

SHORT COMMUNICATION

Do learning disability services need epilepsy specialist nurses?

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Epilepsy is known to cause higher rates of morbidity and mortality than in the general population. It is estimated that one third of people with a learning disability also have epilepsy, and that their epilepsy is generally more difficult to control. Given these two statements and with the trend to place the majority of people with learning disabilities in small community homes rather than large medical institutions, it follows that there is a need for up-to-date information and education for individuals and carers in a variety of settings to ensure best care and quality of life is achieved. Is there a need for specialist epilepsy nurses to work in this field?

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Key words: epilepsy; learning disabilities; specialist nurse.

A variety of studies have been undertaken to determine the coexistence of learning disability and epilepsy. One such study quotes the risk of active epilepsy in the general population as 0.6%, in those with an IQ of 50–57 as 5.0%, with an IQ of 20–50 as 30%, and in those with an IQ less than 20, it is 50%¹.

Table 1² is indicative of a trend that has occurred nationwide in recent years, leading to a high percentage of people with a learning disability and epilepsy being cared for in the community by carers with little or no training or experience of epilepsy. This information has implications for primary health services to adequately manage the care of these individuals, and this may be to ensure that specialist input is sought.

A diagnosis of epilepsy for anyone can lead to fear and stigmatization due to ignorance, by the public, employers, schools and in many aspects of general life. This can result in a breakdown in the person's social life and lead to mental and physical ill health. For someone who has a learning disability the outcome can be similar, but with the addition of epilepsy, the person may be marginalized by society and perceive that they are by the general medical profession. The NHS document *Signposts for Success*³ has acknowledged this in several of its recommendations for good practice.

The aims of epilepsy management are:

- (1) To reduce seizure-related morbidity, such as head injuries, burns and scalds, which will help to cut the number of A & E admissions. This may be improved by education on safety, risk taking and first aid.
- (2) To reduce seizure-related mortality, such as drownings and accidents, and to raise the awareness of SUDEP.
- (3) To reduce treatment-related morbidity, by monitoring side-effects. This is like 'walking a tightrope between control of seizures, oversedation and cognitive impairment'⁴.
- (4) To reduce psycho-social morbidity and enhance quality of life in the community. This can be achieved by helping to reduce overprotection whilst maintaining safety appropriately, and by encouraging participation in sports and social activities, and activities of daily living. These may be curtailed by over anxious carers who may veto such activities as attendance at discos, any alcohol intake and any forms of independence.

Table 1: Changes in the place of residence of people with learning disabilities in the City of Westminster and the Royal Borough of Kensington and Chelsea 1983–1995.

	1983	1988	1993	1995
	No. (%)	No. (%)	No. (%)	No. (%)
Number of people with learning disabilities aged 20 years and over				
Living at home	99(15)	147(19)	147(20)	159(23)
Living in hospital	366(54)	253(33)	170(23)	44(6)
Living in community residential accommodation	217(32)	372(48)	429(58)	495(71)
Total	682	772	746	698

This management can be shared by a multi-disciplinary primary care learning disability team, which may have access to consultant neuropsychiatrist/psychiatrist, community nurses, psychologist, dietician, speech and language therapist, occupational therapist and physiotherapist, behaviour support team and social services.

The epilepsy specialist nurse would link into this team at times of crisis for short-term intervention, be a resource for other team members, and have an educational input in a variety of settings.

The idea of specialist nurses is not new and is well established in other areas such as asthma, diabetes, and palliative care. The government has acknowledged this in the new NHS when it states 'The government is particularly keen to extend developments in the role of nurses working in acute and community services... taking on leadership roles, monitoring and educating nurses and other staff, managing care, developing nurse-led clinics and district-wide services... across organisational and professional boundaries ensuring continuity and integration of care'⁵.

There is a number of areas where education can be a key role for the specialist nurse. One setting may be with other professionals, in order to update them on current thinking in various aspects of epilepsy and its management. This may include GPs and practice nurses, to possibly help them audit the practice and establish review clinics, with guidelines on when referral to secondary or tertiary care may be needed. The issue of care plans for giving rectal diazepam in emergency situations may require liaison, to ensure appropriate action by all carers.

Carers, parents, residential homes, training centres and school staff and employers may all appreciate help and advice in aspects of diary keeping, first aid and safety and in the giving of rectal diazepam. This would hopefully help both in the medical management and in the quality of life of the client.

For the accurate detection and classification of epilepsy in people with learning disabilities there are

various difficulties. The clients themselves are less likely to be able to recognize, interpret or communicate feelings associated with an aura. People with learning disabilities sometimes present with similar behaviours such as automatisms, tics and drug-induced movements and postures. There are also some difficulties discriminating between challenging behaviours and seizure patterns. Some of these difficulties can sometimes be helped with discussion between all the individuals who care for the person by taking a thorough history and description. Video recording of events can sometimes also help to disentangle the problems of diagnosis.

Accident and emergency departments and wards caring for people admitted with epilepsy and learning disability may be helped to care for the individual. It would be an advance in care to dispel the terms 'epileptic', 'E.P.' or 'known epileptic', which are too often used. Not only is it demeaning, but can lead to inappropriate care.

Disability employment officers may, with up-to-date knowledge, be in a better position to find employment for those people with epilepsy, and will lead to a greater understanding by employers.

What does an individual with a learning disability and epilepsy understand about the condition themselves? Are they frightened by their seizures? How do they feel post- and inter-ictally? These are questions which may be addressed by a specialist nurse, either individually or in small groups. Unfortunately there are very few resources suitable for people with learning disabilities at present to help them explain their feelings or to understand the condition.

Another important role for the specialist nurse is in liaison between primary/secondary/tertiary care to enable seamless delivery of care. Help can be given to gather relevant information from all sources of care, in order to present a whole picture to the consultant. Information and advice given by the consultant can also be disseminated and reinforced in all areas of the community care setting.

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