

# Neurodigest

Update on Neurology  
for Primary and Community Care

ISSUE 3: 2017

ADVANCES IN CLINICAL NEUROSCIENCE & REHABILITATION

Reviews

Top Tips

Commissioning

Rehabilitation



In partnership with the Primary Care Neurology Society

# News

## GENERAL

### Community based care model - the way forward for person-centred neurology care

'Delivery of person centred co-ordinated care for people with neurological conditions by encouraging the adoption of community based care model(s)' is one of the key aims of the recently launched community neurology project. A further aim is to 'Develop an evidence base to demonstrate and help commissioners understand the value and benefits of good community neurology.' Read more about how these aims are due to be achieved at

[www.neural.org.uk/nhs-england-community-project-for-neurology](http://www.neural.org.uk/nhs-england-community-project-for-neurology)

### Neurology Data Packs Released

The Right Care programme, now being taken forward by Public Health England and NHS England recently released new 'neurology focus packs' which are tailored to each Clinical Commissioning Group. The packs provide a range of statistical information on neurology services relevant to



each local CCG area. The data is drawn from Public Health England's Neurology Intelligence Network, which produces statistics and analysis on neurology services and outcomes. Further details of the packs can be found at [www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value](http://www.england.nhs.uk/resources/resources-for-ccgs/comm-for-value)

### Rehabilitation data in the latest NHS Rightcare long term conditions data packs

NHS RightCare has published a CCG data pack focused on long term conditions, which contains data on a number of disease areas and elements of care, including rehabilitation. The pack contains a number of new indicators not included in previous packs. It also includes case studies, tools and guidance to support CCGs to make improvements to long term conditions care in their local health economy. To access data pack which are bespoke to each CCG see [www.england.nhs.uk/rightcare/intell/cfv/data-packs/](http://www.england.nhs.uk/rightcare/intell/cfv/data-packs/)

### Improving Management of Common Neurological Conditions in Primary Care

This was a key theme of work for the London Strategic Clinical Network throughout 2016. The SCN developed several novel video based and Royal College of GPs (RCGP) approved educational

tools to support GPs managing patients with common conditions such as headache, dizzy spells, and transient loss of consciousness. In addition, the SCN will be sending out a series of information sheets regarding common conditions. To access the information sheet on headaches and view the videos which feature P-CNS chair Dr Nassif Mansour see [www.p-cns.org.uk/common\\_conditions-focus\\_on\\_headache.pdf](http://www.p-cns.org.uk/common_conditions-focus_on_headache.pdf)

### New Commissioning Approach to Reduce Unplanned Neurology-related Admissions

The London Neuroscience Clinical Network is proposing a new commissioning approach to address these issues and raise the quality and efficiency of services for people with neurological conditions. Here are links to three papers describing developed interlocking models examining new approaches to:

- The management of common conditions in the community by a provider network using a tiered approach. [www.londonscn.nhs.uk/publication/community-neurology-service-for-common-neurological-conditions/](http://www.londonscn.nhs.uk/publication/community-neurology-service-for-common-neurological-conditions/)
- Acute neurology services at a secondary care level led by neurologists [www.londonscn.nhs.uk/publication/hyper-acute-neurology-services-for-dghs-and-regional-neuroscience-centres/](http://www.londonscn.nhs.uk/publication/hyper-acute-neurology-services-for-dghs-and-regional-neuroscience-centres/)
- The adoption of patients with neurological conditions into integrated care systems by providing the tools and knowledge necessary to make this successful [www.londonscn.nhs.uk/publication/delivering-integrated-care-for-those-with-a-long-term-neurological-condition/](http://www.londonscn.nhs.uk/publication/delivering-integrated-care-for-those-with-a-long-term-neurological-condition/)

### Commissioning Guidance for Rehabilitation published by NHS England

The release of this Commissioning Guidance document "is a vital new tool for commissioners, patients, their families, clinicians and provider organisations", says Lindsey Hughes, NHS England's Improving Rehabilitation Services Programme Lead. It is a welcome boost for rehabilitation services. To access the guidance see [www.londonscn.nhs.uk/publication/delivering-integrated-care-for-those-with-a-long-term-neurological-condition/](http://www.londonscn.nhs.uk/publication/delivering-integrated-care-for-those-with-a-long-term-neurological-condition/)

### What is good adult rehabilitation?

To help answer this question, Wessex Strategic Clinical Networks published a document that sets out what they regard as the principles and expectations for good adult rehabilitation. To read the document see [www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations](http://www.networks.nhs.uk/nhs-networks/clinical-commissioning-community/documents/principles-and-expectations)

**These news pages contain just a few of the clinical papers that readers of Primary Care Neurology Society and the Community Therapists Network newsletters have highlighted. You will find more details of all these news articles plus others online at [www.neurodigest.co.uk](http://www.neurodigest.co.uk).**

## HEADACHES

### Treating headache with regular BOTOX treatment - is it effective?

According to results from the recent PREEMPT study the answer is yes. The results of the trial lead the authors to conclude that Onabotulinumtoxin A treatment is an effective treatment to reduce the headache-related disability and improve patients' quality of life when patients are treated regularly every three months and consistently overtime. Read the full study <http://link.springer.com/article/10.1186%2fs10194-016-0634-9>

### 'Satiety Hormone', leptin linked with Migraine with Aura

A recent study published in Cephalgia has found that leptin levels were found to be significantly higher in subjects with migraine. Read more at <http://cep.sagepub.com/content/early/2016/05/11/0333102416648650.abstract?rss=1>

### A promising treatment for migraine

A recent review has highlighted the growing evidence for the use of non-invasive neurostimulation methods for treating migraine. What's more, the review also concluded that the methods are devoid of serious adverse effects, allowing their combination with drug therapies. To read more about this work see <http://cep.sagepub.com/content/early/2016/03/25/0333102416636022.abstract?rss=1>

## PARKINSONS

### The future generation of advanced therapies for Parkinson's

If you're interested in what the future holds for the treatment of Parkinson's disease, then you may wish to read the report by Dr Kieran Breen of the European Medicines Agency Committee for Advanced Therapies. In it he explores some of the most exciting areas of research for potential Parkinson's treatments and cures – including stem cell-based therapy and gene therapy. See <http://parkinsonslife.eu/the-future-generation-of-advanced-therapies-for-parkinsons/>

If you have any patients that are into using mobile apps then this article on '8 more apps you need to try' could be useful. <http://parkinsonslife.eu/8-more-apps-for-the-parkinsons-community-you-need-to-try/>

### Improving mild cognitive impairment in Parkinson's disease

It has recently been shown that applying transcranial direct current stimulation lead to improvement in motor abilities and a reduction of depressive symptoms. The researchers also noted that the Parkinson's Disease Cognitive Rating Scale and verbal fluency test performance increased following the stimulation. Details of this study can be found at <http://onlinelibrary.wiley.com/doi/10.1002/mds.26561/abstract>

### Improving speech in Parkinson's patients

'Parkinson's Life' recently reported that the most typical speech and voice problems in people living with Parkinson's are low volume (hypophonia) and 'word finding problems' (cognitive-linguistic decline). With hypophonia, there may also be a change in perception. The voice has become softer, but to the individual it still feels normal, and a request to be louder is often met with resistance or a comment such as "that feels like I'm shouting." To read the article in full including 6 tips for improving speech in Parkinson's patients see <http://parkinsonslife.eu/mary-spremlu-voice-aerobics-speech-therapy-parkinsons-patients/>

## EPILEPSY

### First Guideline for Epilepsy in Pregnancy

This new guideline provides recommendations on the care of women with epilepsy during the pre-pregnancy, antepartum, intrapartum and postpartum periods. It has been produced by the RCOG and endorsed by the Association of British Neurologists, Epilepsy Action, Royal College of General Practitioners, Royal College of Midwives and Royal College of Physicians. Access the new guideline at [www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68/](http://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg68/)

### Ketogenic dietary therapies in adults with epilepsy: a practical guide

Interest in the use of ketogenic diets for epilepsy continues to grow, and so the review by Natasha Schoeler and Helen Cross in *Practical Neurology* is very timely. In the review they aim to familiarise the reader with the evidence base for these diets and give practical advice on starting and maintaining them in adults. Read at <http://pn.bmj.com/content/16/3/208?etoc>

### Epilepsy in the elderly

Epilepsy in the elderly is not often discussed in the literature, but one recent paper has highlighted the fact that 'The elderly constitute the largest and fastest continuously growing population among patients with status epilepticus', which is a life-threatening neurological emergency. In the paper, the authors suggest that the newer intravenous antiepileptic drugs, 'appear to be reasonable treatment options for elderly patients.' However, more evidence from clinical trials in this specific age group is required. Read at [www.ijge-online.com/article/51873-9598\(16\)0002-8/abstract?cc=y](http://www.ijge-online.com/article/51873-9598(16)0002-8/abstract?cc=y)

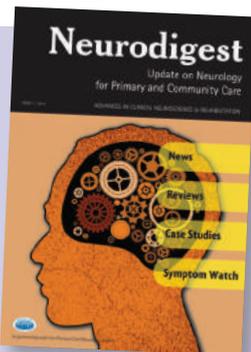
## COGNITION

### How the GP can support a person with dementia

The Alzheimer's Society have published a guide on their website entitled "How the GP can support a person with dementia". If you would like to read more about how the Alzheimer's Society believe GPs can support a person with dementia then see [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentid=94](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentid=94)

### Functional Cognitive Syndromes

Though more difficult than functional movement disorders to diagnose, functional cognitive syndromes, which can be triggered as a result of a mild traumatic brain injury, can be diagnosed positively in many and should not be considered a diagnosis of exclusion. At a P-CNS half day seminar, Dr Mark Edwards, Consultant Neurologist explained that treatment is possible, but it must start with a shared understanding of functional neurological symptoms on the part of the patient and clinician. Read his article on this topic at [www.acnr.co.uk/2013/06/mechanism-of-functional-neurological-symptoms/](http://www.acnr.co.uk/2013/06/mechanism-of-functional-neurological-symptoms/).



### Offering solutions to the challenges of dementia in primary care

Professor Alistair Burns and Dr Peter Bagshaw recently wrote in an article published on NHS England's website that 'there are a number of different models of primary care and dementia and we thought it would be helpful, as a way to stimulate discussion, to describe, from our point of view, three principal challenges for which there may be some solutions'. To read more about the proposed solutions see [www.england.nhs.uk/2016/03/alistair-burns-18/](http://www.england.nhs.uk/2016/03/alistair-burns-18/)

### Chocolate and better cognitive function.

This is a topic that has been highlighted in the mainstream media many times and remains contentious. However, recently published data from a cross-sectional analyses on 968 community-dwelling participants, aged 23-98 of the Maine-Syracuse Longitudinal Study has found that 'More frequent chocolate consumption was significantly associated with better performance on the Global Composite score, Visual-Spatial Memory and Organization, Working Memory, Scanning and Tracking, Abstract Reasoning, and the Mini-Mental State Examination'. Read more about the findings at [www.ncbi.nlm.nih.gov/pubmed/26873453](http://www.ncbi.nlm.nih.gov/pubmed/26873453)

### Cognitive Function, Dementia and Diabetes Treatment

A recent review has been published which discusses the increasing data that is accumulating to suggest that antidiabetes treatments have potential for the treatment of cognitive function and dementia. Read more at <http://link.springer.com/article/10.1007%2fs40266-016-0375-0>

# Welcome

Welcome to our third edition of Neurodigest, a journal that likes to Hoover up the best of neurological care in the community from around the UK and present it to you in an easy to digest form.

