‘I think it’s difficult to get a promotion because if they see that you’re taking on too much pressure, and have a seizure, they won’t give you the [higher] job. They’ll take you to the interview process, and then they’ll give it to someone else, just so that you don’t think there’s a rat in the kitchen.’*

*‘I was told that, “if you want to go to a senior position, will you be able to cope with the pressure?” I was thinking, “you can’t say that me can you?” But I’ve got that doubt about what discrimination is.’*

People with epilepsy

This suggests a need for employment support to identify discriminatory workplace behaviours and practices and to suggest ways of tackling these.

## 6.2 Bad experiences at work

Many of the people with epilepsy who attended the focus groups had experienced challenging experiences at work encompassing recruitment and relationships with colleagues. The problems they reported were consistent with findings in the literature. Perceived stigma has been reported in earlier studies about epilepsy and employment. For instance, in a recent Australian survey of 343 people with epilepsy, 48 per cent of respondents reported perceptions of unfair treatment as a result of their epilepsy and 47 per cent cited examples of discrimination at work (Bellon et al, 2013). An American experimental study of epilepsy-based discrimination in the workplace examined the influence of stigmatisation on the workplace outcomes of hypothetical employees with children with epilepsy (Parfene et al, 2009). The 56 participants 'acting as employers' made recommendations about the hypothetical employees' workplace rewards (promotion, salary increases) and penalties (job termination). The outcomes for parents of a child with epilepsy were fewer workplace rewards and greater workplace penalties than for employees with children with asthma. This suggests that stigma by association with someone with epilepsy might also be an issue in the workplace.

Reducing stigma by educating employers about epilepsy and addressing common misconceptions is clearly an area of need.

### 6.2.1 Disclosing epilepsy during recruitment seen as risky

The majority of people with epilepsy who took part in this research were firmly of the opinion that it was better not to disclose the fact that they had epilepsy during recruitment, since disclosing carried the risk that the employer would turn down their application. This was often based on personal experience: several people suspected that employers had not called them to interview or offered them a job after they had revealed their condition. While it was hard to evidence discrimination – employers had tended to provide plausible alternative reasons not to take their application forward – focus group participants felt strongly that it had happened.

#### **Diane did not disclose her epilepsy, but a seizure led to her resignation**

When Diane applied to work as an office cleaner, '*I used my brain...*' and she opted not to disclose her epilepsy to the cleaning agency. She concluded that this meant she was able to get the job. However, just over a week later she had a seizure at home. After her recovery, she did not return to work because she did not want anyone at her workplace to know she had epilepsy. It appeared that she thought it very likely the employer would dismiss her, so she pre-empted this by resigning.

Reluctance to disclose is a recurrent theme in the research literature. For example, in a Polish study in which 197 adults with epilepsy answered a questionnaire, only 42 per cent of those who were professionally active had told their employer that they had epilepsy, and this was usually due to previous negative experiences (Staniszewska et al, 2015). An American study investigating discrimination faced by young people and adults with epilepsy in employment concluded that most perceived and actual discrimination occurs

after recruitment rather than during ‘hiring situations’ (Hawley et al, 2012). However, on the evidence of the current research, people with epilepsy perceive discrimination to also be common during recruitment. They concluded that disclosing epilepsy to an employer during application carries an inherent risk of discrimination and dismissal. This chimes with the experts’ conclusion that employers would show less enthusiasm for and flexibility about recruiting someone with epilepsy than they would in finding solutions to allow an existing employee who developed epilepsy to remain in their employment.

Among people in the current study, those that chose not to disclose were worried about the legality of not doing so. For example, one individual described the dilemma of choosing whether or not to disclose his epilepsy in online job application forms. Some job portals required an applicant to tick a box confirming that all of the information supplied in the application was true. This made him nervous and he had decided on multiple occasions not to submit applications for that reason. Another individual pointed out that in a recent application for a large public sector employer epilepsy was not included on a list of health conditions. This made her unsure whether or not to disclose.

### People with epilepsy noted the risk of revealing epilepsy during recruitment

*‘I try not to mention the epilepsy at all until I’ve got my feet in the door and nice and comfy under the table, so to speak, because on the odd occasion I have mentioned it, I’ve not heard anything further...’*

*‘I have been offered jobs in the past [then] mentioned my epilepsy and the job has gone. Even though I have eight O levels, four A levels and a degree...’*

*‘I think employers [find it] easy to disregard an application on just hearing the word ‘epilepsy’. I was told, although I had all the qualifications, traits and knowledge for the job, they told me there and then I couldn’t have it.’*

*‘I have [had] lots of interviews in the past two months. As soon as I say epilepsy they do not want to know.’*

People with epilepsy

## 6.2.2 Reluctance to give adjustments

People with epilepsy discussed how difficult they found it to negotiate adjustments with employers. Key issues were that that obtaining an adjustment involved them being treated as different from colleagues, and creating extra work for line managers - both elements were seen as creating resentment amongst employers and colleagues.

