... and Ipsen played an important part in keeping it that way. For Paul who suffers from a debilitating disease, sharing a barbecue with his friends is priceless.

Each year, Ipsen invests 20% of its sales in R&D to further its expertise in three specialty care areas: urology-oncology, endocrinology and neurology. The company also has a significant presence in primary care. In more than 100 countries, Ipsen employees devote their energy and skills to developing innovative therapeutic solutions for debilitating diseases and improving the quality of life of patients. www.ipesen.com
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If you have any comments or questions about Neurodigest, please email the Publisher, Rachael Hansford at rachael@acnr.co.uk.

A full PDF of this issue of Neurodigest is available to download from ACNR’s website at www.acnr.co.uk
Call for better integration of community services

If Community Services are to be a driving force in improving the health of individuals and communities they need to be better integrated with other parts of the health and social system, according to a new King’s Fund report. They also need to be more closely involved in key decisions about patients. To read more about the key findings and policy implications see www.kingsfund.org.uk/publications/community-services

How to deliver better integrated care

Vision, leadership, culture, local context integrated teams and time; these are the key ingredients to successful integration and better outcomes (service and patient) according to a report published by the Institute for Research and Innovation in Social Services. To read the report see http://iriss.org.uk/resources/delivering-integrated-care-and-support-insight

Approx 1.5 million neurology outpatient appointments in 2012/2013

This is just one of a number of key facts recently reported in the ‘Compendium of Neurology Data, England - 2012-2013’ published by the Health and Social Care Information Centre. This report represents the first collection of neurology data for use by commissioners, providers, patients and their respective charities. To read this compendium see http://www.hscic.gov.uk/catalogue/PUB13776

Does the MS Nurse prevent avoidable emergency admissions?

The unpredictable nature of MS can give rise to use of emergency and unscheduled care services due to relapse or worsening symptoms, frequently triggered by onset of infection. The evidence of whether or not the MS Nurse can prevent avoidable emergency admissions is discussed by Debbie Quinn and her colleagues Amy Bowen and Alison Leary in a letter recently published in ‘Multiple Sclerosis Journal’. The letter is only partially available to view from http://msj.sagepub.com/content/early/2014/02/13/1352458514523499?papetoc so if you want to make contact with the authors please email alisonleary@yahoo.com

Epilepsy Rescue Medication Training

A new website www.epilepsy-education.com has been launched to provide training on administering emergency rescue medication. Developed by medical experts in the field of epilepsy, this new resource should assist in ensuring people with epilepsy can receive emergency rescue medication in a safe and dignified manner. This web resource includes a standardised 30 minute e-learning test package to enable trainers to test the attendees of their course to deliver consistency and gain confidence of a basic level of competency in delivering rescue protocol medication.

Need for better methods to measure outcomes of specific vocational rehabilitation in MS

This is the conclusion of a recent paper by Catherine Doogan and Diane Playford, who also state that helpful interventions include early disclosure, proper workplace accommodation, education of employers, and government-funded initiatives to support disabled employees. Further details of the paper can be found at http://msj.sagepub.com/content/early/2014/02/13/1352458514523499?papetoc

News from NICE

New Quality Standard for Treatment of Anxiety Disorders: NICE have recently released this Quality Standard to improve recognition, assessment and availability of treatments for anxiety disorders in children, young people and adults with anxiety disorders. The Quality Standard can be accessed from http://www.nice.org.uk/newsroom/pressreleases/AnxietyDisordersQualityStandardPublished.jsp

New Evidence Update on Epilepsy: NICE have recently released new evidence in support of the clinical guideline - CG137. To read this new evidence see https://www.evidence.nhs.uk/about-evidence-services/bulletins-and-alerts/evidence-updates
A warm welcome from Neurodigest. I very much hope that this, our first edition, will entertain and educate in equal measure. Neurodigest aims to bring together health professionals involved in the planning and implementation of care for patients with chronic neurological conditions and to identify and disseminate best practice. It is aimed particularly at those health professionals working in primary care and within a community setting.

David Bateman starts by outlining the exciting opportunities CCG commissioning provides. The ability for stakeholders to plan a joined-up service, tailored to local requirements, is indeed a vision for the future we would all welcome. GPwSI have been a part of that vision for a number of years now. They have been integral in blurring/breaking down the primary/secondary care boundary. Estelle McFadden outlines how it has been possible to take specialist skills out of the hospital and into the community for the benefit of all parties.

Who to worry about and who to reassure is the question we grapple with in general practice on a daily basis. As primary care physicians we always fret about missing the one serious secondary headache among many. Andrew Dowson provides us with a guiding light through this mire to help direct our management of this most common of neurological symptoms.

One of the corner stones of good care for patients with epilepsy is prompt and regular access to specialist services. Greg Rogers, in his role as clinical champion, outlines how, with the support of the RCGP, he has embarked on a 3 year mission to reduce the “treatment gap”. Karen Lanyon highlights the importance of looking beyond the seizure frequency to identify patients suffering from low mood, anxiety or cognitive difficulties which can all conspire to effect compliance with taking anti-epileptic medication.

The treatment of Parkinson's Disease has certainly become more complex over the last 15 years, although sadly there is some merit in the view that this has not lead to the improvement in motor control we would have wished for. Dr Barnes outlines some of the pitfalls to avoid in prescribing for this patient group, along with a reminder to watch out for patients with Parkinsonism on “dizzy pills”. We have however become much more successful in understanding and treating some of the non-motor complications. Shahid Dadabhoy reminds us of some of these symptoms and provides management strategies. We may not feel confident in altering our patient's dopaminergic therapy but we should be actively seeking out and helping our patients manage these symptoms in the community.

Of course what patients really need is access to a team based approach for their needs, bringing together an integrated professional skill mix to maximise their quality of life. Catherine Atkinson outlines the gold standard approach from the Royal Free Neurological rehabilitation centre and its extensive community team.

Sadly Keith Swankie’s story is all too familiar. The diagnosis of rare conditions, particularly ones that mimic more common ones, is always a challenge and reminds us all to keep thinking, particularly if patients don’t fit in the boxes we have made for them.

Changing tack, Sue Thomas educates us on the important role of Neurological Commissioning Support. If we know what is going on then we can design the appropriate services to improve the quality of care with a by-product of increased efficiency, rather than that being the goal. These changes are being implemented across the 12 strategic clinical networks in England. We have asked 4 of these SCN to shine a spotlight on what they are doing to bring David Bateman's vision of the future to fruition.

We very much hope you enjoy reading Neurodigest. Should you wish to offer your thoughts/comments on any of the subjects being aired, or you would like to contribute to a future issue please get in touch with the Publisher via Rachael@acnr.co.uk.

Alistair Church, Neurodigest Editor

Joining the Primary Care Neurology Society (P-CNS)

If you want to update your knowledge of neurology, you may wish to join the P-CNS for a small one-off joining fee of £45. Not only do you get access to various resources, including video presentations (topics include headaches, Parkinson’s disease and MS), but you will be able to access Europe’s leading neurosciences e-learning resource, e-brain. To find out more and to join, visit our website www.p-cns.org.uk

Upcoming P-CNS workshop – Achieving Better Headache Management in Primary Care

June 17th, Ely, Cambridgeshire.

Go to www.p-cns.org.uk for further details.
**Masterclass - Practical Management of Sleep Disorders**

**Thurs 5th June 2014, NeuroSupport, Liverpool**

This one day interactive and informative workshop will allow you to explore the fundamentals of sleep, what can go wrong and what you can do to help people get better sleep.

Andrew Green, who will lead this masterclass, recently co-edited Sleep: Multi-Professional Perspectives in which he wrote two chapters and contributed to several others.

5 places available at £135. Once these are taken the prices are £145 (CTN members)/£175 (non members).

**Neuro-Fatigue: Management of fatigue in people with neurological conditions**

**Thurs 26th June, 52 Club, Gower St, Central London**

We are pleased to offer another opportunity to attend this popular workshop run by neuropsychologist Dr Anita Rose. This workshop provides various practical tips and strategies for any health professional working with patients who live with long term neurological conditions including Brain Injury, MS, Parkinson’s and Stroke.

Places currently available at £145 (including lunch) for members /£175 for non members.

