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Dudley
Joint Commissioning Strategy for Long Term Neurological Conditions

2009-2014

For review in 2012

Contents

Executive version

Why are we having this strategy?

This strategy serves several purposes. Firstly there was and is a need to have a concerted focus and improve services for people with neurological conditions and their carers. Secondly it closely follows the guidelines and 'Quality Requirement's' that are set out in the National Service Framework for Long Term Conditions (DH 2005). Thirdly the strategy was developed around the needs and issues that were raised following a local consultation and recently commissioned data by the PCT that found that the number of people registered on a GP practice in Dudley totalled 18, 734. This equates to approximately one in every sixteen within Dudley having a neurological condition.

What are long term neurological conditions?

A 'long term neurological condition results from disease of, injury or damage to the body's nervous system (i.e. the brain, spinal cord and /or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life.

Introduction

The Strategy for the development of services for Neurological Long Term Conditions has been prepared jointly by a multi-agency group consisting of Dudley Primary Care Trust, Dudley Group of Hospitals, Dudley MBC, users of Services and Carers plus representatives of the Voluntary Sector.

This strategy is concerned specifically with long term neurological conditions. Other long term conditions are addressed in other strategies.

We aim to improve services by:

- Delivering on the Quality Requirements in the National Service Framework for Long Term Conditions
- Developing and re-designing clear pathways for people to access and move through services
- Improving access to information, advice, education and support for example developing a website in Dudley on neurological conditions and support networks and developing information prescriptions
- Improving the patient experience and quality of life (with services personalized to meet people's needs)
- Strengthening joint working across agencies, developing new models of service provision
- To improve the service in line with evidence based research and meeting or exceeding the recommendations in relevant policies or guidelines.
- Developing an action plan and setting priorities.
- Monitoring & evaluating the impact of these changes by on-going engagement with service users and carers.

Neurological conditions workshop

A workshop consultation was held on May 12th 2008 at Saltwells Education Centre. The aim was to ascertain the lived experience of carers, service users and frontline staff so that real issues are captured and addressed in developing improved services.
The workshop focused on key aspects of the patient journey which included 'Early signs and diagnosis, Treatment and Services, Support and Follow-up and on-going care'. At the end of the sessions the different groups were asked to highlight the top three things that were of concern or needed to be addressed. A series of patient outcomes evolved from the workshops and actions to take these forward are outlined below.

Commissioning intentions for patient outcomes

1. Patients, Service Users and Carers are better supported in primary care.

Actions

A Dudley multidisciplinary neurological primary care team aligned with a neurological rehabilitation team that have the right workforce skills, with the main focus in Primary Care and providing care closer to home. The team will consist of the specialist nurse for Parkinson's disease and Multiple Sclerosis, an occupational therapist, physiotherapist, speech and language therapist, psychologist & IAPT (Increased Access to Psychological Therapies), pharmacist, administrator and team leader. Support and links will also be provided by a dietitician, social services and the Integrated Living Team.

2. The patient will have knowledge and information about what is going to happen to them throughout their journey:-

   Actions:
   - **Development of Dudley Neurological website to support information sharing and a central database (links to libraries and local sources including voluntary organizations)**
   - **Development of Information prescriptions,**
   - **Development of care pathways and protocols**

3. Every patient with a Long term neurological condition will have a personalised, individual care plan:-

   Actions:
   - **To ensure all neurological patients have a patient held record**

4. Carers needs are addressed:-

   Actions:
   - **The development of access to respite.**
   - **Carers have input into the care plan and their needs are taken into account.**

5. Every patient has access to specialist/expert advice when it is required.

   Actions:
   - **Development of care pathways (see appendix 12** for draft pathway of Multiple Sclerosis in the main strategy document**)**

A major part of this strategy represents improved communication & education and will be achieved by the above proposals. Future resources may be required as care pathways are developed.

In addition the strategy also includes a number of recommendations that are specific to services Acquired Brain Injury (ABI) including an integrated care pathway and improved data recording for this clientt group.

Consultation

A strategic consultation document was developed with a series of questions and was out for consultation across the Borough from November 10th 2008 to February 16th 2009.
There was a good response to the strategy which can be found in **appendix 13.**

Conclusion

The National Service Framework for neurological conditions stated that change cannot happen overnight and that time is needed to train staff and develop new services and facilities hence it is a 10 year framework for implementation. Thus there is an acknowledgement services in Dudley have a long way to go but with the development of a dedicated neurological team that will act as a hub and a clear plan on taking services forward we are in strong position. It is no coincidence that other PCT's and Boroughs are looking at how we have developed and particularly how we have had such excellent engagement with service users and carers.
This strategy is by no means concluded but one that will evolve and be revisited every two years.

1. INTRODUCTION

Introduction

This strategy links to the Dudley Commissioning Framework for Long Term Conditions that was agreed by the Dudley PCT and MBC after a lengthy consultation with service users, carers and stakeholders. This included a series of 'Think Tanks' held across the Dudley Borough in 2007. This strategy builds on this process in one of the key areas identified, that of long term conditions and specifically 'users and carers' of neurological conditions.

The Strategy for the development of services for Neurological Long Term Conditions has been prepared jointly by a multi-agency group consisting of Dudley Primary Care Trust, Dudley Group of Hospitals, Dudley MBC, users of Services and Carers plus representatives of the Voluntary Sector. The strategy group has also had sub-groups focusing on the development of care pathways and Acquired Brain Injury.

This strategy is concerned specifically with long term neurological conditions. Other long term conditions are addressed in other strategies.

In essence we recognise that services for neurological conditions in the last few years have not had adequate investment in certain areas or the high profile of services. However the National Service Framework for Long Term Conditions (DH 2005) focused exclusively on neurological conditions and with additional guidance from the Care Services Improvement Partnership plus supported documents and papers from the Neurology Alliance and others it is an opportune time for a service area that requires a concerted focus. Through this Strategy we seek to readdress the balance, improve the quality of services provided and shape the future direction of services.

We aim to improve services by:

- Delivering on the Quality Requirements in the National Service Framework for Long Term Conditions
- Developing and re-designing clear pathways for people to access and move through services
- Improving access to information, advice, education and support for example developing a website in Dudley on neurological conditions and support networks and developing information prescriptions
- Improving the patient experience and quality of life (with services personalized to meet people's needs)
- Strengthening joint working across agencies, developing new models of service provision
- To improve the service in line with evidence based research and meeting or exceeding the recommendations in relevant policies or guidelines.
- Developing an action plan and setting priorities.
- Monitoring & evaluating the impact of these changes by on-going engagement with service users and carers.

Consultation

This strategy builds on an on-going consultation with users of services and carers that was commenced in May 2008 as part of the strategy.
A strategic consultation document was developed with a series of questions and was out for consultation across the Borough from November 10th 2008 to February 16th 2009.
There was a good response to the strategy which can be found in **appendix 13.**

2. VISION

Our Vision

Our vision for neurological conditions is the start of a journey that the strategic group and team will take time to develop and implement.

NHS and Social Care services in Dudley seek to commission a high quality, integrated and evidence based service for people which is appropriate to need – delivering the Right Service, in the Right Place for the Right Need in a timely, responsive and non discriminatory manner. This is in line with our overarching commissioning framework for Dudley and Strategic Plan. It is also in line with the directive of the White Paper 'Our, Health, Our Care, Our Say' for supporting people in their own homes and also 'Putting People First: A shared vision and commitment to the transformation of Adult Social Care'.

We aim to develop Neurological Services that are person centred and promote independence, well-being and choice.

We will develop integrated services reducing the barriers between health and social care and engage fully with colleagues in the Independent and Voluntary Sectors in achieving a co-ordinated and effective service.

Services will support people and their carers, as appropriate, in the community and preferably in their own homes as far as possible but with specialist support and in-patient or care home placement when necessary.

We recognise the importance of securing quick and accurate diagnoses at the earliest possible time and that means strengthening the skills, resources and capacity within primary care.

We will develop integrated pathways of care to provide people with co-ordinated and consistent care.

3. NEUROLOGICAL CONDITIONS & CLIENT GROUP

We engaged with service users, carers and clinicians to draft this strategy. We know that neurological medical conditions have an enormous impact on the whole of a person's life. Such conditions require alterations to daily life, learning new skills, and realistic planning so as to minimise the effect of the condition on individuals and families. These conditions and their treatments can affect mood, cognitive processing (thinking), self-esteem, relationships and quality of life, sometimes leading to stress, anxiety and or depression. These psychological changes are not only distressing in themselves, but can also effect people's ability and motivation to understand, make informed choices about and to pursue treatment regimes. Good care can help prevent the development of or reduce the impact of psychological distress associated with physical health conditions.

<u>What are long term neurological conditions?</u>

A 'long term neurological condition results from disease of, injury or damage to the body's nervous system (i.e. the brain, spinal cord and /or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life.

Long term neurological conditions can be broadly categorised as follows:

a) Sudden-onset conditions usually due to trauma, for example acquired brain injury or spinal cord injury, followed by a partial recovery (Note stroke for all ages is covered in the NSF for Older People)

b) Intermittent and unpredictable conditions, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed.
c) Progressive conditions, for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (e.g. motor neurone disease) deterioration can be rapid (Note dementia for all ages is covered in the NSF for Older People).
d) Stable neurological conditions but with changing needs due to development or ageing, for example post-polio syndrome or cerebral palsy in adults.

What these conditions have in common is the potential for causing great disability. This may be intermittent as in migraine or epilepsy, permanent as in a head injury or progressive as in multiple sclerosis or other neurodegenerative disorders. Many of these conditions are truly 'long term conditions' which a patient will live with for many years.

(See prevalence and specific conditions in epidemiology section)

Client Group

- The client group that is primarily the focus in this strategy is all adults over the age of 16.

Neurological conditions are common

About one in six to one in eight consultations in primary care relates to a nervous system symptom of some kind (Neurological Alliance 2003) and about one in five admissions to hospital are due to a neurological problem (Morrow and Patterson 87).

There are many forms of disability due to neurological conditions

''What I would really like is my freedom back. I wish I could drive a car and go wherever I want, whenever I want. I wish you could make it all go away without me having to take my pills everyday. And I wish you could make people understand that if I have a fit I do NOT want to be carted off to casualty again. Disability is not just about being not able to walk or throw properly.
Person with epilepsy

4. DEMOGRAPHY

Demography

The number of older people is rising in Britain. The population aged 65+ and 85+ are projected to increase by 24% and 52% respectively by 2020.

The strategy for future service development has to take full account of the projected demographic changes over the next decade.

Demographic statistics for Dudley

Although the population of Dudley is forecast to increase by just 1% by 2020; the number of people aged over 75 years is forecast to double, giving 7-8,000 more over 75 year olds. Of these, 3,000 or so are forecast to be over 85 years. The ethnic population (6.3% 2001 Census) is also likely to increase and the age profile, which is currently younger than the white population, will change. This will add to the increasing demand for services for older people.

Deprivation

Life expectancy in Dudley has risen in the last 20 years, but at a slower rate than nationally in recent years. There is still a gap of 6.6 years between Norton ward with the highest life expectancy and St James' ward with the lowest. Whilst Dudley's overall deprivation is similar to the national average, 8 wards fall into the most 25% deprived nationally.

Comparisons regionally and nationally show that that Dudley has a higher proportion of people of pensionable age and a lower proportion of people of a working age.

The number of people (per 1,000 population) contacting Dudley MBC adult social care for services tends to be higher than most other authorities both regionally and nationally. This increase is, in part, due to the high numbers of local people with physical disability, frailty and sensory impairment. Over 35,000 (11.5%) people identified themselves as being a carer. On a conservative estimate this is worth over £97,000,000 to the local economy. Carers provide a key contribution in supporting people with long-term illness or disability and due to the predicted increase in the numbers of older people, their role will become even more crucial in the future.