### Busy colleagues don’t like to make allowances

Even though his employer was generally sympathetic about his epilepsy, Matt felt that he could not automatically ring up his employer and ask for a day off if he was feeling out of sorts. It was also difficult to proactively ward off the onset of a seizure by telling colleagues that he needed a break, when colleagues were busy and pressured themselves:

*‘It’s whether you want to tell them. Especially if it’s a busy day and everybody’s got stuff to do and you want to go have a minute’s break and sit down.’*

### Line manager's refusal to discuss adjustments led to Karen's resignation

Karen worked in office administration but found it difficult to take minutes during large meetings. Her line manager took her to one side and told her: *'I'm beginning to doubt you're even competent enough to use a computer'*. Karen was shocked at her manager's lack of understanding: *'[They] were giving me stuff to do and I said, "You've not given me the chance to explain that I'm struggling." They didn't let me get a word in to explain what I needed'*. Karen thought that this was probably discriminatory but concluded that it was not worth taking legal action. She phoned in sick and then resigned from the job.

Supporting people with epilepsy to have assertive conversations with employers about disclosure and adjustments is another key area of need for employment support.

### 6.2.3 Seizures strain employer-employee relationship

Several people with epilepsy described feelings of frustration with the way that employers had responded to their seizures. In these cases, the employers knew about the epilepsy beforehand and had appeared sympathetic and accepting of their condition. However, when the seizure occurred, the employers' attitude changed to become more negative and judgemental. At the root of this, it appeared that employers were shaken by the occurrence of a seizure, particularly if it had taken place in work. It was also apparent that they were unsure how to handle the recovery process, with employers also seeming frustrated by the length of time needed for the person to recover. The relationship with the employee became more acrimonious after the seizure and the trust between employer and employee was compromised. The case study below provides a relevant example.

#### Adrian's employer became less supportive after seizure

Adrian developed epilepsy spontaneously in his early 20s. He was able to carry on working for his existing professional services employer. Initially his employer was sympathetic, but when Adrian sustained an injury to his face as a result of falling during a seizure, his line manager refused to allow him to work at home. Adrian experienced his employer's attitude as becoming less supportive and more negative after the seizure.

This reflects employer interview findings (see sections 4.1 and 4.5) that there is a 'fear' element to employers' misunderstandings about epilepsy; as already mentioned, this means it is important to address employers' fears up front when educating employers about epilepsy. The research literature also indicates that seizures can lead to difficulties with colleagues. For example, in Staniszewska and colleagues' survey of 197 adults with epilepsy, about 48 per cent of respondents declared that epilepsy hindered their employment and 77 per cent admitted that having a seizure at work had negatively affected them (Staniszewska et al, 2015). In Wo and colleagues' interviews with 21 people with uncontrolled seizures, they found that when employers lacked knowledge of how to manage a seizure, this had a negative emotional impact on colleagues, disrupted work flow and sometimes led to unnecessary hospital admissions (Wo et al, 2015b). Conversely, supportive employers who were understanding and knew enough about epilepsy had a positive impact on the employability of people with uncontrolled seizures.

In the current study, participants who had experienced a negative response from an employer following a seizure were more likely to express exasperation with employers and request that the employer '*do the research [about epilepsy] themselves*'. To avoid a negative response the start of employment is probably the best time for employees to proactively and positively 'self-advocate' with employers. There is also a need, early in employment, to negotiate with employers and agree a process to manage any subsequent seizures and recovery periods. These options are discussed further in chapter 7.

### 6.3 Summary

People with epilepsy need information and support in advocating for themselves in conversations with their employers. This could include help with how to explain and evidence their health condition, 'self-managing' their condition at work and responding to discrimination. Particular attention needs to be paid to making disclosure easier and to proactively agreeing with employers a seizure 'plan', so that potential conflict over recovery processes and timings is circumvented. These areas are expanded on in section 7.

## 7 What should employment support for people with epilepsy look like?

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This chapter considers what employment support for people with epilepsy should look like, according to the literature reviewed and the discussions with experts, employers and people with epilepsy. It includes advice for how charities that support people with epilepsy and other conditions might best work with and influence employers.

As we have seen, while educating employers has been identified as important, the discussions with people with epilepsy also highlighted an additional need: for people with epilepsy to be better supported in their conversations with employers. This would help people with epilepsy demonstrate to employers more convincingly that, in the words of one expert, *'they're a safe bet and can make it [employment] work'*.

These two areas of need could be tackled jointly, with an approach that brings together both employer and the person with epilepsy in a constructive conversation about the practicalities of handling epilepsy at work. This and other areas for Epilepsy Action to explore are discussed in this chapter. Many of the suggestions encompass support already provided in some form by Epilepsy Action. While endorsing Epilepsy Action's existing approach, the suggestions also cover ways in which current support and information could be re-packaged or communicated differently, to have even greater impact.