**Introduction to Compassionate Focused Therapy following Acquired Brain Injury**

**Wed 2nd and Thurs 3rd July 2014, Ely, Cambridgeshire**

This workshop provides an introduction to the CFT model and its application in the context of acquired brain injury. In addition to this, the workshop will provide experiential opportunities to practice some of the core CFT exercises. The workshop will be a mix of PowerPoint presentations, videos and experiential exercises.

Attendance at 1 of the two days £125 (including lunch)

Attendance at both days is £225 (including lunch)

**Helping Your Patients to Manage Cognitive Impairment**

**Thurs 10th July, 52 Club, London**

This very popular course also run by the neuropsychologist Dr Anita Rose, is an ideal workshop offering practical tips and strategies for any health professional working with patients where a decline in cognitive function is an issue, such as Brain Injury, Dementia, MS, Parkinsons and Stroke.

There are 5 special offer places available at £135 on a first come, first served basis. Thereafter, prices are £145 for members/£175 for non members.

**Making Sense of the Muddle: Understanding the Dysexecutive Syndrome**

**Friday 24th October 2014, Ely, Cambridgeshire**

This intermediate level course focuses on the dysexecutive consequences of brain injury, assessment of executive dysfunction, and practical interventions for managing these. The course will focus on rehabilitation interventions for executive functions, which are known to significantly impact upon a person’s independence and limit social and vocational participation.

Places are £125 (including lunch)

For further details and to book a place on any of these events, please visit www.communitytherapy.org.uk
Despite the controversy about CCG commissioning, it provides a remarkable opportunity to radically improve neurology services. Whereas previously only routine outpatient (OP) neurology appointments have been commissioned, there is now an opportunity to commission a specific urgent and acute neurology service and a NeuroCare service for patients with long term neurological conditions. Acute neurology services should be commissioned for a population of 500,000, given existing arrangements, but it can be smaller for routine outpatient services and long term neurology conditions. This depends on local discussions between the local Neurologists, GPs and CCG neurology leads.

The Royal College of Physicians/Association of British Neurologists (RCP/ABN) report (June 2011) highlighted the poor care that patients with acute neurological disorders receive and how this can easily be improved. Frequently these patients do not see a Neurologist on admission leading to possible poor outcomes. Evidence shows that providing liaison neurology, so that these patients are seen earlier, halves length of stay, changes management and reduces unnecessary investigations. The benefit of making such changes is illustrated by PHE figures showing that 70,000 patients were admitted with a final diagnosis of tension headache in England last year, at a probable cost of 21 million pounds. The NASH report revealed the poor care provided for patients with acute seizures attending hospital. Also commissioning urgent clinics can reduce admissions for seizures and acute headache which our CCG here in Sunderland have commissioned in preference to some routine appointments. Big improvements in care can be achieved at less cost.

Patients with long term conditions need care plans and organised care which have been shown to improve care and reduce emergency admissions. Group CCGs can commission specific services for Parkinson’s disease, multiple sclerosis and epilepsy along similar lines with multidisciplinary clinics done in the community alongside GPs. None of these patients need to be seen in secondary care. This idea is supported by the recent RCP initiative to develop community services with support from the local DGH specialists. It would allow sessional employment of all the necessary clinicians to provide a comprehensive service e.g. designated therapists and specialist nurses would also run clinics alongside. This would revolutionise care and management of patients with long term neurological conditions, with access to the appropriate clinicians in one place at one time!

Patients with long term conditions need care plans and organised care which have been shown to improve care and reduce emergency admissions. Group CCGs can commission specific services for Parkinson’s disease, multiple sclerosis and epilepsy along similar lines with multidisciplinary clinics done in the community alongside GPs. None of these patients need to be seen in secondary care. This idea is supported by the recent RCP initiative to develop community services with support from the local DGH specialists. It would allow sessional employment of all the necessary clinicians to provide a comprehensive service e.g. designated therapists and specialist nurses would also run clinics alongside. This would revolutionise care and management of patients with long term neurological conditions, with access to the appropriate clinicians in one place at one time!

Patients would have local access to therapists. Specialist nurses would spend more time in the community skilling up and supporting practice nurses and community matrons. Local GPs would have their own service to refer to. Local GPs would sit in with the Consultant to learn the necessary skills to eventually run much of these clinics themselves. They also know the social and domestic background of these patients with better access to social care.

Neurology OP services are a classic example of the problems with supply sensitive care. OP numbers have risen exponentially over the past few years with the introduction of targets to the disadvantage of acute and long term care. OP access can be modernised by forming a committee of local Neurologists and GPs to scrutinise referrals and offer initial advice and guidance, if appropriate, instead of an appointment. This enables advice without delay. It can shorten waiting times by 40%. NeuroMail (an email service linking GPs with a Consultant Neurologist) can also be provided to offer advice and guidance for existing or more urgent new problems.

CCG commissioning along these lines would significantly improve care at lower cost. The opportunity must not now be missed!

REFERENCES
Establishing a GPwSI neurology service
Improving services for people with neurological conditions

Dr Estelle McFadden graduated from Dundee in 1996, before moving to Leeds to take up a position at Leeds General Infirmary as a Medical SHO and attained Membership of the Royal College of Physicians (MRCP). She gained experience in Neurology and Rehabilitation Medicine in Yorkshire and also undertook a period of research at the University of Leeds resulting in the degree of Doctor of Medicine (M.D), before deciding on a career in General Practice. Dr McFadden joined Bowling Hall Medical Practice in September 2007, and as a member of the Royal College of Physicians and the Royal College of General Practitioners has combined these skills to become a GPwSI (GP with Special Interest) in Neurology for Bradford & Airedale Primary Care Trust.

Dr Estelle McFadden

Neurodigest recently asked Bradford GPwSI, Dr Estelle McFadden a number of questions about their primary care neurology service.

How should a GP practice persuade the CCG that there is a need for practitioner with special interest in neurology service (PwSI)?
It is important to point out to the commissioners that a PwSI can provide a cost effective service compared to the standard hospital tariff with shorter waiting lists, which helps to ensure patient satisfaction. It also supports the need to provide more care in the community. In terms of selecting the patients that are suitable for a PwSI service, it’s essential to have full inclusion and exclusion criteria. It is also important to develop strong links with secondary care so that this is readily accessible to patients who require secondary care input.

How should the service ensure that there is both a service and educational partnership between the secondary care team and the PwSI service?
One of the first steps in establishing a GPwSI service and developing credibility with the secondary care team is to have a Consultant Neurologist involved in providing training. This helps the Consultant to assess the level of knowledge within the service.

Developing a good working relationship with the Lead Consultant to then develop a tight patient inclusion and exclusion policy will have a significant impact on establishing a strong partnership. For example, NICE guidelines specify that people with Parkinson’s disease (PD) should be referred quickly and untreated to a specialist with expertise in the differential diagnosis of PD.

Anyone with a severe and progressive neurological condition should be referred to an appropriate specialist (e.g. Neurologist or Care of the Elderly Physician). Other inclusion and exclusion criteria can be found in the table below.

How long should each session run?
According to the ABN guidelines a Trainee Neurologist should allow 40 minutes per session to assess a new patient and a Consultant Neurologist generally allows 30 minutes. We believe a GP should be regarded as a trainee Neurologist and will take up to 40 minutes with a new patient and 20 minutes for a follow up appointment.

<table>
<thead>
<tr>
<th>Conditions Treated</th>
<th>Exclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>An patient requiring a Neurological Opinion including but not limited to the following:</td>
<td>• Age &lt;16</td>
</tr>
<tr>
<td>• Headaches</td>
<td>• Patients requesting a second opinion who have already seen a Consultant Neurologist</td>
</tr>
<tr>
<td>• Sensory disturbance</td>
<td>• Chronic fatigue</td>
</tr>
<tr>
<td>• Blackouts/funny turns’</td>
<td>• Memory dysfunction</td>
</tr>
<tr>
<td>• Dizziness where a neurological cause is suspected</td>
<td>• Complex movement disorders</td>
</tr>
<tr>
<td>• Tremor</td>
<td>• TIA</td>
</tr>
<tr>
<td>• Restless legs syndrome</td>
<td>• Progressive weakness</td>
</tr>
<tr>
<td>• Patients with established diagnosis of epilepsy requiring advice or review where this service offers a more convenient venue than those offered by other services (i.e. Bradford Epilepsy Service)</td>
<td>• Patients who wish to see a Consultant Neurologist</td>
</tr>
<tr>
<td></td>
<td>• Acute cases which require admission</td>
</tr>
</tbody>
</table>
How much paper work do you estimate to be generated by each PwSI session?
Each clinical session generates approximately 1 hour’s worth of paper work for the GP.

