

## Introduction



Welcome to this latest edition of Disability in Focus which we have produced to coincide with the CWU Disability Conference in Birmingham. Thanks to all those that have

contributed and I think we have some good articles. You must not miss the anecdote from Sean McGovern (see page 7), which I just love.

The disability conference should prove interesting with perhaps a few motions that might stir a lively debate. There are many individuals with a variety of disabilities under attack by the government through its agents ATOS. They are trying to get as many back to work through fair means or foul and with the threats to benefits through cuts and reassessment it's never been more important to promote fairness and justice and to rally public opinion.

### **Letter**

*Thank You to CWU DAC – I would like to thank the CWU Disability Advisory Committee (DAC) for the help and support they provided to me when dealing with a complex disability related case for a CWU Royal Mail member recently.*

*The expert disability legislation advice and support that they provided was invaluable to me and assisted not only myself but also the CWU member and the Royal Mail management to resolve the disability related issues involved in the case.*

*I have often wondered what the CWU DAC actually does. Now I know – thank you.*

**Kate Stewart**  
CWU Equality Officer  
Leicestershire branch.

# What is Epilepsy?

*Jacqui Stewert looks at epilepsy and seizures*

Epilepsy is defined as a tendency to have recurrent seizures (sometimes called fits). A seizure is caused by a sudden burst of excess electrical activity in the brain, causing temporary disruption in the normal passing motions between brain cells. This disruption results in the brain's messages becoming halted or mixed up.

The condition can be difficult to diagnose as there are so many types of symptoms. People can be misdiagnosed with conditions such as vertigo, fainting and heart disturbances. There are many types of seizures ranging from brief absent moments to episodes of losing consciousness, falling to the floor and convulsing.

## Facts about epilepsy

Epilepsy is one of the most common disorders of the nervous system and affects around 500,000 people in the UK. There are around 50 million with epilepsy in the world.

Epilepsy can develop at any time, though the occurrence of new cases is more common in children or people over 60 years of age.

In most cases the cause is unknown. Epilepsy is neither contagious, nor hereditary but a person with a family member with the condition may be more at risk.

## Epilepsy Triggers

- \* Alcohol & recreational drugs
- \* Excess binge drinking
- \* Late nights & lack of sleep
- \* Stress
- \* Missing medication
- \* Flashing lights
- \* Hormone changes (especially in women during menstrual cycle or menopause)
- \* Fasting

The condition can be controlled by medication and most people with control and monitoring can have a normal day to day life. Treatments need to be regularly reviewed as drugs are constantly improving.

As epilepsy is a long term condition with people experiencing more than one seizure and the condition has to be controlled by medication it is covered under the Equality Act 2010 (DDA).

It is up to you if you want your colleagues to know about your epilepsy. Bear in mind that, if people know about epilepsy, they will usually feel more confident about helping you if you have a seizure.

Many people find that by being open, their colleagues have a positive attitude towards the condition. If you think it would help, you could ask your employer to arrange some training for your colleagues to increase awareness and understanding of epilepsy. Your employer can't let other people know about your epilepsy without your permission. This is to comply with the Data Protection Act. If you do agree to let work colleagues know, you could sign a consent form. This would give your employer permission to tell one or more named individuals.

For further information, help and advice call freephone **0808 800 5050**  
**email:** [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

# Campaign for Statutory Carers Leave

*Chris Jeffrey outlines his campaign to obtain statutory carers leave*

I have been running a campaign for the past couple of years to get statutory carers leave. I got involved due to my own circumstances, where every time I have to go into hospital my wife has to work her hours before she can take me.

There's been a lot of government action on the issue of maternity/paternity leave over the years but an equal society demands that people with disabilities and their carers should be put on an equal footing. Of course my wife and I are not the only ones who would benefit from a positive outcome to this campaign as there are many people who find themselves in the same situation.

I have been in touch with Carers UK, The Princess Royal Trust for Carers, Disability Now, the Daily Mirror, Disability Alliance and Carers First. I have also contacted Dame Anne Begg, chair of the Work & Pensions Select Committee and Greg Clark, MP for Tunbridge Wells, who has passed my letters and correspondence on to Lord Freud, the Minister for Work & Pensions.

Lord Freud stated during one debate that disabled people should have better access to social interaction and employment and that the government was committed to encouraging responsibility and fairness, and championing disability equality.