### 7.1 Personalised toolkit for conversations about epilepsy

#### 7.1.1 Tools for self-management and positive disclosure

As experts pointed out in chapter 4, self-management - encouraging people to be active in managing their health condition - is a relatively new concept in research into best practice in health and wellbeing at work, but it is an important one to prioritise for conditions like epilepsy. Experts argued that the individuals with epilepsy are best placed to identify the guidance and support they need. However, this approach requires people with epilepsy to have the necessary insight into their condition and the self-confidence to have conversations with employers to proactively manage their condition at work. As chapter 6 explained, people with epilepsy often felt that they did not understand their condition well enough to adopt a self-management approach. In addition, they often felt anxious about openly disclosing their condition, because of fears about employer discrimination.



### 7.1.2 Toolkit content

Across all the research participants, there were calls for user-friendly ‘toolkit’, ‘booklet’ or ‘pamphlet’ for use by employers and people with epilepsy, to encourage and guide a constructive dialogue about health and work.

#### Employer requested ‘information pack’

Brian worked for a manufacturing business, managing employees in a welding workshop using dangerous machines. He would like a new employee with epilepsy to have an ‘information pack’ that they would hand to him on ‘*day one*’ of their employment, so that Brian could work through the health and safety issues, and ensure that the employee with epilepsy can produce quality work to production standards and timings. Brian wanted clear health and safety guidelines explaining how the employer stands legally if someone with epilepsy has an accident at work. Brian thought it was important not to push the health and safety concerns into the background, but it was also important not to emphasise the problems. He thought a ‘*low key*’ and practical approach to managing epilepsy at work was the right one.

To promote positive disclosure and active self-management, people with epilepsy and their employers would benefit from a clear and practical framework in the form of a toolkit to guide their conversations, taking them through the phases of employee and employer interactions, to include:

- Disclosing epilepsy – if, when and how to do this – making clear that it is the person with epilepsy’s choice whether to disclose, but suggesting points to cover in discussions.
- First aid – what first aiders and others need to know.
- Creating a seizure and recovery plan.
- Identifying and removing health and safety risks.
- Employer’s liability insurance.
- Adjustments to the workplace and ways of working, including suggestions for common scenarios such as driving to work, working remotely.
- Communicating with colleagues about epilepsy – who to tell and what to say.
- Hints and tips to help with memory loss and concentration.
- What constitutes discrimination – how to prevent it and how to address it.

An example of this approach is an online toolkit to help employers support employees’ mental health and wellbeing, created by Business in the Community in partnership with Public Health England (Business in the Community website, 2018).

### 7.1.3 Customisable format

Some participants suggested that the toolkit could take the form of online, customisable information that allows the user to select from a menu and print off bespoke information according to different types of epilepsy (experts suggested that listing the main types,

rather than an exhaustive list, would be best) and whether the epilepsy is controlled or not. The employer and the person with epilepsy could print off copies of this personalised guide to read separately, then work through the checklists together (see 7.1.5).

#### 7.1.4 Key messages

Experts recommended that key messages should be the fact that epilepsy is common, can be well controlled with medication, should differentiate between the main types of epilepsy and should explain, in a clear and matter-of-fact way, using everyday language and a positive tone, what to do in the event of a seizure. By providing advice on how to have conversations about epilepsy it could help to prevent disputes and grievances and reduce dismissals and resignations. Informing employers of the likelihood that people with epilepsy could have a mental health condition, would enable them to signpost employees to sources of mental health support.

The focus should be on showing what an individual can do, not what they cannot do. Experts thought that this would help employers to see *'what's in it for me'*, making clear the business benefits.

People with epilepsy would like the messages to focus on moving employers' perceptions into a less fearful and less overly-protective attitude, and getting epilepsy out into the open.

*'We want it to be seen as – not the norm – but it [epilepsy]'s not unusual.'*

*'I'd just like to be treated like a normal person and get on with my work. I don't want to be tip-toed around just because I've had a seizure...'*

*'It still seems to one of those things that is swept under the carpet.'*

People with epilepsy

#### 7.1.5 Checklist approach

A checklist approach was felt to be valuable and experts suggested different ways this could be used. These would enable safety concerns (see sections 5.2.1 and 6.1.2) to be assessed in a systematic and measured way. Checklists could be incorporated within a toolkit.

For example, the 'work ability model' was recommended by one expert. This involves a checklist approach that considers people's abilities systematically against the demands and requirements of a job (European Agency for Safety and Health at Work website, accessed 30th October 2018). The results of the checklist are then used to adjust the role to best enable an individual to succeed in the role. The work ability model encourages cooperation between employees and managers.

A further suggestion was the use of driver licence-style guidelines to assess people's ability and safety while using machinery at work, as described below.