We start with a problem which tests the best of us - trying to tease out what causes the "bump" in the night. This can indeed be a nightmare. Neurodigest is indebted to Gary Dennis for shining a light into this dark nocturnal world, highlighting the complex interplay between epilepsy, sleep, parasomnias and REM behaviour disorders.

Having a child with a diagnosis of refractory epilepsy can be a challenge for any family. Following a strict ketogenic diet can only add to this stress. Ewan Forbes outlines the reasoning behind such dietary manipulation and provides valuable information for the support available to families as well as clinical commissioners looking to set up a ketogenic service.

Increasingly services need to prove their worth. If you can't provide qualitative evidence of effectiveness then you are likely to find yourself under increasing pressure. Rehabilitation services have not been immune from rationalisation. The ability to benchmark your service against alternative models allows for improvement through the dissemination of best practice, and Pam Enderby offers TOM (therapy outcome measure) as a validated tool to accomplish both of these requirements.

Neurodigest is grateful to Paul Morrish for pointing out that us GPs don't always find neurology easy. He demonstrates another example of the inverse care law. 1 in 5 GP consultations are neurological - trying to sift out the serious from the less so is challenging, yet our neurological training is for the most part woeful. A recipe only benefiting the authors of "Avoiding Errors in General practice."

Those of us who work within the traditional model of outpatient care are fully aware how out dated it can be. Seeing patients twice a year for a matter of minutes to try and deal with a patient's complex and changing needs has its limitations. Stephen Williams gives a glimpse of a brave new world, placing the patient firmly in the centre of their care - care which is centred within the community they live in. It seems so intuitive. Why aren't we all doing it? Building on the need for more community-

based service, the East Midlands NHS Clinical Networks report on the meeting held in 2016, at which 40 colleagues from across the East Midlands and further afield came together in an event where energy, ideas, tenacity and particularly, a shared commitment to developing quality services for people with long term neurological conditions were evident. At that meeting participants were provided with an opportunity to network, share learning and progress and ascertain the extent to which the commissioning guidance that had been launched 6 months earlier 'Community-based rehabilitation of people with long-term neurological conditions - Commissioning guidance and sample service specification', had informed work in their areas.

Motor neuron disease (MND) is the perfect example of the type of condition that both Paul and Stephen are describing. A GP might only come across a new diagnosis once or twice in a career. With its insidious onset and rarity it is the perfect storm for a delayed diagnosis. Patients with MND require a highly organised level of care which is likely to involve many disciplines. The best models demonstrate strong levels of communication and are embedded in the community, placing the patient firmly in the middle. Gary Dennis and Rachael Marsden provide an overview of the 2016 NICE guidelines for the assessment and management of MND.

Neurodigest is thankful to Greg Rogers for reminding us of the size of the treatment gap which exists within epilepsy care in the UK, along with some big numbers which show there is significant room for improvement. A good start would be to take on board his top tips, or even complete the BMJ learning model on "Epilepsy: diagnosis and management in primary care" over lunch!

Improving our care for patients with Epilepsy requires change in commissioning of that care. There is little cheer in Olivia Rzadkiewicz's article highlighting the lack of CCG provision for assessment of health and social care needs for people with epilepsy. However, help is at hand for those that want it. The Epilepsy commissioning toolkit is available to support the commissioning process and allow the benchmarking of existing services against epilepsy quality standards.

Wishing you all a bright and successful 2017.

Alistair Church  
Neurodigest Editor



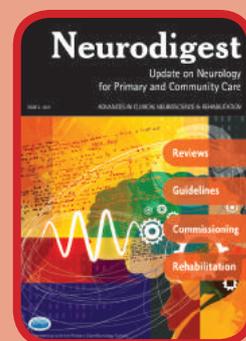
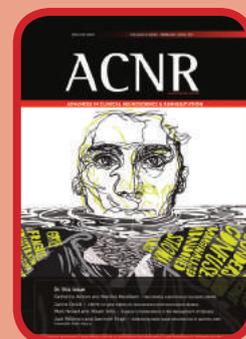
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## Neurodigest

Published by Whitehouse Publishing, in partnership with The Primary Care Neurology Society

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## PRINTED BY

Warners Midlands.  
Tel. 01778 391000

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# The relationship between sleep and epilepsy



**Dr Gary J Dennis**

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## Introduction

Sleep and epilepsy are intimate bedfellows, having an impact on each other and adversely affecting quality of life and daytime performance. Sleep has an important role in memory consolidation. Sleep deprivation impairs this process and epilepsy can upset this delicate balance. Sleep disorders are up to three times as common in epilepsy and can be a major contributor to refractory seizures, poorer quality of life and possibly SUDEP. Recognition of the comorbid sleep disorder and successful treatment can lead to significant improvements in seizure control. Many patients with epilepsy have seizures in sleep, some exclusively so. Often diagnosis is difficult due to incomplete histories from sleep partners. Even when telemetry facilities are available, data can be difficult to interpret and EEG is not always diagnostic. To add to this complexity, epilepsy treatments often have impact on sleep. Understanding this complex relationship can lead to better treatment outcomes for patients. This review will begin with diagnostic issues, moving on to the effects of epilepsy and its treatments on sleep, the effects of sleep disorders on epilepsy and concludes with practical advice on assessment.

**Figure 1**



A video EEG image of a nocturnal seizure showing short lived dystonic posturing of the right hand seen immediately on waking. 30 stereotyped attacks were recorded over 2 nights. The EEG was normal throughout. Awareness was reported for most attacks although the hand posturing was not recalled by the patient.

## Differentiating Epilepsy from other Sleep Disorders

Table 1 summarises clinically important details which help in differentiating epilepsy from other sleep disorders.

Derry et al (2006 & 2009) have produced very useful clinical tools to help differentiate nocturnal seizures from other sleep disorders with diagnostic accuracy up to 94%, however comorbidity is common and an awareness of the characteristic

**Table 1: Clinical features of disorders commonly producing sleep attacks.**

Disorder	Age of onset	Patient Awareness	Leaves the bed	Stereo-typed behaviour	Complex behaviours	Incontinence / tongue bites / injury	Daytime somnolence	No. of attacks per night	Typical duration of attack	Typical time of night
Epilepsy <sup>8</sup>	Any	Variable but usually poor	No	Yes (posturing, head version)	No	Yes	Variable	Often multiple	Seconds - minutes	Any
Non REM Parasomnia <sup>8</sup>	Childhood	None or very limited	Common	No	Yes (talking, walking, eating, intercourse)	No (rarely sustain injury)	Variable (if severe consider comorbid sleep disorders, OSA, PLMS etc)	Singular	< 30 minutes	Within 2 hrs of sleep onset
REM Behaviour Disorder (RBD) <sup>12</sup>	Middle age to elderly (mostly male)	Variable but can be significant (distressing dreams etc)	No	No	No	No (but injury sustained in violent acts)	No	Can be multiple	Seconds	> 4 hrs after sleep onset
Non -Epileptic / Functional attacks <sup>8</sup>	Young adult	Poor	Variable	No	Variable	Variable	Variable	Variable	Usually prolonged	Any
Periodic Limb Movements in Sleep	Elderly	Poor	Never	Yes (small amplitude flexion of legs)	Never	Never	Common	Numerous 10s – 100s)	Seconds	Any

features of the more common conditions enhances the history taking process. During nocturnal seizures patients rarely leave the bed space, attacks are often brief and stereotyped and can cluster throughout the night (figure 1). Incontinence, tongue trauma and wakeful seizures are strong pointers. Postictal symptoms on waking such as generalised aching, headache and amnesia of the preceding day's events are strongly associated.

Parasomnia episodes are seen in either rapid eye movement (REM) or non-REM (nREM) sleep. REM parasomnia (REM behavior disorder (RBD) is almost exclusively seen in elderly subjects with a male predominance, often associated with alpha synucleinopathies. Dream enactment occurs due to a lack of muscle atonia during REM sleep. Attacks occur late in the sleeping period where a higher concentration of REM sleep is seen. Patients often recall their dreams, behaviour is often violent and attacks are repeated each night. The American Academy of Sleep Medicine suggests RBD is diagnosed with polysomnography (PSG) as it can sometimes be difficult to differentiate it from epilepsy on the history alone.

nREM parasomnias generally arise in childhood, they are less frequent and usually singular during the early part of a sleeping period. Patients are more often amnesic to the event however, some recollection of the later stages of events is often reported due to awakening, often in a confused state. Injury is rare, behaviour is often complex and attacks can be prolonged but usually not more than 30 minutes. Excessive daytime somnolence is generally not a direct consequence of nREM parasomnias but if severe one should consider comorbid sleep disorders such as obstructive sleep apnoea (OSA) and periodic limb movements in sleep (PLMS).

### Night terrors and confusional arousals

Differentiating between these two types of common nREM parasomnias often causes difficulty. Night terrors are exclusively a paediatric condition and don't persist into adulthood. Although deeply asleep the child appears awake and is inconsolably terrified, often screaming loudly. Events can last up to 1 hour but they are not remembered. Confusional arousals occur in adulthood when an abrupt but incomplete awakening occurs from slow wave sleep (SWS), often associated with distressing dreams which can be recalled, leading to confusion and sometimes injury. Diagnostic difficulty can arise when the arousal is due to a short seizure and the confusion due to postictal phenomena.

## THE EFFECTS OF EPILEPSY ON SLEEP

### The effects and consequences of epilepsy on the sleep EEG

Objective PSG assessments show that inter-ictal epileptiform discharges (IEDs), increase in sleep especially in N3 nREM sleep although seizures seem to predominate in lighter nREM sleep. Nocturnal seizures lead to reductions in REM sleep and increases in nREM sleep. These changes are also seen when a wakeful seizure has occurred the previous day. Seizure types have differing relationships with sleep with focal epilepsies being more likely to disrupt sleep than IGE. Even in seizure free states interictal temporal lobe epileptic discharges seem to disrupt sleep when compared with frontal lobe epilepsy (FLE) and IGE. Temporal lobe epilepsy (TLE) correlates with worse sleep efficiency and increased stage shifts and awakenings. Despite this frontal lobe seizures are seen more commonly in sleep than temporal lobe seizures. Uncontrolled epilepsy in sleep can lead to memory impairments and excessive daytime somnolence (EDS).

**Table 2: Common effects of AEDs on sleep symptoms / disorders**

AED	Improves	Worsens
Lamotrigine (LTG)	-	Insomnia
Levetiracetam (LEV)	-	Fatigue / Somnolence OSA <sup>(a)</sup>
Carbamazepine (CBZ)	Insomnia	Fatigue / Somnolence
Sodium Valproate (VPA)	Insomnia	Fatigue / Somnolence
Phenytoin (PHT)	-	Fatigue / Somnolence Insomnia
Topiramate (TPM)	OSA <sup>(b)</sup>	-
Pregabalin (PGB)	Insomnia	Fatigue / Somnolence OSA <sup>(a)</sup>
Gabapentin (GBP)	Insomnia	Fatigue / Somnolence OSA <sup>(a)</sup>
Phenobarbitone (PHB)	Insomnia	Fatigue / Somnolence OSA <sup>(a)</sup>
Lacosamide (LAC)	-	Fatigue / Somnolence
Zonisamide (ZON)	OSA <sup>(b)</sup>	Fatigue / Somnolence
Perampanel (PER)	-	Fatigue / Somnolence OSA <sup>(a)</sup>
Oxcarbazepine (OXC)	-	Fatigue / Somnolence
Ethosuxamide (ETH)	OSA <sup>(b)</sup>	-
Benzodiazepines (BZP)	Insomnia	Fatigue / Somnolence OSA

(a) – due to weight gain (b) – due to weight loss

### The effect of epilepsy treatments on sleep

AEDs and epilepsy surgery can affect sleep. However the particular effects can be unpredictable.