5. EPIDEMIOLOGY

Neurological Conditions by Number of Patients (Dudley)

Condition	Male	Female	Total
Migraine	3559	8181	11740
Intracranial injury 132 (NB: over one year) Head injury 113 " " " "	147	98	245
Epilepsy	1897	1722	3619
Parkinson's disease	372	286	658
Multiple sclerosis	170	337	507
Spinal cord injury	232	145	377
Dystonia	145	227	372
Essential tremor	138	142	280
Cerebral palsy	127	99	226
Encephalitis	71	92	163
Spina bifida and congenital hydrocephalus	74	83	157
Muscular dystrophy	86	56	142
Myasthenia gravis	41	38	79
Post-polio syndrome	43	25	68
Charcot-Marie-Tooth disease	26	21	47
Motor neurone disease Pseudobulbar palsy Progressive muscular atrophy Progressive bulbar palsy	22	5	27
Huntington's disease/ Huntington's Chorea	13	14	27
Total	**7163**	**11571**	**18734**

Source: Miquest extracts taken from GP surgeries during June and July 2008

See **Appendix 10** for National Prevalence from the Neurological Alliance

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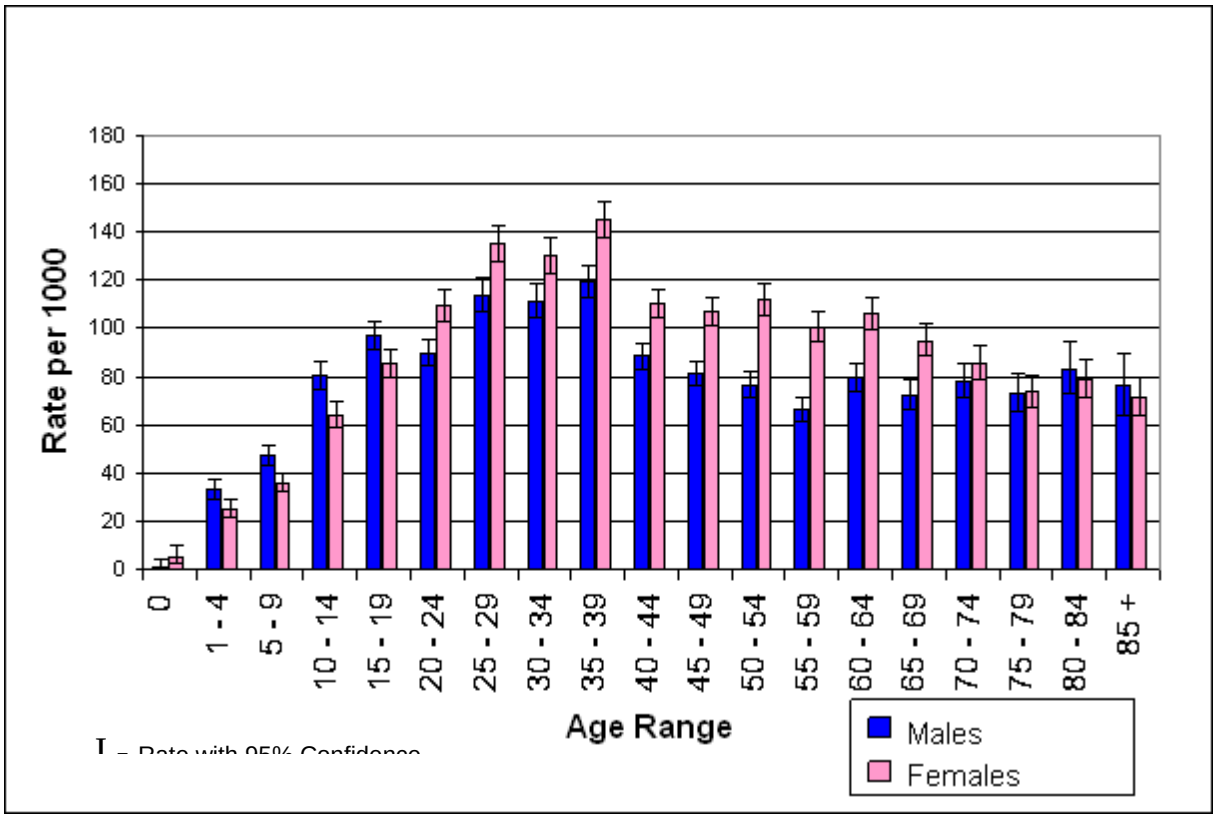
Dudley PCT

All Neurological Conditions Rates per 1000 GP registered population by Age Range and Sex



Source: Miquest extracts taken from GP surgeries during Jun - Jul 2008

	Number of Patients			Rate per 1000	
Age Range	Male	Female	Total	Male	Female
0	2	9	11	1.1	5.3
1 - 4	220	162	382	32.9	24.9
5 - 9	458	343	801	47.3	35.6
10 - 14	687	517	1204	80.3	64.2
15 - 19	939	766	1705	96.9	85.0
20 - 24	906	978	1884	89.8	109.1
25 - 29	932	1098	2030	113.9	135.3
30 - 34	873	1070	1943	111.1	130.3
35 - 39	1046	1321	2367	119.2	145.0
40 - 44	999	1241	2240	88.5	110.0
45 - 49	890	1188	2078	81.2	107.2
50 - 54	701	1007	1708	76.3	112.1
55 - 59	652	984	1636	66.1	100.5
60 - 64	691	932	1623	79.3	106.1
65 - 69	518	722	1240	72.6	94.8
70 - 74	460	588	1048	78.3	85.7
75 - 79	337	435	772	73.1	73.7
80 - 84	226	354	580	83.3	79.0
85 +	131	284	415	76.3	71.3
Total	**11668**	**13999**	**25667**	**81.4**	**94.6**

6. NATIONAL CONTEXT

The National Service Framework (NSF) for Long term Conditions (DH 2005)

The NSF aims to transform the way health and social care services support people with long term neurological conditions. Key themes are independent living, care planned around the needs and choices of individuals, easier timely access to services including diagnosis and treatment, and joint working across all agencies.

The NSF defines 11 quality requirements intended to transform the way health and social care services support people with long term neurological conditions to live as independently as possible. It is explicitly stated that the NSF focuses on people with long term neurological conditions and is a 'long term' ten year programme for change. The Dudley Strategy Group is committed to delivering the Quality Requirements (QR's) as far as possible.

The QR's are based on national evidence and what people with LTC shared about their experiences and needs

QR 1: Person centred care
People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, to support them to manage their condition themselves.

QR2: Early recognition, prompt diagnosis
People suspected of having a neurological condition are to have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

QR3: Emergency and acute management
People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

QR4: Early and specialist rehabilitation
People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

QR5: Community rehabilitation and support
People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

QR6: Vocational rehabilitation
People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

QR7: Providing equipment and accommodation
People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

QR8: Providing personal care and support
Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

QR9: Palliative care
People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

QR10: Supporting families and carers
Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

QR11: Caring for people with neurological conditions in hospital or other health and social care settings
People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

These quality requirements can be broadly grouped into:

QR1: a person centred service
QR2 and QR3: prompt diagnosis, appropriate referral and treatment
QR4 – QR6: rehabilitation, adjustment and social integration
QR7 – QR11: life long care and support for people with long term neurological conditions, families and carers.

- The Dudley Neurological Strategy Group are participating in a Quality Neurology Assessment Audit that will identify any gaps that need to be addressed in the above quality requirements of the NSF for Neurological Conditions.

7. LOCAL CONTEXT: VIEWS OF SERVICE USERS & CARERS

May 12th workshop with users of services and their carers.

A workshop consultation was held on May 12th 2008 at Saltwells Education Centre. The aim was to ascertain the lived experience of carers, service users and frontline staff so that real issues are captured and addressed in developing improved services.

The information gained form the workshop has contributed to the development of care pathways also known as patient journeys for people with neurological conditions with the aim of improving the access and quality of services. This is an important element of developing the Dudley wide strategy for people with neurological conditions and their carers.

The workshop focused on key aspects of the patient journey which included ‘Early signs and diagnosis, Treatment and Services, Support and Follow-up and on-going care’. At the end of the sessions the different groups were asked to highlight the top three things that were of concern or needed to be addressed as below:

Early signs and diagnosis	**Treatment and Services**
• Education for GP's and Health professionals (more informed) • Speedier diagnosis – GP's referral to consultant and investigations. Time between GP & consultation, time available to discuss with GP, no support in between. • No support directly after diagnosis (information is out of date and the wait for further investigations) • Information to be provided at an early stage • Improve communication between professionals and patients • Improve administration/communication – speed up process • More knowledge awareness of neurological conditions across all care environments • Specialist support e.g. Nurse, who to contact (key coordinator) • Local Support Group – speak to others in the same situation • People to believe you have the illness • Help with finance / benefits	• Bureaucracy – assessment, repeating story • Waiting time – through pathway • Need for specialist neurological team – all ranges of staff, primary and secondary care • More local knowledge and services notably around medication support • More support for carers and families • More local neurologists – to give more time to patients • Time: value of out-patient appointments, issues re travel, waiting, medication, cancelling appointments • Specialist advice & information: consistency and pro-active, a point of contact • More specialist nurse time, co-ordination – hospital, communication • Visits at home • Non-assumption of patients knowledge of their needs • Information prior to discharge – set in motion prior to discharge
Support	**Follow-up / on going care**
• Neurological specialist care / team: (coordination of services) psychological support, voluntary groups, primary / secondary • Finance: Direct payments, choice flexibility • Medication: information of side effects (complexity), support, Trust of professionals, improving knowledge of nurses, • Key worker: Therapist / specialist nurse to be point of contact or coordinator and source of information – frequent access to key-worker, one person cannot do this for everyone • More support for patient and carers – being directed in the right direction for medical and social help • Patients want to be **listened** to properly • Need for coherence in services. All professionals to know what is available. Currently services very ''bitty''. (INFORMATION). • Accessibility: (access information). Improvements needed for travel, parking, appointments support etc • Generally with monitoring, planning, condition. Psychological support with adjustments. • GP should have more input into the coordination of care • More involvement of Psychologist, Community Review and Social worker referral	• Specialist care team (neurological) e.g. include nurses, occupational therapists etc • Self medication in hospital – support for carers, training for carers • Support Groups – self/peer support with specialist nurse, time to discuss wider/sensitive issues in depth. Useful to meet people of same age at same stage of disease & information support group • Someone at the end of the telephone who you can talk to – who knows what they are talking about and can advise • Support people to live how they want to live – make their own choice and make own decisions, rather than professionals telling people what to do • Difficulties with timely intervention v progression of disease (time waiting) • Lack of age appropriate placement, e.g. care homes (quality of life issues) • Services reactive not pro-active e.g. waiting for the crisis rather than daily management. More preventative work needed. • Support needs to happen sooner rather than later for getting back into the system including back into work including via a voluntary basis, more disability employment advisers • Have a mentor in the system / Advisers in general practice and access advisors

Strategy response to service users and carers

See also appendix 13

We recognise that there are many areas to address in neurological services.

Section 10 identifies that there are many excellent services that are currently operating but in some areas these are fragmented and there are pressures on the service that needs to be addressed.

In section 9 we focus on the aims and proposals to improve the neurological conditions service in Dudley.

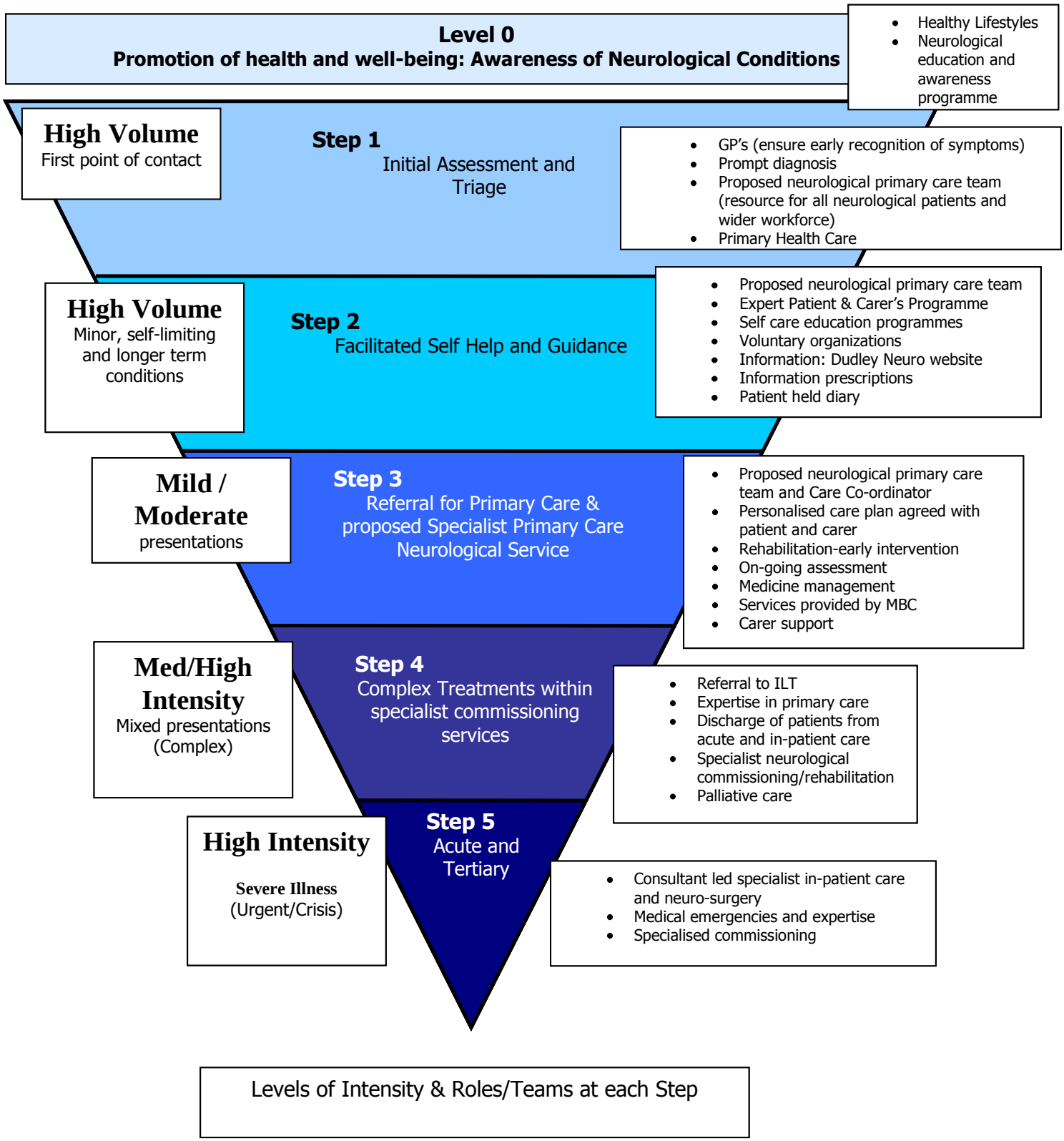
8. PROPOSED SERVICE MODELS / ACTION PLAN

What we will do / propose to do / aims

There are many established services that support people with neurological conditions but in many areas this is fragmented. To address this we have plans for a Specialist Neurology Team and a Neurological Care Pathway/Model of Care, Neurological conditions website, an ABI care pathway and the introduction of a Neuro-psychology service.