### Driver licence-style guidelines to determine if employee with epilepsy can use machinery at work

A physician and occupational health expert thought that the clear evidence-based guidelines that the Driver and Vehicle Licensing Agency (DVLA) uses to define when people with epilepsy can or cannot drive could be a useful template to create similar guidelines to assess whether someone with epilepsy can do safety critical work such as operating machinery. These guidelines should, he suggested, be tailored to the individual job and would include questions such as: what are the risks? What would mitigate the risks? What is the evidence to show that the risk is greater or reduced? These systematic assessments would not be carried out by the employer but by a clinician: either the individual's GP or - where available - an occupational health adviser. In addition to helping people with epilepsy and their employers, the guidelines would also help clinicians who, he said, tended to be overly cautious in their advice about employment for people with epilepsy.

An expert in employment support for people with disabilities and health conditions used the concept of 'job carving': the employee and employer together systematically appraising each task on a job description to *'break it [the job description] down'* and identify any tasks that might be difficult, given the employee's epilepsy symptoms, and then either removing those tasks from the job description ('job carving') or identifying adjustments.

The emphasis on a checklist approach would, experts thought, give the conversations between employer and employee a practical emphasis and allow both parties to feel that they were tackling things in a purposeful structured way, which appears likely to go some way to addressing the fears and assumptions that can arise.

#### 7.1.6 Medical professionals' endorsement

Within the customisable toolkit there could be space for the person with epilepsy's medical professional to add their recommendation about their ability to work and the adjustments required (see section 7.3.3 below) which would give added reassurance to both the employer and the person with epilepsy, and allow the person with epilepsy to speak with more authority. Employers often wanted to hear from the individual's clinician and sometimes wanted the option to be able to share information with first aiders and this could be included as a hand-out section here. As indicated in section 7.3.3 below, experts involved in academic and applied research about health and wellbeing thought that health professionals could do more to show how work can be a positive health outcome in itself.

#### 7.1.7 Local advocacy

As discussed in section 6.1.1, people with epilepsy who participated in this research sometimes felt reticent about discussing their health condition with colleagues, negotiating adjustments to the workplace or challenging employer discrimination. To help address this and to supplement the use of the online toolkit, Epilepsy Action's local branches could provide face-to-face advocacy for people with epilepsy, to help them in their conversations with employers. The experts interviewed explained the value of such an approach. The Disability Employment Advisor (DEA) and Work Coach expert found that

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sustained face-to-face coaching was effective in helping people with epilepsy who are unemployed or economically inactive to enter employment or to move closer to the labour market. In addition, Professor Stephen Bevan highlighted the benefits of new models of employment support which are being tested in the Individual Placement and Support (IPS) trials (NHS England, 2018). IPS brings Employment Specialists into clinical teams to provide individualised holistic support to jobseekers and their prospective employers. This evidence-based programme has so far been used mental health conditions, but Professor Bevan suggested that the principles could be successfully applied to epilepsy. Under IPS, the Employment Specialists help people with health conditions into employment, using a holistic and case-managed approach. They coach people in what they might say to employers and peers about their health, and advocate for them when required. The support does not stop at the point that the person gains a job, as they can continue to meet regularly to discuss how things are going. The Employment Specialists can act as mediators if situations arise that might affect the wellbeing of someone in work. They can also provide general information about the health condition to the employer when needed.

Epilepsy Action could consider whether their local branches are in a position to adopt this kind of wraparound advocacy to help people with epilepsy into sustained employment, for example through partnering with health services. Partnerships with healthcare professionals are discussed further under section 7.3.4.

## 7.2 Education and training

Employers and people with epilepsy indicated that it would be helpful to have additional training and education available to supplement information provided in the toolkit or pamphlet. Many felt that a blend of a direct and honest conversation with the person with epilepsy and some professional training and guidance would work best.

Earlier studies have also highlighted the need for improved employer education about epilepsy. For example, the 2001 IBE Employment Commission obtained questionnaire responses from employment rehabilitation professionals (reported in Chaplin 2005). These revealed that the measure rated as highest priority in smoothing the transition from school into employment for people with epilepsy was to increase employers' awareness of epilepsy<sup>6</sup>. A UK neuro-psychologist who specialises in epilepsy-related research has suggested that educating employers about epilepsy should focus on the areas of health care, job suitability, recruitment and selection, and assistance at work (Baker, 2017).

Most employers routinely consulted websites about health conditions and would expect to be able to do this in relation to epilepsy. As the participant below pointed out, e-learning can help start the conversation about epilepsy and address misconceptions. This endorses Epilepsy Action's existing training provision. YouTube films for example, were seen as a good way of communicating people with health conditions' lived-experience.

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<sup>6</sup> Other factors prioritised were: specialised occupational guidance and careers services; increasing awareness of mainstream employment and education services; case management/career planning.

*'If there was an online [training] facility for them [employers] to go to get the basics, it might start that conversation which so far, in my eyes, doesn't seem to be happening.'*

Person with epilepsy

The Institute for Employment's work with mental health charity MIND has shown how effective e-learning, for example for line managers, can be as a means of tackling assumptions and myths about a health condition.