#### AEDs

Few studies have been conducted in this complex area. Those which have are limited by short duration and inadequate controls for seizure types and polypharmacy. It appears that AEDs can improve sleep, however it is uncertain if this is due to improved seizure control or independent sleep consolidation. Unfortunately AEDs commonly produce daytime fatigue and at higher doses excessive daytime somnolence (EDS). This can be an advantage in patients with insomnia. Some AEDs are associated with significant weight gain which can lead to OSA. Care must be taken when using sedating drugs such as the benzodiazepines (BZPs) in patients who may be prone to sleep disordered breathing as apnoeic episodes may increase. Care should be taken when labeling EDS as a side-effect of AEDs as this risks under interpreting the disruptive effects of un-recognised nocturnal seizures and polysomnography (PSG) may be required to differentiate between the two.

The effects of AED withdrawal on sleep must also not be overlooked. Withdrawal of a sedating drug may lead to reductions in sleep. Withdrawal of mood stabilising AEDs (i.e. VPA, CBZ, LTG, TPM) may lead to worsening depression and anxiety all of which can precipitate insomnia and nREM parasomnias. Withdrawal of TPM can lead to weight gain which may precipitate OSA.

#### Chronopharmacology

Chronopharmacology holds great potential when applied to the management of epilepsy; it recognises that circadian rhythms exist in absorption and metabolism of drugs. Without changing the total daily dose of PHT and CBZ in epilepsy patients, serum levels increase and seizure control improves by administering proportionally higher doses at 2000 hrs compared with the morning.

#### Epilepsy surgery

Resective epilepsy surgery is now widely used to treat refractory epilepsy. However, only one study of 17 patients has evaluated sleep pre and post operatively using PSG. Although

**Table 3: Comorbid sleep disorders in epilepsy patients**

Sleep disorder	Prevalence Rates	Reference	Commonly used non-AEDs which may worsen the disorder
Insomnia	52% (vs 38% controls)	Khatami et al 2006 <sup>(37)</sup>	Caffeine Stimulants (methylphenidate, modafinil, amantadine) Alpha-blockers Beta-blockers Corticosteroids SSRI antidepressants ACE inhibitors Angiotensin Receptor II Blockers Cholinesterase inhibitors H1 antagonists Statins
OSA	30%	Malow et al 2000 <sup>(33,1)</sup>	BZPs
CSA	3.7%	Vendrame et al 2013 <sup>(32)</sup>	BZPs
PLMD	17%	Malow et al 1997 <sup>(40)</sup>	Antidepressants (except bupropion) Neuroleptics Antihistamines
RLS	18% (vs 12% controls) ns	Khatami et al 2006 <sup>(37)</sup>	Antidepressants (except bupropion) Neuroleptics Antihistamines
EDS (>10 on Epworth Sleepiness Scale)	19% (vs 14% controls)	Khatami et al 2006 <sup>(37)</sup>	BZPs Mirtazepine Tricyclic antidepressants Neuroleptics Dopaminergics

ns = non significant

no overall benefit was seen, patients who attained better post operative seizure control had greater improvements in total sleep times and arousals. Vagal nerve stimulation (VNS) has shown increases in SWS and nocturnal sleep latency in a study of 15 children with refractory epilepsy. However, in adult populations it can lead to deterioration in sleep disordered

breathing in up to 31% of patients thus changes in snoring and EDS should be closely monitored post VNS insertion. Deep brain stimulation (DBS) is now a recognised epilepsy surgery technique. Anterior thalamic nucleus DBS has been found to increase electroclinical arousals on average 3.3 times more frequently during stimulation periods compared to non-stimulation periods in a small study of 9 patients.

### THE EFFECTS OF SLEEP DISORDERS ON EPILEPSY

Sleep disorders are up to three times as common in patients with epilepsy compared with controls.

Sleep deprivation is often associated with an increase in IEDs and poorer epilepsy control, with 77% of JME patients reporting more seizures when sleep deprived. AEDs are associated with weight gain, and mental health disorders and both of these conditions predispose to sleep disorders. OSA is often caused or worsened by increases in the BMI and is known to have prevalence rates up to 30% in epilepsy populations and is associated with worsening seizure control. TLE has a greater association with OSA than extra temporal seizures. Management of OSA with continuous positive airway pressure (CPAP) produces improvements in epilepsy control with seizure freedom seen in almost 20% in a randomised controlled trial of 68 using therapeutic vs sham CPAP. Impressive responder rates (>50 % seizure reduction) have also been reported in trials of CPAP for OSA in epilepsy subjects (OR 32.2). Mood disturbance is also very prevalent in epilepsy patients. Sleep disorders are commonly associated with these mental health problems. Concurrent use of antidepressants is common, thus an awareness of the effects of these drugs is required when evaluating sleep complaints in epilepsy patients to ensure their contribution is not overlooked (table 2). RBD can be mistaken for epilepsy and can be effectively treated with removal of the antidepressant or the use of melatonin. RBD, restless leg syndrome (RLS) and periodic limb movement disorder of sleep (PLMD) are also commonly precipitated by antidepressant and neuroleptic drugs, however RLS and PLMD occur in a primary

**Table 5: Abbreviations**

ADNFLE	Autosomal dominant nocturnal frontal lobe epilepsy	LTG	Lamotrigine
AED	Anti epileptic drug	nREM	Non rapid eye movement sleep
BCECTS	Benign childhood epilepsy with centrotemporal spikes	OSA	Obstructive sleep apnoea
BMI	Basal metabolic rate	OXC	Oxcarbazepine
BZP	Benzodiazepine	PER	Perampanel
CBZ	Carbamazepine	PGB	Pregabalin
CPAP	Continuous positive airway pressure	PHB	Phenobarbitone
CSA	Central sleep apnoea	PHT	Phenytoin
DBS	Deep brain stimulation	PLMD	Periodic limb movement disorder of sleep
EDS	Excessive daytime somnolence	PSG	Polysomnography
ETH	Ethosuxamide	RBD	REM behaviour disorder
FLE	Frontal lobe epilepsy	REM	Rapid eye movement sleep
GBP	Gabapentin	RLS	Restless leg syndrome
IED	Interictal epileptiform discharges	SUDEP	Sudden death in epilepsy
IGE	Idiopathic generalised epilepsy	TLE	Temporal lobe epilepsy
JME	Juvenile myoclonic epilepsy	SWS	Slow wave sleep
LAC	Lacosamide	VNS	Vagal nerve stimulation
LEV	Levetiracetam		

form in the absence of pharmacological triggers and can significantly disrupt the quality of sleep although the evidence available suggests they are no more common in epilepsy subjects compared with controls. There is no published evidence on the impact of treating RLS/PLMD on seizure control, however this should be considered good practice.

**Conclusions**

Epilepsy and sleep and its disorders are very closely associated and improvements in the recognition and management of either will have beneficial effects on the other (see table 4 for practical tips on clinical assessment). Research in this field is still in its infancy compared with other neurological conditions, however greater awareness and investment promises much for epilepsy patients.

**Table 4 : Practical tips for the evaluation of sleep problems in epilepsy patients**

Diagnosis	FLEP scale <sup>11</sup> CHIAD Tree analysis <sup>12</sup>
Clues regarding the onset of symptoms	Drug commencement Drug withdrawal Weight gain Epilepsy surgery / VNS
Assess for comorbidity	RLS (IRLS scale) <sup>42</sup> OSA (Berlin questionnaire, <sup>43</sup> STOP BANG questionnaire) EDS (ESS) <sup>44</sup>
Optimise sleep hygiene	Regular bed and wake up times Remove bedroom technology Avoid caffeine after 1800 hrs Avoid large meals after 1800 hrs Reduce evening fluid intake No daytime naps

**Therapy Outcome Measures for Rehabilitation Professionals**  
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The Motor Neurone Disease Association is pleased to announce the launch of the Transforming MND Care audit tool. The tool has been designed for health and care professionals to support implementation of the NICE MND guideline (NG42) which was published in 2016. We worked with health and social care professionals to produce a fit for purpose instrument. The objective of developing the tool was to help teams measure their level of compliance with the standards outlined in the guideline. For more information visit [www.mndassociation.org/transformcare](http://www.mndassociation.org/transformcare)

The MND Association has an effective partnership with the Primary Care Neurology Society. This connection is important as the role of the primary care practitioner is significant in diagnosis and crucial in the ongoing support for the person living with MND as they access the numerous services involved in their care. The new audit tool will be useful for primary care colleagues to get a snapshot of the various data being gathered by health and care teams, which will support their understanding of the best care they can expect for their patients.

Interested teams can carry out the clinical audit by inputting relevant information into the Excel-based spreadsheet provided. There is also an accompanying patient experience survey for use, the results of which also inform the final audit conclusions. The data input will populate graphs that display feedback results in a visual way. All outcomes will feed into an improvement plan ready for discussion and to agree action by the team.

By completing the audit teams are able to:

- benchmark current performance
- focus efforts to improve outcomes for people living with MND
- plan cost-effective improvements
- enhance professional practice
- better understand the experiences of people with MND using the service
- improve multidisciplinary working and communication with partner organisations.

To receive a copy of the tool please email [audittool@mndassociation.org](mailto:audittool@mndassociation.org) or telephone 01604 611770.

# Nutricia: Helping to Support the Need for Ketogenic Diets in the Epilepsy Population

## Ewan Forbes

BSc (Hons) PGDip RD, Medical Affairs Manager,  
Metabolics & Ketogenics, Nutricia

Approximately 600,000 people in the UK have a diagnosis of epilepsy. The prevalence rate of epilepsy in the UK is approximately 9.7 per 1,000 or 0.97%<sup>1</sup>. Although epilepsy is treatable with anti-epileptic drugs in the majority of cases, about 30% of patients suffer from drug-resistant epilepsy<sup>2</sup>. Patients with uncontrolled epilepsy heavily depend on informal care (family and friends) and on healthcare professionals. Complications due to intractable epilepsy result in frequent inpatient admissions and often involve transfers to intensive care units. Patients with drug-resistant epilepsy can potentially benefit from a ketogenic diet<sup>3</sup>.

### What is ketogenic therapy?

The ketogenic diet (KD) has been used for the management of epilepsy since the 1920s. It evolved from the observation that extended fasting led to significant seizure improvement. This effect can be replicated by altering the macronutrient intake in the diet, triggering a metabolic shift away from carbohydrate (glucose) to fat (ketones) as the predominant dietary energy source. The classical KD is a high fat, low carbohydrate, adequate protein diet that is based on inducing ketosis through providing a high ratio of ketone producing foods (predominantly fat). The rationale of a significant carbohydrate restriction is that, in response to lower glucose availability, changes in insulin and glucagon concentrations will direct the body towards fat oxidation and shift metabolism from 'glucocentric' (glucose) to 'adipocentric' (ketone bodies). The diet is calculated according to energy requirements and the sought after ketogenic ratio of fats to carbohydrate and protein, commonly 3:1 or 4:1. Other versions of the classical KD have been introduced in more recent years including the medium chain triglyceride (MCT) ketogenic diet (MCT KD) and the modified ketogenic diet (MKD).

### Efficacy for the ketogenic diet

Efficacy of the ketogenic diet in the dietary management of paediatric refractory epilepsy has been demonstrated in a number of randomised controlled studies, systematic reviews and meta-analyses. The findings have been very consistent, with approximately 50-60% of responsive patients having a >50% reduction in seizures, 30% having a >90% seizure reduction and 10% becoming seizure free<sup>4</sup>. NICE guidelines for management of paediatric epilepsy make the following recommendation:

*"Refer children with epilepsy whose seizures have not improved on appropriate AEDs to a tertiary paediatric specialist for consultation on the use of a ketogenic diet."*<sup>5</sup>

Despite these recommendations few patients in the UK are given the opportunity to access KD.