- **Develop a Model of Care for Neurological Conditions as an outcome of the workshop**

Neurological Model of Care – Stepped Care Model



1 Patients, Service Users and Carers are better supported in primary care.
Actions
A Dudley multidisciplinary neurological primary care team aligned with a neurological rehabilitation team that have the right workforce skills, with the main focus in Primary Care and providing care closer to home. The team will consist of the specialist nurse for Parkinson's disease and Multiple Sclerosis, an occupational therapist, physiotherapist, speech and language therapist, psychologist & IAPT (Increased Access to Psychological Therapies), pharmacist, administrator and team leader. Support and links will also be provided by a dietitician, social services and the Integrated Living Team.

2. The patient will have knowledge and information about what is going to happen to them throughout their journey:-

   Actions:
   a. **Development of Dudley Neurological website to support information sharing and a central database (links to libraries and local sources including voluntary organizations)**
   b. **Development of Information prescriptions**

Information prescriptions will contain a series of links or signposts to guide people to sources of information about their health and care – for example information about conditions and treatments, care services, benefits advice and support groups. Information prescriptions will let people know where to get advice, where to get support and where to network with others with a similar condition. They will include addresses, telephone numbers and website addresses that people may find helpful, and show where they can go to find out more. They will help people to access information when they need it and in the ways that they prefer.

   c. **Development of care pathways and protocols**

3. Every patient with a Long term neurological condition will have a personalised, individual care plan:-

   Actions:
   - **To ensure all neurological patients have a patient held record**

4. Carers needs are addressed:-

   Actions:
   - **The development of access to respite.**
   - **Carers have input into the care plan and their needs are taken into account.**

5. Every patient has access to specialist/expert advice when it is required.
   Actions:
   - **Development of care pathways (see appendix 12** for draft pathway of Multiple Sclerosis in the main strategy document**)**

A major part of this strategy represents improved communication & education and will be achieved by the above proposals. Future resources may be required as care pathways are developed.

9. ACQUIRED BRAIN INJURY (ABI)

Within Dudley there has been a sub-group of the main neurological conditions strategy group looking at ABI with user representation and representatives from health and social care.

Adult Social Care

The Directorate of Adults, Community and Housing will assess for and provide a range of services to support people with (amongst other things) long term neurological conditions. Assessment and Care Management teams are based in five localities and in the hospital. For a full description of the services that are available following assessment please see **Appendix 8.**

Introduction

There is recognition locally and nationally that acquired brain injury (ABI) is a specialist area of need warranting specialist services involving multi-agency workers from the NHS and Social Care, private and voluntary sectors. Multi-disciplinary approaches are critical if people with ABI are to have a seamless care Journey, with effective rehabilitation and community, reintegration. With the number of people surviving each year it is clear that a comprehensive range of services will is required to meet their need.

Currently, it is unclear as to what processes are in place to facilitate the journey of ABI patients during hospital admission through to discharge. It has been established, locally that there is presently no recognized way to measure the numbers of people with ABI, therefore evidence on which to base local planning and to improve the patients journey needs to be explored in terms of service development.

Data for Hospital Admissions 2006-2008

Information obtained regarding the amount of patients that had been admitted between 2006--8. Local figures were compiled by Matron for Long Term Conditions, Modern Matron and Integrated Living Care Team and are demonstrated in the following figures.

Dudley Group of Hospital NHS trust Directorate of finance and information Completed spells of Dudley patients with a diagnosis of Z50 and all points Excluded the under 16	Total
Grand total	71

Dudley information department. ABI	173

Referral to Integrated living care team

ABI Referrals and outcomes of discharges by Year.

Referrals received by year:

New referrals						
Year	**New BI**	**Old BI comm Based**	**Transferred From ILT**	**Re referrals**	**Closed**	**Cases Open**
2000	3	3			0	**6**

2001	14	14	18		13	**39**
2002	9	10		**2**	9	**51**
2003	16	10	1		18	**60**
2004	16	8		**1**	17	**68**
2005	14	7		**4**	29	**62**
2006	13	11	1	**7**	15	**79**
2007	7	8	0	**4**	16	**80**

Referred By:

Year	**Social services**	**RHH**	**Self/family**	**Headway**	**PC Therapist**	**Moor Green**	**Other**
2007	3	5	4	1	2	1	3

Brain injury with rehabilitation codes are used for those patients with ABI that are transferred to A2 ward only at Russell's Hall Hospital. Not all ABI's are transferred to A2. A2 is a stroke rehabilitation ward in DGOH.

Recommendations

1. Data Collection on the incidence of prevalence, types of severity of head injury and disability within Dudley requires standardization.

   Action = For discussion with consultants and the information analyst.

2. A database with more explicit codes for ABI would ensure consistent local and national data collection about patients with Acquired Brain Injury. In addition it would contribute to the unbundling of tariffs.

Admission into Hospital

Mild Head Injury cases are discharged from Russell's Hall Hospital with no medical follow-up after discharged and with limited information regarding their head injury.

Moderate and severe head injury that are managed in hospital often are not seen or wait some time before seeing a Neurological Consultant, Occupational therapist, physiotherapist, psychologist etc.

Referral to the Integrated Living Team (ILT) which is a community based service for ABI clients that provides assessment and case management, are often only informed about these clients if there is an issue/ crisis regarding family support funding for Moseley Hall or West Park.

Outcomes from analysis of the Dudley Neurology sub-group on ABI

- There is very little information given on discharge for Mild head injury patients and no follow up appointment.
- There is a delay in processing referrals to Consultant Neurologist for Moderate to severe Head injury patients.
- Delay in Neurological Rehabilitation from allied health professional Occupational Therapist Physiotherapy and ILT ABI.
- Patients with ABI can be discharged home prior to a full risk assessment.

Recommendations / Actions

1. Development of Acquired Brain Injury Pathway (see appendix 9)
2. To undertake analysis for specialist support combined with designated bed provision.
3. Agreed time scale for referral to neurologist for advice and management

4. Agreed care planning that is patient and carer/family centered
5. Specialist nurse to flag and track patients through acute trust into primary care.
6. Agreed time scale for referral to Neurological rehabilitation.

Community:

- No dedicated Neurological out patient service in Dudley.

Recommendations

1. To undertake analysis for a Neurological consultant / specialist nurse or AHP / Consultant Nurse or AHP for those mild, moderate and severe patients who have been discharged and /or reintegrated into community.
2. To incorporate with other neurological conditions.

Supported Housing
Currently this is obtained out of area. There is no supportive living accommodation for the younger adults

Actions

- To develop Intermediate Care provision for ABI patients with access to rehabilitation therapists
- To improve the availability of supportive living accommodation within Dudley closer to home

10. CURRENT SERVICE PROVISION AND RESOURCES

Services currently provided and commissioned in Dudley that support people and their carers with neurological conditions as of September 2009.
Below is a table of the varied professionals and agencies that maybe involved in the care of a person with a neurological condition at different stages of their illness. Communication between these professionals and agencies is key to providing person centred care.

Service or specialist	Specialist Service	Current level of service provision
Neurologist Consultant	Dr Etti	Based at Russells Hall Hospital and University Hospital Birmingham
	Dr Corston	Based at Russells Hall Hospital and University Hospital Birmingham and at Wolverhampton New Cross
	Dr Aung (rehabilitation)	Based at West Park Hospital within Wolverhampton PCT
Diagnostics in Neurology (RHH)	Dr Peter Oliver, DGOH	Based at DGOH
Specialist Nurses & AHP's	Continence Service Manager/CNS, Gill Davey	The service has an open referral system as long as the patient has a Dudley GP Seen at home or at clinics what ever is suitable for the patient
	MS Nurse Dawn Price	
	Parkinson's Disease Nurse: Trudy Neave	Patients are seen at all stages of PD from diagnosis through to palliative care. Currently holds 6 clinics throughout the Dudley area as well as home visits.
	Nurse Consultant: Amira Obeid	Clinical remit involves reviewing top 100 patients who are frequent emergency admitters to Russells Hall Hospital
	Specialist Pharmacist: Alison Tennant	Pharmaceutical advisor for Dudley PCT/lead for the Practice Based Pharmacist service within the PCT.
	Specialist Pharmacist: Clair Huckerby & Janine Barnes	Pharmaceutical advisor for Dudley PCT/Clinical and operations lead for the Practice Based Pharmacist service within the PCT.
	Specialist Physiotherapy	1.46wte Senior Physiotherapists of which 0.16wte (6 hours a week) is ''borrowed'' from the palliative care post for end stage neuro patients. Based at Kingswinford HC.
MDT	Primary Care Occupational Therapy (Teams include Adult Rehabilitation, Reablement, Intermediate Care and Palliative Care)	Rehabilitation is client centred and focuses on identified patients goals. This may include personal and domestic Activities of Daily Living, mobility and transfers, access to leisure and return to work. Assessing and prescribing equipment to assist with tasks is a component of Occupational Therapy intervention.
		Out-patient Occupational Therapy based at Rehabilitation Centre at Corbett Hospital. Provides assessment and intervention for reablement and equipment
	Physiotherapy	Other members of community Physio team may see some neuro patients but that

		resource is only approx 1.00wte for the whole borough. Outpatient Physiotherapy provided at Russells Hall Hospital 0.8 WTE Band 6. Includes individual treatment and MS patients and Parkinson's patients exercise groups.
	Speech and Language: Sarah Little	The Adult Community Speech and Language Therapy Team is based at Russells Hall Hospital and sees referrals from DGoH and Dudley PCT. It is 1.6 WTE. There are no designated sessions for patients with long term neurological conditions. Therapy is patient centred with shared goals, in the form of individual sessions and/or group sessions e.g. for patients with Parkinson disease there is a maintenance group at Merry Hill with visiting speakers and an intensive therapy group at RHH. Patients can be seen in a variety of locations e.g. home visits, nursing/residential homes, RHH etc. There is also the Speech and Language Therapy team based at the Rehabilitation Centre at Corbett Hospital. The majority of this team's caseload is Stroke patients although they are referred some patients with long term neurological conditions that have MDT needs.
	Dietician: Yvonne Smith	The community dieticians are based at S.H.S.C.C and provide advice to patients regarding diet especially nutrition support. IT is 2.7WTE. Clinics are held at each of the main health centres and some GP practices. House bound clients can be seen at home, each dietician having a geographical area and designated nursing homes. There is not a designated service for neurological conditions
	Community Nursing	Case Managers, Thunderburds, District Nursing
	Integrated Living Team (see additional information in appendix 6)	CLS service for disabled people who have complex physical impairments or progressive medical conditions. ABI team provides assessment and Case Management service for clients with acquired brain injury. DOVES: Provide support workers/volunteers to promote independence and social integration.
	Specialist Epilepsy Service for people with a Learning Disability	The psychiatrists at Dudley PCT have specialist knowledge and significant experience of managing epilepsy in people with a learning disability. Although complete seizure freedom is not always possible, the medical staff will endeavour to ensure that the person with epilepsy is taking the most appropriate drug or combination of drugs according to their seizure type or syndrome, whilst also aiming to maintain the best possible quality of life. Medication reviews are regular and any concerns about the epilepsy itself or its treatment and side effects can be discussed at the appointment, as well as worries

		about general health and well being. The doctors will also discuss issues such as the risks of sudden death, behavioural changes that may be associated with epilepsy or its treatment and any tests that need to be done such as blood tests, or EEGs. The Epilepsy Specialist Nurse will provide information and advice on: • What epilepsy is • Diagnosis • Reasons for tests and what the results mean • Seizure types and what to look for • First aid for seizures • Triggers • Writing a seizure description • Recording • SUDEP (Sudden Unexpected Death in Epilepsy) • Minimising risk • Drug side effects and the importance of compliance • Lifestyle issues • Specific women's issues • Status epilepticus • Use of rescue medication • Accessing further support and information from voluntary services. The Epilepsy Specialist Nurse can also provide general epilepsy training and training on administration of rescue medications (i.e. Rectal Diazepam or Buccal/Intranasal Midazolam)
	Pharmacists	
	GP's	
	Psychology: Sara Shreeve & Eva Matussek	Access for some patients via DGOH consultant referral. Aims to assist people and services in adapting to and developing flexible and creative solutions for difficulties posed by illness
	Social Workers	Social Work teams for Adults are based in Locality teams in Sedgley, Dudley/Netherton, Brierley Hill, Stourbridge and Halesowen.
	Intermediate Care: Jenny Cale	

	Continuing Health Care: Jenny Cale	
	Expert Patient Programme	Providing courses in support of self health care and well-being
	Wheelchair service	Patients with neurological conditions are assessed and supplied with appropriate wheelchairs and related equipment, subject to eligibility, following receipt of a referral from their GP or other healthcare professionals. Such professionals or the patient themselves can request a reassessment at any time once they are in the system. A stock of manual, powered and comfort wheelchairs are kept aside for patients with end-stage degenerative conditions, so that provision can be made quickly at the point of need, subject to availability.
	Moving and Handling Teams	See Disability Services, Parkes Hall Centre.
	Public Health	Health promotion and physical activities
Primary Care Trust	Strategic Commissioner Lead for Neurological Long Term Conditions: Andrew Hindle	Chair the Strategy Group and coordinate the Strategy
	Clinical Lead for Neurological Long Term Conditions	To be appointed
Dudley MBC: DACHS	Commissioning Manager: Physical services and voluntary sector:	Commission services from the independent and voluntary sector
	Housing	Dudley's Housing Options Service provides help and advice on any type of housing issue that you may have from dealing with disputes with your neighbour, to looking for a new home. This service covers all housing tenures and includes advice on adaptations and supported housing. Further information can be found at: http://www.dudleyathome.org.uk/Data/ASPPages/1/131.aspx
	Benefits	The Benefits Shop, Priory Street, Dudley DY1 1HF, Tel.(01384) 812639 (Mon – Fri 9.30 til 12.00, Mon, Tues, and Thurs 2.00 til 4.00) Fax (01384) 812644, Minicom 18001 01384 812639.
	Education	See Education and Learning website at Dudley.gov.uk or Dudley Council Plus on (01384) 812345
	Meals on wheels service	The Locality office would assess and recommend appropriate meals provision, contact (01384) 812345
	Care at Home	Care at Home or Direct Payments for personal care, household management, meal provision, evening service (tuck in or peripatetic night care/assessment, night sitting), contact Locality Office (01384) 812345

