



Thames Valley  
Strategic Clinical Network

# TRANSFORMING COMMUNITY NEUROLOGY

What Commissioners Need to Know

**Part C – Examples**

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## Document Information

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## Credits

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## BACKGROUND

### Intended Audience

This information will be valuable for commissioners and clinicians in Clinical Commissioning Groups (CCGs). It may also be of interest to Specialised Commissioning, service providers addressing neurological needs, and people living with neurological conditions.

### Aims of this Guide

From April 2016 Clinical Commissioning Groups have responsibility for commissioning all GP-initiated outpatient services, and all non-specialised services for patients with neurological conditions (Specialised Commissioning will be responsible for inpatient care within neurosciences centres, consultant-to-consultant referrals and specialised drugs and devices).

The **Five Year Forward View**<sup>a</sup>, published by NHS England in 2014, set out a future vision for the NHS based around new models of care. The vision calls for a radical re-think on traditional ways of providing care for neurology patients, focussing on locally-provided integrated care, organised around the patient. This is particularly relevant for people with long-term conditions, including those with neurological disorders;

This guide aims to support commissioners to develop their thinking and progress their plans to transform neurological care in line with the vision set out in the Five Year Forward View. It sets out principles to embed in local transformation programmes rather than prescriptive action lists, as every case will be different. Much of the advice is of relevance to a wider transformation agenda, beyond community neurology.

### How to Use this Document

The information has been organised into three parts:

- A** The **Transformation Guide**, sets out the **context and case for change** then introduces the **key features of new models of care**.
- B** The **Reference Reports** document presents the **original individual findings** written by the project's leads on the core topics, which informed the writing of the Transformation Guide.
- C** To illustrate what is already being achieved around the UK by using new models of care, this compendium of **Examples** is also provided.

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<sup>a</sup> Available to download from <https://www.england.nhs.uk/ourwork/futurenhs/>