### Perception of the ketogenic diet

Historically the ketogenic diet has been considered a restrictive

diet that is hard to comply with and limits food choices of children who already have a difficult life. Recent advancements in the availability of computer meal planner programmes, dedicated ketogenic chefs, and recipe developments have helped challenge this perception. Furthermore, charities such as **Matthew's Friends** and **Daisy Garland** provide education, support material, recipes and helplines for families. New recipes and specialist products, such as KetoCal, provide families with choice, variety, palatability, independence and peace of mind.

Although following a ketogenic diet has become easier and more palatable, it is still recognised that the diet requires a medical team, including a well-trained and experienced dietitian.



### Ketogenic services in the UK

Currently in the UK there are 23 specialist paediatric centres providing a ketogenic diet service for children. On average, 1.0 wte Dietitian maintains a case load of 29 patients with 18 new children started on the diet each year. Many of these centres, however, report that demand on their service is high, with waiting lists for patients wanting to commence a ketogenic diet often in place.

The Nutricia team has recently developed a generic business case for establishing funding for extending or establishing new ketogenic services. The business case has been developed in collaboration with a clinical commissioner to provide a framework to apply for NHS funds. Trusts looking to set-up or extend pre-existing ketogenic services are invited to use the business case to help gain financial support.



To request a copy of the business case uploaded on to a memory stick, please contact the Nutricia resource centre on: 01225 751098.

### REFERENCES

- 1 Joint Epilepsy Council, 2005. *Epilepsy prevalence, incidence and other statistics*. [online] (Accessed 12/04/2012)
- 2 Kossoff EH, et al. *Optimal clinical management of children receiving the ketogenic diet: recommendations of the International Ketogenic Diet Study Group*. *Epilepsia* 2009, 50(2):304-17
- 3 Kinderan R, et al. *Research into the (Cost-) effectiveness of the ketogenic diet among children and adolescents with intractable epilepsy: design of a randomized controlled trial*. *BMC Neurology* 2011, 11:10
- 4 Kossoff EH, Wang SH. *Dietary therapies for Epilepsy*. *Biomed J* 2013, 36:2-8  
NICE guidelines for management of paediatric epilepsy 2012, <http://guidance.nice.org.uk/CG137>

# Crossing the work health divide - Better engagement with employers

## Executive summary

The Community Therapists Network (CTN) has been in existence for just over 10 years, having evolved from the Community Rehabilitation Team Network set up by Prof Pam Enderby and colleagues in 1996. The CTN offers information, training and education to allied health professionals who provide care and support for people living with long-term conditions in the community, and those professionals working in vocational rehabilitation (VR). This report summarises presentations and discussions from the CTN meeting entitled 'Crossing the work health divide - Better engagement with employers', held in Birmingham on 13 October 2016.

The meeting began with an overview of recent work from the University of Nottingham Rehabilitation Research team lead and presented by Professor Kate Radford. Despite national and local policy support for return to work (RTW) following ill health, there is inadequate provision of VR services across the UK. An early stroke-specific VR intervention was developed based on gaps identified in existing local stroke rehabilitation services, and this was evaluated in two pilot studies. This intervention showed encouraging results (for work outcomes and cost-effectiveness) regardless of whether it was delivered by a 'non-tethered' therapist (who was free to move across health services to create a multidisciplinary rehabilitation team) or by a therapist based within the community stroke team.

Yash Bedekar, an independent senior occupational therapist, considered ways to translate findings from research, including studies of VR interventions for RTW following stroke and traumatic brain injury at the University of Nottingham, into practice. Although clinical practice policy is based on research evidence, updates to policy may not occur for many years. Insights gained from research, such as the employers' views on what support they would value in a VR process, can help VR service providers identify ways to engage as early and effectively as possible with these key stakeholders. Research findings can also guide how VR therapists engage with clients, for example in providing personalised/tailored information or acting as advocates during discussions with their employer.

Ruth Tyerman from the Community Head Injury Service in Aylesbury shared her team's experience in preparing business cases to establish a VR service and maintain/expand an existing VR service. Suggested content outlines for each scenario, along with useful sources of evidence and information to include in these were explored, for example to establish the need for a local VR service and align the proposed service with relevant best practice models and UK quality standards. The importance of sharing outcomes data from local services to contribute to the national evidence base for VR, and thus support future business cases was highlighted.

Kate Radford returned to the lectern and talked about 'Key outcomes to measure in vocational rehabilitation – the what and how?'. She explained that in addition to supporting a business case, VR outcomes data may also be useful for evaluating a service, monitoring effectiveness and costs, or to demonstrate an impact on clients' lives. But importantly, when gathering this data, there needs to be a clear understanding of who will use the information

and who will be influenced by the outcomes being measured, and to select appropriate standardised tests on this basis. In practice, a user-friendly outcomes assessment questionnaire can be designed which captures primary and secondary outcome measures from VR service users. For the VR service providers, measuring the process of deployment (alongside measurement of outcomes) gives useful insights into resource use and whether the service delivered is adhering to its original model.

When an employee has a health condition and/or impairment, support for employers can come via Vocational Rehabilitation or Occupational Health (OH) providers. Sarah Woodbridge, a Specialist Occupational Therapist at Derby Teaching Hospitals NHS Foundation Trust, examined the overlaps between how these services address the employer and employee's needs and wants, and differences between their remits, work assessment formats, duration and flexibility. For instance, the VR approach for assessment and support is typically longer and more complex than that for OH, however VR has advantages for the employee (for example, by supporting both physical and mental health) and the employer (for example, by mentoring and facilitating the client during RTW, thus relieving their line manager of this workload).

The conference programme also highlighted the importance of supported employees' mental health. Lynn Aggett and Richard Frost from Workways, supported by Devon Partnership NHS Trust, outlined their supported employment service and a job retention service for people with mental health issues. Lynn Aggett described the supported employment service, where an Individual Placement and Support (IPS) approach assists clients who are actively looking for paid employment. The IPS model has 8 clearly defined principles, all of which must be adhered to in order to be most effective. Ongoing support for IPS implementation is available from the Centre for Mental Health. Richard Frost explained that for the Workways employment retention service, the ability to act as an independent mediator was important. The employment specialists delivering this service typically split their time 50:50 between supporting the client and the employer. Workway's clients and their employers are also signposted to relevant organisations/schemes for additional support where needed, e.g. the DWP, MINDFUL EMPLOYER, etc.

During the meeting, two interactive sessions chaired by John Pilkington, Chair of the Vocational Rehabilitation Association (VRA) allowed attendees to put their own questions to a panel of experts. The first of these Q&A sessions focused on addressing the challenge of helping people with long-term health conditions stay in, or get back to work. Members of the panel who provided overviews of their work in VR and challenges faced in this area were: Yash Bedekar (on behalf of Carina Humphreys) from the Royal Free Foundation Trust's VR service, David Imber from the VRA, Rohina Begum from the Chartered Society of Physiotherapy, and Amanda McBurney from the Mental Health Support Service at Remploy. The second Q&A session provided top tips for mental health at work. For this, the experts were Chris Morgan from the Mental Health First Aid National Training Team, Jane Bradshaw, an Independent Neurology Nurse Consultant and Expert Patient, and Richard Frost from MINDFUL EMPLOYER.

To access more detailed coverage of the meeting please go to this article online at [www.neurodigest.co.uk](http://www.neurodigest.co.uk)

# A generic outcome measure for rehabilitation — a tool for commissioning



**Professor Pam Enderby**

Professor Pam Enderby MBE PhD is Professor of Community Rehabilitation at The University of Sheffield. She established the first AAC centre in the UK in 1980, and was awarded a Fellowship of the College of Speech Therapists in 1983. In 1993 Professor Enderby was honoured with an MBE for services to speech and language therapy.

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No one will be surprised to learn that rehabilitation and enablement services commissioned by the UK's National Health Service and mostly provided by Allied Health Professionals shows great variation in their staffing (grades and types), general resources, modes of practice, service users catered for (types and ages), care models, and intentions. Much of this variation is associated with the history of configurations of service provision over previous decades – few, if any, services have been organised on the basis of patient outcomes as it is difficult to capture such outcomes for this heterogenous group.

Whilst there has been a substantial increase in research investigating specific interventions for specific groups of patients receiving rehabilitation including randomised controlled trials and other appropriate methodologies, the evidence base is still thin given that the majority of patients receiving rehabilitation (both children through to older adults) have a range of comorbidities rendering it necessary to combine interventions, adjust goals and therapy approaches and making it unlikely that they would be included in any research project. Most research requires clear definition of those patients included and those excluded, and there is a requirement to consider the fidelity to the intervention

***‘Rehabilitation achieves this by focusing on the impact that the health condition, developmental difficulty or disability has on the person’s life, rather than focusing just on their diagnosis. It involves working in partnership with the person and those important to them so that they can maximise their potential and independence, and have choice and control over their own lives. It is a philosophy of care that helps to ensure people are included in their communities, employment and education rather than being isolated from the mainstream and pushed through a system with ever-dwindling hopes of leading a fulfilling life.’***

being investigated. Such research helps in establishing a better understanding of underlying conditions and the theoretical basis of different interventions, but clinicians often find it difficult to inform their practice based on these due to the challenge of generalising such precise findings to the caseloads that they serve.

The Commissioning Guidance for Rehabilitation published by NHS England (March 2016)<sup>1</sup> reflects the complexity of meeting the needs of a broad range of individuals who require and would benefit from rehabilitation.

But this guidance also acknowledges the need to ensure that services are commissioned and monitored in an appropriate fashion, services learn from best practice and the most cost-effective approaches are used.

It is not uncommon for a particular Health Service Trust to provide excellent services for particular client groups but fall down in services to other groups (NHS Atlas of Variation 2015)<sup>2</sup>. Furthermore, it may not be recognised that this is the case by either the Commissioner or the provider of the services. This is probably why The Commissioning Guidance for Rehabilitation<sup>1</sup> emphasises the importance of collecting outcome data and engaging in audit and benchmarking which can identify strengths and weaknesses.

The objectives of benchmarking are (1) to determine what and where improvements are called for, (2) to analyse how other organisations achieve their high performance levels, and (3) to use this information to improve performance.

In order to conduct benchmarking such as has been undertaken in, for example, the very successful Stroke National Audit Programme<sup>3</sup> and the National Audit of Intermediate Care,<sup>4</sup> it is necessary to identify the necessary data to collect and an appropriate outcome measure. However, due to the broad number of health and social care professionals as well as the number of different client groups receiving rehabilitation there are numerous outcome measures available to choose from. But this causes the problem that different services favour different approaches to outcome measurement, making it difficult to compare and contrast service provision. A generic measure which could be used alongside more specific outcome measures may assist more general comparison of services.

***‘Focusing on outcomes is one way of enabling the transformational change required in the healthcare system.’***  
**p19 Commissioning Guidance for Rehabilitation**

The Therapy Outcome Measure (TOM)<sup>6</sup> was designed to be a simple, reliable, cross-disciplinary and cross-client group method of gathering information on a broad spectrum of issues associated with therapy/rehabilitation. It has been rigorously tested for reliability and clinical validity and can be used by physiotherapists, occupational therapists, speech and language therapists, podiatrists, dieticians, rehabilitation nurses and others

involved in rehabilitation.