	Disability Services	O.T. assessments, equipment, advice and adaptations recommended – minor or major in any tenure, contact Parkes Hall Centre.
	Disabled Living Centre	assessment and demonstration centre at Jack Newell Court, Coseley with follow up visits, contact Parkes Hall Centre.
	Moving and Handling Team	Advice, training and equipment to assist carers to lift safely, contact Parkes Hall Centre
	Dudley Community Alarms using Telecare Technology	Dudley Community Alarms, Telecare and Telemedicine , contact Dudley Community Alarms and Telecare on (01384) 812040
	Direct Payments	Direct payments support team, A4e support provider, user forum, contact Locality Offices Tel (01384) 812345
	Vision Support Services Team	Vision Support Services Team – Rehabilitation Workers assess, train, advise, issue equipment to people with a visual impairment contact Parkes Hall Centre,
	Deaf Support Services Team	Deaf Support Services team – social work service to people who are profoundly Deaf, environmental support, lip reading classes for people with a hearing impairment. BSL interpreting service also provided by DACHS Contact Deaf Support Service (01384) 813462.
	Community Equipment services	CES is operated by DACHS but utilised across both health and social services. Staff in both agencies are authorised by their managers to be a prescriber according to their roles and responsibilities, each person has a PIN in order to request items. Equipment requests contact Parkes Hall Centre.
Palliative Care Services	District Nursing Teams	Provide palliative and end of life care to patients and support to the carers in the patients own home
	Joint Agency Palliative Care Support Team	A team of generic health and social care assistants with palliative care training who provide comfort, care and support to patients & carers, in conjunction with the DN and GP. The patient has a prognosis of 4-6 weeks and has requested to die at home.
	Specialist Community Palliative Care Team	Consists of nurses, occupational therapy and physiotherapy who manage patients with complex palliative and end of life care needs.
	Mary Stevens Hospice	Providing respite and day care for people with neurological conditions. 40% of users are non-cancer
	Marie Curie Services	Commissioned service that provide Care Support in patients own home (malignant and non malignant disease)
Voluntary Sector & Support Groups Also see Appendix 11 for details of Voluntary Sector &	Multiple Sclerosis Society: Joanne Seaborne	
	Parkinson's Disease Society	
	Motor Neurone Disease Association: Jackie Dornford May	There is a Regional Care Development Adviser covering Dudley as part of a wider area in the West Midlands, plus a Volunteering Development Co-ordinator and a team of Association Visitors, who are trained volunteers. The Association Visitors are able to

Support Group		provide ongoing support for people with MND, and their families. There are also Association Branches and Groups in the West Midlands that are involved in raising awareness, influencing, fundraising and providing information and support for people with MND and their families and carers
	Headway	Local group affiliated to Headway the brain injury association, UK's leading Brain Injury charity. Offer support for brain injury survivors, their family and carers through information, listening and understanding brain injury; a Day Opportunities service providing rehabilitative group sessions, encouraging independence and social inclusion; provide information and support on acquired brain injury for professionals
	Huntington's disease Society	Has a central information service, a regional care advisory service, local branches and groups throughout the country and a research programme. It offers a helpline service, a twice yearly newsletter, publications and information, a welfare grant fund and a respite and residential care fund. Details of all services can be found on the website www.hda.org.uk
	Langstone Society Community Support	A service level agreement with DACHS for the provision of specialised, community-based 1:1 support to people with acquired brain injury and related conditions. Includes training in activities of daily living. Also supports people with individual budgets.
	The Jennifer Trust for Spinal Muscular Atrophy	This is the only national charity in the UK dedicated to supporting people affected by SMA. Details of the charity can be found on the website www.jtsma.org.uk
	Progressive Supranuclear Palsy Association (PSP)	Core support to families is the PSP Nurse Specialist Team, who operate a 24/7 telephone helpline for families and direct carers. Further information is available on the website www.pspeur.org
	Myasthenia Gravis Association (MGA)	First port of call for information and advice for people who have just been diagnosed and the aim is to 'welcome the newly diagnosed sufferer into the myasthenic family'. Further information can be found on the website www.mga-charity.org
Information & Advice	Specialist Support Groups	
	Citizen Advice Bureau	
	Benefits Information Shop	Run by Dudley MBC
	Shaw Trust	Information and support for people trying to return to work
	CADAL: Care and Disability Advice Line	Funded by the Local Authority to provide independent advice on all aspects of disability and benefits.
Carers	Dudley Carers Support: Care Coordinator: Christine Rowley	Carers network and support group meetings, Young Carers, Carers Newsletter, Direct Payments
	Crossroads	Provides Carers Support
	Hospice Group	Offers support for carers looking after someone with a neurological condition that is attending the hospice

	Expert Patient Group	'Looking after me' = specialist course for carers
	Acquired Brain Injury Team	Case Mangers provide support for people caring for someone with an ABI
	Marie Curie	Provide Specialist Care Support
Rehabilitation and Respite	West Park in Wolverhampton	Rehabilitation Service
	Specialised Commissioning Services	
	Moseley Hall Hospital in Birmingham	Rehabilitation
	Cheshire Home	Respite and Institutional Care
	Helen Ley: Leamington	Respite
	Regional rehabilitation services: Selly Oak, Birmingham	Provides a day centre, orthotics and counselling
	BIRT: Brain Injury Rehabilitation Trust	
Day Services	Headway	Day Centre
	Mary Stevens Hospice	Day Centre
	Queens Cross	Provides day opportunities Monday to Friday within Dudley for people aged 18-65 with long term conditions, following an assessment. The service incorporates outreach activities, travel training, skills training as well as a building based service.
Wheelchair service		Patients with neurological conditions are assessed and supplied with appropriate wheelchairs and related equipment, subject to eligibility, following receipt of a referral from their GP or other healthcare professionals. Such professionals or the patient themselves can request a reassessment at any time once they are in the system. A stock of manual, powered and comfort wheelchairs are kept aside for patients with end-stage degenerative conditions, so that provision can be made quickly at the point of need, subject to availability.

11. LEARNING AND DEVELOPMENT

- **Clinical Nurse Specialists**
  They need to be enabled to empower the rest of the workforce (allocated time) who care for people with neurological conditions particularly Parkinson's Disease and Multiple Sclerosis. This would take the form of developing education programmes

- **Expert Patient Programme and Expert Carer Programme**
  Expand and improve access to self care educational programmes for people with neurological conditions

- **The development of the Dudley Neurological website**
  The website will be used a learning development tool for both health professionals and the public for accessing further information, education and resources.

- **Dudley Dignity in Care Programme**
  The PCT along with Dudley MBC and the Independent sector are embarking on an ambitious dignity in care programme across Dudley. This will comprise of Dignity Champions who are health care workers and professionals from all sectors of the health economy including the PCT, Local Authority and the independent sector. The Champions attend a two day workshop covering all aspects of care and will then have a remit of cascading the same sessions to their colleagues.
  In addition there will be a monthly rolling programme of all the themes that will be accessible to everyone. A key aspect of the programme is to raise awareness of improved quality care, dignity and values that will include caring for those with neurological conditions.

- **Future Neurological Care Pathways**
  The Strategy Group is committed to a wide education programme for all staff who will be involved in or input into the emerging care pathways

General Practitioners
The following passage is extracted from **'Action on Neurology', Improving Neurology Services – a practical guide: Modernisation Agency 2005.**

Many doctors would rate their understanding of the brain and nervous system as less good than other organ systems. This comes from a combination of the genuine complexity of the brain and a tendency for teaching to focus on the detail of the brain function rather than basic principles. The popular perception that the brain is amazingly complex is summed up by phrases such as ''You would need a brain surgeon to do that''! The result is that neurology, for many doctors, may be consigned to the ''too difficult'' box before they have even started. This is most unfortunate, since although some neurological diseases do require special diagnostic and therapeutic skills, many are common disorders which are straightforward and easy to diagnose and treat.

When they are in training, doctors often receive limited formal neurological teaching. That which they do get has often focused on the relatively rare disorders seen in teaching hospital neurology wards rather than the common conditions seen in the community. It is not surprising that many doctors' confidence in the diagnosis and general management of neurological conditions is not great. However, the skills of a well trained general practitioner and their team are crucial in managing long term conditions. Their communication and networking skills, together with a real understanding of the psychological and social impact of these diseases on individuals and their family and carers make them a crucial lynchpin in patient care.

Social Care Staff

Social Care staff have a range of training provided according to their role and experience.

Basic training in customer awareness, equality and diversity is mandatory as is Disability Awareness training.

Care staff undertake NVQ training in care and promoting independence.

As well as in house training staff can attend specialist courses (on neurological conditions) if this is identified as a training need and part of their development.

The Directorate of Adults Community and Housing consults with users and carers in a number of ways. We engage in regular forums with representatives of user and carer groups, and hold specific consultation events on documents such as the Older Peoples Strategy, the Physical and Sensory Disability Strategy. These events are attended by Commissioners and Heads of Service who have responsibility for service design and improvement. The result of the consultation is fed into team plans for the coming year and updates are given to the groups via the Forum meetings.

12. PSYCHOLOGICAL HEALTH NEEDS

Psychological therapies have an important place amongst the range of treatments available as part of a comprehensive service for people with neurological conditions.

Psychology and Health

Medical conditions, especially those with a neurological component have an enormous impact on the whole of a person's life. Such conditions require alterations to daily life, learning new skills, and realistic planning so as to minimise the effect of the condition on individuals and families. These conditions and their treatments can affect mood, cognitive processing, self-esteem, relationships and quality of life, sometimes leading to stress, anxiety and/or depression. These psychological changes are not only distressing in themselves, but can also effect people's ability and motivation to understand, make informed choices about and to pursue treatment regimes. Good Psychological care can help prevent the development of or reduce the impact of psychological distress associated with physical health conditions.

(To include new PSYCHOLOGY FOR NEUROLOGICAL CONDITIONS IAPT)

Please see Appendix 7 for further information

13. CO-MORBIDITY (THE OVERLAP OF MENTAL & PHYSICAL ILLNESS)

There are particular issues that need to be highlighted in re to co-morbidities including neuro-psychiatry assessment and chronic-fatigue syndrome particularly as there are people that are referred to neurology with this condition.

We aim to strengthen the development of the pathways for long term conditions and ensure there is improved access to services and a seamless approach.

14. THE CONTRIBUTION OF CARERS

We believe that support for carers should be included in all levels of service provision so that carers can maintain both their caring role (if they wish and are able to do so) and their own health.

Please see **appendix 2** for further information

15. THE CONTRIBUTION OF SERVICE USERS

There will be an on-going forum with users of services and their carers. This will ensure there is monitoring of services and a feedback loop.

We are participating in a Quality Neurology Assessment Audit that includes working with users and carers. This will identify any gaps that need to be addressed in the quality requirements of the NSF Neurological Conditions.

We will also be participating in a neurological alliance across the West Midlands to work more closely with the Third Sector

As part of on-going consultation the Neurology Strategy will be included on the agenda and disseminated for Action for Disabled People and Carers (Dudley) and Dudley Council for Voluntary Services.

16. ACUTE CARE

Please see appendix 1 for a response to the NSF for Long Term Conditions from the 'Association of British Neurologists' 2007

17. SELF-CARE MANAGEMENT PROGRAMMES

Self Management Programmes:
There are group training sessions for people living with long term health conditions. The programmes currently available are generic 'Chronic Disease Self Management Courses' such as the Expert Patient Programme.

Self management courses aim to empower patients to take more control of their health condition, to be more active in the management of their condition and to take more responsibility for their health. Outcomes have included a reduction in Doctors and Nurses visits, reduction in hospital in-patient bed days and emergency admissions, improvement in medication compliance and self reported feelings of well-being.

Expert Patient Programmes
(See appendix 3 for more information on the Expert Patient Programme and self-care triangle)

18. ASSISTIVE TECHNOLOGY

The Dudley Community Alarm and Telecare Service operates 24/7 365 days a year. The main function of the service is to enrich and improve the quality of life of vulnerable people, by increasing their levels of safety and independence in their own homes, whilst enabling them to retain their privacy and control over their own individual lifestyles in the community.

(See appendix 4 for more detailed information on assistive technology)

19. INDIVIDUAL/PERSONALISED BUDGETS

The Department of Health states in the document Transforming Social Care that "in the future, all individuals eligible for publicly funded adult social care will have a personal budget (other than in circumstances where people require emergency access to provision); a clear upfront allocation of funding to enable them to make informed choices about how best to meet their needs…"

An individual budget is one where the service user is given a level of funding to purchase their assessed care – it can include personal care, Supporting People monies, Disabled Facilities Grants, Independent Living Fund, Access to Work and Community equipment.

The service user has an overall individual budget for all these services, which they can choose to take as a Direct Payment or services, or a mixture of both.

A personal budget is the social care element of this. The intention is that all service users will be given a personal budget in the future as part of the changes in social care to ensure service users are given choice and control over the services they receive.