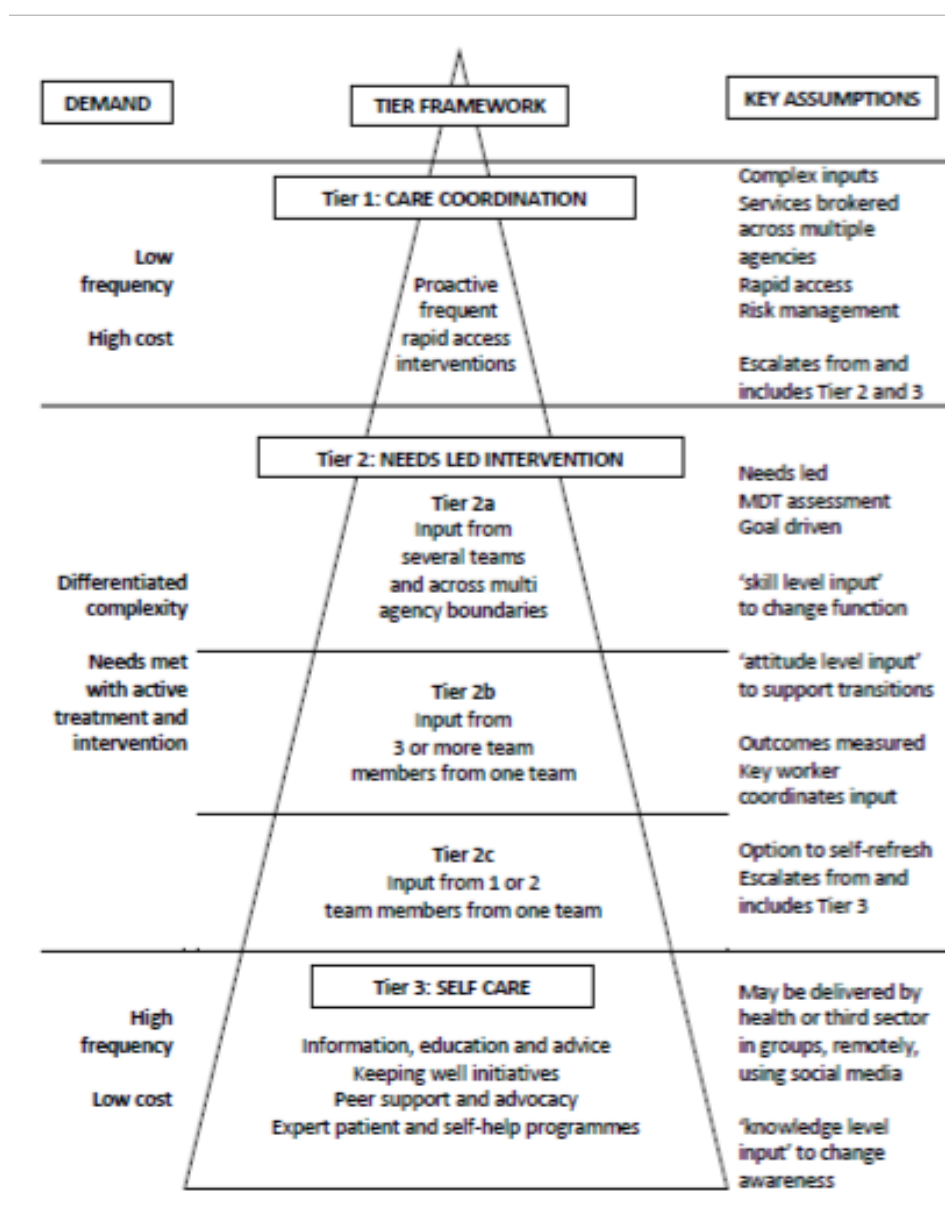
Examples

## CASE STUDIES

A neurologically impaired population will require a wide range of services to be provided, with a multi-agency collaborative to provide an effective ‘end-to-end’ community neurology service. Models of care can be virtual or physically co-located, but will need to be organised to provide team working of experts, who meet frequently to co-ordinate activities and review data on performance.

A three tier framework, as illustrated in Figure 1, may be used to define and differentiate contribution of multi- agencies, with services delivering intervention one or more tiers. As per defined clinical need, a patient may change between tiers and move between services within the same tier over time. What follows is a selection of real-life examples from around England for each of the tiers.

**Figure 1: 3-tier Framework**



## Examples

### Tier 1: Care Coordination

#### DEMAND:

- Low numbers of patients;
- High costs incurred due to need for multiple daily inputs across a variety of teams;
- Escalates from and includes Tier 2 and 3 interventions;

#### ASSUMPTIONS:

- Proactive vigilance and frequent forecasting of future needs;
- Rapid access interventions to support patients who experience sudden changes in need;
- Complex input with one coordinator brokering services across multiple agencies including input from highly specialist, specialist and non-specialist teams;
- Risk assessment and management to ensure a safe environment for patients, families and carers;
- May include the need to assess for and access high cost specialist equipment;
- Should have rapid access to highest level skillsets required to prevent unnecessary morbidity and hospital admission;

#### CASE STUDIES:

- 1 – Nottingham CityCare Community Neurology Team
- 2 – Sheffield Neuro Case Management Service

**Case Study 1**

Tier:	1 (Care coordination)
Location:	East Midlands
Provider:	Nottingham CityCare Community Neurology Team
Service:	Rapid response team for multiple sclerosis (MS)

**A rapid-access team to help avoid A&E admission after a relapse**

Nottingham CityCare Community Neurology Team are a community-based health and social care team who work with any adult (except stroke) with confirmed neurological conditions and a rehabilitation need.

Nottingham CityCare is part of social enterprise and commissioned by Nottingham City CCG, covering a population 342,000.

The team includes a number of specialist nurses (for multiple sclerosis, Parkinson's disease, Huntington's disease and epilepsy), therapists, a dietician, social workers, a psychologist, occupational therapists from social services, and support staff. The team provides hospital in-reach to outpatient clinics and ward visits, home visits and also community-based clinics across the city of Nottingham.

**'Added value'**

A service review highlighted a number of avoidable admissions, for patients attending A&E with relapse, which could have been managed at home with additional support from MS nurses. In collaboration with the A&E department, an MS pathway was created to provide a structured assessment for people with MS presenting to A&E. The pathway now allows immediate issues to be addressed, then patients are discharged back to community with proactive nurse follow-up to prevent further unnecessary admission. The service was further extended to out-of-hours GPs so the same care could be followed without the person attending A&E.