I have also met Mark Williams, MP for Ceredigion, who tabled a ten minute rule bill on the plight of carers. I was interviewed by a reporter from the Kent & Sussex Courier who thought the campaign was a good idea and wondered why nobody had thought of it before. I was due to have a meeting with Adrian Bailey, chair of the Business Innovations & Skills Select Committee, on the 11 October at the House of Commons. So all in all the profile of the principle of statutory carers leave has been enhanced, but there's still a lot of work to be done

If there was statutory carers leave in place, carers could return to the work environment without jeopardising caring needs. If statutory carers leave were in place carers may be better off and able to continue their role again without jeopardising care needs. They may also be less reliant on Carers Allowance and other welfare benefits.

# Having a stroke

## *John James gives a personal reflection on having a stroke*

After many years of being active in both the trade union movement and politics, in May 2008, I stood in the local elections as a Labour candidate for Landore Ward.

Saturday 1 March started as an ordinary day. I had four appointments to attend to at the local community centre where I was holding a surgery. I returned home after the surgery, prepared myself a light lunch, after which I settled down to read my newspaper. I had read one or two pages when I realised that I was having difficulty, as I tried to turn the page, in grasping the paper with the forefinger and thumb of my right hand. I remember being very confused and indeed surprised as to why I could not do this simple task. I did though realise that something was seriously wrong.

I calmly went upstairs; at this stage I do not remember either having a limp or any difficulty in walking. I collected my pyjamas, and returned downstairs to collect my toiletries. At around 2.20 pm I called the emergency services.

It was at this point that my difficulties really began. The operator on the call asked which services I required and I was unable to make myself understood. As I live on my own, until then, I had not been required to converse with anyone. This was the first time in the course of the events that I became worried. Fortunately, with my mumblings and thanks

to the operators training, we were able to confirm my name and address and which service I required.

It was around this time that I suspected that I had suffered a stroke as my symptoms had reminded me of my mother who had suffered a stroke some years ago.

The ambulance quickly arrived and I was taken to the casualty department in Morrision Hospital where I underwent some initial tests. Then, at around 7 pm, I was transferred to the medical assessment unit. Although my precise memory of this time is quite vague I do remember that the entire right hand side of my body was now affected.

My right arm and right leg were paralysed, the right side of my face had dropped and, according to relatives, I had become incoherent. After receiving further tests and treatment on Sunday evening, I was considered stable and moved to the stroke ward. I had been advised that my stroke was caused by a bleed in the brain.

Over the years and as a consequence of a previous heart condition, I had been taking an aspirin tablet daily; this was stopped as the treatment for a bleed and the treatment for a clot are different. I needed to have my blood thicker not thinner. As a result of the stroke not only had the fingers on my right hand become stiff, they had swollen to the size of sausages, so I had a compression bandage fitted. I also had to wear compression stockings on my legs.

On 4 March I underwent an assessment and a day later my treatment started.

Physiotherapy was to be principal treatment and I was surprised to find that this hospital department is only open 08.00 am-16.00 pm, Monday to Friday.

It was on the 5 March that I got out of bed on my own and sat in a chair. After the stroke I was mobile quite quickly although there was one occasion when I fell over whilst in hospital.

Looking back over what is still a relatively short time, my biggest improvements were made over the first three weeks; it has been little by little since then. I was very fortunate to have the knowledge and experience of someone else suffering from a stroke; my reactions were immediate, I sought medical assistance. Even though it is 10 to 11 weeks since I suffered the stroke I still find myself unsteady on my feet when twisting or turning to my right. My swallowing has been affected; I find that I have a build up of saliva which can be a nuisance to deal with, especially if I have a long sentence to deliver. I did have a minor relapse, at around 9 to 10 weeks, my speech worsened but it is now improving again.

I am continuing to have problems with the sensation of touch on the fingers of my right hand as I don't have a true feeling of how hard I am pressing the keys on a key board. I have a similar problem when using a light switch. My hand writing continues to be illegible.

***The information following on the right has been reproduced from a CWU Equality factsheet and is very useful. Read it. If you suffer a stroke, the information might improve your quality of life, and in some instances save your life.***

## What is a Stroke?

A stroke is a disruption in the blood supply to the brain. Most strokes are caused by blockages (usually blood clots) disrupting the brain's blood supply. These are called ischaemic strokes. Some strokes are caused by bleeds. These are called haemorrhagic strokes.