20. HOUSING

What is Dudley doing to help people with long term conditions?
By 2015 we will have built 5 Extra Care Housing Schemes for older people where integrated care and support packages will enable people to live in a supported housing environment. Beacon Centre for the Blind are also building an Extra Care scheme designed primarily for older people with a sensory impairment. Both schemes will include opportunities to rent and purchase properties within the schemes.

All new housing association properties that are built in Dudley from 2011 will be to 'Lifetime Homes Standards.' This means that they will have level access and contain design elements that make it possible for people in wheelchairs or with mobility problems to live in them more easily e.g wider door frames, raised electrical sockets, stairs suitable to accommodate a stair lift. Many of the properties that are being built now are already being built to this standard.

Dudley MBC will continue to fund adaptations, housing related support services and care packages to enable people to live independently in homes of their choice for as long as possible. This will include the use of new telecare technology which includes community alarm pendants, falls sensors, electronic pill dispensers and other innovative technology that can make a real difference to people in housing need.

We are working with Bromford Housing Association to improve the housing choices open to people with a long term disability. This includes promoting Home Ownership for Long Term Disabilities (HOLD). This product enables people with a long term disability to purchase a share of a property of their choice (part own/part rent) and the housing costs are met by a combination of an interest only mortgage payment and housing benefit. More information can be found at:
http://www.bromfordgroup.co.uk/main.cfm?Type=BHHOLD&MenuId=1&Menu2Id=460

We will be working with Dudley PCT on developing care pathways that include the provision of suitable housing for people with long term neurological conditions.

Housing adaptations - Private and Public owned property

The Council has improved the way it provides major adaptations for disabled people by -

- Streamlining the adaptations process across public and private sectors to reduce unnecessary delays.
- Keeping customers informed of the likely waiting times at each stage of the process.
- New contact in place for procuring and recycling lifts in public and private sector property.
- Minor adaptations - we have contracts in place to ensure these are fitted with 7 working days in private or public property.
- Borrowing an additional £1M in each of 08/09 and 09/10 to supplement the already increased grant funding in the private sector, as well as increased funding for public sector.

(See appendix 5 for further information)

21. RESPITE

A Social Worker can help with respite by first carrying out an assessment to determine needs. They will then try to arrange respite to meet the needs of the disabled person and their carers which may include:-

Sitting service
Carers Direct payment
Direct Payment to the disabled person

Day opportunities/care
Support Groups
Residential/nursing care
Support to the disabled person in carrying out daily tasks or accessing community activities.

Further information on respite services can be found in section 10 of current services'

22. THE VOLUNTARY SECTOR

Details of Local Voluntary Organisations/ Support Groups for People with Long Term Neurological Conditions

There are a number of voluntary organisations which work nationally that have a web site and may have a presence within the West Midlands and/or Dudley area.

Please see **Appendix 11** for detailed information on voluntary organizations

23. MEDICINES AND NEUROLOGICAL CONDITONS

There are a number of factors that need addressing in this area.

Dudley Drug Formulary
This has recently been updated but drugs for conditions such as Parkinson's Disease need a full review to examine the choices available to clinicians for prescribing. Newer entities need to be examined and considered for inclusion on the basis of the clinical and cost effectiveness of the product. This is the role of the Area Medicines Management Committee in the PCT to task local clinicians to review the area and submit recommendations to the committee. Training and education for clinicians in the use of these drugs should also be addressed.

Patient information
Information about the products and how to gain the best from them is essential for patients to understand and comply with medication regimes in order to gain the most health benefit from them. Information on different formulations such as patches or liquids need to developed to ensure that the most appropriate patients who will gain the most benefit are aware and offered the choice. This will require multidisciplinary clinical input in conjunction with patients to ensure the information is usable and relevant.

Patient support
Prescribing the medicines is only one facet of the management of a condition. Some patients and carers require practical support in terms of provision of a formulation that ensures a patient can actually take the medication. They may need assistance in complying with complex regimens or review of the regimens to personalise them to deliver outcomes that matter to the patient. This element of care is being addressed through other workstreams in community pharmacy contract development and older peoples support. Neurology patients must form part of the patient groups being considered for these services.

24. END OF LIFE CARE

Background

The National End of Life Care programme (2004) was established to help health and social care professionals throughout England to improve end of life care for their patients, regardless of their diagnosis, age, gender, level of ability or care setting. Around half a million people in England die each year, and the care provided to these people, and their families and carers, forms a significant proportion of the workload for many health, social care, and voluntary sector staff. However, very often care for this vulnerable/important group is not coordinated effectively across the different service providers, and is not designed around people's expressed wishes and preferences about their care.

In response to these challenges, the government put in place a number of initiatives to improve care for people at the end of life. These include

- NHS National Service Frameworks: CHD, Renal, Older persons, Long Term Conditions, Diabetes.
- Building on the Best (DH, 2003);
- NHS Cancer Plan (2000)
- Emergency Care Policy
- NCE Guidance Improving Supportive and Palliative care for adults with cancer (2004)
- Mental Capacity Act (2005)
- Our Health, Our Care, Our Say' (DH 2006)
- 'Our NHS, Our future' (DH 2007).
- NHS Next Stage Review (2008)
- End of life care strategy (2008)

The principal aims of these initiatives are to bring about a step change in access to high quality care for all adults approaching the end of life, irrespective of age, gender, ethnicity, religious belief, diagnosis or care setting, and which respects each individual's needs and preferences.

In 2007 every PCT was tasked with reviewing their end of life care service provision as part of their Operating Framework. The aim of this was to identify existing services, to highlight where the gaps in service provision are and to then develop an action plan and long term strategy based on local needs and identified gaps.

Within Dudley we are committed to implementing the National End of Life Care agenda and have been involved in the development of the regional End of Life Clinical Pathway Group (CPG) as part of Our NHS Our Future (2007).

We have a Palliative Care/End of Life Care Steering Group with representation from Primary and Secondary care, Voluntary and Charity organisations and Dudley Adults Social Care providers. We are now in the process of developing our own end of life care strategy and have outlined our action plan and commissioning intentions for the next 5-10 years. This local strategy will reflect the national and regional intentions of providing excellent end of life care to all patients whatever their diagnosis and whatever the care setting.

Priorities for development

Nationally, regionally and locally, end of life care groups recognize that palliative care services are not always equitable or fair, that patients do not die where they would choose to and experience unnecessary symptoms. The End of life Care Programme and more recently the End of life Care Strategy (2008) advocate and support the use of a whole systems approach which involves:

- Earlier identification of people entering the end of life stage
- Care planning and assessment
- Coordination of care
- Delivery of high quality services in all locations
- Management of the last days of life
- Care after death
- Support for carers throughout the persons pathway and after their death.

To help deliver this whole systems approach the national programme and strategy recommends the use of tools to support clinicians and enhance patient and carer

experience. The three possible models of care which follow the patient through their pathway of care with a terminal illness are:

The Gold Standards Framework (GSF)
The Liverpool Care Pathway (LCP)
Advanced Care Planning (The Preferred Priorities of Care (PPC) is an example of advanced care planning)

The Gold Standards Framework (GSF)

The GSF is a systematic approach to improve and optimise the care of patients in the final year of their life within the community.

It builds on the good work that is already established but formalises best standards of care into normal practice.

By ***identifying*** patients in need of palliative/supportive care in the last year of their life, by ***assessing*** their care needs and then ***communicating*** and ***coordinating*** these care needs within the team, improves the quality of palliative care and enables more patients to die in their preferred place of choice.

Advanced Care Planning (ACP)

Advanced care planning is a process of discussion between an individual and their care provider and might include the persons concerns, what is important to them, their understanding of their illness and their preferences for types of treatment or where they wish to be cared for. This discussion should be documented, regularly reviewed and communicated to other key persons involved with the patient.

The Liverpool Care Pathway (LCP)

The LCP was initially developed to take the best of hospice care into other care settings such as hospital, community and care homes.

It is a document that replaces all other documents for patients in the last few days of their life. The LCP promotes good communication with the patient and their family/carers, anticipatory prescribing, good symptom control and assesses spiritual and psychosocial needs.

These recommended tools are being rolled out within the Dudley Health Economy and are different levels of implementation.

However these tools and guidelines were originally developed around palliative care services for patients with cancer and so more recently these have been adapted and developed so that they can be used as tools for all clinicians and in any care setting and for all patients whatever their diagnosis.

Furthermore it is widely acknowledged that there are significant differences in the palliative care needs of those with long term neurological conditions compared with those who have cancer (O'Brien 2001).

For example the disease trajectory can be hard to predict as it could be a very sudden, rapid deterioration such as Motor Neurone Disease or it could be a very long and protracted journey such as that in Parkinson's disease. Symptoms such as pain control, nausea or vomiting become complex if the patient has cognitive, behavioral or communication difficulties.

The National Guidelines to Good Practice for long term neurological conditions(LTNC) recommend:

1. That a person with a LTNC should be referred to specialist palliative care services if they have:

- A limited lifespan – usually 6–12 months, *and/or*
- Distressing symptoms – especially pain, nausea and vomiting, breathlessness, which fall within the remit of the palliative physician, *and/or*
- A need or desire for end-of-life planning, with or without competence issues.

2. A person who is dying from an LTNC should have timely and ongoing access to specialist palliative care services which include:

- Symptom control
- Planning and support to the end of their life
- Aftercare and bereavement support for their families.

Within Dudley Primary Care over 90% of GP practices have a supportive and palliative care register which includes all patients who have end of life care needs. Within this framework are guidelines and clinical indicators which help practitioners identify patients with LTNC specifically Multiple Sclerosis, Parkinson's disease and MND.

The Liverpool Care Pathway has been adapted for local use to reflect local and regional guidelines concerning symptom control in cancer and non malignant disease as well. The training programme aimed at generalists working in the community has focused on this approach to end of life care to improve access and equity for all our patients. This training programme will continue to develop and reflect any local or national changes or recommendations.

Advanced Care Planning is in the early stages of implementation within Dudley and a training programme is being delivered in conjunction with the local hospice to give clinicians the knowledge and skills to have the complex end of life care discussions that patients may have. This training will be all inclusive to all clinicians who have patients with end of life care needs.

Future developments

The NSF for Long Term Neurological Conditions (LTNC) advocates lifelong care for people with LTNC and recommends provision of palliative care services to support people to the end of their lives.

In Dudley we will seek to ensure that:

- All patients are identified earlier on in their disease progression so that clinicians can begin to have appropriate end of life discussions.
- Clinicians have the knowledge and skills to care for the specific palliative care needs of patients who have LTNC. This may include adjusting the assessment tools used to assess for pain. They will also need to consider the communication methods for patients with cognitive impairment and ensure they are complying with national guidelines within the MCA (2005) regarding assessment of capacity.
- Generalist have access to specific training in postural handling and physical handling e.g. a patient with severe spasticity (O'Brien 2001)
- That primary care registers reflect the end of life care needs of all patients.

- That the Liverpool Care Pathway is used and implemented at the appropriate time for all patients.
- That specialist palliative care is provided on need such as complex symptoms, specific requests for specialist advice regarding treatment options, advanced care planning etc.
- Specialists in all areas will have access to advanced care planning training
- Improve referral pathways so that generalists and specialists can access all end of life care services
- Ensure that any new services or redesign of existing services reflect the needs of patients who have LTNC
- That consideration is given to the specific needs of formal and informal carers both during the patients pathway and afterwards through death and bereavement
- That patients with LTNC and their carers have access to support, counselling, financial advice and bereavement services
- We will ensure that any new services or redesign of existing services will reflect national recommendations such as NICE Guidance on Supportive and Palliative Care (2004), NSF Long Term Neurological Conditions (2005) National Council for Palliative Care and Focus on Neurology (2007) and the Good Practice Guidelines for Long Term Conditions (2008) (NCPC, Royal College of Physicians (RCP) and BSRM

25. IN CONCLUSION

The National Service Framework for neurological conditions stated that change cannot happen overnight and that time is needed to train staff and develop new services and facilities hence it is a 10 year framework for implementation. Thus there is an acknowledgement services in Dudley have a long way to go but with the development of a dedicated neurological team that will act as a hub and a clear plan on taking services forward we are in strong position. It is no coincidence that other PCT's and Boroughs are looking at how we have developed and particularly how we have had such excellent engagement with service users and carers.
This strategy is by no means concluded but one that will evolve and be revisited every tow years.

Appendix 1

Management of acute neurological conditions from the 'Association of British Neurologists' 2007

- Every patient with an acute neurological condition requiring admission to hospital should have access to an opinion from a neurologist within twenty-four hours.
- This could be achieved by Trusts providing a consultant neurologist led ward round on a daily basis. This has been proven to substantially reduce length of stay, use of investigations and enable earlier correct diagnosis.
- This could often take place in the medical assessment unit following the emergency physician's ward round with referral of those patients requiring an urgent neurological opinion.
- Out of hours advice should be provided by the regional neurological centre, whereby patients requiring urgent assessment would need to be transferred and others could either be discharged with an urgent out patient appointment, or kept in hospital until the next available neurology consultant-led ward round.
- Trusts should obtain DGH based neurologists or visiting neurologists to provide five day cover. Approximately one PA per day would be required for this, with appropriate support staff (neurology specialist registrar or trained associate specialist). DGHs should make formal arrangements with their regional neuroscience centre for out of hours cover.
- The trust would need to develop:
  Neurology team
  Neurology ward
  Neurology trained nursing staff
  Local facilities for EEG, EMG and NCS
  Lead radiologist with interest in neuroradiology

Monitoring / Performance Indicators:

- What proportion of patients with acute neurological emergency see a neurologist within 24 hours of admission?
- In what proportion of these is the diagnosis changed?
- In what proportion are the investigations changed?
- Has the DGH got a Neurology team? Yes/No
- Has the DGH got a Neurology ward? Yes/No
- Has the DGH got Neurology nursing staff? Yes/No
- Has the DGH got a Lead Radiologist with an interest in Neuroradiology? Yes/No
- Has the DGH got local facilities for EEG, EMG and NCS? Yes/No
- Does the A & E have written proforma for the management of blackouts and headache? Yes/No

Appendix 2

The Contribution of Carers in Dudley

Statistics

On a conservative estimate the contribution of the Borough's 35,000 carers is worth over £97,000,000 annually to the local economy. Carers provide a key contribution in supporting people with long-term illness or disability and due to the predicted increase in the numbers of older people, their role will become even more crucial in the future. The 2008 National Carers Strategy: *Carers at the heart of 21st century families and communities e*mphasizes that supporting carers is the responsibility of all national and local agencies

Contribution of carers

Families and carers play an essential part in the day-to-day care of patients.