## Examples

### Case Study 2

Tier:	1 (Care coordination)
Location:	Yorkshire
Provider:	Sheffield Health and Social Care Foundation Trust
Service:	Neuro case management service

#### **A case management service, coordinating multi-agency input for complex and at-risk patients**

The Neuro Case Management Service (CMS) is a unique community-based service that covers a population of 560,000 across Sheffield. The team in-reaches across the health and social care networks, including GP surgeries, Sheffield Teaching Hospitals; consultants, specialist nurses, intermediate care, district nurses, and assists with transitioning clients from Paediatric Services, voluntary and charity organisations, Mental Health Teams, Adult Learning Disability Teams, clients' homes, community settings and care homes.

Funded by a block contract with Sheffield Clinical CCG, CMS runs with 2.6 WTE band 7 Case Managers with a background in Occupational Therapy and General Nursing, and experience in neurology, continuing health care, and palliative care. With about 15,000 people living with a known neurological condition in Sheffield, CMS have a caseload of 350 clients who have varying degrees of complexity, with approximately 160 requiring active case management at any one time.

The key objective of CMS is to navigate clients with neurological conditions through the health and social care system. This is achieved by brokering the appropriate providers in relation to the individual needs and priorities of the client. Duplication of referrals is reduced and resources across health and social care are coordinated to provide a proportionate response to a given situation. Crises are either prevented by timely recruitment or the impact on the system is minimised by coordinated and complex management applied and monitored by the CMS.

Work of CMS is either provided face-to-face or by telephone, depending on the situation and preference of the client. Clients are supported to manage their own condition, receiving information of the services involved in their care, who to contact if they need further information via a care plan. CMS provide management to a community of clients with the most challenging degenerative conditions and, as complexity increases, more services become involved to address a wide range of issues. The emergence of problems may be inconsistent and unpredictable. The reconciliation of these factors requires coordination across a range of statutory and non-statutory health and social care providers.

This coordination is captured in a care plan document. The provision of care plans is also intended to encourage discussion and to plan for future needs so as to reduce the impact of the disease progression or social situation. The Case Managers gather information across a variety of domains which formulates a complexity profile of needs.



### **Case Study 2, continued...**

A level of risk is attributed to the complexity profile which helps identify immediate but also predicted points of instability or vulnerability across the client's situation.

The provision of a care plan also allows communication of these predicted crises, or difficult transitions, so that an appropriate and timely response can occur as it is required. This is regularly reviewed by the CMS and also by care planners, working in services who adhere to the care planning principles and therefore trigger the need for further case management if significant and unstable circumstances occur.

#### **'Added value'**

CMS maximise timely and proportionate intervention and minimise the impact of complex conditions on health and social care service provision. By acting as a primary filter and recruiting appropriate resources in direct relation to the prevailing needs of the client, the client care pathway is clearer, services come in at the right time and the right place, optimising available resources.

## Examples

### Tier 2: Needs Led Intervention

#### DEMAND:

- Time limited spell of active treatment and intervention;
- Differentiated complexity and associated intensity delivered to meet clinical need;
  - Tier 2a - Input from several teams and across multi agency boundaries
  - Tier 2b - Input from 3 or more team members from one team
  - Tier 2c - Input from 1 or 2 team members from one team
- Escalates from, and includes, Tier 3 interventions.

#### ASSUMPTIONS:

- Team assessment undertaken and team built to match patients' prevailing needs, including access to multiple services;
- May include:
  - hands-on 'skill level input' to change functional performance
  - 'attitude level input' to support adjustment and transitions including mental health initiatives
  - interventions to support family and carers to care for the patient
- Anticipated length of spell defined by identified active GAS goals;
- Outcome measures used to capture added value across domains (for example: impairments, activities and participation, QOL and other PROMs);
- Input coordinated by a named key worker or navigator who links together services and evaluates impact of contribution, including input from highly specialist, specialist and non-specialist teams;
- Includes scheduled review and pathways to self-refer and refresh input;
- May include the need to assess for, and access, specialist equipment;
- Will require a range of workforce skills, both generic to long-term conditions and condition-specific.