It aims to be quick and simple to use, taking just a few minutes to complete. It was based on examining the goals used in rehabilitation with unselected patients and their carers and has been used for treatment planning, clinical management, audit, benchmarking and research.

The TOM<sup>6</sup> allows therapists to describe the abilities of a patient in four domains, the first three of which are based on International Classification of Functioning (WHO) definitions as detailed in the rehabilitation guidance<sup>1</sup>:

Impairment	Dysfunction resulting from pathological changes in system
Activity restriction/ function	Functional performance/ independence
Participation	Integration in society (including employment, education and recreation)

The fourth domain of well-being, of both the patient and the carer was added to the TOM due to the finding that having an impact on well-being is an objective of rehabilitation in many if not all client groups and thus needs to be separately identified in the outcome measure.

TOM<sup>6</sup> has an 11 point ordinal scale. A rating from 0 to 5 is made on each domain, where a score of 0 is profound, 3 is moderate and 5 mild. For example a score of 0 for 'Activity' represents a patient who is totally dependent/unable to function; a score of 3 for 'Impairment' represents a patient who has a moderate dysfunction resulting from pathological changes; a score of 5 for 'Participation' represents a patient who is integrated and able to maintain their expected different roles in society, is valued by others, and exercises choice and autonomy. A score of 0.5 or ½ a point may be used to indicate if the patient is slightly better or worse than a descriptor.

The TOM Core Scales has been adapted into scales that relate to conditions that are familiar to a range of health care professionals involved in rehabilitation/enablement and acute care. These scales (47 are available in the third edition) have been adapted by specialists working in the relevant areas. The book provides background as to how the tool was developed, how TOMs can be introduced to a team or service, guidance on how to use the tool and guidance on how to analyse data.

Research underpinning the TOM<sup>7-17</sup> suggests that some services emphasise and have an effect on improving the underlying condition (impairment) whereas others concentrate on having an impact upon improving activity, social participation or well-being and that services can have significantly different patterns of outcome.

The Royal College of Speech and Language Therapists are the first of the Allied Health Professional groups to review appropriate outcome measures with the objective of gathering data on all clients receiving intervention by a speech and language therapist.

They considered 60 candidate outcome measures commonly used within the profession and which had been identified by their membership against 11 criteria which included a range of psychometric properties. The Therapy Outcome Measure was identified as the core measure which after piloting will be used to collect national data, allowing information related to the impact of SLT to be gathered and compared.

Rehabilitation requires not only highly sensitive and specific outcome measures for use by the different professionals involved, but also generic measures in order that the overall impact can be gauged, compared and integrated into continuing quality improvement.

## REFERENCES

- 1 Commissioning Guidance for Rehabilitation published by NHS England (March 2016) Publications Gateway Ref No. 04919 <https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf>
- 2 NHS Atlas of Variation 2015. Public Health England [http://www.rightcare.nhs.uk/atlas/RC\\_nhsAtlas3\\_HIGH\\_150915.pdf](http://www.rightcare.nhs.uk/atlas/RC_nhsAtlas3_HIGH_150915.pdf)
- 3 Sentinel Stroke Audit. Royal College of Physicians <https://www.rcplondon.ac.uk/projects/outputs/sentinel-stroke-national-audit-programme-ssnap>
- 4 National Audit of Intermediate Care. 2015 NHS Benchmarking Network. Document reference: NAIC2015 <https://www.rcplondon.ac.uk/projects/outputs/sentinel-stroke-national-audit-programme-ssnap>
- 5 International Classification of Functional Disability and Health. 2001. World Health Organisation, Geneva
- 6 Enderby P, John A, 2015. *Therapy Outcome Measures for Rehabilitation Professionals*. 3rd Edition J&R publications. Guildford
- 7 Enderby P, Hughes A, John A, Petheram B. Using Benchmarking data for assessing performance in occupational therapy. *Clinical Governance: An International Journal* 2003;8(4):290-295.
- 8 Enderby, P. (1999) For richer for poorer: outcome measurement in speech and language therapy. *Advances in speech language pathology* volume 1 number one pp. 63-65.
- 9 Enderby, P. and John, A. (1999) *Therapy outcome measures in speech and language therapy: Comparing performance between different providers*. *International Journal of Language and Communication Disorders*, 34, 417-429.
- 10 Enderby, P., John, A., Hughes, A., and Petheram, B. (2000) *Benchmarking in rehabilitation: comparing physiotherapy services*. *British Journal of Clinical Governance*, 5(2), 86-92.
- 11 Enderby, P. and Kew, E. (1995) *Outcome measurements in physiotherapy using the World Health Organisation's classification of impairment, disability and handicap: a pilot study*. *Physiotherapy*. Volume 81 number four pp. 177-183.
- 12 John, A. (1993) *An Outcome Measure for Language Impaired Children Under Six Years: A Study of Reliability and Validity*. MSc. Thesis, City University.
- 13 John, A. and Enderby, P. (2000) *Reliability of speech and language therapists using therapy outcome measures*. *International Journal of Language and Communication Disorders*, 35, 287-302.
- 14 John, A., Enderby, P., and Hughes, A. (2005a) *Benchmarking outcomes in dysphasia using the therapy outcome measure*. *Aphasiology*, 19(2), 165-178.
- 15 John, A., Enderby, P., and Hughes, A. (2005b) *Comparing outcomes of voice therapy: A benchmarking study using the therapy outcome measure*. *Journal of Voice*, 19(1), 114-123.
- 16 John, A., Enderby, P., Hughes, A., and Petheram, B. (2001) *Benchmarking can facilitate the sharing of information on outcomes of care*. *International Journal of Language and Communication Disorders*, 36 Suppl. 385-390.
- 17 Ryan, A. (2003) *An Evaluation of Intensity of Community Based Multidisciplinary Therapy Following Stroke or Hip Fracture for People Aged 65 and Over*. PhD Thesis, University of Sheffield.

# Learning and Commissioning



**Paul Morrish**

Paul Morrish qualified in 1983 and trained in General Practice at Milton Keynes. He went back into hospital medicine and then neurology. He worked in research in Parkinson's disease, and was Neurology Consultant in Sussex and in Gloucestershire where he pursued an interest in neurology service development and education. He now works part-time as a Neurologist in Bristol and helps the Neurology Information Network with data analysis and interpretation.

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If we are to improve the care of patients with neurological symptoms and illness, then continuing education in neurology and interaction between local GPs and Neurologists must be a component of every commissioning agreement. I don't know of a single commissioning agreement yet where that is the case.

A GP friend of mine was reading the other day, and as she read on, her expression changed from enthusiasm to concern and then to something approaching panic. The book was "Avoiding Errors in General Practice"<sup>1</sup> and the changing expression needs no explanation. It's a useful exploration of medical errors in General practice and how best to avoid them. The authors present forty cases of medical error of which nine are neurological. I might

moan about delayed presentation and unnecessary referral to neurological outpatients, but I also know that amongst those many patients seen in primary care every week with headache, dizziness or tingly numb legs there will be the occasional sinister neurological illness. The task of working out which is which when given ten minutes, an ophthalmoscope and a wonky tendon hammer must be a challenge.

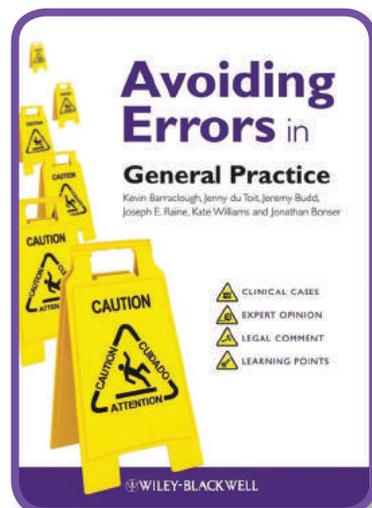
I can't speak for any GP, but let me hazard some guesses why neurology is difficult for GPs. The first is that it is difficult for all of us. Indeed, it is more worrying rather than reassuring

when a colleague displays their bravado and suggests it isn't. Neurologists get it wrong, though hopefully less often than non-specialists. We might tell you that we have identified the site and nature of the lesion by our finely tuned clinicians' ears and hands but most of us will also scan the wrong body part with dismayingly regularity. Not enough patients know how to give a textbook history of their neurological complaint, and signs like spasticity can be

there one day and gone the next. The seemingly "hard" sign of a plantar response can vary with the weather. Some neurological illnesses begin and progress so insidiously that the patient may not know when it started, let alone their GP. A GP may have the benefit of seeing one patient over several consultations, but that doesn't necessarily help them pick out the key neurological symptom when it is aired. Neurologists sometimes take more than thirty minutes to listen to the history, even for a headache, and it may be more the case in neurology than other medical specialties that if we don't know the diagnosis after taking the history it's better to re-take the history than to press blindly on. The things we do differently to the GP are to spend more time interrogating each symptom, and then examining and re-examining until things make sense. To make sense of a presentation it helps to have the context of familiarity with neurological illness; it's really much easier if you've seen it before. There is also the rarity of many neurological illnesses in the community, the one presentation of MND every ten years or the one MS every four years. We also procrastinate and we sometimes await events, but we can do that because our specialist label allows it. Finally both Neurologists and GPs ought to bemoan the paucity and quality of training in medical school and in GP training, whether that is for the recognition of the rarity or for preparing for the everyday neurology of General practice. Many medical students still learn from a week on a ward, an enthusiastic registrar in General medicine, or an Academic Neurologist with a particular interest in mitochondrial cytopathies. Many of the District General Hospitals around

which GP training is based may have only a visiting Neurologist and no neurology ward. Only one or two GPVTSs include time in neurology outpatients; given the frequency of neurological presentation, it should be much more. The difficulty with neurology may also be related to the rapidly changing nature of neurology itself. In less than thirty years we have gone from no scans to CT scans, to MRI scans, and then to MRI scans with such resolution and multiple image analysis modalities that many of the things they detect are incidental. Meanwhile headaches and epilepsies are sub-grouped and classified, then re-grouped and re-classified as knowledge progresses and fashions change.

It is surely better use of a Neurologist's time to be helping a group of local GPs to learn than to be seeing patients that could, with a little information transfer, be managed in General practice; it is surely not too much to ask of each GP practice to ensure that one or two of the doctors take part in an educational session with their local neurology department, if they have one, once or twice a year. If you agree, then please drop a hint to your local commissioners.



## REFERENCES

1. *Avoiding Errors in General Practice: Clinical Cases and Medico-legal Issues*. Kevin Barraclough, Jenny du Toit, Jeremy Budd et al. Wiley-Blackwell London 2013

# NHS England Community Neurology Project

Neurological conditions are many and varied. The term covers a huge variety of significant health problems, from isolated injuries to recurrent or progressive conditions. Whilst awareness of Parkinson's disease, multiple sclerosis and epilepsy is high, transverse myelitis, acoustic neuroma, neurofibromatosis, dystonia, congenital hemiparesis – the list goes on and on – much less so.

Despite the almost nebulous perception of neurology it often surprises people that there are over 12 million cases in England alone. In fact, 17% of all GP appointments, and almost 1 in 5 hospital admissions, are for people with neurological conditions. A typically-sized Clinical Commissioning Group area may have about 60,000 patients with a neurological condition and almost of them will require long-term care and support.

Despite this, integrated care and care planning for these patients is the exception rather than the rule; Only one in ten have a written care plan and only a handful of those patients were actively involved in designing theirs. Patients may see a health care professional for a few hours each year and for 99% of the time they have to self-manage their condition. A recent NHS England patient survey found that those with neurological conditions report having the highest levels of pain, anxiety and depression.