The brain depends on a supply of blood for the oxygen and nutrients it requires to function properly. When the blood supply is disrupted, brain cells are starved of oxygen and nutrients. This causes damage to the brain tissue.

If you suspect someone is having a stroke call 999. Stroke is the leading cause of adult disability in the UK. Strokes can affect people of any age but are more common in older people.

Some people have a temporary blockage in the blood supply to their brain which clears of its own accord, quickly and before lasting damage to the brain is done. This is called a transient ischaemic attack (TIA)

### What are the symptoms of stroke?

Each person is affected differently by stroke and individual's symptoms depend on which parts of the brain are affected and for what specific functions these parts of the brain are responsible.

The severity of the symptoms depends on how much damage is done to the brain. The main symptoms of stroke are physical problems in one side of the body (numbness, weakness), drooping in one side of the face, speech problems (slurred speech, muddled words) and visual problems (blurred vision, loss of vision). In more ►

► serious cases, the person might lose consciousness. The onset of stroke symptoms is usually sudden. Strokes can occur while people are sleeping. If this happens, people can wake up with the symptoms.

People might also experience longer-term effects such as psychological problems (for example, depression or difficulty controlling emotions), bowel or bladder problems (incontinence) and problems with swallowing. Other symptoms can include pain, dizziness and balance problems, memory problems, a loss of awareness of one side of the body (neglect) and fatigue.

### What causes strokes?

Most strokes are caused by damaged arteries (the blood vessels through which blood flows from the heart to the rest of the body). Damage to the arteries carrying blood to the brain can cause strokes in the same way that damaged arteries in the heart can cause heart attacks.

Our arteries tend to harden, narrow and weaken as we get older but people with high blood pressure, smokers, people with high cholesterol and people with heart disease or diabetes (or a family history of heart disease or diabetes) are at an increased risk.

### Recovery

Most people tend to make their best recovery in the first few weeks and months after the stroke but people can continue to recover slowly over the months and even years. If you have any physical problems after your stroke, it is likely that you will benefit from physiotherapy. A physiotherapist can help your physical recovery and the recovery of movements such as walking.

If you have any speech problems it is likely that you will benefit from speech and language therapy. A speech and language therapist can help with the recovery of your communications skills. They can also help if you have swallowing problems.

You might also benefit from occupational therapy. An occupational therapist can help you redevelop the skills you need to perform everyday activities at home like washing and cooking.

They can also recommend special equipment or adaptations to your home to make life easier.

Around a third of people make a good recovery, around a third are left with some form of disability and around a third die from their stroke.

### Information

For more information on the issue, you can use the following link and helpline number:

**[www.brainandspine.org.uk](http://www.brainandspine.org.uk)**

**Tel: 0808 808 1000**

A wide range of equality factsheets on a variety of issues can be downloaded from the following link:

**[www.cwu.org/factsheets](http://www.cwu.org/factsheets)**

# Taking Responsibility for Our Own Actions?

*Sean McGovern, Secretary of the Trade Union Disability Alliance, reveals how the Work and Pensions Secretary Iain Duncan Smith has little regard for the rights of the disabled*

A lovely 'you-couldn't make-it-up' incident presented itself to me recently...

I took part in Channel 4's 'Street Riots: The Live Debate' over in a studio in Covent Garden. It's nice being picked up by a chauffeur driven car; deposited into the heart of the West End; and, by-passing queues to be admitted into the green room for free nosh and drinks.

But, I deviate. Eventually we were herded into the studio and the warm-up guy did his stuff. Presenter Krishnan Guru-Murthy then gives the running order of the show and introduces us to Iain Duncan Smith, Hilary Benn MP, Adrian Mills an Ealing restaurateur (his restaurant was ransacked and looted), Paul Gladstone Reid a composer, pianist, singer-songwriter and producer, and a rather taciturn policeman. He subsequently referred to all explanations and views contrary to his own as 'excuses'.

The debate went fairly well. Duncan Smith and the businessman holding the old law-and-order line about people-have-to-take-personal-responsibility-for-their-own-actions. The line about cutting benefits and evicting parents of children convicted of looting followed.

The Tory line when confronted with problems is always to fall back on the old chestnut of family values and personal responsibility. And Duncan Smith ensured that nobody, whether they agreed with him or not, left the studio without his message messing around with their heads.

