epilepsy and social work support

This report gives the findings from an exploratory quantitative research project, conducted at the Sir William Gowers Unit at Epilepsy Society.

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introduction
Social workers who work on the Sir William Gowers Unit are in a unique position to be able to work directly with people living with epilepsy. As so little is known in this area I felt that there was a need to undertake an audit in social work support for people with epilepsy. I have been working with people with epilepsy since 2001.

The areas I looked into were:
- how many people are provided with an assessment under The Community Care Act (1990);
- how the social work service provided on the unit compares with the social work service received in the community; and
- whether the unit social workers and the community social workers are meeting the NICE guideline for epilepsy and the National Service Framework for Long Term Conditions.

For those unfamiliar, a definition of social work is necessary. The world of social work is ever changing and the definition is currently under review. Having checked with The British Association of Social Workers I was directed to the International Federation of Social Workers for their definition. It states that:

“The social work profession promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well being. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work.”

International Federation of Social Workers - www.ifsw.org (2013)

The Sir William Gowers Unit is a 26-bedded unit at Epilepsy Society that specialises in the assessment and treatment of people with epilepsy. The unit is affiliated to the National Hospital for Neurology and Neurosurgery (NHNN) at Queen Square, London. Patients from both Epilepsy Society and NHNN can come to the centre for assessment. Patients can also be referred from other hospitals throughout the country.

Social workers who work on the Sir William Gowers Unit play a vital role in providing specialised support to patients with epilepsy. They see patients who have come into the unit from all over the country who may or may not have been seen by their local authority social services regarding their epilepsy before their admission.

The method best suited to this research was a questionnaire which was given to patients on the unit who had seen the social worker. I am aware that adopting a single method of research may result in unreliable results, but felt that this method would enable me to access information from patients directly. By meeting with the patients directly I was able to assess whether more assistance was required from family and carers to gather relevant information.

The questionnaire used was based on a single assessment process which in turn was developed in consultation with patients. I chose a sample size of 100 participants which is felt to be an adequate sample size for a small-scale social research project. The information for this research was gathered over an 18 month period.

Note: patients who were diagnosed with non-epileptic attack disorder were not included in this research.
results

The key results of the research were as follows.

- The social workers on the unit are in a unique position to see patients with epilepsy and provide key support with their social care needs.

- 60 patients were seen by the social worker during their admission to the unit. 34 of these 60 had not seen a social worker through their local authority.

The results do not tell us why 34 of the patients were not seen in the community when it is a National Service Framework (NSF) quality requirement that: “people with a long term neurological condition are offered integrated assessment and planning of their health and social care needs”. Department of Health (2005).

In addition, the NICE guideline states in particular that: “individuals with epilepsy and their families and or carers should be given and have access to sources of information (where appropriate): social services”. NICE (2012).

It appears that local authorities across the country are not complying with the NSF and NICE guidelines. Recently a Health Minister spoke of: “...frustration that NICE guideline and National Service Framework for the condition were not being implemented everywhere, leading to a big difference between best and worst services’. The Health Minister went on to ask the Care Quality Commission to ‘undertake a special review of the way that trusts around the country apply the guidelines for long term conditions’”. Swanborough N (2010).

The Health Professions Council no longer exists and has been replaced by the Health and Care Professionals Council (HCPC). The Health Minister above did not ask for the review to look at local authority social services social work support for people living with epilepsy. This is an oversight as our results suggest that local authority social services are not seeing all those who are in need of social work support. Social workers are well placed to support people who have epilepsy and the social stressors that go with it.

“The direct effects epilepsy can have on the daily functioning of people with epilepsy, (prejudiced) attitudes, stereotypes and behaviours encountered in society both from lay people and professionals (for example from close relatives, friends, neighbours, but also from colleagues, teachers, employers or physicians) can be more disabling than the seizures themselves and will strongly burden their lives”. Suurmeijer T et al (2001).

“Social workers are ideally situated to help to reduce/remove the barriers that people face. Research informs us that a reduction/removal of stress levels can lead to a reduction in the amount of seizures experienced.” Yuen AW et al (2007).

- 57 respondents received an assessment on the unit.

This included giving information about their entitlement to an assessment as outlined in The National Health Service and Community Care Act (1990). The 34 respondents who were not seen by a social worker from their local authority may not have been aware that local social service departments have “a duty to assess any person who appears to them to be in need of community services”. Brammer, A. (2003)

- 56 respondents on the unit received benefits advice, while only 22 received this advice locally.

Financial restrictions are very common among people with epilepsy and this is due, in part, to difficulties finding and keeping a job which results in people having to depend on benefits. At the time of the research, people with a disability were entitled to apply for Disability Living Allowance (DLA) and may also have been entitled to other benefits which aim to financially support a person who has epilepsy and cannot find or keep a job. Disability Living Allowance is also designed to provide financial support for care to assist people with epilepsy.
From 8th April 2013 Disability Living Allowance was replaced by Personal Independence Payment (PIP) for people aged 16 to 64. PIP helps towards some of the extra costs arising from health conditions or disability. It is based on how a person’s condition affects them, not the condition they have. In addition, Universal Credit was launched in 2013 and replaces:

- income-based Jobseeker’s Allowance;
- income-related Employment and Support Allowance;
- Income Support;
- Child Tax Credit;
- Working Tax Credit; and
- Housing Benefit.