A fifth of patients say they do not feel they get enough support. The impact of this can be evidenced in the high number of emergency admissions for people with long-term neurological conditions (700,000 during 2012/13 at a cost of £750 million),

## Stephen Williams

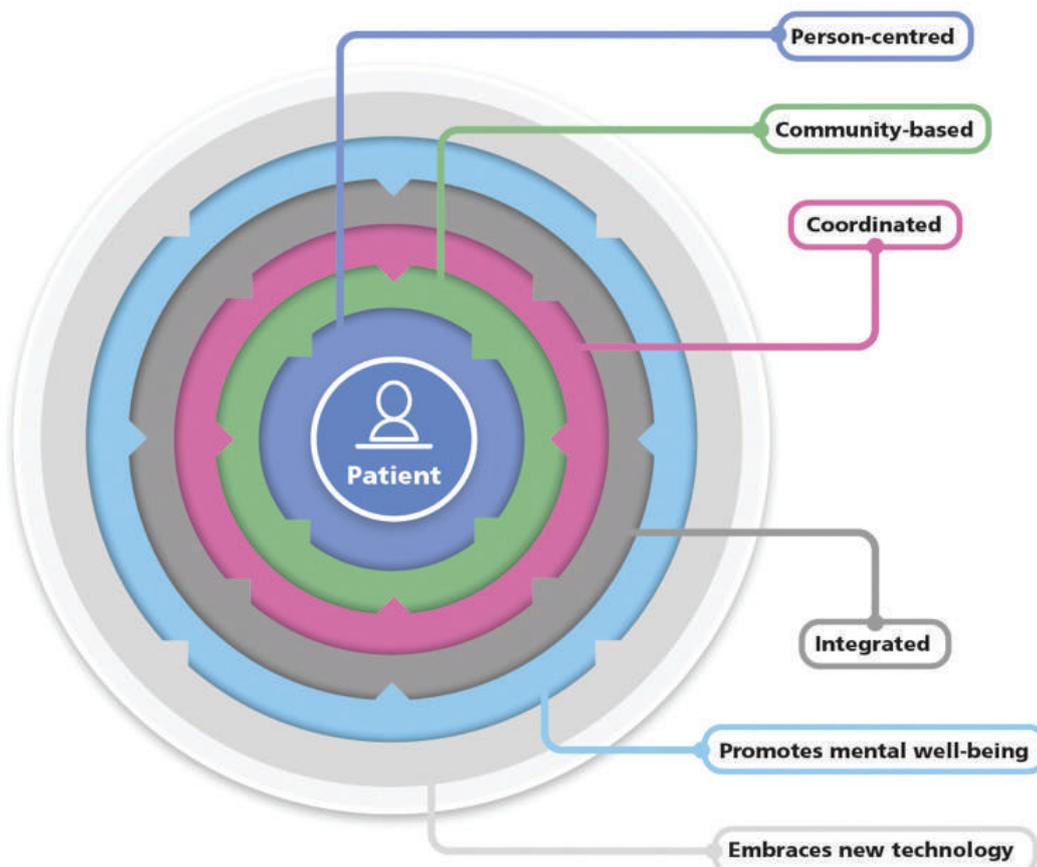
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many of which might have been avoided by providing more timely and appropriate care or support to patients.

Failing to access appropriate care can lead to poorer outcomes for people affected by neurological conditions and put pressure on other parts of the health and social care system. Reports by the National Audit Office and the Public Accounts Committee in 2011 demonstrated that current service configurations are failing people with neurological conditions. These reports identified a number of problems, including: delays in receiving a diagnosis, a lack of access to information and care that is fragmented and poorly-coordinated.

A few years after the original PAC report, NHS England published its Five Year Forward View, in which it called for more integrated approaches to care delivery to be developed to improve the quality and efficiency of services and improve patient outcomes, moving care closer to home from acute services to community services wherever possible. This is especially relevant to people living with long-term neurological conditions and it was with this in mind that NHS England's Long Term Conditions Support Unit established the Community Neurology Project in 2015.



Managed by Thames Valley SCN, the project's aim is to stimulate the delivery of person-centred coordinated care for people with neurological conditions by encouraging the adoption of community based care models.

Shifting when and where care takes place (to a more appropriate time and place), involving the patient more in their care and support planning, addressing their mental health needs alongside their physical health needs and improving coordination between service providers can have profound benefits: reducing health system costs and pressures; improving access to health services and delivering better patient experiences and outcomes.

Working in collaboration with Sue Ryder, Windsor Ascot and Maidenhead CCG, Neural Pathways (UK), Royal Holloway London University and Southampton University Hospital, with clinical leadership from Professor Zameel Cader, Consultant Neurologist at Oxford University Hospitals NHS Trust, the project team researched a number of key themes in the field of community-based person-centred coordinated care and wrote a Transformation Guide to support commissioners, launched at a well-attended conference last summer.

The centre piece of the guide is a new care model, based on community-based coordinated care which integrates services across sectors and organisational boundaries that embraces opportunities offered by new technology to support both the physical and mental health needs and priorities of the individual. No matter what the pathway or condition, these five features should always be present.

The project team found a number of excellent examples of care being provided in a community setting to take account of patients' needs and priorities, yet these were the exception rather than the rule. There is great variation between conditions and between areas across England. NHS RightCare data shows

that in over half of CCGs neurology has the highest spend and poorest outcomes of any long-term condition.

The apparent complexity of neurology mentioned earlier may be one explanation but the project team discovered that funding flows and a lack of information may also be inhibiting the development of services which match patients' needs and priorities. Current payment models (block contracts in over 90% of community care contracts) mean there is little or no link between funding and patient outcomes so little incentive to change the status quo of the system. There is also wide variation in prices paid around the country, with some CCGs paying much more than others for similar neurological services.

The Five Year Forward View recommends the use of performance data to guide in commissioning and funding decisions. Fewer than 1% of CCGs use outcomes-based measures, undermining any ability to reform contract payment mechanisms. The project team found that there is a lack of data on outcomes and costs in relation to long-term neurological conditions so a priority for the next phase of the project is to better understand what data would be beneficial and support the development of appropriate data sets and the routine collection of data to aid commissioners. One area the project team are exploring is the potential to link previously unrelated sets of anonymised data to present a better picture of what neurological services are being accessed, and how often, together with presenting information on a single dashboard or webpage and this will be the focus for the project team in the coming months, working alongside commissioners in the Thames Valley area.

The Community Neurology Project would like to hear from organisations currently planning or running initiatives in neurology. Please tell us about your scheme and how it is improving care for patients with long-term neurological conditions.



## communitytherapists network

The Community Therapists Network provides information, training and education to a UK network of AHPs and nurses who work within rehabilitation & intermediate care settings. Included in this network are: Dietitians, Nurses, OTs, Physios, Psychotherapists, Psychologists, Rehab Assistants, SLTs

### Benefits of membership

Access to member's website with resources including:

Video, audio & slide presentations, access to articles and documents relevant to community therapy, regular e-newsletters, Neurodigest magazine ([www.neurodigest.co.uk](http://www.neurodigest.co.uk))

Also, enjoy discounted CTN events such as:

- *Learn how to use the Therapy Outcome Measure (TOM)*
- *Sleep Disorders: How can I help?*
- *Crossing the Health/Work Divide – engaging with employers*

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[info@communitytherapy.org.uk](mailto:info@communitytherapy.org.uk)

# The NICE Guideline on Motor Neurone Disease

Professor David Oliver & Rachael Marsden on behalf of the Guideline Development Group



**Professor David Oliver**

David Oliver has recently retired as a Consultant in Palliative Medicine at the Wisdom Hospice in Rochester and is an Honorary Professor at the University of Kent. He has written and lectured widely on the palliative care of people with neurological disease, and in particular motor neurone disease. He was Chair of the NICE Guideline Development Group for the MND Guideline.

Rachael Marsden is an MND Advanced Nurse Practitioner & Care Centre Coordinator in Oxford. She was part of the MND NICE guideline development group.

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**Rachael Marsden**

In February 2016 the National Institute for Health and Care Excellence issued the Clinical Guideline 42 – Motor Neurone Disease: assessment and management. This Guideline aims to help in the care of people with MND, using an evidence based approach and applies across both community and hospital settings<sup>1</sup>.

The main recommendations include:

### Recognition and referral

- A protocol and pathway for referral should be available in all areas
- Awareness of possible symptoms should be encouraged – in particular the “Red Flags” suggested by the Royal College of General Practitioners and the MND Association<sup>2</sup>
- If MND is suspected a referral should be made without delay
- Information should be provided for patient and family at all stages

### The impact for the patient

We know from a survey by the Motor Neurone Disease Association (MNDA) that many people are waiting over 18 months to be diagnosed. The Red Flag system suggests to GPs that if a patient has painless, progressive weakness they should be referred directly to neurology for an urgent appointment.

### Information and support at diagnosis

- The diagnosis of MND should be given by a Consultant Neurologist with the knowledge and expertise in MND
- It is important to ensure:
  - People are asked about their wishes for information and involvement of family/carers
  - Information on MND is provided as they wish
  - A single point of contact for the MND Multidisciplinary Team (MDT) should be available
  - Follow up appointment should be made with a MDT member within 4 weeks
  - A referral for social care should be made
    - ~ If there are social care needs
    - ~ To ensure carers are aware of Carer’s Assessment, and assessments are made financially and for care

### The impact for the patient

Being diagnosed with MND can be totally devastating. It is important that the diagnosis is made by a Consultant Neurologist who is also an expert in MND and can provide up to date and accurate information on MND. The person should leave the consultation with contact details of the specialist team and enough information so that they do not feel abandoned and unsure of what to do next.

### Organisation of care

- Co-ordinated care should be provided from a clinic based MND multidisciplinary team
  - Based in hospital or community
  - Including health and social care professionals
    - ~ With expertise in MND
    - ~ Staff able to see people at home
  - Ensuring communication to all health and social care professionals/family/carers
- Coordinated assessments should be undertaken every 2-3 months according to the person’s needs and they could be seen earlier if there are changes in condition. If a person cannot attend clinic, care should be facilitated within the community. It is important to ensure all are informed of key decisions, with close liaison with General Practitioner

### The impact for the patient

Due to the changing nature of the disease a patient may have more than 10 people involved in their care at any one time. These professionals should have expertise in MND care, act in a coordinated way to prevent repetition and ensure that the patient’s needs are addressed and any interventions that become necessary are organised at the correct time, to prevent unnecessary crisis arising.

### PSYCHOLOGICAL AND SOCIAL CARE

- The MDT assessment should include discussion of the psychological/emotional impact of MND and information should be offered

### PLANNING FOR END OF LIFE CARE

- All professionals should be open to discuss end of life care whenever the person asks and provide advice on:

- Support and advice on advance care planning – including what may happen and the consideration of advance care plans
- Anticipatory medication at home - “Just in Case Kit”
- Specialist palliative care involvement
- The person’s wishes
  - ~ Place of care
  - ~ Place of death
  - ~ What to happen if deterioration/other illness
- As end of life approaches
  - Provision of additional support so family are able to reduce their caring responsibility and spend time with the person, and ensure access to equipment to help care at home

*The impact for the patient*  
 Many professionals are worried about broaching the subject of dying with their patients, but by doing so, the patient is able to be in control of their lives and make plans accordingly.

**PROVISION OF EQUIPMENT**

- Physiotherapy and Occupational therapy assessments should be undertaken with regular review
- Equipment should be provided without delay to maximise daily living and independence
- Equipment should be able to change as deterioration occurs and be integrated with other aids – eg AAC devices

*The impact for the patient*  
 Patients will be offered and issued specialist equipment in a timely manner and this will be able to match their changing requirements, enabling them to live their lives to their full potential and not be restrained by having to wait for the correct piece of equipment.