The show ended and the floor manager wanted us, wheelchair users, to wait until the studio was cleared. No way Pedro! I'd sat for an-hour-and-a-half in a lot of pain, and needed to pee, quite quickly. So, I got out first, or so I thought, and headed for the lift to take me to the ground floor and the adapted toilet.

Up we went. Out of the lift, throw a right. Bob's your uncle, there's the 'special' loo waiting to accept yours truly.

A young geezer all skinny jeans, Loake's brogues and Ralph Lauren cardigan, looked at me as I reached for the door. "Sorry sir, there's someone in there, he won't be a minute," he says. "Okay mate" I say; relief, hopefully, a minute or two away.



Three minutes later the door to the disabled toilet opens, the one with the big sign announcing in pictogram the universal symbol of disability, and out strolls Iain Duncan Smith.

Oh glory! Hallelujah! My peeing need seemed to vanish from my mind as I mentally uncrossed my legs and said to Duncan Smith: “This is an adapted toilet, see the sign?” He uncomfortably acknowledged this. “Why are you abusing this facility? I’ve had to wait in extreme pain and discomfort because you think you’re above the rules that everyone else accepts,” I said.

Duncan Smith, is somewhat trapped, because I’ve placed my wheelchair between him and the door, and my PA is standing by my legs, so the trapped rat can’t vault over me and do a runner. Then I have him on the ropes, just waiting to deliver my coup de grace, down drop his gloves, his guard is gone as he splutters out “I’m sorry, but somebody told me I could use it”.

And, in true Sun headline grabbing thought – GOTCHA! “So, if someone told you to pick up that TV because it was going begging, you’d pick up the TV?” I asked. “What’s happened to your sense of personal responsibility for your own actions?” I pressed. “Are you exempt from the rules and regulations you spent the past hour telling us we must adhere to because that’s how we maintain an orderly society?” I finished pushing my way into the loo.



Duncan Smith, thinking he could do a runner took full advantage of the cessation in my harangue and just as he thought he’d escaped the loony wheelie, I looked into the bowl and spotted he hadn’t flushed the loo.

“Oy!” I shouted, arresting IDS’s flight: “Do you know it’s customary to flush the khazy after use?”

abject contempt and ‘beam-me-up-Scotty’, as he drew an embarrassed grin across his face while hastily turning a corner to the safety of the street.

# The value of the BT Passport Scheme

*Nicki Coughlin spells out the benefits of the BT passport scheme*

The CWU DAC would like to remind BT members and reps of the benefits of using the passport scheme which is available within BT to support all members who have long term health conditions/disability, long term mental health conditions and caring responsibilities for dependants.

## Benefits of the BT passport scheme:

- \* When a line manager changes, the individual does not have to go through everything involved in his or her situation again to explain or justify what has been agreed in the past by way of support. The new line manager is simply advised that the individual has a BT Passport within the personal file. It then becomes the responsibility of the new manager to ensure they are aware of the contents and agreements, if there is a BT passport already in place.
- \* If the job requires changes in the future within BT, the needs and circumstances are already documented and any agreements must be continued and any new situations that arise can be quickly highlighted and discussed, if the person has a BT passport already in place.

- \* If a person becomes redeployed from a BT job in the future, the passport will ensure that all agreements are maintained and circumstances taken into consideration whilst sourcing a suitable new role for the individual by HR. It can also help to ensure the individual is placed into the correct re-deployment process within BT, if a BT passport is already in place.

- \* If agreements that are made in line with BT policy are not maintained in the workplace, the BT passport helps to provide the CWU representative with documented evidence that the individual has been failed.

Remember that you control and own your BT passport. Nobody can change the details without your consent. A copy is retained and placed in the personal file that only the BT line manager has access to. Nobody else within BT knows you have one unless you choose to tell them. The circumstances of the individual are at the heart of the process – how many work processes can you say that about? Don't delay, get your passport today!

**For further information about the BT Passport scheme please contact Linda Roy or Fevzi Hussein at the CWU Equal Opportunities Department.**

# Equality Officer's seminar focuses on Obsessive Compulsive Disorder

*National Equality Officer Linda Roy reports on the annual equality officer's meeting*

The Equality Department held a seminar at CWU HQ on 12 July. The seminar is held annually, offering as an opportunity for equality officers and others who deal with equality issues within the workplace to have an insight into some of the industrial issues affecting both telecoms and postal constituencies. It also offers an opportunity to get general updates from some of our most trusted partners in the area of employment law.