Source: Disability Rights UK (2013)

Each time there is a major change to the benefits system many recipients become anxious and confused, and may become worried about filling in the forms or attending an assessment of their individual needs. The new benefits changes affect everyone who is claiming, or could claim, a benefit. It is vital that information about benefits is given in order to provide relevant, up-to-date advice about benefits, changes and appeals procedures.

- 49 respondents on the unit received information about housing, while only 21 received this locally.

Many people with epilepsy may be living in unsuitable and dangerous accommodation. Giving information about appropriate housing, or who to contact to access information, can be very helpful.

- 48 respondents on the unit received support around transport issues, while only 20 received this locally.

Many people with epilepsy are unable to drive due to having seizures. Up-to-date information about the driving regulations needs to be given. Information about free or reduced travel on public transport, Taxi card schemes, local community transport and shop mobility needs to be given to enable people to access local amenities and work. Currently, people with epilepsy who are reliant on public transport are not able to use bus services for free before 9.30am. Epilepsy Society is lobbying central government to make changes to the times that people with disabilities can access public transport if they are unable to drive, and to allow them to have an escort on public transport.

- 53 respondents on the unit received information about MedicAlert, while only 16 received this locally.

MedicAlert medical jewellery has been specifically designed to provide information about a person and their medical condition to helpers and emergency services. If a person with epilepsy who has a seizure while unaccompanied in the community wears MedicAlert jewellery, it can provide vital information that can be used to inform the helper or emergency services who can then deliver appropriate care. A number of other medical jewellery providers are also available.

- 40 respondents on the unit received information about carer’s assessments, while only 21 received this locally.

People may not know that anyone can be a carer and that carers are entitled to a carer’s assessment in their own right due to The Carers (Recognition and Services) Act 1995. Our social workers can provide a carer’s assessment on the unit, or can make contact with an individual’s local authority social services to make a referral for a carer’s assessment if that is preferred.

- 56 respondents on the unit were given support with reducing risks in the home, while only 26 received this locally.

Many accidents happen in the home and living with epilepsy can mean that a person is more likely to fall or injure themselves following a seizure. Falls often happen in the home environment so raising awareness about risks in the home, and making recommendations about ways to reduce risks, is an important part of the social work role as it promotes independence, problem solving, empowerment and wellbeing.
• 43 respondents on the unit were given information about training, employment and education, while only 17 received this locally.

Finding and keeping a job can be difficult for someone with epilepsy. This may be due to the employer’s attitude to epilepsy rather than the employee’s ability to do the job well. Individuals with epilepsy may not be familiar with the Equality Act 2010, and may face discrimination in the work place because of their epilepsy. Similarly, employers may not be aware of their obligations under this act. A social worker can provide information about occupational health, ACAS (Advisory, Conciliation and Arbitration Service), and unions that can assist with employment issues. It is also helpful to provide information about organisations that provide advice and guidance about work, education and learning for people with a disability and to direct them to the Disability Employment Adviser at their local Jobcentre Plus.

• 55 respondents on the unit were given information about other helpful organisations, while only 19 received this locally.

There are a number of national and local helpful organisations. Being given information or signposted to them will enable a person to access sources of advice and guidance, depending on what they require.

• 47 respondents on the unit received emotional support from the social worker, while only 12 received this locally.

A study by S. Gillam in 2004 found that only 1 of 47 responses to a questionnaire mentioned a social worker in terms of support. This may indicate that people who have epilepsy do not see a role of social worker in terms of support. This may be because people with epilepsy have internalised, medicalised views of themselves and their condition. Providing emotional support is a fundamental part of the social work role.

All of these interventions comply with the International Federation of Social Workers’ definition of social work: to promote social change, problem solving in human relationships and to empower and liberate people to enhance well being.

**conclusion**

Patients with epilepsy in the Sir William Gowers Unit are more likely to be seen by a social worker who provides them with support, than to see a social worker in the community. Also, for some people, they may have seen their local social worker but the social worker may not have sufficient knowledge about epilepsy and how living with it affects an individual. ‘The National Occupational Standards for Social Work (May 2002), were compiled via consultations with service users, their carers and carers organisations. The standards outline the values, ethics and expectations of social workers working in the community. Section 1.f. of the standards requires social workers to: “inform individuals, families, carers, groups and communities about what is available, beyond the brief of their organisation.” A community social worker can find a store of information about the condition by simply keying in the word ‘epilepsy’ into an internet search engine.

The social work service at the Sir William Gowers Unit meets the NICE guideline that “individuals with epilepsy and their families and or carers should be given and have access to sources of information (where appropriate): social services”.

The social work service at the Sir William Gowers Unit meets the NSF quality requirement for a person-centred service where “people with a long term neurological condition are offered integrated assessment and planning of their health and social care”.

The results of this research show that social workers who have a specialised knowledge of epilepsy and how it impacts on a person’s life, are better placed to support a service user with epilepsy to access information, support and guidance to enable them to live as normal a life as possible. The results are a useful source of information for social workers in the community who are currently, or may in the future be, working with adults with epilepsy to enable them to provide a comprehensive assessment of their needs.

The author acknowledges that the research was not comprehensive. Not all patients on the unit were seen by a social worker. No questions were asked about age, gender or ethnic background.

References


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