#### CASE STUDIES:

- 3 – Barnet Community Neuro Conditions Management Team
- 4 – Colchester Neuro Rehab Team
- 5 – Changing Lives reintegration service, Tyneside

### Case Study 3

Tier:	2A/2B (Needs led intervention)
Location:	Barnet, London
Provider:	Royal Free Hospital, Neuro Rehabilitation Centre
Service:	Community Neuro Conditions Management Team

#### **A community-based neurology service with access to neurologist sessions**

The CNCMT in Barnet covers a population of 356,000 and provides a community-based neurological service to adults with long term neurological conditions. The team includes therapists and specialist nurses and can admit directly to 2b beds with neurologist sessions.

The team group clients with similar conditions into pathways of intervention that may need similar approaches, whilst still allowing a flexible response to variable needs throughout a client's lifetime. These clearly defined care pathways have a specified duration and a standard number of sessions:

1. Crises management
2. Rehabilitation
3. Disability management
4. Resettlement
5. Self-management
6. End of life care/complex case management

Each care pathway or 'intervention package' includes a full initial assessment; goal focussed intervention as required and clear communication with referrer and client post assessment and at discharge. It provides guidance to the number of sessions offered per professional and the overall timescale of intervention.

At referral screening, the care pathway will be identified, to aid with case mix and management, and at the initial assessment the team member(s) and client, together, will then review the level of intensity of intervention required to achieve the client's goals for that specific episode of intervention. This will be clearly documented on the patient's goals sheet and initial assessment summary letter.

Patients with complex needs, and those who have a rapidly changing clinical course such as motor neurone disease, are supported by Neuro-navigators, who rapidly link with other providers such as tissue viability, continence, wheelchairs and specialised seating and respiratory physiotherapy. They broker care and support for families across multiple agencies linking in with their GP, social services and medical consultants as required. In addition, Barnet's multi-disciplinary team complex case forum for neurological conditions run six weekly meetings, covering clients in crisis and those with complex care needs.

### Case Study 4

Tier:	2B (Needs led intervention)
Location:	North east Essex
Provider:	Colchester Community Neuro-rehabilitation Team
Service:	Colchester Neuro-rehabilitation Team

#### A hospital-based therapy team with community outreach rehabilitation

The Colchester Neuro-rehabilitation Team is a hospital based therapy team providing community outreach and secondary care in-reach rehabilitation for a population of approximately 350,000 across north east Essex.

Clinics are held the community hospitals in Clacton-on-Sea and Harwich and the team see patients in their homes, including residential and nursing homes, and treat in a variety of places including Headway facilities, at college, and in community gyms.

Patients already known to the team are seen on the ward, if requested, and share skills with the therapists on the stroke unit. Skills are also shared during monthly joint neuro-orthotic clinic and neuro-wheelchair clinics and join musculoskeletal physiotherapy colleagues for joint sessions when indicated.

Bi-monthly multi-disciplinary team meetings are also held to discuss all patients with motor-neurone disease in the area. This is attended by the local Motor Neurone Disease Association visitors, a speech and language therapist from a community provider, a dietician and a representative from the hospice.

Support and education is also provided to the wards and community services as requested (for example: spasticity management with the therapists working with people with learning disability in the community).

Keeping fit programmes are advocated, with patients attending their local swimming pool, exercises classes at local gyms and specialist classes such as a yoga for people with neurological conditions (run by the local Parkinson's UK team). We have a local gym designed for people with multiple sclerosis and we are about to introduce a specific exercise class for people with multiple sclerosis.

The team manages patients from diagnosis to end-of-life and works closely with local hospice services to ensure a seamless service. A recent development is the involvement of a community respiratory physiotherapist jointly working with the neuro-physiotherapist in the community to see patients with respiratory issues with the aim of keeping people at risk of chest infections, such as less mobile patients and those with respiratory impairment, such as patients with motor-neurone disease, well at home and out of hospital.

## Case Study 5

Tier:	2C (Needs led intervention)
Location:	North Tyneside
Provider:	Momentum Skills
Service:	“Changing Lives” Community Integration Service

### A service to support individuals to reintegrate into their local community

Funded by the Big Lottery for an initial 3-years, the ‘Changing Lives’ Community Integration Service provides long-term support to individuals with brain injury, stroke and other neurological conditions.