**NUTRITION**

- From diagnosis assess weight, nutrition and swallowing
- If there are suspected swallowing problems ensure a swallowing assessment
- Discuss gastrostomy early and regularly
- If gastrostomy is needed this should be placed without delay

*The impact for the patient.*  
 If patients can stay well-nourished throughout their disease and do not lose appreciable weight there is evidence to suggest that they will stay stronger for longer.

**COMMUNICATION**

- Assess needs for communication, including face to face, telephone/email/social media
- Provide equipment and ensure it is integrated with other aids

*The impact for the patient*  
 Patients and families tell us that one of their greatest frustrations is not being able to communicate effectively. With the correct aids, at the appropriate time, this frustration can be reduced.

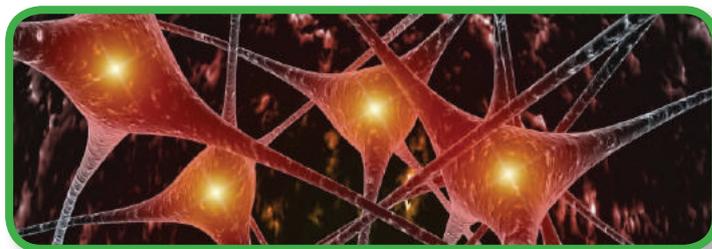
**MANAGEMENT OF SALIVA PROBLEMS**

- Advice on posture/diet/swallowing/oral care
- Antimuscarinic medication trial - Glycopyrrolate/glycopyrronium bromide, Hyoscine hydrobromide
- Injection of Botulinum toxin A into salivary glands may be considered

*The impact for the patient*  
 It should be possible to enable a patient to manage their secretions so that they are not embarrassed by drooling or distressed. Thick secretions may be more difficult to help effectively.

**RESPIRATORY FUNCTION**

The previous Guidelines on Non-invasive ventilation have been



- updated and incorporated into these Guidelines<sup>3</sup>
- Assessment of respiratory function should be undertaken regularly
  - Discussion of management of breathlessness, including non-invasive ventilation and medication in helping breathlessness – eg opioids
  - Offer non-invasive ventilation
    - If there is likely to be a benefit for the person
  - Before starting NIV there should be risk assessment by the MDT and Palliative care strategies should be in place – eg use of opioids and provision of “Just in case” anticipatory medication
  - Stopping NIV
    - There needs to be careful consideration of the plan to stop NIV
    - Ensure there is support from professionals who have expertise in stopping ventilation, using palliative medication, supporting the person, family/carers/health and social care professionals and the legal and ethical aspects

*The impact for the patient*  
 This guideline now encourages discussion about planning for the future and also how to support people living with MND, and their families, when they wish to use NIV and to withdraw from using this NIV if this is their wish.

**COGNITIVE ASSESSMENT**

- At diagnosis or if there is a concern about cognition or behaviour explore these areas with the person and their family
- Tailor discussions to the person’s needs, taking into account their communication ability, cognitive status and mental capacity

*The impact for the patient*  
 There was a time when MND was thought to be just a muscle wasting disease. However now professionals are more aware of how cognition can be affected in MND and how important it is to understand how this can impact on a person’s care and their family.

There has also been an Economic assessment of the Multidisciplinary Team Clinic approach and this was found to be cost effective. These recommendations now need to be implemented. Over the coming months all involved in the care of people with MND will need to assess how they comply with the Guidelines and look at the changes that may be necessary.

**REFERENCES**

1. National Institute for Health and Care Excellence. Motor neurone disease: assessment and management. NICE Guideline NG 42. NICE 2016. [www.nice.org.uk/guidance/NG42](http://www.nice.org.uk/guidance/NG42)
2. Motor Neurone Disease Association/ Royal College of General Practitioners <http://www.mndassociation.org/forprofessionals/information-for-gps/diagnosis-of-mnd/red-flag-diagnosis-tool/>
3. National Institute for Health and Clinical Excellence. Motor neurone disease. *The use of non invasive ventilation in the management of motor neurone disease.* NICE Clinical guideline 105 NICE 2010.

# RCGP Clinical Priority for Epilepsy: The top five tips for improving epilepsy health care provision

Epilepsy was chosen as a clinical priority, partly in response to numerous reports which provided evidence of the need to improve services for epilepsy. The All Party Parliamentary Group reports that whilst only around 50% of the population with epilepsy are currently seizure free it is usually possible to achieve seizure freedom rates of 70%. This highlights that there is a 20% treatment gap.

Seizure freedom reduces the standardised mortality rate to nearing that of the general population. Uncontrolled epilepsy has a high cost in terms of social and physical well-being as well as generating unnecessary expense to the NHS. In the recent CCG-Outcome Indicator Set epilepsy ranked the fifth highest long term ambulatory condition to require unplanned admission to hospital. It is not surprising then to discover that amongst the findings are:

- **400 avoidable deaths a year from epilepsy**
- **69,000 people living with unnecessary seizures**
- **74,000 people taking drugs they do not need**
- **£189 million needlessly spent each year.**

These are the top five tips suggested by Dr Greg Rogers, Clinical Champion for Epilepsy 2013-15, which GPs can follow to help reduce the impact of those affected by epilepsy and improve epilepsy health care provision.

- 1. Seizure freedom:** If a person has ongoing seizures, with or without loss of awareness and has not been reviewed and given a management plan by specialist care, offer referral to the local epilepsy service.
- 2. Psychosocial support:** General Practice is about holistic care. Reducing the psychosocial consequences of epilepsy can be identified by GPs being aware of the increased likelihood of depression and anxiety in this group. The pros and cons of SSRI treatment and referral to the local counselling services can be offered. Sign posting to the voluntary services and support for this can be found on Epilepsy Action's website. <https://www.epilepsy.org.uk/info/depression>
- 3. Women and girls with epilepsy:** The MHRA have altered the guidance for sodium valproate following new further evidence of its teratogenicity and advise that all women at risk should have a discussion with an epilepsy specialist involving assessment of the risk/benefit.
- 4. Knowledge of Epilepsy:** Undergraduate and postgraduate education on epilepsy can be scanty and one of the best ways to remedy this is through eLearning. An ideal package is the BMJ Learning 'Epilepsy: diagnosis and management in primary care'. <http://learning.bmj.com/learning/module-intro.html?moduleId=10048059>

A GP in Lymington, Hampshire, he has a special interest in epilepsy and was the recently appointed RCGP clinical Champion for Epilepsy. Greg was a member of the guideline development groups for the NICE Epilepsy Update, 2012 and the NICE epilepsy quality standards and commissioning framework, 2013. Prior to that he was a member of the NICE Transient Loss of Consciousness Guideline, 2010.



**Dr Greg Rogers**

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## 5. Epilepsy in the elderly, especially those with dementia:

The prevalence of active epilepsy in the elderly population is up to 1.5%, but among nursing home residents may exceed 5%. Atypical presentations may also include altered mental status, periods of staring, unresponsiveness, brief losses of consciousness, inattention, memory lapses or confusion. Should major seizures occur, their characteristics are similar to those in younger people – important markers being lateral tongue biting, waking in an ambulance or in hospital, or significant injuries.

For more information please refer to the RCGP Epilepsy Resources page. <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/epilepsy.aspx>

## REFERENCES

1. A Critical Time for epilepsy in England: 22 January 2013
2. 'Wasted Money, Wasted Lives; The Human and Economic Cost of Epilepsy in England 2008'
3. CCG Outcomes Indicator Set: Emergency Admissions NHS Information Centre march 2013 <https://catalogue.ic.nhs.uk/publications/hospital/outcomes/ccg-indi-mar-13/ccg-ind-toi-mar-13-v4.pdf>
4. <https://www.gov.uk/drug-safety-update/medicines-related-to-valproate-risk-of-abnormal-pregnancy-outcomes>
5. [http://www.medscape.com/viewarticle/733423\\_1](http://www.medscape.com/viewarticle/733423_1)

The screenshot shows the RCGP Learning website interface. At the top, it says 'RCGP Learning Essential CPD for primary care'. Below that, there's a navigation bar with 'Home', 'Courses', 'Essential Knowledge Updates and Challenges', 'Updates', 'Essential Knowledge Update 12: Oct 2013 (Reviewed ...)', and 'Summary'. The main content area is titled 'Essential Knowledge Update 12: Oct 2013 (Reviewed Apr 2016)'. It includes a list of topics, with some highlighted in green, indicating they were audited as current/applicable evidence or guidance up to 23<sup>rd</sup> April 2016. The topics listed are: Management of Adults with Coeliac Disease, Psychosis & Schizophrenia in Children & Young People, Long Term Follow Up of Survivors of Childhood Cancer, The Professional's Guide to Parkinson's Disease, Quality Standards for Epilepsies in Adults, Children & Young People, Assessment & Management of Psoriasis, Good Practice in Prescribing & Managing Devices, and Assessment & Treatment for People with Fertility Problems. At the bottom, it says 'Start Essential Knowledge Update 12'.

# Toolkit helping commissioners provide better health services for people with epilepsy



**Olivia Rzdakiewicz**  
Online Reporter, Epilepsy Society

An online epilepsy toolkit, specifically for commissioners, is helping to provide all the information required to ensure high quality services for the 500,000 people living with epilepsy in England.

The 'Epilepsy Commissioning toolkit' [www.epilepsytoolkit.org.uk](http://www.epilepsytoolkit.org.uk) was launched by the two leading epilepsy charities, Epilepsy Society and Epilepsy Action in September 2015 and has 275 subscribers at time of writing.

It was created as an accessible, online resource in response to a 2014 survey of Clinical Commissioning Groups (CCGs) that identified gaps in planning and provision for people with epilepsy. The survey found that 39 per cent of District General Hospitals had little or no acute neurology service. CCGs were contacted by Epilepsy Action, who discovered that 78 per cent of the groups that responded had not produced, and had no plans to develop a written needs assessment of the health and social care needs of people with epilepsy, despite the fact that 40,000 seizure-related admissions occur every year in English hospitals.

There was a need to support CCGs seeking to understand the national provision for epilepsy, particularly after the removal of two Quality and Outcome Framework (QOF) indicators in 2013. The first QOF recorded the percentage of patients aged 18 or over on drug treatment who had been seizure free for the last 12 months. The second meant that women



The photograph shows Juliet Ashton, who helped develop the toolkit, explaining how it works to the South East Essex Epilepsy Support Group. Juliet was at Epilepsy Society and was the first National Nurse Consultant for epilepsy.

were given information about the teratogenic risks of epilepsy medication far enough in advance. Both indicators had provided an opportunity for the target patients to see their GP, as well as providing valuable data for use by CCGs.

Commissioners reported challenges locating the information required to support epilepsy service review. Many CCGs are at different stages in the process of commissioning epilepsy services, from no current commissioning intentions through to contracting a service model.

Nine CCGs with experience in commissioning epilepsy services supported the development and testing of the toolkit. They helped to co-produce the commissioning tools for epilepsy, shaping content according to what commissioners want and need.

The toolkit contains nine sections that take users through the flow of the whole commissioning process including patient and public involvement at every stage. Each section contains practical examples based on CCGs experience, as well as providing some established tools and information, such as NICE guidance and quality standards, audit tools, and interactive tools.

Using the toolkit allows services to calculate local populations of people living with epilepsy, access examples of service models, set outcomes, and create business cases. Users can access an epilepsy specialist nurse impact tool to track outcomes on a monthly basis against activity and interventions.



Most importantly, the toolkit allows users to measure best practice against the nine epilepsy quality standards.