What sort of administrative support is required and is appropriate funding for this provided?
Clinics are run in different General Practice locations (in the north and the south of Bradford) and so administrative support is provided to set up and arrange the clinics. That involves managing room bookings, drafting the clinic lists, organising dictaphones so they are available at the clinic. Then there is the costs incurred from the dictation including the resulting letters.

How much does it cost to send a patient to PwSI service?
There will be a local tariff agreed.

Neurology clinic letters can be quite time consuming, as can the results from investigations, with the need for further correspondence about these with patients.

How is this factored into the PwSI contract?
A General Practice session is considered to be 4 hours and we would allow for 3.5 hours of patient consultations with the additional time for administrative work.

How does your service go about accessing investigations?
This is no different to a standard General Practice. Patients are referred on to the local hospital trust.

How much does it costs to send a patient to PwSI service?
There will be a local tariff agreed.

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How does your service go about accessing investigations?
This is no different to a standard General Practice. Patients are referred on to the local hospital trust.

How do you keep up to date and fulfil your Personal Development Plan (PDP)?
We have a Continuing Professional Development (CPD) meeting with the Consultant Neurologist every three months. In the meeting, a review of the key issues raised in the journals is provided; any new research is also discussed. A GPwSI will also give a presentation in order to strengthen their knowledge base; any challenging patients will be discussed with the Consultant. If there are any gaps in knowledge identified then the GPwSIs will attend appropriate training courses.

Diagnostic pathways for headache: the red flags that may indicate more serious pathology

The vast majority of headache symptoms are benign and relate to the well-known and common conditions of tension-type headache (TTH: episodic and chronic), migraine (with or without aura: episodic and chronic), medication overuse headache (which may arise from TTH or migraine) and cluster headache. Other headache subtypes are much rarer and are encountered infrequently in the primary care clinic. The so-called sinister headaches, which have serious and sometimes life-threatening pathology, are very rare. However, they are frequently uppermost in the patient’s and doctor’s mind on presentation and the possibility of a sinister headache must be dealt with during the initial headache consultation.

This brief paper describes the signs and symptoms of sinister headaches (known as red flags) for the health care practitioner in primary or secondary care to consider when assessing a new patient presenting with headache. The guidance is based on evidence-based clinical guidelines designed for primary care and on our combined experience of patients encountered in the headache clinic and at Migraine Action (Figure 1).

Acute symptoms
The acute symptoms described below usually mean that the patient is likely to need urgent hospital admission. A sudden onset, severe headache or acute new neurological deficit may indicate an intracranial bleed or some other intracranial catastrophe. Symptoms such as fever, meningism, photophobia, confusion, falling consciousness level or seizures may indicate a serious infection such as meningitis, encephalitis or an abscess.

Acute/subacute symptoms
The acute and subacute symptoms described below usually mean that the patient is likely to require an urgent hospital admission or an urgent specialist review. Symptoms of jaw claudication, polymyalgia, temporal artery tenderness and raised ESR may indicate cranial arteritis. Brief episodes of uni-ocular vision loss, morning headache that clears on sitting, headache associated with cough and papilloedema are symptoms of raised intracranial pressure. Progressive limb or facial weakness, gait unsteadiness, confusion, personality change, new visual field
proposed an algorithm to screen patients for sinister headache (Figure 2), incorporating the patient’s age, headache onset and acuteness and presenting symptoms, which is generally applicable and practicable to apply in clinical practice:

- New-onset, acute headaches associated with a range of other symptoms (e.g. rash, neurological deficit, vomiting or tenderness, accident or head injury, infection or hypertension) and neurological change/deficit that do not disappear when the patient is pain-free between headache attacks.
- Non-reproducible (isolated) symptoms (e.g. unusual symptoms in a patient), prolonged auras, very acute headaches (time to maximal intensity <5 minutes) and headaches with neurological deficit with a history of <6 months (suggestive of brain tumour).
- Headache that is subjectively the ‘worst’ experienced, but which is different from other severe headaches previously experienced, and onset at a very young (<5 years) or old age (>50 years).

In addition, simple questioning may provide pointers to problems with other conditions, e.g. chest disease. Simple tests, deficit, double vision, ptosis (including Horner’s Syndrome), dysarthria or cranial nerve palsy may indicate a progressive neurological deficit. Focal or generalised seizures and bizarre or stereotyped sensory or visual symptoms may indicate cortical irritation. However, sensory and visual symptoms are also encountered in migraine with aura, and a differential diagnosis needs to be considered in these cases. Postural headache and headache associated with cough may signify meningeal irritation. In this case, the physician should also consider investigating the possibility of infection (see above).

### Serious cases
The physician should pay particular attention in patients with:
- New-onset headache plus a past history of neoplasm, which may indicate a malignancy.
- New-onset headache in older age groups.
- Where the headache is progressively worsening in the absence of other features.

### An algorithm for sinister headache
The Migraine in Primary Care Advisors group (MIPCA) have proposed an algorithm to screen patients for sinister headache (Figure 2), incorporating the patient’s age, headache onset and acuteness and presenting symptoms, which is generally applicable and practicable to apply in clinical practice:

### DEFICIT
- New-onset,
- acute headaches associated with a range of other symptoms (e.g. rash, neurological deficit, vomiting or tenderness, accident or head injury, infection or hypertension) and neurological change/deficit that do not disappear when the patient is pain-free between headache attacks.
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- Headache that is subjectively the ‘worst’ experienced, but which is different from other severe headaches previously experienced, and onset at a very young (<5 years) or old age (>50 years).

In addition, simple questioning may provide pointers to problems with other conditions, e.g. chest disease. Simple tests,
e.g. blood count, ESR (in patients aged >55 years) and serum biochemistry can also provide important clues to diagnosis.

**MRI scanning**

Current guidelines\(^1\) indicate that an MRI scan may be considered for headache following diagnosis and treatment if the following conditions are met:

- Treatment failure.
- Reconsideration of red flags following hospital admittance or specialist review.
  - Where there is chronic headache resistant to treatment.
  - Patient or physician uncertainty as to diagnosis and/or treatment.
  - Patient suitability and consent.

Neuroradiology will consider both MRI and CT scanning to be appropriate screening procedures. Although CT scanning is quicker and therefore, more easily available, it does have limitations. CT tends to be used for more acute situations and MRI is particularly useful when there is a query around the base of the skull, as this procedure gives a clearer view. There may be variations in availability of MRI, depending on the locality of the GP practice.

MRI scans cannot currently be requested by local General Practice for acute headaches and the GP is advised to admit or refer the patient urgently, depending upon the clinical situation. However, GP-arranged MRIs are allowed for patients in the community with chronic headache where the result is expected to be negative and that management will continue in primary care.

**REFERENCES**


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**Figure 2. MIPCA algorithm to screen for sinister headaches.**\(^2\)

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**Dr Andrew Dowson**

Dr Andrew Dowson worked as a GP for several years before becoming a specialist in headache. He is the Director of Headache Service at King’s College Hospital, London and also has a clinic at the satellite Princess Royal University Hospital in Bromley. He is Clinical Lead for the MSc course in Headache being developed at Edinburgh University. He has several General Practice based, headache-focused positions including Clinical Lead of the East Kent Headache Service. He is immediate past - Chairman of Headache UK, and Chairman of MIPCA (Migraine in Primary Care Advisors), Migraine Actions, Medical Advisory Board and the Primary Care Neurology Society.

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**Keith Redhead**

Keith Redhead is a GP and GP Trainer in Kings Lynn. He is the Neurology Lead for the West Norfolk CCG. He has a special interest in neurophobia and together with the Neurologists and Radiologists from Queen Elizabeth Hospital, Kings Lynn has developed a Headache pathway for primary care.