Working in partnership with the Stroke Association, the service assists stakeholders across the North of Tyne region to re-integrate back into their local community and provide meaningful activities and social interaction; empowering our client group and in turn maximising their independence.

As the service offers self-management for service users who are offered opportunities to learn about their condition, a range of coping strategies for common barriers to social integration such as low confidence, anxiety and depression and also condition management in terms of healthy eating and exercise opportunities.

These opportunities are offered both on a one-to-one basis and also through a range of peer group activities. The team consists of 2.5 WTE Community Integration Coordinators, 1 Assistant Psychologist and 0.5 WTE Job Coach plus a range of volunteers providing support from administration, buddying and befriending, one-to-one support and group support.

The main aim of the ‘Changing Lives’ project is to reduce the levels of social isolation and psychological barriers experienced by individuals with long-term neurological conditions within their local community. This is achieved by using focused goal planning, with all project service users who, with the support of the project staff, work towards realistic social and occupational goals with the aim of increasing independence and social inclusion with their own community.

At the end of the three-year project, over 200 individuals from the North of Tyne region have been referred to the ‘Changing Lives’ service and have completed an initial assessment with the Assistant Psychologist. In total, clients have set 389 individual goals with the support of their key worker and 75% of all goals set have been achieved, demonstrating that service users accessing the support available via the ‘Changing Lives’ project are experiencing success and making personal progress.

## Examples

### Case Study 5, continued...

The service has generated a 43% improvement in service users 'feeling positive' during and / or after contact with 'Changing Lives'. 27% reported improvement in 'lifestyle' while the statistics also report a 43% change in 'managing symptoms'. Additionally, there is a 14% improvement in work related activity which indicates that a number of service users have reintegrated into their community before considering returning to work, education or training.

In terms of improving psychological wellbeing, the data shows a 55% improvement in psychological wellbeing for service users from the baseline recording at the induction to service, to the final recording at completion of service demonstrating that the service has hit its goals of reducing social isolation and increasing psychological wellbeing.

### 'Added value'

To demonstrate the financial impact made by the project over its three-year lifespan, a 'Return on Investment' (ROI) exercise was completed. The potential savings made are significant when applied to a population, demonstrating excellent return on investment to beneficiaries such as Department of Work and Pensions and the health and social care economy.

### Tier 3: Self Care

#### DEMAND:

- Information to support self-management and staying well delivered to high volumes of patients;
- Low cost input provided via:
  - time limited 'expert patient' groups
  - non-face to face methods such as help-lines
  - technology such as health and wellbeing apps, websites, social media
- 'Prescribed' as a first line intervention for people who are well.

#### ASSUMPTIONS:

- 'Knowledge level input' to change awareness;
- Modular education, self-help programmes and expert patient group sessions developed and delivered jointly by health care and third sector providers;
- Keeping well initiatives delivered closer to home, using non-clinical environments;
- Peer group support with health care agency 'drop in' used to prevent social isolation and provide informal monitoring of overall health and wellbeing;
- Advocacy and sign-posting services to reduce unnecessary demand on health care systems;
- Clear signposting to escalate needs when circumstances change.

#### CASE STUDIES:

6 – TVDNY Neurological Alliance

7 – West Essex Neuro Community Team

8 – LOHO project

9 – The Parkinson's Pathway

10 – Cumbria Headache Forum

## Case Study 6

Tier:	3 (Self-care)
Location:	Tees Valley, Durham and North Yorkshire
Provider:	TVDNY Neurological Alliance
Service:	Advocacy, Information & Signposting Service

### Raising awareness of living with a neurological condition to statutory bodies

Tees Valley, Durham and North Yorkshire Neurological Alliance provide support for anyone living with - or caring for someone with - a neurological condition. We work alongside people in their own home, at local community centres, in residential care, at the rehabilitation centre, local libraries and so on.

The service arose from to address a lack of understanding about neurological need and the impact of stress on mental health, coping skills and crisis management. The service aimed to raise awareness of the reality of life with a neurological condition to statutory sector agencies (health, social care, DWP and the courts). In addition, the service aimed to help improve resilience by reducing stress, reducing the impact of uncertainty and preventing disengagement leading to crisis.