Epilepsy Action's education and training provision could also complement the UK Government's efforts to boost Jobcentre Plus staff's understanding of disabilities and health conditions (Department for Work and Pensions, Department of Health, 2017). Looking ahead over the next ten years, Government has prioritised the provision of specialist training for Work Coaches, to ensure that they have a good grasp of how a complex health condition might affect an individual's ability to work. Potentially Epilepsy Action could provide expert educational material as part of this training and development.

## 7.3 Campaigning

Experts, employers and people with epilepsy thought that Epilepsy Action could learn from successes of some of the attitude-changing campaigning work carried out by other charities working with health conditions. Examples were given from MIND's recent work on mental health and from Macmillan's cancer campaigns. Such campaigns were perceived to have been highly effective in reducing stigma in relation to these health conditions. Participants in this research hoped that epilepsy would go through the same re-appraisal, so that the general public and employers no longer see epilepsy as a blanket high-risk diagnosis, but are better able to distinguish between different types of epilepsy, and gain an understanding of the fact that epilepsy can be well controlled. Experts thought that epilepsy charities could also 'piggy back' messages about epilepsy on wider disability campaigns. One expert noted that changing attitudes towards epilepsy and employment could take five to ten years' of sustained campaigning, but pointed out that mental health charities have proven that this can be achieved.

### 7.3.1 A person-centred and whole organisation approach to health and wellbeing

A person-centred and whole organisation approach to health and wellbeing has been recommended as effective in enabling people with health conditions to remain in work. The recent Work, Health and Disability Green Paper examined how employers can be supported to establish good practices and supportive workplace cultures (Department for Work and Pensions, Department of Health, 2017). The main areas of activity proposed included: addressing stigma, monitoring workplace health, accessing information, support and peer networks, and promoting health and preventative and rehabilitative support, such as phased returns to work.

One of the ways that employers can embed a whole organisation approach to health and wellbeing is by participating in the Disability Confident scheme (UK Government Disability

Confident web page, November 2018). This commits employers to improvements in five areas: inclusive and accessible recruitment; communicating vacancies; offering interviews to disabled people; providing reasonable adjustments; and supporting existing employees who develop a disability to stay in work. One employer who was interviewed for this research discussed how their organisation had signed up to become a Disability Confident employer and had wholeheartedly adopted a person-centred and whole-organisation approach to health and wellbeing, as set out in the case study below.

### **Good practice example of person-centred and whole-organisation approach to health and wellbeing**

A large public sector organisation's health and wellbeing support was built around a 'person centred approach', tailored to individual employees. The organisation encouraged a culture of openness to facilitate self-management and the use of their services. They ran internal campaigns that advertised the available services (counsellors, occupational health advisors) and also have nominated 'wellbeing champions' who wrote blogs on wellbeing at work which were distributed internally. They are launching 'avatars' with health conditions who will reflect on how it is to work for the organisation with particular conditions. The overall aim was to promote openness, tolerance and awareness. They would also seek guidance from the person with epilepsy on first aid and assistance to be provided in the case of a seizure and provide them with an informed 'buddy' to assist, in addition to training other staff on how to provide this. Again, they would seek guidance from the individual themselves on how best they can facilitate their workplace wellbeing.

Alongside other charities, and as part of pan-disability and pan-health condition campaigning, Epilepsy Action could advocate for such approaches. This could help epilepsy to be seen not as something alien and frightening, but as just another health condition amongst many, that can be planned for as part of a whole-organisation and person-centred approach.

### **7.3.2 Case studies that challenge assumptions and demonstrate adjustments**

As we have seen, employers can make unhelpful assumptions about people with epilepsy's ability to work safely in different job roles and environments. People with epilepsy also sometimes appeared to limit themselves to jobs in familiar settings rather than pursuing opportunities that would fulfil their talents.

Challenging some of these assumptions and behaviours could be addressed by publicising case studies of individuals with epilepsy who work in unexpected roles or settings, and hearing their and their employers' shared perspective on why this works, how adjustments were negotiated and what value the person with epilepsy's skills, knowledge and experiences brings to the organisation. An expert suggested that eye-catching new adjustments such as technology-based solutions to enable remote working are likely to be of particular interest to people with epilepsy and their employers. Such case studies would help demonstrate to employers the added value to their business that employing someone with epilepsy can bring.