- We acknowledge in this Strategy the enormous contribution they make.
- We need to ensure that we can meet their needs as individuals and allow them the opportunity to contribute to the development of mental health services.
- We recognise the value of their knowledge and experience

We further recognise that supporting carers can pose a challenge, as their needs are often very different from, and sometimes opposed to, the wishes of those they care for. We need to ensure that in meeting the needs of one we are not further disadvantaging the other. Only by adopting a 'partners in care' approach can we begin to resolve this

Co-caring and carers' own health

We recognise that there are many cases of co-caring where two people are supporting each other and may need support not just to maintain their own health but in their caring role

Support for Carers in Dudley

We already have a Carers Strategy in Dudley that takes us to 2012. It highlights that carers' main priorities are for (in no particular order):

- Information that is easy to understand and freely offered
- All agencies to work together
- where to get help in a crisis
- help for the person they care for
- financial security
- a break (respite) from their caring role
- recognition of their own expertise

Carers have a legal right to an assessment of their own needs. In Dudley we have protocols in place to ensure that carers assessments are completed when service users are being supported under the Single Assessment Process and the Care Programme Approach.

Services for Carers

Many of our services, including some personal care and day opportunities are provided to the client to give the carer a break.

In addition:

- We offer short break sitting services, provided in house and by independent and voluntary agencies
- Carers Direct one off payments can be made to carers to allow them to fund a break, leisure opportunities etc
- A number of specialist voluntary organisations including Headway, MS Society, Parkinson's Disease Society and the Huntingdon's Disease Association provide support to carers and families as do generic groups such as Crossroads and the Carers Forum
- Dudley Carers Network provides regular signposting information and support through a Helpline, newsletters and fact sheets
- The Carers' Forum and other groups give carers a chance to be involved in planning and consultation
- Through Welfare Benefits Officers, the Benefits Shop and the Pension Local Service we can offer benefits advice to carers

We also regard the carer's assessment itself as an important service – giving carers a chance to discuss that concern them and helping them to feel equipped to carry on caring.

Vision for carers in Dudley is that

- carers will be respected as expert care partners
- carers will be supported to have a life of their own;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well
- carers will treated with dignity

Appendix 3

Expert Patient Programme
Add in Caring for me

Introduction

The Expert Patients Programme (EPP) is a training programme which aims to improve quality of life by developing the confidence and motivation of people to use their own skills and knowledge to take effective control over life with a long term health condition. It provides opportunities to people including parents, young people and their carers who live with long term illness to meet other people with similar conditions and develop new skills and support networks to better manage their condition within the community.

The EPP is one among a range of new policies and programmes to modernise the NHS to emphasis the importance of the patient in the design and delivery of services. Fundamental changes are taking place within the NHS to empower patients, recognise that patients and professionals each have their own area of knowledge and expertise and need to work together.

Background

Plans for the establishment of an Expert Patient Programme were announced in the 1999 Health Strategy White Paper Saving Lives – Our Healthier nation and later reaffirmed in the NHS Plan of July 2000 which can be downloaded from the Department of Health website.

An Expert Patients Task Force was set up in late 1999 under the chairmanship of the Chief Medical Officer, Professor Liam Donaldson, to recommend a new programme that would bring together the valuable work of patient and clinical organisations in developing self-management initiatives. Task Force members included representatives from the medical profession, non-governmental organisations, and experts in the fields of self-management training and research.

Features of the EPP Training Course

The EPP course is based upon the **Chronic Disease Self-Management Program** (CDSMP) developed and researched over the past twenty years by a team led by Professor Kate Lorig at the Patient Education Research Centre, Stanford University, California. The programme has been used in Australia, Europe, USA and by a number of patient bodies in the UK.

The course deals with issues of pain management, stress, low self image and the development of coping skills. Each course is run following the scripted course manual over six consecutive weekly sessions of 2.5 hours each week. Each week, two course tutors lead 10-16 participants through structured course material covering topics such as relaxation, diet, exercise, fatigue, breaking the symptom cycle, managing pain and medication, and communication with health care professionals. Participants on the course will be provided with a course book called **Living a healthy life with chronic conditions.**

The course is delivered by volunteer tutors who live with a long term health condition themselves and hence are able to deliver the training with better understanding.

Experience shows that some participants having received the training may be interested in delivering the course and becoming a Volunteer Tutor themselves. If this is appropriate they can become trained to do so and therefore help cascade the training. Initially patients may not perceive themselves as being experts but having been through the programme people can

feel empowered to help others by delivering the training and participating in further developing the programme.

Benefits

Benefits to patients;

- Improved Self Efficacy
- Improved communication with Health Care Professionals
- Better fatigue control
- Lower levels of depression
- Improved symptom control
- Less isolated/ meeting people who understand how they feel
- Better awareness of the community and heath resources available.

Benefits to GP Practice and wider NHS agenda;

As a consequence of attending a lay led self management course many patients gain sufficient insight, commitment and energy to:

- Act as advocates for their patient group
- Support the PPI agenda
- Increase volunteer capacity

Evidence gained from a comparison of before and after evaluations show that 4-6 months after completing the course

- GP consultations decreased by 7%
- Outpatient visits decreased by 10%
- A&E attendances decreased by 16%
- Pharmacy visits increased by 18%

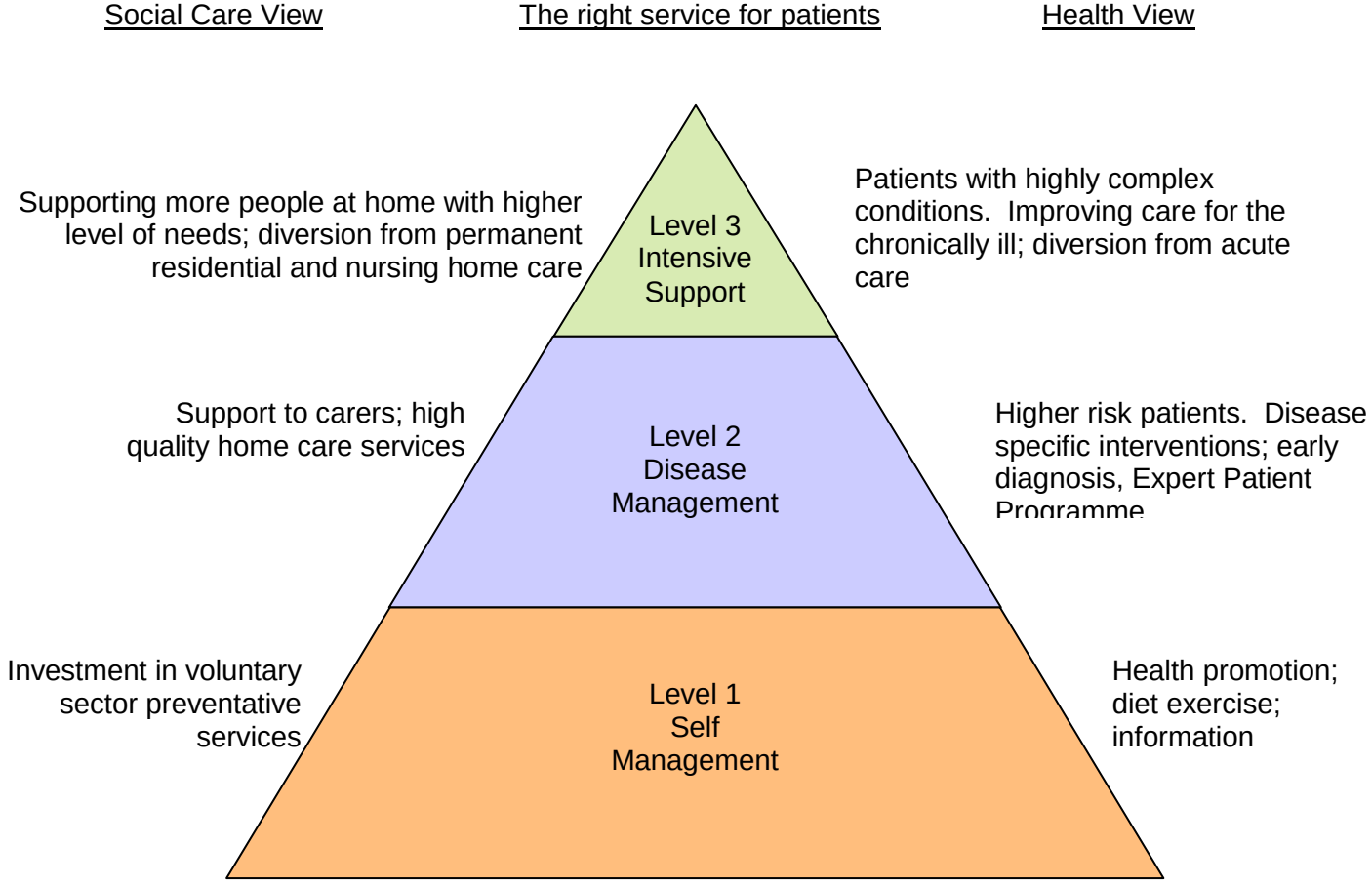
Lay led self-management can contribute to achieving a number of major Government Policy initiatives such as;

- Health of the Nation
- National Service Frameworks.
- NHS Plan
- 'Our health our care our say' and other related whitepapers
- Choice
- Public Patient Participation
- Self Care
- Investing for Health

Delivery of local programmes can also have synergies with other national priorities, e.g.

- Partnership building
- Promotion of independence
- Facilitating greater social inclusion
- Targeting health action areas
- Building healthy communities

Triangle / pyramid of care as a way to illustrate the importance of self care



Appendix 4

Dudley Community Alarm Service

The Dudley Community Alarm and Telecare Service operates 24/7 365 days a year. The main function of the service is to enrich and improve the quality of life of vulnerable people, by increasing their levels of safety and independence in their own homes, whilst enabling them to retain their privacy and control over their own individual lifestyles in the community.

The individual alarm and telecare assistive technology devices are easy to install. All installations are carried out by a trained Community Alarm Officer. The devices use sensors in the home to monitor and/or trigger an alert to potential accidents and emergencies. For example; falling, flooding or fire. The sensors deployed are installed after an assessment by a Community Alarm Officer and are tailored to each individual Service User's requirements.

The sensors can be linked to Dudley Community Alarms by a telephone line and alert the trained operators within seconds if there is a problem in the home. The member of staff will action each alarm and ensure the Service User receives the help they need, providing reassurance and confidence to the Service user and their carers. Or the alarm call can be transmitted to a Carer pager/mobile phone with a nominated responder who will provide the appropriate support.

Referrals for individual alarms and telecare devices are received from a number of different agencies across statutory, private and voluntary organisations. Also individual Service User's and their friends and family also make self referrals to Dudley Community Alarms and telecare services.

The Community Alarm Officers will also undertake maintenance/faulty equipment visits. If staff are unable to rectify the fault they will refer the fault to an engineer to ensure service continuity. The Community Alarm Officers will also undertake emergency responder visits to Service User's if they have no-one to support them and their informal carers.

The Dudley Community Alarm Service works in true partnership with sheltered housing staff and their Emergency Response Team and at night with the Social Care Emergency Duty Team and Peripatetic Night Care Team all of which are co-located on the same site.

Telecare - An examples of how it might benefit people with Epilepsy

People who suffer with epilepsy can be supplied with a (bed) epilepsy sensor, an individual alarm and on occasions a fall detector. The preference of many is for the sensor to be supported by the local alert to the pager or mobile as opposed to the Centre.

Key positives: reassurance (user and carer), specific benefits for the Carer (ability to sleep better, go to work etc.); provision of information has also been used in other initiatives across the Country to assist diagnosis treatment.

Alternative and Augmentative Communication systems:

Any client having difficulty making themselves understood by speech and gesture alone may benefit from using a Low Technology Aid e.g. a communication book or a High Technology Aid e.g. an electronic voice output communication aid (VOCA).

The changing nature of some neurological conditions requires a highly responsive service in order to help the client maintain effective communication.

Speech and Language Therapy (SLT) need to assess the patients needs and can supply Low Technology systems. Working with patients to establish and maintain alternative communication systems increases patient contact time significantly throughout the patient journey. This has service implications for Speech and Language Therapy with no designated time allocated to this highly specialist role.

The regional centre Access to Communication and Technology is commissioned to provide services across the West Midlands Strategic Health Authority. Therefore Dudley PCT is only entitled to a percentage allocation of this service.

Access to Communication and Technology will assess patients for aids within certain criteria

- The patient cannot access or is not expected to access a standard keyboard within the next year.
- The patient can access a standard keyboard but has an additional impairment e.g. visual impairment.
- The patient is known by a local Speech and Language Therapist prior to referral.
- The national standard for a client to wait is 18 weeks.