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**Joanna Hamilton-Colclough**

Joanna Hamilton-Colclough originally trained as a Nurse, is a qualified Life Coach and has studied psychotherapy. She has over 25 years management and operational experience in the charitable sector and was Director of Migraine Action for three years. She has held a number of senior positions in the voluntary sector.

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**Dr Joanna Hamilton-Colclough**

Dr Joanna Hamilton-Colclough has been a member of the Migraine Action Board of Directors for many years and is a Chartered Life Coach. She is also the Migraine Action Director of Patient Services and Information.

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Medication review and co-morbidity in epilepsy

Dr Karen Lanyon completed her General Practice training in Norfolk in 1990. She has lived in Aberdeenshire and worked at Insch Surgery on and off for 18 years. Karen started work as a GP with a Special Interest in Epilepsy at Aberdeen Royal Infirmary in 2005, seeing patients with first seizures and reviewing those with a diagnosis of Epilepsy. Karen continues to work part-time as a GP at Insch Health Centre.

E: karen.lanyon@nhss.net

Dr Karen Lanyon

Annual review of any chronic disease is an opportunity to make a real difference to patients by improving their quality of life. Often, consultations with patients with epilepsy focus on seizure frequency and fitness to drive. There is much more that can be addressed in Primary Care without requiring a ‘Special Interest in Epilepsy’.

General Practitioners receive the maximum remuneration from the Quality Outcomes Framework if 70% of their patients with epilepsy are seizure free but only 52% patients in the UK are actually seizure free¹.

A recent study from General Practice found 30% of patients on anti-epileptic drugs (AEDs) were classified as non-adherent with medication based on patients reporting forgetting or skipping doses, or where patients were identified as having low prescription collection rates². Some patients choose to miss or stop medication due to side-effects or lifestyle choice. Others may be non-intentionally non-adherent due to forgetfulness or misunderstanding of treatment. Primary Care practitioners are in an ideal position to identify medication ordering patterns. Infrequent collection rates can highlight the need to discuss patients’ ideas, concerns and expectations about their medication.

It is well recognised that patients with epilepsy often experience problems with memory. The underlying epileptic lesion can be a factor in short term memory problems, as can ongoing seizures. Anxiety, stress, low mood and some medications can exacerbate this difficulty. It can be useful to patients to acknowledge the link between short term memory loss and epilepsy. Encouragement to use alarms on mobile phones and dosette boxes can help remind patients to take their medication on a regular basis. Most AEDs can be given twice a day. If patients take their medication on an erratic basis they will be more likely to suffer side effects. Restarting at a lower dose and titrating medication whilst encouraging a regular dosing schedule can help with this. If patients continue to experience symptoms, they should be re-referred to Secondary Care for reassessment of their medication. In recent years, the number of AEDs has increased steadily. Although this may complicate management choices, it also offers new options to individualise treatment more effectively. Patients who continue to have seizures on older AEDs should be offered referral to an epilepsy specialist to consider a trial of these medications.

Low mood and anxiety are extremely prevalent in patients with epilepsy. Rates of 21-55% have been quoted. Concern that depression can present atypically in patients with epilepsy has led to development of The Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) which can easily be used in Primary Care and has been validated to detect depression in patients with epilepsy⁴.

A score of >15 has a 90% specificity and 81% sensitivity for diagnosis of major depression⁵.

Once patients are identified as suffering from a depressive disorder there is a reluctance to prescribe anti-depressant medication due to the fear of exacerbating seizures. Electronic prescribing cautions use of such medication in patients with epilepsy. Recent evidence has shown the risk of seizures with antidepressants is dose dependent and is reported to be higher with tricyclic antidepressants, with an incidence of only 0.4% to 1–2% with newer anti-depressants. Low mood can affect quality of life as much as seizures and patients with depression are often less likely to be seizure free.

An Annual review that focuses on patient ‘well-being with particular regard to mood and the patients’ ideas and concerns about their medication can be conducted by members of the primary care team. This can help improve the quality of life for patients with epilepsy.

REFERENCES

3. National Sentinel Clinical Audit of Epilepsy-Related Death 2002
The 20% Treatment Gap
Community based studies have revealed that whilst around 50% of people with epilepsy are seizure free this figure could be improved to around 70% using the treatments currently available, i.e. there is a 20% treatment gap. This is of great consequence, for rendering someone seizure free reduces the risks of mortality and morbidity and allows people to live lives free from the consequence of having a seizure.

RCGP’s commitment
The Royal College of General Practitioners (RCGP) clinical priority area of epilepsy commenced in April 2013. This programme of work is led by the Clinical Innovation and Research Centre (CIRC). The overarching mission of the programme is to:

“Improve the quality of care both clinically and holistically, in General Practice for people living with epilepsy”

The RCGP aims to raise the awareness of areas selected as a clinical priority and build support for General Practitioners and their teams. This is achieved through building working relationships with relevant third sector stakeholders, opinion and policy makers to produce a range of educational, research and commissioning products.

Proposal overview
The overarching mission of the programme is to improve the quality of care both clinically and holistically, in General Practice for people living with epilepsy. Within this RCGP propose four key aims:

1. **Reduce the treatment gap** by way of education and programmes of work to reach people not accessing epilepsy care
2. Facilitate GPs to help reduce the psychosocial consequences of epilepsy and strengthen links to supporting stakeholders

Dr Greg Rogers
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 recent 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.

In his spare time Greg enjoys sailing and reading and hopes to finish his PhD on epilepsy service provision and re-design (UCL) this year!
E: greg.rogers@nhs.net
in this work
3. **Encourage research and audit** to further test and improve care for people with epilepsy
4. **Increase the capability of epilepsy specialist care** to achieve these aims by supporting further recruitment of GPs with extended roles in epilepsy

Across all the aims and objectives RCGP will aim to ensure there is increased awareness of epilepsy by NHS policy makers, primary healthcare professionals and the general public. This will hopefully be achieved through building relevant stakeholder relationships by pro-actively working with the ILAE, voluntary sector, enhancing links with NICE and the Department of Health, and working closely with the All Parliamentary Committee. We have only just begun this project but already we have been greatly encouraged by the offers of support we have received, so please watch this space.

**REFERENCES**
1. The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care NICE Clinical guidelines, CG137 - Issued: January 2012
5. Reuber, M et al. Seizure, 2008,17, p84

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**Symptom Watch**

Mood, guts, sleep, steadiness and pain: A practical guide to some non-motor symptoms in Parkinson’s disease

Dr Shahid Dadabhoy is a full time jobbing GP and GP Trainer in Chingford, North East London. Amongst his special interests are the long term management of neurological conditions.

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Dr Shahid Dadabhoy

From my experience of managing people with Parkinson’s disease (PD), although doctors tend to concentrate on the more visible motor symptoms, it’s often the non motor symptoms that have a more disruptive impact and are more troublesome for patients than the motor symptoms. The non-specialist, whether in a Primary Care consulting room or indeed at the bedside in an acute trust is more likely to be requested to address the former. However, there is an incorrect assumption that restoration of dopamine levels will also address NMS. This article is meant to be a quick guide for generalists to help PD patients with some NMS issues across locales of care in a practical way.

**Affective symptoms**

It’s unsurprising that anxiety and depression symptoms are common in PD, particularly as dopamine is not the only neurotransmitter to be depleted in PD. Disruption of the serotonergic, cholinergic, and adrenergic pathways are implicit in the development of some of the non-motor complications such as anxiety, depression and cognitive decline and it’s important to be aware that these symptoms do not respond to dopaminergic replacement therapy.

Confusingly however, some symptoms of depression and PD overlap. Experiencing anhedonia, defined as lowered ability to experience physical or social pleasure, is thought to be a useful discriminator, should you suspect the patient is experiencing depression as a result of their PD. Anhedonia, is considered a good discriminating symptom to look for in this context to identify depression in PD.

For depression and anxiety in PD, Cognitive Behavioural Therapy is a valid approach but there maybe practicalities regarding access especially for patients with limited mobility. Pharmacological methods are also effective for PD associated affective disorders. Selective serotonin reuptake inhibitors (SSRI) are preferred given the adverse profile of drugs with cholinergic side effects such as Tricyclic Antidepressants (TCAs).