*'Giving people sheltered employment is not satisfying, work is a source of fulfilment and achievement, this needs to be seen.'*

Expert

*'Perhaps if I was able to read about professionals in a number of various job roles [...] who have epilepsy and their success stories and how it is possible, [that] would've given me a little more confidence throughout those initial stages [when first diagnosed], when nothing seems possible [and needing] reassurance that finding a job was doable.'*

Person with epilepsy

A few experts suggested that tackling unhelpful stereotypes about epilepsy and employment and unhelpfully over-protective attitudes are particular concerns for young people. This suggests that case studies could be usefully incorporated into Epilepsy Action's work with children and young people, their parents and carers, and with schools, colleges and universities and other organisations that support children and young people with epilepsy. This could help young people with epilepsy to feel more positive and confident about the types of jobs and careers that are open to them. This type of intervention could complement Jobcentre Plus' Support for Schools programme, which targets careers advice at young people aged 12 to 18 who, due to health or disability, face potential disadvantage in the labour market (House of Commons Library, August 2018).

There also appeared to be an appetite for more high profile case studies from Epilepsy Action, incorporating celebrities with epilepsy talking publicly about their condition and employment.

### 7.3.3 Involvement of healthcare professionals and organisations

As shown in section 7.1.6 above, employers would welcome the inclusion of a clinician's expert guidance as part of a toolkit for the employer and person with epilepsy. Experts involved in research about health and wellbeing thought that health professionals could be more involved in helping people with health conditions to move into work. For example, Professor Stephen Bevan pointed out that work is usually not mentioned in the diagnostic process in the UK. He thought that NHS clinicians should be routinely advising patients about whether they are ready to work or not, and about how to manage their condition in work and this information should be routed to employers. This approach is already being used in the IPS trials, as described in section 7.1.7.

In support of this, the desk review identified earlier research that recommended greater involvement of healthcare professionals in vocational support. For example, a peer-reviewed article about a specialised vocational rehabilitation programme in the United States for people with epilepsy had successfully introduced psychosocial care and partnering with employers alongside medical care (Fraser et al, 2018). A German study evaluated the activity of 24 'network teams' of physicians, therapists, consultants from social services, employment offices and rehabilitation between 2010 and 2013 (Knieß et al, 2014). The network of professionals collaborated to reduce the risk of people with epilepsy losing their job and their combined efforts led to 70 per cent of programme participants retaining their jobs. Communication and intensive networking between



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medical professionals and the other disciplines were found to be key drivers for the success of this programme. A white paper on the medical and social needs of people with epilepsy and intellectual disability called for a holistic approach, with greater collaboration between medicine, education and employment services, combined with social engagement (Kerr et al, 2014). Sung and colleagues thought that healthcare providers should become more familiar with vocational rehabilitation provision (Sung et al, 2014).

In the current study an expert clinician thought that NICE too had a role to play, by adjusting its guidelines on medication for epilepsy to take into account whether particular medication causes side effects that might restrict the person with epilepsy's ability to work.

Epilepsy Action, the experts thought, could play a role in lobbying NICE and the NHS about the need to bridge the gap between healthcare professionals and employers, encouraging epilepsy consultants, GPs and other healthcare professionals to discuss with people with epilepsy their working lives, in order to support work as a health outcome. This could synchronise well with UK Government's efforts to support healthcare professionals in addressing barriers to work (such as using Fit Notes to enable healthcare professionals to talk to a patient about health and work) and in developing tools that raise the profile of work as a health outcome (such as requiring health data systems to routinely collect information on individuals' employment status) (Department for Work and Pensions, Department of Health, 2017).

There might also be scope for Epilepsy Action to advise on local employment and health services. Increasingly UK Government is favouring solutions in which local partners deliver integrated approaches to improving health and work (ibid.). For example, the Department for Work and Pensions is working with nine local authorities in piloting Local Supported Employment, while the Innovation Fund is being used to develop health-led IPS trials that partner local health service commissioners and providers with Jobcentres and councils (see section 7.1.7 above). It appears important for Epilepsy Action's expert voice to be heard both nationally, and at this local partnership level, to help influence local employment and health support for people with epilepsy.

### 7.3.4 Wider engagement with employers

Experts, employers and people with epilepsy would like to see Epilepsy Action engage with and influence employers at a senior level. For example, people with epilepsy noted shortcomings in the way that job application forms and portals require applicants to declare health conditions. They thought that this should be brought to employers' attention, as in the case study below.

#### **Influencing employers to improve job applications' health information**

Angela thought it would be helpful if job application forms' questions about health conditions included the option to give further information, such as whether the condition is controlled by medication, when a seizure last took place and whether the applicant has a driving licence: *'That way employers have an initial deeper understanding than just knowing you're "epileptic", a term that to those who don't know a lot about is easily stereotyped and could be a red flag,*

*when actually someone like myself could have been seizure-free for years'. Angela would like to see this change brought to employers' attention.*

This was an example of something that the charity could tackle, via conversations with industry leaders. Visible buy-in from industry leaders was seen as important, to include conversations with key influencers in occupational health and human resources. Organisations such as CIPD, the Institute of Directors and the Federation of Small Businesses could be drawn into the debate about epilepsy and employment.