Guest speakers included Cathy Ferrett from Changing Faces – a charity that supports and represents people who have disfigurements to the face, hand or body from any cause, Linda Stewart from Simpson Millar – who gave an update on equality legislation and Sally Brett from the TUC who spoke on the Equality Act 2010.

Everyone enjoyed the day immensely and found it very informative. Delegates had the opportunity to ask questions and share information with each other. One of the topics raised was in regards to Obsessive Compulsive Disorder and as a result the Equality Department agreed to highlight the issue to all members.

**What is Obsessive Compulsive Disorder (OCD)?**

- Obsessions: repetitive intrusive thoughts: worrying or upsetting thoughts/fears that won't go away
- Compulsions: actions or thought processes done to relieve the anxiety about the intrusive thought

**Common forms of Obsessive Compulsive Disorder (OCD)**

Excessive anxiety, fear and/or concern about:

- Dirt or germs
- Anticipated negative events (fire, flood, crime, etc); Feeling responsible for harm (eg. fire, flood, violence)
- Exactness/order
- The body and/or physical symptoms
- Upsetting religious/blasphemous thoughts
- Distressing sexual thoughts
- Urge to hoard
- Disturbing images of violence
- Recurring thoughts or music

**Related Disorders**

- Body Dysmorphic Disorder (BDD): fixation with a real or perceived defect in appearance
- Trichotillomania (TTM): compulsive hair pulling
- Compulsive Skin Picking (CSP): often a form of BDD

**Common Compulsions:**

- Checking
- Repeating acts
- Mental rituals
- Ordering or arranging
- Hoarding (compulsive collecting)
- Counting

**Is treatment available?**

Up to 1.8 million children, teenagers and adults in the UK live with OCD. This debilitating disorder breaks up families, causes loss of employment and exclusion from education. The good news is that there is effective treatment.

- Cognitive Behavioural Therapy (CBT) has been found to be clinically effective in 80% of cases
- Anti-Obsessional medication called SSRIs have been found to be clinically effective in 60% of cases

*OCD is a spectrum disorder and while many of us moderately experience some of these thoughts and behaviours, it is only when they interfere with day to day life that they become a disorder.*

**You have horrible thoughts that won't go away**

leave me alone, leave me alone, leave me alone

**You hate your own appearance and looking at yourself**

hate what I see, hate what I see, hate what I see

**You wash your hands in the day**

wash your hands in the night


day, night, day, night, day, night, day, night

**You check things all the time to make sure it's OK**



check double-check, check double-check

Request for materials – please copy this form, complete the sections and return to:  
 OCD Action, Suite 506-507, Davina House, 137-140 ...

Obsessive Compulsive Disorder (OCD) is a clinically recognised disorder that affects up to 3% of the UK population. It is identified as one of the top ten disabling disorders by the World Health Organization (WHO). If you or someone you know is affected contact:



**Help & Information:**  
**0845 390 6232**  
**(020 7253 2664)**  
**www.ocdaction.org.uk**

# The Disability Advisory Committee

The Disability Advisory Committee (DAC) requires trade union reps with an interest in disability issues

The Committee is a key contact for disabled members or members with a long term illness that may be covered under the new Equality Act 2010 (formerly the Disability Discrimination Act).

For help and advice, contact your local unit rep, equality officer, disability champion, branch office, or visit the CWU website at: [www.cwu.org](http://www.cwu.org)

You can also email [equality@cwu.org](mailto:equality@cwu.org) or phone the Equality Department on **0208 971 7238**

Join **Facebook** too for the latest on disability updates or contact DAC members on the **CWU Disability Network**.



[lroy@cwu.org](mailto:lroy@cwu.org)  
020 8971 7238

[www.cwu.org](http://www.cwu.org)

The logo for the Communications Workers' Union (CWU), featuring the letters "CWU" in a stylized, white, sans-serif font with a swoosh underneath.

*The communications union*

# Come and see the CWU DAC on the attack!

- ★ *Ever wondered: “what does the Disability Advisory Committee actually do?”*
- ★ *Ever thought: “who are the people on the DAC?”*
- ★ *Do you have a Disability Rep/Champion in your branch interested in becoming more involved with disability work, but not sure how they can?”*
- ★ *Did you know that branches can send observers to future DAC meetings at CWU HQ?*

For details, please email **Linda Roy**  
CWU National Equality Officer at:  
**lroy@cwu.org**  
Tel: **020 8971 7238**



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