#### 'Added value'

For an initial £5,000 of grant funding:

1. appropriate outcomes were secured for six people through work assessment/welfare benefit tribunals, preventing stress from requiring medical interventions, GP appointments and additional medications;
2. enabled two people to engage with volunteering opportunities after being marginalised by a neurological condition, supporting them back into employment with job references.



## Examples

### Case Study 7

Tier:	3 (Self care)
Location:	West Essex
Provider:	St Clare Hospice
Service:	West Essex Neurological Community Team

#### Hospice-based educational support to patients and their carers at end of life

St Clare Hospice in West Essex serves a population of 300,000 by providing hospice-based services to patients and their carers with life-limiting neurological conditions.

Despite having a community team with expertise in neurological conditions, the needs of this group of patients was unmet:

- Carers were not able to access carer support as they were unable or unwilling to leave the patient in order to attend a carers group;
- Patients were finding it hard to access the services of the community team, and were unclear about who did what;
- Patients were fearful of attending a hospice due to perceptions that hospices are for patients dying with cancer.

A collaboration between the hospice and community team developed a bi-annual hospice-based group to support patients and carers living with life limiting, progressive neurological conditions. The group is intended for patients and their carers to attend together, and encourages access to palliative care services, self-management, and education to address physical, spiritual, psychological, social and emotional issues.

The sessions are delivered in a sequence designed to facilitate the development of a therapeutic alliance; building trust and confidence in the participants and staff. This was felt to be particularly important due to the difficult topics that are discussed within the group.

Some of the sessions are delivered with patients and carers together, other sessions are delivered separately, to give both groups the opportunity to discuss topics openly that they may not want to discuss with their loved ones present. There is a planned outline of content to be covered each week, but this is adjusted and amended depending on the group's needs and interests.

#### 'Added value'

Evaluation forms from patients and carers showed that 92% of people who attended felt having access to MDT was useful, with 96% going on to access other hospice services. For example: the numbers of patients accessing day therapy at the hospice in the year pre group 19 vs the year post group 49 representing a 258% increase.

## Case Study 8

Tier:	3 (Self care)
Location:	Argyll, western Scotland
Provider:	NHS Highland
Service:	Lorn and Oban Healthy Options (LOHO) project

### Leisure centre-based exercise programme to keep people well

Lorn and Oban Healthy Options is a community enterprise initiative set up in 2012 to provide exercise opportunities for people with chronic health conditions.

The 23,000 population is spread over a large rural area around Oban in the Argyll, on the west coast of Scotland, including 6 inhabited islands.

Specialist neurological services require a 180-mile round trip for patients from the Oban area, preventing any real option for meaningful rehabilitation. In addition, the NHS resources available to deliver local rehabilitation services are limited. Providing high quality patient focused local rehabilitation services at no additional cost to the NHS was the aim of the LOHO project.

Initial LOHO consultation takes place in GP practices and flags up patients with neurological long term conditions who would benefit from re-engagement in physical activity. Traditional approaches to this tend to focus on providing rehab in NHS physiotherapy departments or specialist units, adopting prescriptive exercise programs. The LOHO project aimed to ensure people requiring ongoing rehab input could do so in the same place as family and friends, or in a location suitable for them, engaging in activities that were enjoyable and important to them in order to meet their goals.

After an initial physiotherapy assessment, goals are set by the patient and findings handed over to an exercise professional. The exercise professional then worked with the patient to identify suitable treatment locations, such local leisure centre, the multiple sclerosis therapy centre, in the patient's home or any other community venue depending on patient needs and wishes.

A treatment programme of up to 12 weeks is then delivered by the exercise professional with the aim that after the 12 weeks, patients are comfortable using mainstream leisure services and can carrying on exercise activities which they enjoy with minimal further input from professionals.

### 'Added value'

Subjective reports were obtained from those participating as part of a formal evaluation report into overall LOHO services. (electronic copy available). A significant cost saving of approximately £15,000 was made when comparing the cost of providing traditional NHS rehabilitation services for 27 patients over the course of one year.

## Case Study 9

Tier:	3 (Self care)
Location:	East London
Provider:	The Homerton, City & Hackney CCG
Service:	The Parkinson's Pathway

### Integrated pathway for people accessing Parkinson's disease services

To provide a more seamless service for people with Parkinson's, an integrated care pathway between in-patient clinics and the adult community rehab team has been developed, including Consultants, Parkinson's disease CNSs, community and the in-patient team. The service aims to serve patients across the City of London and Hackney.