The voluntary sector has some voice output communication aids accessed by a standard keyboard for patients to loan e.g. The MND Association. However these aids are not suitable for all patients needs.

Aids have also been funded by applying to charitable organisations.

Appendix 5

Housing Supply

There are 130,591 households within the Borough. Of these 78% (102,615) are owner occupied or owned by private sector landlords, 18.34% (23,951) are owned by the local authority, 2.96% (3,873) are owned by housing associations (Registered Social Landlords) and 0.11% (152) are owned by other public sector organisations.

Dudley's Housing Needs Survey indicated that 88% of households live in accommodation that is suitable for their needs.

Predicted population changes
It is projected that Dudley's population will increase by 1,500 people by 2021.

By 2021 the number of people in the following age groups will have declined:
0 - 19 year olds
30 - 44 year olds

By 2021 the number of people in the following age groups will have increased: 20 - 29 year olds
45 - 64 year olds
65+ age group (largest increase)
80+ age group

Predicted changes to household sizes
The average household size is predicted to fall from 2.46 in 2001 to 2.19 by 2021. This is largely due to people living longer (outliving their partners) and relationship breakdowns.

Households with a physical disability or sensory impairment
28% (34,651) households contain a member with a disability. Of these 18% have a long term life limiting illness. You are more likely to have a disability if you are a mortgage free owner occupier (more age related disabilities as you are likely to be an older person), a council or housing association tenant (in proportion to other tenure types there are more wheelchair suitable or adapted council and housing association properties than any other tenure type). You are less likely to be an owner occupier with a mortgage or live in a privately rented property.

What is Dudley doing to help people with long term conditions?
By 2015 we will have built 5 Extra Care Housing Schemes for older people where integrated care and support packages will enable people to live in a supported housing environment. Beacon Centre for the Blind are also building an Extra Care scheme designed primarily for older people with a sensory impairment. Both schemes will include opportunities to rent and purchase properties within the schemes.

All new housing association properties that are built in Dudley from 2011 will be to 'Lifetime Homes Standards.' This means that they will have level access and contain design elements that make it possible for people in wheelchairs or with mobility problems to live in them more easily e.g wider door frames, raised electrical sockets, stairs suitable to accommodate a stair lift. Many of the properties that are being built now are already being built to this standard.

Dudley MBC will continue to fund adaptations, housing related support services and care packages to enable people to live independently in homes of their choice for as long as

possible. This will include the use of new telecare technology which includes community alarm pendants, falls sensors, electronic pill dispensers and other innovative technology that can make a real difference to people in housing need.

We are working with Bromford Housing Association to improve the housing choices open to people with a long term disability. This includes promoting Home Ownership for Long Term Disabilities (HOLD). This product enables people with a long term disability to purchase a share of a property of their choice (part own/part rent) and the housing costs are met by a combination of an interest only mortgage payment and housing benefit. More information can be found at:
http://www.bromfordgroup.co.uk/main.cfm?Type=BHHOLD&MenuId=1&Menu2Id=460

We will be working with Dudley PCT on developing care pathways that include the provision of suitable housing for people with long term neurological conditions.

How to access housing (all tenures)
For further information on how to access housing in Dudley (all tenures) visit:
http://www.dudley.gov.uk/housing

This includes information on how to access low cost home ownership (shared ownership/Home Buy products), council housing (Dudley at Home), housing associations, information on private renting, supported housing and information on how to access assistance to improve your existing housing conditions.

Appendix 6

Integrated Living Team

The Integrated Living Team (ILT) was established in April 1995 for the Metropolitan Borough of Dudley in the West Midlands. This was following a period of consultation with younger disabled people, on the type of service they required to meet their needs.

ILT works from the principle of promoting the independence and the quality of life of all its clients by using a person centred approach guided by a social model of disability. It offers a community based service for people in their own homes. Referrals are received from Health, Directorate of Adult, Community and Housing Services (DACHS), families, carers, voluntary agencies and by self referral.

The service is provided for people aged between 16 and 64 with complex or severe physical impairments, progressive degenerative conditions (that will lead to complex or severe physical impairments) and acquired brain injury. A large proportion of clients have long-term neurological conditions.

ILT is jointly managed and funded by Dudley Group of Hospitals NHS Trust and DACHS. It is able to offer access into health, local authority, voluntary and independent sectors. The Team does not duplicate or substitute for any existing resource but will help the client access them and work in partnership to get the best result.
The service that is offered is personalised to the individual needs of the particular client. Involvement may be brief or lengthy, intervention wide ranging or specific and is always informed by the wishes of the client.

ILT operates a review system so that regular contact can be maintained with individual clients. Informal contact with past and present clients is achieved through a regular newsletter.

Engagement with users of the service has been sought through the ILT forum, which meets every 6-8 weeks. Service users' views have been sought on such things as team literature and the content of the Team newsletter.

ILT has three components: the Acquired Brain Injury Service (ABI), the Community Lifestyle Service (CLS) and DOVES a Supporting People Project.

Team members from ABI and CLS are drawn from senior professional therapy, nursing or Social Work backgrounds.

Acquired Brain Injury Service

The service uses a case management model to enable individuals with acquired brain injury to maintain or improve their independence, social skills, confidence, self-esteem and quality of life and supports them to access social and leisure opportunities in the community. Long-term open access enables clients to access the service as and when required.

The service facilitates a seamless transition from hospital to home.

Individuals with acquired brain Injury are often discharged from hospital without follow up services.

The case manager will identify needs and level of intervention required i.e. regional specialist rehabilitation service or local primary care services.

Assessments based on the Social Model of Disability are used to identify needs, identify aims and set short term goals.

Interventions may include:

- Implementation of a rehabilitation plan to introduce strategies, using support workers to achieve goals
- Facilitating access to local services and referral to appropriate services e.g. Benefits
  Housing
  Headway – day activities/support
  One to one support
  Education
  Employment
- Raising funds to purchase non statutory services, aids and equipment e.g. external memory aids, information publications for clients and carers, structured social and leisure activities e.g. gym membership
- Long term monitoring and evaluation with regular reviews
- Brain Injury education, training and support for families, carers and support workers.

The Team is a member of UK Acquired Brain Injury Forum (UKABIF) and Brain Injury Social Work Group (BISWG), facilitating a regional group. Both national organizations promote awareness of provision of resources; provide information and expert input to policy makers within Brain Injury, through bringing together professionals within this specialised area.

The Service is recognised as an example of good practice and is cited as such under Quality Requirement 5 in National Service Framework for Long Term Conditions.

Community Lifestyle Service

CLS offers a service to people with complex or severe physical impairment, with 57.3 percent of clients having long-term neurological conditions. Clients are allocated to a clinical specialist who will discuss issues with the client that they have identified as important to them. Many clients need help to clarify their needs, wishes, and desires and to prioritise them. Following discussion with the client the clinical specialist will use their expertise, extensive contacts, knowledge of services available and a problem solving approach to establish options and opportunities for the client to choose from.

Where an unmet need is established we will progress this by using a problem solving approach to establish options and opportunities from which clients can choose. Typical areas of work include: housing, education, work, leisure, travel e.g. learning to drive, and use of public transport, information resource, independent living, and health issues.

Key service activities include:

- Domiciliary visits
- Health promotion and crisis prevention
- Source of specialist advice
- Telephone support
- Review system
- Fund raising

Team Members have enhanced scope of practice through:

- Development of Access to Communication and Technology (ACT) Link Worker
- Development of Local Authority Contact Officer for Independent Living Fund

- Involvement in working parties and steering groups e.g. Multiple Sclerosis (MS) Steering Group.

As part of the service that we provide for clients there is the option for ABI and CLS to refer clients when appropriate to DOVES.

DOVES

DOVES provide an enabling service via Support Workers and volunteers. The service is jointly funded by DACHS and Supporting People (a Government initiative). DOVES is a user led service that works one to one with clients to agree outcome focussed programmes that enable individuals to reach their full potential.

Typical areas of work include:

- Support to manage independent living
- Hobbies and leisure pursuits
- Travel training.

Integrated Living Team
Corbett Outpatient Centre
Vicarage Road
Stourbridge
West Midlands
DY8 4JB

Tel: 01384 244654
Fax: 01384 244651
Email: integratedlivingteam@dgoh.nhs.uk

Appendix 7

Psychology and Health

Medical conditions, especially those with a neurological component have an enormous impact on the whole of a person's life. Such conditions require alterations to daily life, learning new skills, and realistic planning so as to minimise the effect of the condition on individuals and families. These conditions and their treatments can affect mood, cognitive processing, self-esteem, relationships and quality of life, sometimes leading to stress, anxiety and or depression. These psychological changes are not only distressing in themselves, but can also effect people's ability and motivation to understand, make informed choices about and to pursue treatment regimes. Good Psychological care can help prevent the development of or reduce the impact of psychological distress associated with physical health conditions.

Dudley Clinical Health Psychology Services

Clinical Health Psychology Services Aims to address some of the above issues. The aim of the Dudley Service is to assist people and services in adapting to and developing flexible and creative solutions for the difficulties posed by illness and treatment.

In order to achieve this we offer

- Specialist interventions with individuals to enable them to develop the necessary skills and abilities to cope with their emotional and physical needs and their daily lives in order to maximise psychological and physical well-being; and to develop and use their capacity to make informed choices in order to enhance and maximise independence and autonomy.
- input which can enhance healthcare staff's ability and confidence to assess and respond to the broader psychosocial needs of patients in order to prevent problems from becoming magnified, entrenched and resistant to amelioration (support, advice, consultancy, teaching, training)
- a psychological resource for those working with and planning care for people with Health Problems.

Appendix 8

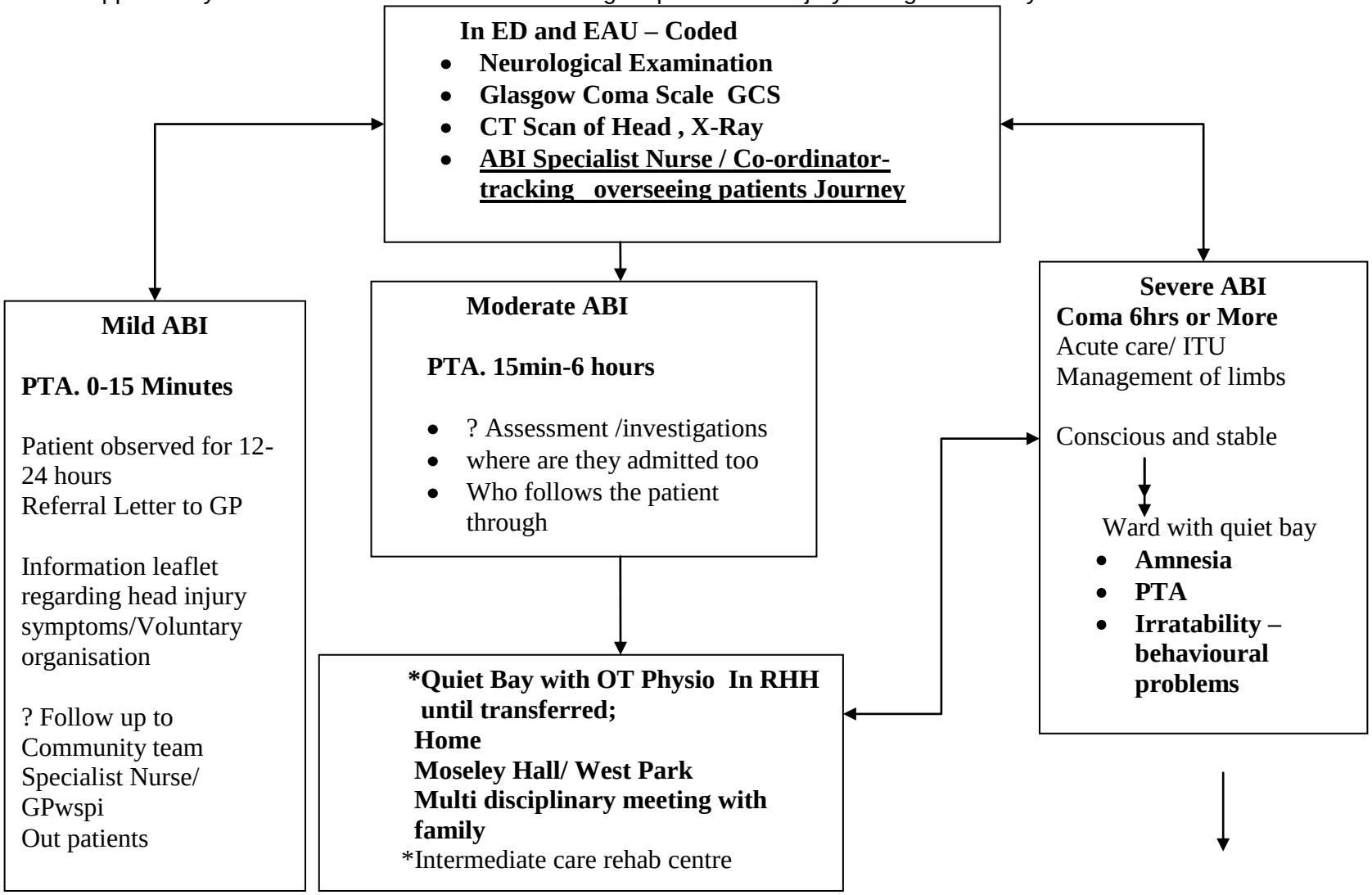
Directorate of Adults, Community and Housing Services (DACHS) in Dudley