As ever benzodiazepines are best avoided as, in the longer term, they worsen the slurring of speech, drowsiness and gait disturbance.

**Constipation**

Given the alterations that occur to the autonomic nervous system (ANS), which is responsible for regulating smooth muscle activity, it’s no surprise that PD can have a profound effect on the gut.

The motor effects of relative immobility, difficulty in chewing fibre, problems maintaining adequate fluids and trouble using abdominal musculature conspire to make about half of PD patients chronically constipated. Simple measures such as increasing fluids, changing food presentation to aid mastication and making fibre more palatable are useful initial steps. A review to eliminate anticholinergic drugs is also logical and useful. If

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epurients are indeed necessary, given the aspiration risk, avoid lactulose.

**Sleep**
Disrupted sleep is a very common problem associated with Parkinson’s. Sleep symptoms, particularly parasomnias and REM Sleep Disorder, are often harbingers for the onset of PD and are worth inquiring about when the condition is suspected. Patients frequently lose their bed-partner to another room. Unfortunately, the sleep disorder symptoms can remain throughout the course of the illness. Paradoxically at least half of patients report that they have daytime sleepiness.

As ever, careful history taking is mandatory. Drugs such as Amantadine and Selegiline are stimulants and changing the dosing in relation to proposed sleep patterns is useful.

Practical issues such as a difficulty in turning over may make a patient in bed uncomfortable enough to stay awake. The use of “slippery” satin bed sheets can provide a useful solution. Or, if excessive sweating is a problem, then cotton sheets would be more appropriate. Occupational therapists can be invaluable in this kind of context.

**Orthostatic hypotension**
This is a very tricky symptom to deal with. It exacerbates an already high risk of falls from motor symptoms. In addition, given the fact that orthostatic hypotension may predate motor symptoms, it can even be mistaken for cardiovascular disease.

Fludrocortisone remains the mainstay of pharmacological management but a review of existing medication is worthwhile. Reconsider drugs which may worsen matters such as TCAs. As ever non-pharmacological interventions such as balance classes or an Occupational Therapy led reappraisal of activities of daily living could be tried either alone or combined with drug treatment.

**Pain**
A review of all the facets of Pain in PD is an article, at least, in itself and only a few key points can be covered here. Up to half of PD patients have pain symptoms with a very wide spectrum of presentations. Careful history taking is important if only simply to avoid exacerbation of other PD symptoms through ill-judged prescribing. PD medication can be sometimes culpable. For example, dopaminergic agonists such as Amantadine or Entacapone can cause headaches. Similarly, abrupt withdrawal of antiparkinsonian medication can cause pain alongside acute akinesia (or akinetic crisis). Be clear about the nature of the pain that is the problem.

**Final remarks**
Non-motor symptoms remain overlooked in PD but present sometimes a bigger impact to patients and their carers. Successful management involves careful history taking, reappraisal of medication, non-pharmacological methods and if necessary prescribing. It always fascinates me how sometimes the simplest measures can have the most profound effects. For example a couple of well placed handrails near a commode can sometimes do more good than a script of epurients for constipation. At the same time the same handrails can reduce falls in the bathroom during turning or transfers.

Parkinson’s UK has an excellent downloadable questionnaire (available on http://www.parkinsons.org.uk/content/non-motor-symptoms-questionnaire) to identify NMS.

Listening, basic appraisal of medical knowledge and common sense will always be rewarded by the continuing gratitude of patients and their carers.

**REFERENCES**

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**Common Prescribing errors in primary care when managing Parkinson’s disease patients**

Dr Janine Barnes works as a Neurology Specialist Pharmacist for Dudley CCG, running weekly clinics for Parkinson’s disease patients. Such patients are often prescribed dopaminergic medications in order to manage their symptoms. In this short article Dr Barnes highlights prescribing errors that can keep recurring in primary care, particularly with the non-ergoline dopamine agonists: Ropinirole and Pramipexole.

There have been several incidences of the Ropinirole starter pack being requested by primary care. Over a 28 day period the drug is titrated up from zero to 1mg TDS, and GP surgeries have erroneously put this drug on repeat prescription, so the patient starts a cycle of zero to 1mg TDS Ropinirole every 28 days, which often causes unwanted side effects.

There have also been a number of dosing errors when prescribers have been switching between the base and salt of Pramipexole. To date I have encountered three patients prescribed large overdoses of the dopamine agonist causing significant side effects and two hospital admissions.

Another area that causes prescribing problems is when a Parkinson’s disease patient prescribed the monoamine oxidase B inhibitor, Rasagiline, requires an antidepressant. The
Secondary Care following blood tests, which were all returned as normal (routine full blood counts and thyroid function tests are performed to eliminate a blood or thyroid imbalance causing Parkinson’s like symptoms and also to check ceruloplasmin and copper levels in the blood, to rule out the possibility that Wilson’s disease could be contributing to any presenting symptoms. Once these bloods have been returned as normal we would continue to manage the symptoms as those of Parkinson’s disease). Her symptoms were slowness of gait and bradykinesia and rigidity of the right hand side. She also had an infrequent rest tremor on the right hand side. Following diagnosis she was started on Co-careldopa 62.5mg and this was gradually uptitrated to 125mg TDS. Over the next 12 months she was initiated on Ropinirole XL 4mg OD and Rasagiline 1mg OD. The Consultant overseeing her care had not been informed that she had been prescribed Prochlorperazine 5mg TDS for giddiness for many years. The patient was scheduled for a review in the community Parkinson’s disease clinic and asked to bring all her medication with her. At this point the Prochlorperazine was identified and discontinued. Within weeks her symptoms started to improve and all her Parkinson’s disease medication was slowly reduced and eventually discontinued.

This case highlights the importance of obtaining a full and correct patient history and also ensuring that any dopamine blocking drugs are discontinued if clinically appropriate to do so.

Examples of drugs to be avoided by patients diagnosed with Parkinson’s disease:

Listed below and in the adjacent table are typical examples of drugs to be avoided when patients present with additional symptoms:

For hallucinations/confusion - avoid Chlorpromazine, Fluphenazine, Perphenazine, Trifluoperazine, Flupenthixol and Haloperidol. If an antipsychotic is necessary then low dose Quetiapine can be prescribed or Clozapine could be considered if the necessary monitoring is available.

For nausea and vomiting - avoid Metoclopramide and Prochlorperazine. If an antiemetic is required, Domperidone, Cyclizine or Ondansetron are better alternatives.

Vigilance is also required with the use of antihistamines, antidepressants and antihypertensives e.g., calcium channel blockers.

A specific case study:
A 62 year old female was diagnosed with idiopathic Parkinson’s disease by a Consultant Neurologist in

<table>
<thead>
<tr>
<th>Drug</th>
<th>Treatment of Hallucinations/Confusion</th>
<th>Treatment of Nausea/Vomiting</th>
<th>Vigilance is required with the use of</th>
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<tbody>
<tr>
<td>Chlorpromazine</td>
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<td>Fluphenazine</td>
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<td>Perphenazine</td>
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<td>Trifluoperazine</td>
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<td>Haloperidol</td>
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<td>Quetiapine</td>
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<td>Clozapine</td>
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<td>Metoclopramide</td>
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<td>Prochlorperazine</td>
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<td>Domperidone</td>
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<td>Calcium Channel Blockers</td>
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Key: X – Not recommended ✓ – Recommended ✓† – Vigilance required

Table highlighting drugs to avoid (and use) when treating hallucinations and nausea

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**Dr Janine Barnes**

Dr Janine Barnes works as a Neurology Specialist Pharmacist for Dudley CCG, running weekly clinics for Parkinson’s disease patients. She was awarded the Royal Pharmaceutical Society’s Clinical Pharmacist of the Year in 2012 for her work in developing a pharmacy-led clinic for people with Parkinson’s that has led to reduced waiting times. She has a PhD in Neurosciences and qualified as an Independent Prescriber in 2007. Janine was accredited as a Pharmacist with a Special Interest in Neurology in 2011.

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“More physio please” - what is community neurological rehab?