## 7.4 Summary

People with epilepsy did not want to be treated as if they were in an overly protected *'bubble'*, but wanted to *'get on'* with their jobs, recognising how important work is to their mental health and wellbeing. It appears to be important that employment support gives the person with epilepsy more confidence to proactively represent their condition to employers and to feel in control of the relationship between their condition and the workplace. It also appears important for employment support to address employers' concerns about safety, productivity and employees' and clients' perceptions. Being able to use branded material from a charity like Epilepsy Action in the form of a customisable and downloadable toolkit, backed up by e-learning resources and face-to-face advocacy from Epilepsy Action's local branches, could help employers and people with epilepsy to have positive, practical conversations that pre-empt disputes, grievances and reduce dismissals and resignations. The research participants would also like to see Epilepsy Action engage in highly visible campaigning work with clinicians, employers and other senior thought leaders in occupational health and human resources, and with the general public, to bring the issues around employment and epilepsy to a wider audience. There also appears to be potential for Epilepsy Action to contribute to local employment and health partnerships.

## 8 What impact could be achieved with good employment support?

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This chapter looks at the impact that could be achieved with good employment support.

Employers thought that, if they knew more about epilepsy, could see how adjustments would be achievable in their workplace and were confident that someone with epilepsy could work with them safely and productively, they would feel more open to employing someone with epilepsy.

People with epilepsy felt that, if they had better support during their conversations with employers, they would be better able to negotiate adjustments, retain their jobs and address discrimination. They hoped that employment support could help them towards greater financial security, employment that fit their talents, improved mental health and enable them to work without fear, shame or embarrassment.

*'[Improved employment support] would take [people with epilepsy's] minds off the illness and give [them] a secure future, not having to rely on the Government to live and giving [them] a sense of equality not inferiority.'*

*'Had employers in my experience had a deeper understanding about epilepsy, and took the time to listen to my individual situation then I could've potentially been offered the job of my dreams [...] Support could've impacted my experiences massively, and made me feel more comfortable in my role.'*

*'On a personal level, it would enable me to contribute to the wider community through paid employment. More importantly it would help me address the deep-rooted feelings of anxiety and low self-esteem which have insidiously affected my mental health over the last decade or so. Regarding the wider epilepsy community, I suspect it would have a similar positive impact on their lives.'*

*'It would make the person feel more secure and comfortable in a working environment with the knowledge that if they were ever to suffer an epileptic seizure at work they would get the right and correct support rather than feel embarrassed or even be reprimanded as if it was their fault. No one invites epilepsy on to themselves.'*

People with epilepsy

Experts predicted that improving employment support for employers and people with epilepsy could eventually contribute to reductions in sickness absence, disputes, dismissals and resignations. By increasing the economic activity and employment rates amongst people with epilepsy, it could reduce productivity losses (Pugliatti et al, 2007) and boost tax revenues.



## 9 Conclusion

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This research is timely given the Government's strategic focus on helping employers to becoming more 'inclusive' and on improving employment support for people who have fluctuating health conditions, and conditions that are less common and more complex (Department for Work and Pensions, Department of Health, 2017).

### 9.1 How does epilepsy compare with other health conditions, in terms of support into employment?

The experts believed that, as with other chronic health conditions, most employers were likely to react negatively to the idea of working with someone with epilepsy. However, they thought this negative response was likely to be heightened by safety concerns about epileptic seizures, influenced by employers' relatively low awareness of the condition. The fact that mental health conditions sometimes coexist with epilepsy could further deter employers from employing someone with epilepsy. The concepts of 'self-management' and 'self-advocacy' have been used successfully with other health conditions and experts thought these could help people with epilepsy to represent themselves more effectively in their dealings with employers.

### 9.2 What information about epilepsy would reassure an employer?

Employers tended to be unfamiliar with the varied types of epilepsy and were often unaware that it can be well controlled by medication. Those interviewed often found epilepsy as a whole off-putting and their opinion did not change much according to the different types of epilepsy symptoms. Employers were usually adamant that someone with epilepsy should disclose their condition. They were particularly worried about the safety of the person with epilepsy in the event of a seizure. Sometimes employers suspected that employing someone with epilepsy could be disruptive and felt that seeing a seizure could cause distress for staff and clients. Employers hesitated about making adjustments for the person with epilepsy because of the predicted costs and logistical challenges. However, they were more likely to favour doing so for an existing employee than a new member of staff. The conclusion from the employers' interviews was that employers needed educating about epilepsy, with a focus on reassurance and demonstrating that employing someone with epilepsy is feasible.

People with epilepsy themselves did not feel in a position to represent their condition well to employers, sometimes because they did not fully understand their own condition as the condition is variable and difficult to pin down, or because previous bad experiences with employers had shaken their confidence. People with epilepsy were frequently reluctant to

disclose their condition until they had been offered a job. Their concern about safety meant they sometimes took jobs that, while safe, did not make full use of their talents. Mental health issues were commonly experienced by people with epilepsy and this was an added barrier to employment. Prior experiences of employer discrimination included not being selected in job applications because of perceived discrimination, employers acting more negatively towards them following a seizure and employers being reluctant to agree adjustments. People with epilepsy tended not to feel able to effectively self-manage and self-advocate about their condition. They would benefit from support to help them have conversations with employers about epilepsy, including helping to make disclosure easier and to negotiate a seizure 'plan'.