Healthcare professionals (HCPs) wishing to make improvements or enhancements to epilepsy services can use the toolkit to understand the commissioning process and engage with commissioners very early on when scoping need and gathering evidence.

In turn, a commissioning flow chart incorporating the planning, procurement and monitoring stages in the form of a checklist has been included to assist commissioners through the process.

The project has gained RCGP and the Association of British Neurologists endorsement and is going through the NICE endorsement process. The toolkit was championed by Dr David Bateman, in his now defunct role as NHS England National

Clinical Director for Adult Neurological Conditions.

He said: "This is an excellent example of how the voluntary sector and commissioners can work together to benefit patients. Epilepsy is a common condition but is often difficult to treat and without the correct care pathways can be an economic burden to the NHS. There are many forms of information, tools and data which exist for epilepsy, however these can be a challenge to find and require some knowledge of what is available. This project has pulled together information and templates to develop best value services to support adults and children with epilepsy."

The toolkit website continues to evolve and be updated with new information to reflect best practice and modern-thinking at the forefront of service developments, to improve services for people living with epilepsy.

# The Neuro LTC project: Providing essential data for the transformation of care for persons with long term neurological conditions

The care requirements of any individual living with a long term neurological condition are likely to vary over time and to stretch across a diverse range of health and social care provisions. Although care should be designed in a way that allows individuals to maintain an optimal level of health and to reduce the risk of poor outcomes, there are difficulties in specifying the needs of individuals and linking these effectively to available resources.<sup>1</sup> In order to do so, it is necessary to understand the various factors that predict on-going care requirements and the nature of health and other events that can lead to an unplanned increase in care. Until now, there has been little systematic research into both.

Patient and caregiver perspectives on the care required by persons with long term neurological conditions have been well-documented.<sup>2</sup> Less studied, however, are the (potentially differing) perspectives of patients, caregivers and healthcare professionals on the different baseline factors that could be used to determine these care needs. Additionally, the existing

Chris Kipps is a Consultant Neurologist at University Hospital Southampton NHS foundation trust and Honorary Senior Clinical Lecturer at the University of Southampton. He is Clinical Director of the Wessex Mental Health, Dementia and Neurological conditions clinical network. He has a particular interest in dementia, long-term neurological conditions and the use of data to support improvements in care.



**Chris Kipps**

studies on care for persons with long term neurological conditions have tended to focus on one particular condition, have been largely qualitative and often fairly subjective in nature, and have generally focused solely on either service users or health care professionals. The possible insights to be gained by comparing data across different conditions, and by utilising a mixed methods approach that combines qualitative data from service users and health care professionals with quantitative data from available databases, have so far been largely neglected.

The Wessex Strategic Clinical Network sought to address a generalised lack of data on neurology services with an Intelligence Report produced in 2015.<sup>3</sup> Alongside an evaluation of the prevalence of neurological conditions across Wessex, the report presented quantitative data on hospital admissions for persons living with a neurological condition, including length of stay and cause of admission. In a discussion of the findings the

authors suggested that there were a significant number of causes for hospital admission that could be potentially avoidable and should therefore be considered in any redesign of community neurology care<sup>4</sup>. These findings are supported by other studies that also highlight the potential of early intervention in preventing unscheduled hospital admissions for people living with long-term neurological conditions.<sup>5</sup>

Whilst there are many valuable studies on some of the causes of unplanned hospital admissions (for example, there is an extensive literature on the prevention of falls for persons with Parkinson's disease), other causes of admissions have been less studied. Additionally, in the existing literature each 'critical event' that leads to an increase in unscheduled care has tended to be handled separately, limiting any comparison between critical events or conditions. There is also an evident divide between qualitative and quantitative studies on the burden of comorbidities for persons living with long-term neurological conditions.

The Neuro LTC study aims to fill some of the gaps in the existing knowledge. The project sets out to better understand the baseline factors that predict care requirements and the critical events that can lead to an unscheduled increase in care for persons living with long term neurological conditions. Five neurological conditions have been chosen for study: Parkinson's disease, epilepsy, Huntington's disease, motor neurone disease and multiple sclerosis. The research project will use surveys, interviews and focus groups with patients, caregivers and health professionals to gain new perspectives on the factors and events that influence care needs. This qualitative data will be complemented with a presentation and examination of quantitative data on unplanned hospital admissions and GP attendances retrieved from the English Hospital Episodes Statistics and the Hampshire Health Record databases. We

hope that adopting a mixed methods approach will allow for a more comprehensive and insightful analysis of factors and events that determine care requirements, and that this will support efforts to improve neurological care in the community.

Future stages of the research intend to utilise and build upon the findings to create models of care in which patients are stratified according to need. Linked to this objective, the Neuroline project (<http://wessexhealthlines.nhs.uk>) has already begun to map neurological services across the south of England.

The over-arching aim is that the findings from the Neuro LTC research project can be used to improve matching of resources to care needs and workforce skillsets, to better inform transformation of neurological community care.

#### REFERENCES

- 1 Cader Z, Kings J, Kipps C, Langdon D, Mannan R, Marsh S, Ross J, Williams S. *Transforming Community Neurology: What Commissioners Need to Know*. Thames Valley Strategic Clinical Network 2016.
- 2 Boersma I, Jones J, Carter J, Bekelman D, Miyasaki J, Kutner J, Kluger B. (2016) *Parkinson Disease Patients' Perspectives on Palliative Care Needs: What Are They Telling Us?* *Neurology. Clinical Practice*. 6(3):209-219.  
Habermann B., Shin JY.. (2016) *Preferences and Concerns for Care Needs in Advanced Parkinson's Disease: A Qualitative Study of Couples*. *Journal of Clinical Nursing*.
- 3 Kipps C, Thomas S, Matthews D.. *Wessex Strategic Clinical Network Neurology Intelligence Report*. Nottingham: NHIS Commissioning Excellence and Wessex Strategic Clinical Network 2016.
- 4 Ibid.
- 5 Thomas S, Mynors G, Simpson S, Meade N, Bowen A.. *Measuring the Burden of Hospitalisation in Multiple Sclerosis: A Cross-Sectional Analysis of The English Hospital Episode Statistics Database 2009-2014*. NHIS Commissioning Excellence and Multiple Sclerosis Trust 2015.

## Predictable bowel management with Peristeen®

Peristeen® is a technique for emptying the bowel by introducing lukewarm tap water into the rectum using a catheter. The user sits on the toilet while the water is pumped into the rectum. The water is then emptied from the bowel, along with the stools, into the toilet. The results are normally so effective that most users only have to perform the procedure every other day.

Peristeen is an innovative Transanal Irrigation system and an effective alternative to other bowel management methods. It has been developed for people who suffer from faecal incontinence or chronic constipation and for those who have to spend a long time on bowel management procedures due to neurogenic bowel dysfunction.

- Peristeen has been shown to improve patients' quality of life as well as reduce GP visits and hospitalisations. Peristeen could help reduce the use of healthcare resources in your centre<sup>1</sup>.
- Bowel irrigation is the recommended treatment when bowel medication fails or is insufficient<sup>2</sup>.

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1 Emmanuel A, Christensen P, Kumar G, Passananti V, Mealing S, Stoerling Z, Andersen F, Sorensen J, Kirzhiblum S. Long-Term Cost-Effectiveness of Transanal Irrigation in Patients With Neurogenic Bowel Dysfunction Who Have Failed Standard Bowel Care. *Value in Health* 18 (2015)

2 Emmanuel AV, Krogh K, Bassocchi G, Leroi A-M, Bremers A, Leder D, van Kuppevelt D, Mosiello G, Vogel M, Perrouin-Verbe B, Coggrave M, Christensen P. Consensus Review of best practice of transanal irrigation in adults. *Spinal Cord*. 2013; 1-7

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# Bladder and Bowel Management in People with Neurological Conditions

The MS Trust recently highlighted that around 75 per cent of people with MS experience bladder problems, which can have a big impact on everyday life. They also drew attention to some of the helpful, simple management strategies that they recommend to patients, which when put in place can help to improve bladder function. These include:

- Considering your level of food and drink intake
- Managing your weight
- Pelvic floor exercises (with tips to strengthen pelvic floor muscles)
- Bladder training

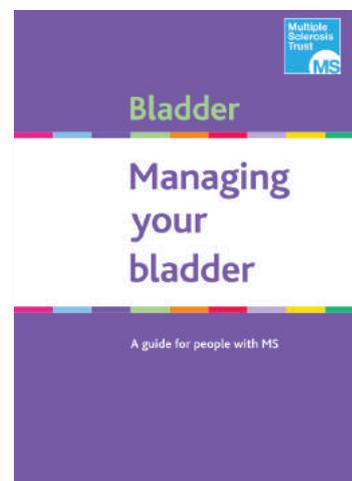
In addition to the bladder issues suffered by people with MS, it is important to be alert to bowel problems. Constipation as well as faecal incontinence, which are common in people with MS, also frequently occur in other neurological conditions such as Parkinson's.

In Parkinson's, given the slowness of movement and rigidity, this will affect the muscles in the bowels. But also, the damage to the nervous system in Parkinson's will add to the complexity of the disrupted bowel movement, as is also the case in other neurological conditions such as MS, Motor Neurone Disease

and spinal cord injury.

Neurogenic bowel, as it is often referred to, results from loss of normal sensory or motor control and may encompass both the upper and the lower gastrointestinal (GI) tract. Patients' quality of life is greatly affected with their symptoms often being socially disabling. Although bowel dysfunction is a common event, to date there have been relatively few studies addressing bowel management.

Additional information for patients on 'Managing your bladder' is available from the new book that the MS Trust have published. Links to details of the book along with further information on bowel management can be found next to this article on [www.neurodigest.co.uk](http://www.neurodigest.co.uk).



## Community Neurological Rehabilitation in the East Midlands

The need for a properly integrated approach to commissioning and providing community services for long term neurological conditions is well recognised. With that in mind, the East Midlands Mental Health Clinical Network launched the 'Community-based rehabilitation of people with long-term neurological conditions - Commissioning guidance and sample service specification' in November 2015. The guidance was the culmination of a significant piece of work by a large and varied multi-agency group comprised of health and local authority organisations, people with lived experience of neurological conditions and their carers, voluntary and community sector organisations. The purpose was to provide comprehensive guidance in the form of a reference document for commissioners to apply to their local needs and situation.

When the document was launched, it was agreed that a follow up meeting should be organised in six to nine months' time, to provide participants with an opportunity to reconvene, network, share learning and progress and ascertain the extent to which the commissioning guidance had informed work in their areas.

Approximately 40 colleagues from across the East Midlands and further afield came together at an event where energy, ideas, tenacity and particularly, a shared commitment to developing quality services for people with long term neurological conditions were evident.

Professor Chris Ward, who covered 'Rehabilitation for long term neurological conditions: commissioning guidance and business case', led the group through a reflection on current commissioning priorities and developments in respect of long

term neurological conditions in the East Midlands, since the Commissioning Guidance was launched in the region.

There was a feedback session on developments in the East Midlands since the launch meeting, and assessment of current commissioning priorities in the region. For example, in Leicester, Leicestershire and Rutland (LLR) the commissioners and providers reported having learnt a lot from their significant journey with regard to neurological conditions over the last two years. They looked at shared learning from other areas and anticipated change will happen through learning. In Lincolnshire, participants noted the need for robust data being available in order to assist the commissioners when considering models, possible configurations and business cases.

A more in depth report from that follow up meeting, held on 9th June 2015 at Kegworth Hotel and Conference Centre, is available online at [www.neurodigest.co.uk](http://www.neurodigest.co.uk)



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