People with long term neurological conditions (LTNC) often see ongoing physiotherapy as the only way to maintain health and independence. A community based neurological therapy team can offer much more.

A broad spectrum of conditions from MND and MS to brain injuries, LTNCs will affect individuals and their families in one way or another for the rest of their life. Symptoms may be primarily physical though there is often a complicated range of functional, cognitive and emotional changes. By using an integrated team approach, often within the person’s home and environment, community based teams offer rehabilitation and disability management to maximise independence, maintain life roles, manage risks and foster a sense of control over the condition. Teams will include a range of therapy disciplines for a holistic approach.

The NSF for Long Term Conditions (2005) highlighted that community rehabilitation is cost effective in re-integrating people into the community, preventing unnecessary hospital admissions, improving well-being, and lessening the burden of care.

With stretched resources, enabling patients to self-manage is key to issues of capacity and demand such as attending a fatigue management course or provision of a home exercise programme. Cross-team liaison with GPs, District Nursing, Social Service and other groups is crucial for provision of optimal care for LTNCs; e.g. medication and complex positioning programmes with GP, District Nurses and care team to manage spasticity at home.

The Royal Free Neurological Rehabilitation Centre (NRC) has a 15 bedded inpatient unit alongside the Community Neurological Conditions Management Team (CNCMT) and Vocational Rehabilitation Service, providing a service to Barnet (North London) and surrounding boroughs. The teams include neuro-specialist Physiotherapy, Occupational and Speech and Language Therapy, as well as MS Specialist Nursing, Neuropsychology, and Dietetics.

The CNCMT was established in 2010 following a review of community rehab services by the PCT commissioner. Growing year on year, the 22-strong team supports nearly 400 people with progressive LTNCs as well as those with newly acquired injuries, averaging 45 referrals/month.

To manage local demand a range of care-pathways allows for a patient-centred approach, aiming to maximise independence and also adapt to the needs of the person and family over differing stages.

- **Crisis management**: May be required for those with highly complex needs to prevent admission to hospital.
- **Rehabilitation**: An intensive episode of community based rehabilitation to improve level of functioning
- **Condition Management**: An episode of intervention to improve disability management
- **Resettlement**: After a hospital stay or moving to a new home to establish a support programme.
- **Self management**: Requiring a programme to support self-care

The Department of Health (2000) highlighted that cross-team liaison with GPs, District Nursing, Social Service and others is crucial for provision of optimal care for LTNCs; e.g. medication and complex positioning programmes with GP, District Nurses and care team to manage spasticity at home.

**Case Report – ‘A patient journey’**

A newly diagnosed young woman with MS was referred into the team and supported by the MS nurse initially regarding DMTs and MS education (Self management). She was added onto the LTC register and was reviewed a year later by the MS nurse and referred for specialist therapy in the Fatigue management programme and leisure centre based exercise group. Following the birth of her first child and subsequent relapse, the OT and PT worked with her again (Rehab) focusing treatment on childcare and improving her mobility and strength. A year later following an MS nurse review she was referred for vocational rehab to support her return to work. She has returned to work 2 days/week, managing childcare and continues to be reviewed regularly by the MS nurse and team as required.

Points to remember when referring to community teams:

- Physiotherapy may be part of the solution but consider the range of MDT professionals to support better management
- Early intervention is key. Refer patients early after diagnosis so community teams can develop rapport, support self-management, anticipate and respond to crises.
- Specialist nurses are a knowledgeable resource for symptom management, often following patients over time and have close links with community services.
- Help manage patient’s expectations – teams may prescribe self-management programmes for patients, though rarely offer ‘maintenance’ therapy – i.e. ongoing regular therapy.
- Different therapeutic approaches and intensity of intervention will be needed dependent on the nature and stage of the condition, as well as psychosocial variables.
- Providing clear reasons for referral will speed up the process. Discuss with the patient what they need as well as want.
Problems with unsteadiness, visual disturbances and behavioural changes can be symptomatic of a myriad of conditions, but they are also key signs of the neurological condition Progressive Supranuclear Palsy (PSP) as one GP discovered...

When Keith Swankie experienced shooting pains in his right arm and stiffness in his right leg in 2008, little did he know he was in the early stages of the neurological condition PSP (Progressive Supranuclear Palsy).

Tests showed up nothing and the symptoms disappeared, so Keith continued living his life as normal. Then in 2009 he fell backwards in his living room and began suffering pains and rigidity in his legs and arms. He was referred back to a Neurologist and as his symptoms worsened with weakness in his arms and legs he was tested for Multiple Sclerosis, but the tests were clear.

After further tests and visits to different specialists he was eventually diagnosed with a functional illness and told nothing more could be done.

Keith’s symptoms continued to get worse. His right eye was closing involuntarily and he was unable to walk without an aid. He then began suffering hallucinations, constipation, inability to mobilise his limbs and tremors in his arms and legs. He also experienced facial spasms and began falling backwards regularly.

Keith’s GP Dr Giles Ledlie was at a loss until, by chance, he attended a conference led by a Geriatrician with a special interest in Parkinson’s Disease and PSP.

“I had never seen a case of PSP before,” said Dr Ledlie, a GP in Angus, Scotland. “But the more the Geriatrician spoke about the symptoms the more I kept thinking of Keith. I spoke to the Geriatrician afterwards and he suggested I refer Keith to his clinic.” Keith was eventually given a diagnosis of PSP, complicated by other symptoms. He is now reviewed regularly by a specialist Parkinson’s team.

“Keith’s diagnosis came about by pure chance,” said Dr Ledlie. “Had I not attended that conference Keith would be no further forward.”

PSP and the related condition CBD (Cortico Basal Degeneration) are rapidly progressing neurological conditions caused by the death of nerve cells in the brain, which affect eye movement, balance, mobility, speech and swallowing.

Over time they can rob people of the ability to walk, talk, feed themselves and communicate effectively. The average life expectancy is seven years from the onset of symptoms.

The prevalence of PSP is 6.4:100,000 but it is thought the reality could be as high as 15:100,000.

Key triggers for GP referral to a movement disorder specialist include:

- Problems with unsteadiness, balance and frequent falls (often backwards)
- Visual disturbances, such as difficulty with gaze, blurring or double vision
- Cognitive difficulties, such as changes in mood or behaviour, including apathy and anxiety.

“A diagnosis of PSP is an opinion from someone with experience,” said Dr Ledlie. “PSP isn’t something that you can test for and that’s what makes it more difficult to diagnose. But GPs have to be aware that there is something wrong and make sure they refer to the appropriate specialist.

“I would say to any GP, if you suspect a movement disorder refer the patient to who ever in your area deals with movement disorders, rather than a general neurological clinic to ensure a better chance of diagnosis,” he added.

PSP and the related condition CBD are rapidly progressing neurological conditions caused by death of nerve cells in the brain...

The PSP Association is a national charity which offers advice, support and information to people living with PSP and CBD, and supports research into the conditions. The charity operates a helpline for people affected by PSP/CBD and healthcare professionals on 0300 0110 122. To learn more about PSP as well as the PSP Association see www.pspassociation.org.uk or telephone 01327 322410.
Neurological Commissioning Support (NCS) is a unique voluntary sector organisation developed by three leading neurology charities; Parkinson’s UK, MS Society and Motor Neurone Disease Association. NCS provides expert neurology advice to health and social care to help improve the quality of services while driving down costs. Epilepsy Society became an affiliate partner in 2011.

From a relatively modest start in commissioning support, business has increased significantly in the last twelve months and NCS has worked with eight strategic clinical networks (SCNs) and a range of clinical commissioning groups (CCGs). Provider trusts like the Royal Free London NHS Foundation Trust and University College Hospital London Partners have also benefited from our expertise.

Much of NCS activity has focused around providing baseline neurology information and data in the areas we have worked, for example Hospital Episodic Statistics (HES) data on numbers of elective and non-elective admissions, length of stay, costs etc. This enables the area to assess its performance and look for ways it can improve. Developing information from this data for specific conditions can be very revealing. For example, data analysed on Parkinson’s in 2012-13, for the BBC 2 current affairs programme, Newsnight, showed that people living with Parkinson’s are much more likely to end up in hospital as an emergency admission that year. That’s two and a half times more than over 65s who don’t have Parkinson’s. In addition, almost half of the Parkinson’s patients had more than one admission. Once in hospital, those Parkinson’s patients each spent three and a half days longer there than over 65s who don’t have Parkinson’s. If planned admissions are included, it became five more days in hospital (Parkinson’s UK).