### **9.3 What should good employment support for people with epilepsy look like?**

Suggestions to improve employment support for employers and people with epilepsy include a personalised online toolkit to support positive, open dialogue between employers and employees. The toolkit would include a menu of options to create a customised print-out relating to particular types of epilepsy, covering disclosure, a seizure and recovery plan, health and safety risks, employer's liability insurance, reasonable adjustments, communications with colleagues, first aid and discrimination. The toolkit could also include checklists to assess, for example, employees' 'work ability', their capacity to carry out job description tasks, or competency to operate machinery. Including a clinical assessment by the person with epilepsy's healthcare professional in the toolkit would also be welcomed by employers. Educating employers about epilepsy, and raising awareness could be supplemented by e-learning packages, building on Epilepsy Action's existing activity in this area. Epilepsy Action's local branches could also provide face-to-face advocacy to assist people with epilepsy in their interactions with employers.

### **9.4 How can charities that support people with epilepsy and other conditions work with and influence employers?**

People with epilepsy, employers and experts called on Epilepsy Action to play a leading role in re-shaping the national conversation about epilepsy, through campaigns that change perceptions about epilepsy, incorporating case studies of people with epilepsy (including celebrities) in unexpected jobs and employers who are taking a person-centred and whole organisation approach to health and wellbeing. The research participants would also like to see Epilepsy Action lobbying clinicians, NHS, NICE, employers and other thought leaders about employment and epilepsy issues. Epilepsy Action may also be able to contribute to local partnerships that deliver employment and health support.

## 9.5 What impact could be achieved with good employment support?

Improved employment support, education and training could help employers to feel more confident about making 'reasonable adjustments' and employing people with epilepsy. If people with epilepsy had better support during their conversations with employers, it would make it easier to enter employment, negotiate adjustments, retain their jobs and fight discrimination. People with epilepsy hoped that getting work could lead to greater financial security and allow them to find suitable employment. Raising the employment rate of people with epilepsy would reduce government expenditure on benefits and boost government revenue from tax receipts.

## Appendix 1: Employer Interviews Stimulus

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### Focal seizures with loss of awareness and no warning

Person A has around four focal seizures a month. During a seizure, he has no awareness of what is happening. His mouth makes chewing movements and he fumbles with his clothes or things that are close by. To onlookers, he will look vacant and will not respond when spoken to. The seizures tend to last for around three minutes, but it takes at least another 15 minutes before he feels back to normal. He does not need any first aid, but he does need someone to guide him away from any dangers (such as stairs) and be calm and reassuring. He is usually able to return to what he was doing before the seizure, once he has had a short rest in a quiet place.

Over the past year, person A has had several changes to his epilepsy medicines, to try and reduce his seizures. Each time the medicines are changed, it can take a few weeks for his body to adjust. During this time he experiences side-effects which include dizziness, headaches and feeling very tired. He usually continues to go to work, but he is not able to operate to his full potential.

### Focal seizures leading to tonic-clonic seizures

Person B has around three focal seizures a month. He gets a strange metallic taste in his mouth and starts feeling sick. When this happens, he has time to lie down in a safe place, in case it develops into a tonic-clonic seizure, which happens around four times a year. If a tonic-clonic seizure doesn't happen, he is usually able to carry on with what he was doing after he has rested for half an hour or so.

If the seizure progresses into a tonic-clonic seizure, he loses consciousness and his muscles go stiff. Then his limbs start jerking quickly and rhythmically. His lips usually go blue and he sometimes loses control of his bladder, so he needs someone to put something soft under his head and to help him maintain his dignity. The whole seizure usually takes about four minutes, after which he needs someone to put him in the recovery position. Afterwards, he usually has a pounding headache and feels sore, tired and very unwell. It can take several hours, even days, for him to feel completely back to normal. He always has to go home to sleep and he needs assistance to get him there.

### **Tonic-clonic seizures without a warning**

Person C has around 12 tonic-clonic seizures a year, some when he is awake and some when asleep. He never gets a warning that one is going to happen, but he is more at risk if he is tired, stressed or forgets to take his epilepsy medicines. He makes an unusual noise in his throat, then his muscles go stiff and he falls to the ground. Then his limbs start jerking quickly and rhythmically. The seizure usually lasts around two minutes and after the seizure, he needs someone to put him in the recovery position. Afterwards, he is usually able to carry on with what he was doing after five minutes or so and he does not want people to make a fuss over him.

## Appendix 2: Rapid Literature Review Shortlist

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