A range of support groups have been established including expert patient groups, disease-specific exercise, and user involvement. The user involvement group is a community group for transitional rehabilitation; they meet every three months and provide suggestions and input in to how current services can be improved. Vocational rehabilitation is also provided by a psychologist and occupational therapist.

#### Parkinson's education group

Aims:

- To provide education on all major areas affecting self-management of PD to client, family and carers;
- To create a supportive forum for individuals to discuss and make sense of their condition;
- To learn strategies for dealing with the physical, functional, communication and emotional adjustment difficulties associated with their condition and recent diagnosis;
- To educate clients on the role of healthcare professionals in managing the condition, referral options and external services available;

#### Parkinson's exercise group

Aims:

- High-level exercise group for clients (who need to be resident in The City or Hackney) with early to mid-phase Parkinson's;
- Contents of the group is based on up-to-date evidence for treatment and considers the neuro-protective influence exercise has on clients in the early phase of Parkinson's disease;
- The group is run in conjunction with the Healthwise team at Britannia Leisure Centre;
- Clients get automatic referral to the Healthwise scheme following the group, therefore encouraging self-management and ongoing exercise post-group;
- The exercise group runs to coincide with the education group.

## Examples

### Case Study 10

Tier:	3 (Self care)
Location:	Cumbria
Provider:	Cumbria Partnership NHS Foundation Trust
Service:	Cumbria Headache Forum

#### Patient educational forum

Cumbria has critically low neurology staffing levels and limited funding for special nursing support. Due to the need to find expertise within a growing population of patients with headache, Dr Jitka Vanderpol set up the Cumbria Headache Forum. The Forum runs as a quarterly large-scale meeting with open free access to all patients with headache. The forum is an educational platform developed to enable patients to take an active role in the management of their headaches and covers a regional population of 500,000.

Topics include self-management, relaxation techniques including visualization, mindfulness exercises, concepts of activity pacing, lifestyle balance, stress management and diet. Headache experts are invited to contribute from both Cumbria and across the country and include GPs with Special Interest (GPwSI), Headache Specialist Nurses, psychologist, physiotherapist and dietary nurses, chaired by Dr Vanderpol, a Consultant Neurologist with expertise in headache management.

This forum concept combines pharmacological treatment with multidisciplinary non-pharmacological treatment and self-management, creating a comprehensive program to increase the likelihood of successfully managing headaches in the community and provides support to patients who feel isolated and unable to cope alone with their condition.

#### ‘Added value’

The forum requires very little investment, with a cost of around £3 per patient per session. Meetings are held for free in a local charity facility and invited speakers do not request a fee. A meeting attracts about 40 patients, some who have been seen initially in a neurology clinic or have read information about the forum in local newspapers or heard about it on BBC radio.

Formal evaluation is underway but the expected benefits of the forum are:

- Improved outcomes in patient care, experience and quality of life via education to promote self-management and a healthy lifestyle;
- Improved access to expert resources via optimising scarce physician time and free skill sharing of other team members;
- Expected reduced admission rate and A&E attendance of headache patients.

## Examples

### Multi-agency Care

#### Case Study 11

Location:	Tyne & Wear
Provider:	Northumberland Tyne & Wear NHS Foundation Trust
Service:	Sunderland and Gateshead CABIS

#### An example of a multi-agency partnership

Sunderland and Gateshead Community Acquired Brain Injury Service (CABIS)

#### Primary KPI:

Reduce unnecessary occupied bed days for acquired brain injury patients in two acute trusts

#### Commissioning Specification:

To provide an end to end multi-provider pathway, including:

- single point of entry to access a collaborative of agencies
- secondary care in reach via a community based team
- home based therapy
- vocational rehabilitation and advice
- peer support and advice
- self-referral, refresh and self-management interventions

Hosted by a primary provider who:

- clinically navigates the patient into, through and out of the system
- manages access to agencies outside the CABIS system
- has responsibility for monitoring all CABIS provider performance
- reports back to commissioner on KPI's for full system