We have worked to try and increase service efficiency alongside improved patient outcomes and satisfaction with services. For example, development of a first seizure clinic in epilepsy to prevent long waits to see a Neurologist for diagnosis and use of community pharmacy to undertake medicines usage reviews in Parkinson’s so that patients were taking medication appropriately. A huge priority for the NHS is saving money but NCS strives to create efficiency to enable investment in services rather than cuts.

A significant amount of work this year will be on working at a locality level to address service transformation, creating models of service provision and integrating care. For example, we are working with East of England SCN on developing an integrated care pathway for people with epilepsy. This means making systems more joined up and dealing with problems proactively before the onset of a crisis.

NCS is also actively supporting commissioning leadership activities with Neurologists, Elderly Care Physicians and Specialist Nurses to ensure they understand how they can engage in commissioning for the benefit of their services.

Neurology has always been low profile in the NHS and current policy is bringing new opportunities for clinicians and commissioners to address service improvements.

We identified that the most common causes for emergency admission in neurology were issues like falls, urinary tract and chest infections and what we needed was GPs and patients to understand how these problems could be prevented. We are now working with the CCG towards a strategy to reduce costly preventable admissions from occurring by developing integrated care pathways for four neurological conditions. These will highlight a more proactive approach to managing patient in the community rather than them using the hospital as their first port of call. There is a greater need for patients to recognise early signs of infection and seek help at that point to prevent acute deterioration.

Knowledge like this enables us to make suggestions for service models that might support service improvement. NHS Vale of York CCG is one area where NCS carried out a ‘Quality Neurology’ audit of services with patients, carers and professionals.

We are about to do a similar audit in Bristol. The strategy is an action plan of short, medium and long-term service changes that will support service change including more self-management programmes for patients to help prevent avoidable admissions.

**Sue Thomas, Chief Executive of NCS**

Sue’s background is in nursing, with extensive experience in Primary Care and commissioning. Sue is a Florence Nightingale Scholar, a Winston Churchill Fellow and has published over 150 papers and 20 book chapters. She regularly speaks at national and international conferences.

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Neurological long term conditions affect nearly 10 million people in the UK population. Yet for nearly a decade, progress on improving care for this cohort of patients has been disappointing.

The commissioning and provision of neurological services is complex, with responsibilities split across clinical commissioning groups (CCGs), specialist commissioners, community services, acute hospitals, primary care, neuroscience centres and social care.

Published in 2005, the National Service Framework for Long Term Conditions outlined recommendations for improving care. However, whilst some services are outstanding, variances remain across the country.

To create alignment in the system across all stakeholders – providers, commissioners and patients – the NHS in April 2013 established Strategic Clinical Networks across the country. There are twelve Strategic Clinical Networks (SCNs) across England and the role of the SCN is to encourage collaborative working across the boundaries of commissioning and provision, in key areas of major healthcare challenge where a whole system, integrated approach is required. Their remit is based on the NHS Outcomes Framework, which sets measures to help the health and care system to focus on quality and safety in the NHS and promote the delivery of both national and locally decided health care priorities.

One key priority for SCNs is to raise the profile of neurology by working with commissioners to develop clear pathways of care that identify the following issues:

1. Impact of neurological presentations on acute services.
2. Mapping of funding responsibility for services, NHS England or CCGs.
3. Best practice integrated pathways to reduce delays in diagnosis, treatment and rehabilitation, to reduce mortality and levels of disability.
4. Identify how and where service provision can be improved to free up capacity in the system e.g. through redesign of clinics and improved primary care symptom management.
5. Improve patient related outcomes and experience through care closer to home.

The London Neuroscience SCN held a launch event in the Summer to begin establishing relationships. The event served to bring stakeholders together to debate the challenges we face and using a proposed strategy as a foundation to set the direction for an improvement work programme.

A themed (rather than condition) approach to priorities for improvement has been developed with four priority areas. All will support primary and community care to improve the patient experience. All will require primary and community care participation and input in their development.

- Commissioning standards for quality and safety in the management of patients with acute and chronic neurological conditions. Covering the entire patient pathway, we will identify the standards our patients and carers deserve to live as normal life as possible. An organisational audit of providers will highlight the variances across London in care and focus future improvement projects.
- Integrated care – These will focus on case management models that efficiently support the patient through their care pathway. It will include individual health and social care plans and self management. The project will specifically cover the interface between health and social care and we are linking with the NW London Integration pilot (over 75s and diabetes) to explore how integrated care for neurological conditions could work.
- Central resource for information – Patient information on conditions and services available in London will be linked to a central online London neurologic directory to signpost patients, carers and professionals.
- Education programmes for non neurologic-trained professionals - these will help to improve how providers work together, particularly at the handover point of the patient pathway. Besides knowledge education we will be looking at IT innovations and decision tools.

To support the work programme, a multi-professional clinical leadership board has been recruited to provide the backbone of evidence based care required for all potential changes; providing necessary governance and direction to the Network’s programme. The group is made up of professionals across the country.
The Yorkshire and Humber region has a population of just over 5 million people, close to 10% of England’s population. Most of the population is concentrated in the big cities and conurbations, especially in West and South Yorkshire, with Leeds, Sheffield, Bradford and Kirklees the four biggest districts. All geographies have seen their populations grow in recent years, with the exception of North East Lincolnshire and Hull. Urban areas typically have an increased percentage of older aged residents which significantly impacts on health care provision across the region (Health & the Economy in Yorkshire & the Humber).

Current work plan priorities across the Yorkshire and Humber SCN include the following:

**Domain 1** - reducing premature mortality
- Linking with the national team to develop clinical indicators for neurology.
- Working with partner health providers to redesign the regional neuromuscular referral pathway.
- In partnership with providers to redesign acute care pathways to promote timely access to neurology opinion and help people feel supported to self manage.

**Domain 2** - enhancing quality of life for people with long term conditions
- Working with health and social care partners to develop a neurology commissioning guide, which aims to help commissioners (and providers) negotiate the complexities between specialist and non specialist care and rehabilitation.

**Domain 4** - Ensuring people have a positive experience of care.
- Developing links with patient and public organisations in order to gain feedback regarding the implementation of the neurological pathways being developed.

**Domain 5** – Treating and caring for people in a safe environment
- Promoting the development and delivery of quality standards across the region in line with the national direction.

The SCN is engaged with all 24 CCGs and has established a clinical expert group for neurology (CEG); members are predominantly regional Consultant Neurologists and this group, alongside our commissioners, will inform the main drivers jointly shaping neurological services locally.

**Yorkshire and Humber**

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**Thames Valley**

The Thames Valley region has a population of about 2.5 million people; it covers Berkshire, Buckinghamshire and Oxfordshire. It is the only region where the Unitary Authority boundaries correspond to the health care boundaries, making it much easier to redesign and commission integrated patient flows. Much of the population is concentrated in urban areas such as Oxford, Reading and Slough; however there are large rural areas based around towns such as Aylesbury and High Wycombe. As with much of the UK there is a growing elderly population but also a large student population based around Oxford and Reading; both these factors will influence and
Impact health care provision across the region and its economy in Thames Valley.

The Thames Valley SCN current work plan priorities across the Thames Valley SCN for neurology are similar to those of the Yorkshire and Humber SCN.

**Priority 1** – Based on Domain 1 of the Outcomes Framework - securing additional years of life for the people of Thames Valley with treatable mental and physical health conditions; Increasing awareness and early diagnosis at emergency presentation in Secondary care.

- Linking with the national team to develop clinical indicators for neurology.
- Neurology (headaches, epilepsy and medically unexplained symptoms) as Ambulatory Care Sensitive (ACS) and recognised as being able to be managed in the community. Project to redesign services to ensure senior decision making at front line matched with appropriate community support so patients receive appropriate treatment management pathways.

**Priorities 2 & 3** - Based on Domains 2 & 3 - to improve the health related quality of life for the people of Thames Valley with one or more long-term conditions, including mental health conditions.

