



Neurological problems, hidden disabilities and  
the workplace

**1 in 6 people** in the  
UK are affected by a  
**neurological problem**



# Neurological problems in the UK

- There are more than 12 million people in the UK living with a neurological problem, which includes:
  - Migraines
  - Traumatic brain injuries
    - Stroke and transient ischaemic attacks (TIAs)
    - Head injuries (including concussion)
  - Parkinson's disease and other dementias
  - Epilepsy
  - Rare or lesser known conditions – e.g. Chiari malformation, transverse myelitis (TM), functional neurological disorder (FND)

# Neurological problems in the UK

- People affected by a neurological problem may experience a wide range of symptoms and effects:
  - Headaches
  - Fatigue
  - Chronic or neuropathic pain
  - Weakness or paralysis in parts of their body
  - Memory problems
  - Difficulties with speech and communication
  - Changes to their eyesight, hearing, taste or smell
  - Personality and behavioural changes
  - Mental health problems

# Neurological problems in the UK

- People with neurological problems have the lowest health-related quality of life of an long term health condition <sup>(1)</sup>
- Globally, neurological disorders are the leading cause of disability and the second leading cause of death worldwide <sup>(2)</sup>
  - In the UK, there is an increasing trend in the number of deaths of people with a neurological problem; and their deaths are more likely to be premature <sup>(1)</sup>
- Despite improvements in prevention and treatment, population growth and aging mean that the number of those affected only continues to grow

# Neurological problems in the UK

- In the UK, there is one neurologist per 91,175 people <sup>(3)</sup>
  - The European average is one per 15,799
- Access to specialist care and support is limited and patients can face a 'postcode lottery' in terms of what care is available to them
- It can take a long time to be correctly diagnosed and getting the right specialists or treatment can be very difficult – if they even exist
- Neurological Alliance have shown that the lived experience of people affected by a neurological problem and the availability and quality of services and care, are not improving <sup>(4)</sup>

# Neurological problems in the UK

- A neurological problem can affect someone's ability to work and prevent them from taking part in their everyday life, changing their role within the relationships they have and how they see themselves as an individual
- Relevant information and support can be hard to find, and often people will have a lot of questions and concerns that they can struggle to find the answers for, or even just someone to talk to about
- These experiences can be distressing, exhausting and very isolating

# Hidden disabilities

- Many neurological problems can be difficult for others to recognise just by looking at someone and can cause hidden disabilities
- A hidden disability is one that affects the individual in ways others can't physically see or immediately identify, or means society has less obvious disabling barriers placed in the way of them living a full life <sup>(5)</sup>
- The Invisible Disabilities Association (US) have suggested that 74% of those with disabilities don't use a wheelchair or anything else that might visually signal their impairment to the outside world <sup>(6)</sup>



# Hidden disabilities

- Having a hidden disability can be difficult for a number of reasons:
  - Not everyone wants to have to go through the process of telling each person they meet about their problem or condition
  - Some people may feel uncomfortable about telling others about their disability, and may keep quiet or not ask for help as a result
  - In some situations, a lack of awareness can lead to others doubting them or demanding proof - such as when using accessible facilities (e.g. toilets or changing rooms) or requesting a priority seat on transport

# Hidden disabilities in the workplace

- In the UK, **7.9 million** people of working age (16-64) reported that they had a disability in July-September 2019, which is **19%** of the working age population <sup>(7)</sup>
- Many of these people face barriers, discrimination and harassment due to a lack of awareness or understanding by their colleagues and employer
- In a Welsh survey about disabilities in the workplace, two thirds felt there was more stigma associated with disabilities that others cannot see <sup>(8)</sup>

# Hidden disabilities in the workplace

- Employers can play a significant role in supporting individuals with a long term condition or a hidden disability
  - Encourage conversation, be flexible, educate other employees, support access to professional expertise and care, ensure a sense of trust and job-security
- It is important to remember that people affected by a hidden disability or invisible illness, already face the challenge of managing their symptoms or condition outside the workplace – and increased stress can sometimes lead to a worsening of their condition

# Developments and positive change

- There have been some positive changes in recent years to better support individuals with neurological problems and hidden disabilities
  - Disabled bathroom facilities with signs that highlight 'not all disabilities are visible'
  - Sunflower lanyards available through airports and supermarkets to enable people with a hidden disability to make staff aware that they may require additional support
  - Blue badge permits are now available to people with hidden disabilities

# What we do and how we help



Helpline



Booklets and fact  
sheets



Online support  
groups

# What we do and how we help

- Talk through any neurological symptom, investigation or condition, even if it is rare, and explain neurological and medical 'jargon'
- Help people understand treatment options and support them to make an informed choice or decision
- Signpost people to suitable services that can be accessed, and give details of further sources of information and support

# References

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