- To optimise recovery and enable people to regain their independence as quickly as possible following ill-health or injury, whether this is from a planned procedure or an emergency event.
- To support CCGs in the adoption and implementation of best practice models of care.
- Drawing on best evidence, provide commissioners with advice on the value and most effective provision of psychological therapies for people with neurological conditions.
- To develop a series of recommendations to improve the quality of services for people with neurological conditions based on the project undertaken by National Commissioning Support.

**Priority 4** - Optimisation of patient pathways across commissioning systems, to enable patients to experience the right care, at the right time in the right place.

- Developing links with patient and public organisations in order to gain feedback regarding the implementation of the neurological pathways being developed through Steering Group and events and working with the third sector such as the Neurological Alliance.
- Set up community support networks to ensure that there is early diagnosis and timely management of neurological conditions to ensure positive patient experience and reducing unnecessary admissions.
- Development of a service model for a Thames Valley-wide integrated care pathway for headache and pain. To involve a GP with special interest (GPwSI) and specialist nurse pilot; Thames Valley wide network of GPwSI supported by Neurologists and Specialist Nurses; links to tertiary centres and specialist expertise.

The SCN is engaged with all 10 CCGs and is looking to establish a clinical expert group for neurology; as with the Yorkshire and Humber SCN, members will be predominantly regional Consultant Neurologists and this group, alongside our commissioners, will inform the main drivers jointly shaping neurological services locally.
Greater Manchester, Lancashire & South Cumbria

Julie Rigby is a Neurophysiotherapist working in in-patient facilities and community settings. She was Director of Greater Manchester Neurosciences Network from 2008–2013 and has been Programme Lead for the SCN for Greater Manchester, Lancashire & South Cumbria since 2013.

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The footprint for our SCN is large with a varied geography and socio-economic population. A network had previously existed for Greater Manchester but there had been no such arrangements in Lancashire and South Cumbria. Over the past few months, the new SCN has focused on developing relationships with key stakeholders across the footprint. This has been relatively straightforward with service providers as many neurology services are provided by three key trusts including two neuroscience centres. Providers of community services are more varied and there is still much to be done in understanding the service provision across the patch.

A stakeholder event was held on the 26th September 2013 following which progress has been made towards developing our work programmes. Based on information received from stakeholders and guidance from the National Clinical Director, Dr David Bateman, the programme of work for our SCN will focus on:

- Improving access to specialist care and investigations in non-specialist hospitals;
- Improving the management of epilepsy, syncope and transient loss of consciousness;
- Improving access to and quality of neuro-rehabilitation services.

There is a challenge in motivating CCGs to engage with the SCN to improve services for people with neurological conditions. The responsibility for commissioning most secondary and tertiary neurosciences services lies with NHS England specialised commissioning teams and with the reduced resources available CCGs are tending to focus their energies on other areas of care.

The Greater Manchester, Lancashire & South Cumbria SCN would welcome the opportunity to work with local GPs, community service providers and Local Authorities to support high quality care for all people with neurological conditions now and in the future.

Strategic Clinical Network for Mental Health, Dementia, Neurological Conditions, Learning Disability and Autism (MHDNL) Strategic Clinical Network (SCN) East of England

Epilepsy Event

Venue: Weston Business Centre, Stansted
Thursday 26 June 2014, 10am – 4pm

Booking a place:
If you would like to book your place please contact Victoria Doyle at victoria.doyle@nhs.net
FIGHT NEURONAL HYPEREXCITATION

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For the adjunctive treatment of partial-onset seizures with or without secondary generalisation in patients aged 12 years and older

PRESCRIBING INFORMATION

Fycompa® (perampanel)

Please refer to the SPC before prescribing.

Presentation: Film-coated tablets. 2 mg, 4 mg, 6 mg, 8 mg, 10 mg, 12 mg perampanel.

Indications: Adjunctive treatment of partial-onset seizures with or without secondarily generalised seizures in patients with epilepsy aged 12 years and older.

Dose and administration: Adults and Adolescents: Starting dose is 2 mg daily. Dose should be titrated based on clinical response and tolerability, by increments of 2 mg/day to a maintenance dose of between 4 mg/day to 32 mg/day. Dose should be taken orally once daily before bedtime. Patients who are taking concomitant medicinal products that do not shorten the half-life of perampanel should be titrated no more frequently than at 1-week intervals. Patients who are taking concomitant medicinal products that shorten the half-life of perampanel should be titrated no more frequently than at 1-week intervals. Withdraw gradually. Elderly and patients with renal or hepatic impairment: Dose adjustments not required in elderly patients. Dose adjustments not required in mild renal impairment, not recommended in patients with moderate or severe renal impairment or patients undergoing haemodialysis. Caution is advised in moderate hepatic impairment, titration should not be faster than every 2 weeks and maximum daily dosage not exceeding 8 mg. Not recommended in severe hepatic impairment. Children and adolescents under 12 years: No data available.

Contra-indications: Hypersensitivity to perampanel, or any reactant. Pregnancy: Not recommended. Lactation: Unknown if excreted into breast milk. A decision whether to discontinue breastfeeding or to discontinue/abstain from Fycompa therapy taking into account the benefit of breastfeeding for the child and the benefit of therapy for the woman.

Warnings and Precautions: Monitor for signs of suicidal ideation and behaviours and consider appropriate treatment. Perampanel may cause dizziness and somnolence and therefore may influence the ability to drive or use machines. At doses of 12 mg/day Fycompa may decrease the effectiveness of progesterone-containing hormonal contraceptives. There appears to be an increased risk of AEs, particularly in the elderly. Abnormal and unstable behaviour has been reported; patients and caregivers should be counselled to report any sudden new-onset or unusual changes in the behaviour of the patient. It is advisable to provide family and carers with the Informed Consent leaflet. Patients should be counselled to seek medical advice for any unusual signs and symptoms. Caution should be exercised in patients with a history of substance abuse and the patient should be monitored for symptoms of perampanel abuse. Patients should be closely monitored for tolerability and clinical response. If sedation or drowsiness occur, patients should be advised to avoid potentially dangerous activities (e.g. driving). No specific drug interactions have been studied. There may be an increased risk of using other antiepileptic drugs concurrently with perampanel.

Drug Interactions: The possibility of decreased efficacy of concomitant non-immune system (CNS) depressants such as alcohol can increase levels of anger, confusion, and depression. The effects of perampanel on tasks involving alertness and vigilance such as driving ability were additive or supra-additive to the effects of alcohol. Side effects: Adverse reactions most commonly lead to discontinuation of perampanel were dizziness and somnolence. Refer to SPC for full list of adverse reactions. Common effects (≥1/10): Nervousness, somnolence. Common effects (1/100 ≤ <1/10): decreased appetite, increased appetite, agitation, anxiety, depression, emotional lability, irritability, insomnia, somnolence, fatigue, feeling cold, increased salivation, weight increases, flushing, postural hypotension, sleep disturbance, fatigue, increased sweating, thirst, diaphoresis, blurred vision, orthostatic hypotension, fatigue, dyspnoea, upper respiratory tract infection, headache, upper respiratory tract infection, flu-like symptoms, rhinorrhea, conjunctivitis, cough, upper respiratory tract infection, pharyngitis, sinusitis, upper respiratory tract infection, ear infection, conjunctivitis, sinusitis, rhinorrhea, cough, itchy nose, sore throat, pharyngitis, sinusitis, rhinorrhea, cough, itchy nose, sore throat, pharyngitis. Blood effects: Anemia, increased total bilirubin, decreased platelet count, increased platelet count, increased white blood cell count, decreased white blood cell count, increased red blood cell count, decreased red blood cell count, increased hemoglobin, decreased hemoglobin, increased hematocrit, decreased hematocrit, increased lymphocyte count, decreased lymphocyte count, increased neutrophil count, decreased neutrophil count, increased monocyte count, decreased monocyte count.

For UK healthcare professionals:

Adverse events should be reported. Reporting forms and information can be found at www.mhra.gov.uk/yellowcard. Adverse events should also be reported to Eisai Ltd on 0208 600 1400/0845 5176 1400 or EUremsinfo@eisai.com.

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Reference:

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