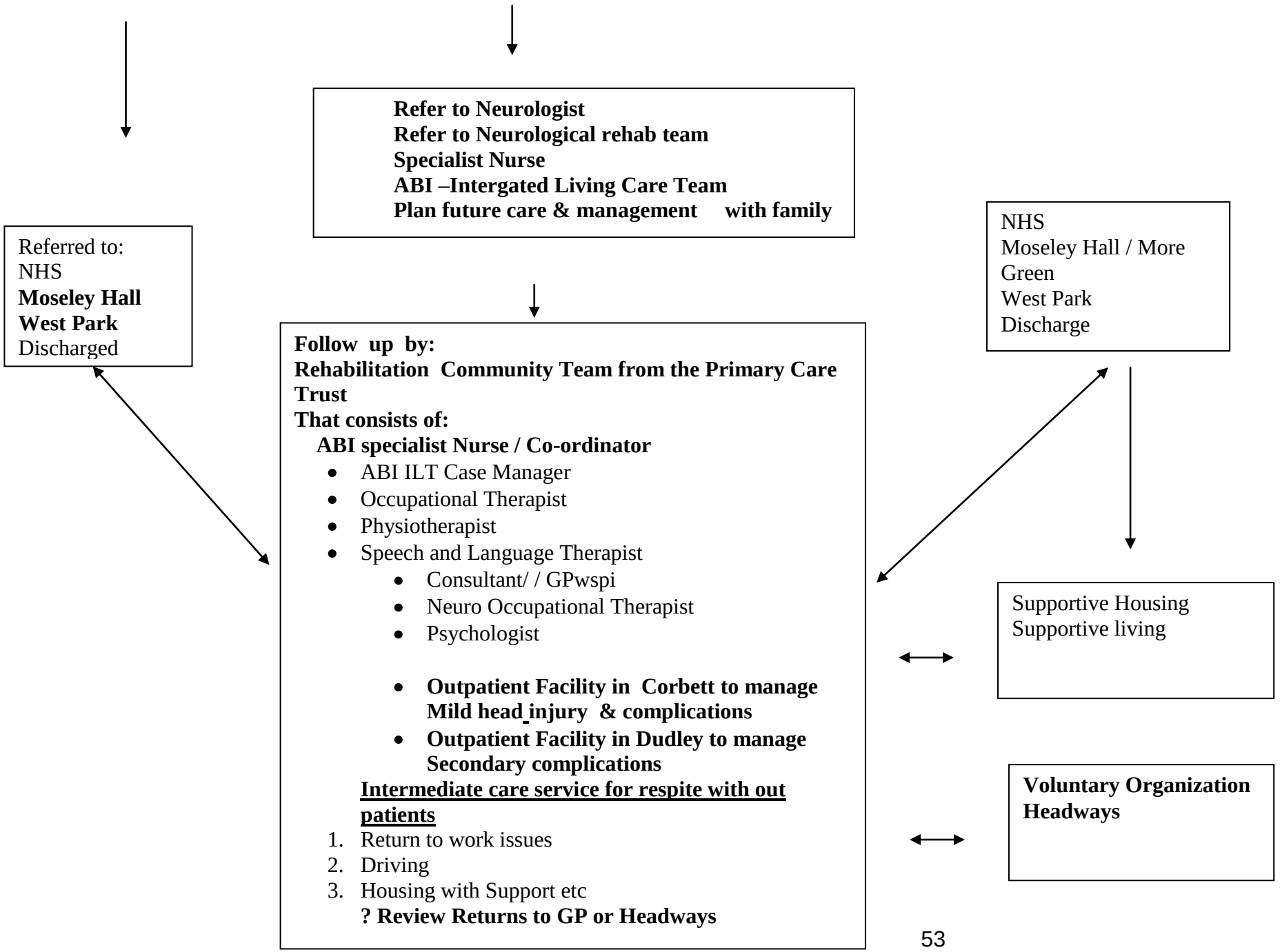
Services provided or funded by DACHS which may support clients with long term neurological conditions.

- Assessment and Care Management – locality teams, one piloting Reablement O.T. working with Duty Social Worker, S.T.A.R.T.
- Care at Home or Direct Payments for personal care, household management, meal provision, evening service (tuck in or peripatetic night care/assessment, night sitting)
- Emergency, planned and ad-hoc respite is provided via: sitting service, Crossroads, Direct Payments for respite, or arranged respite-residential/nursing care.
- Day Opportunities – Direct Payments for alternatives to day care, Queens Cross Network user-led day opportunities and Community Opportunities Programme
- Sheltered/Supported Housing/Extra Care housing
- Integrated Living Team, including Community Lifestyles Service, Acquired Brain Injury Team and DOVES – (Supporting People initiative to fund support workers/volunteers to help disabled people access community facilities)
- Disability Services – O.T. assessments, equipment, advice and adaptations recommended – minor or major in any tenure
- Assisted Living Centre – assessment and demonstration centre with follow up visits
- Community Equipment Services – joint service for delivery, collection and recycling of equipment
- Moving and Handling team – advice, training and equipment
- Dudley Community Alarms, Telecare and maybe Telemedicine in the future
- Direct Payments support team, A4e support provider, user forum
- Vision Support Services team – Rehabilitation Workers assess, train, advise, issue equipment to people with a visual impairment
- Deaf Support Services team – social work service to people who are profoundly Deaf, environmental support, lip reading classes for people with a hearing impairment. BSL interpreting service also provided by DACHS
- Carers services – Carers Co-ordinator, Carers Network, support to Young Carers, Sharing/Respite/Family Carers, Carers Direct Payments, Crossroads, receive funding from Carers Grant. Many voluntary groups also funded by Carers Grant e.g. Altzheimers, TOADS, Orchard Project
- Voluntary organisations are funded/supported to provide a range of services for people with long term conditions e.g. M.S. Society, Parkinsons Disease Society, Partially Sighted Society, Black Country Talking News &Magazine and Asian News, Pocklington Trust, Dudley Stroke Association, Headway Black Country, Langstone Society, M.N.D. Huntingdons Society, Care and Disability Advice Line, CAB

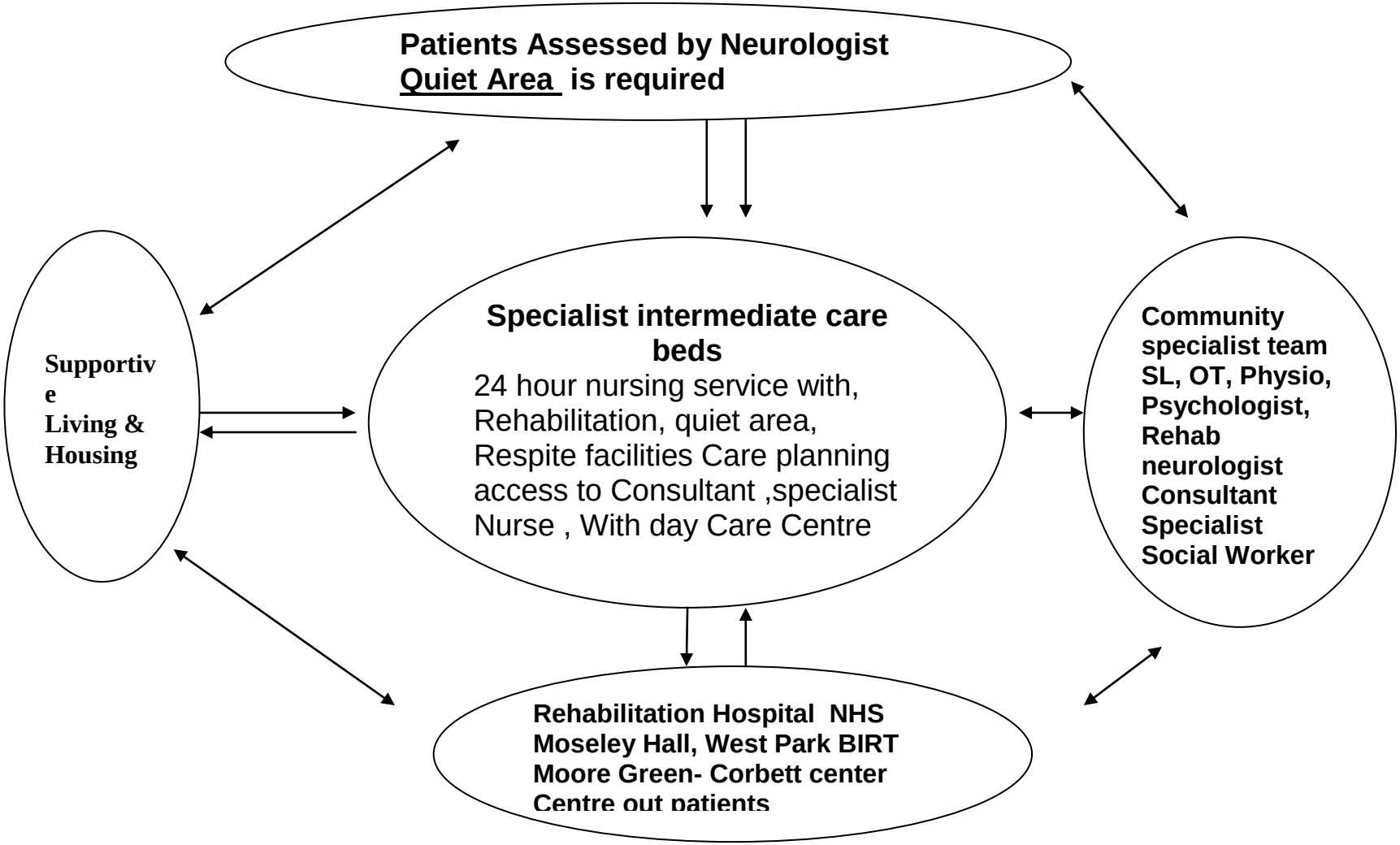
Appendix 9

Acquired Brain Injury Care Pathway Summary of the patient Journey. What should happen if a patient present with Mild Moderate Severe ABI. The actions are supported by N.I.C.E for & Rehabilitation Following acquired Brain Injury not agreed locally




Refer to Neurologist
Refer to Neurological rehab team
Specialist Nurse
ABI –Intergated Living Care Team
Plan future care & management with family
Referred to:
NHS
Moseley Hall
West Park
Discharged
NHS
Moseley Hall / More Green
West Park
Discharge
Follow up by:
Rehabilitation Community Team from the Primary Care Trust
That consists of:
ABI specialist Nurse / Co-ordinator
ABI ILT Case Manager
Occupational Therapist
Physiotherapist
Speech and Language Therapist
Consultant/ / GPwspi
Neuro Occupational Therapist
Psychologist
Outpatient Facility in Corbett to manage Mild head injury & complications
Outpatient Facility in Dudley to manage Secondary complications
Intermediate care service for respite with out patients
1. Return to work issues
2. Driving
3. Housing with Support etc
? Review Returns to GP or Headways
Supportive Housing
Supportive living
Voluntary Organization
Headways

Community Health Model of Care for Patients with Acquired Brain Injury



Appendix 10

Type of Disability/Condition	Prevalence per 100,000 population	Prevalence per 300,000 (similar size to Dudley)
Cerebral palsy	186	558
Charcot-Marie-Tooth disorder	40	120
Dystonia	65	195
Early onset dementia	n/k	
Epilepsy	430-1,000	1,290-3000
Essential Tremor	850	2,550
Huntington's disease	13.5	40.5
Migraine (England)	15,000	45,000
Motor neurone disease	7	21
Multiple sclerosis	100-120	300-360
Muscular dystrophy	50	150
Parkinson's disease	200	600
Post-polio syndrome	n/k	
Spinal cord injury	50	150
Spina bifida and congenital hydrocephalus	24	72
Traumatic brain injury leading to long-term problems	1,200 with long-term problems	3,600

Source The Neurological Alliance

Appendix 11

Details of Local Voluntary Organisations/ Support Groups for People with Long Term Neurological Conditions

There are a number of voluntary organisations which work nationally that have a web site and may have a presence within the West midlands and/or Dudley area.

General Sources of information

Equip the NHS information portal is a good source of information on local groups and organisations within Dudley and West Midlands**.** It is updated regularly so that contact details are as up to date as possible. They also try to validate the quality of information their web address is: **www.equip.nhs.org.uk**

BIVO – Birmingham and District Voluntary organisations is part of Equip and can be searched by medical condition and area web its web address: **www.bivo.nhs.uk**

NHS Direct is also a good source of information and has links to support groups **ww.nhsdirect.nhs.uk** or its telephone number **is 0845 4647**

Local branch libraries within Dudley MBC would be able to assist people to access information and or the internet for those who do not have a web link.

Local Information – Dudley and District

The list below is taken from web sites and EQUIP and is at July 2009. We are not endorsing them, they are provided for information, and there may be other groups as well. Most are National organisations whose websites will have details of local organisations or groups. Be aware: telephone numbers may change, costs to numbers vary.

Type of Disability/Condition	Organisation	Area Covered	Contact Details
Cerebral palsy	Cerebral Palsy SCOPE Dudley and District Spastic Society and PIN	National Dudley	http://www.scope.org.uk Tel:0808 8003333 Local group based in Wordsley contact: 01384 292458
Charcot-Marie-Tooth disorder	CMT United Kingdom	National	www.cmt.org.uk For local details contact 01202 481161
Dystonia	The Dystonia Society	National	www.dystonia.org.uk For local details tel: 0845 458 6211
Early onset dementia	Alzheimer's Society	National Dudley Branch	www.alzheimers.org.uk Helpline: **0845 300 0336**. www.alzheimers.org.uk (then search for Dudley) Local tel contact: 01384 295355
Epilepsy	The National Society for Epilepsy(NSE)	National	www.epilepsynse.org.uk Hepline tel number: 01494 601400

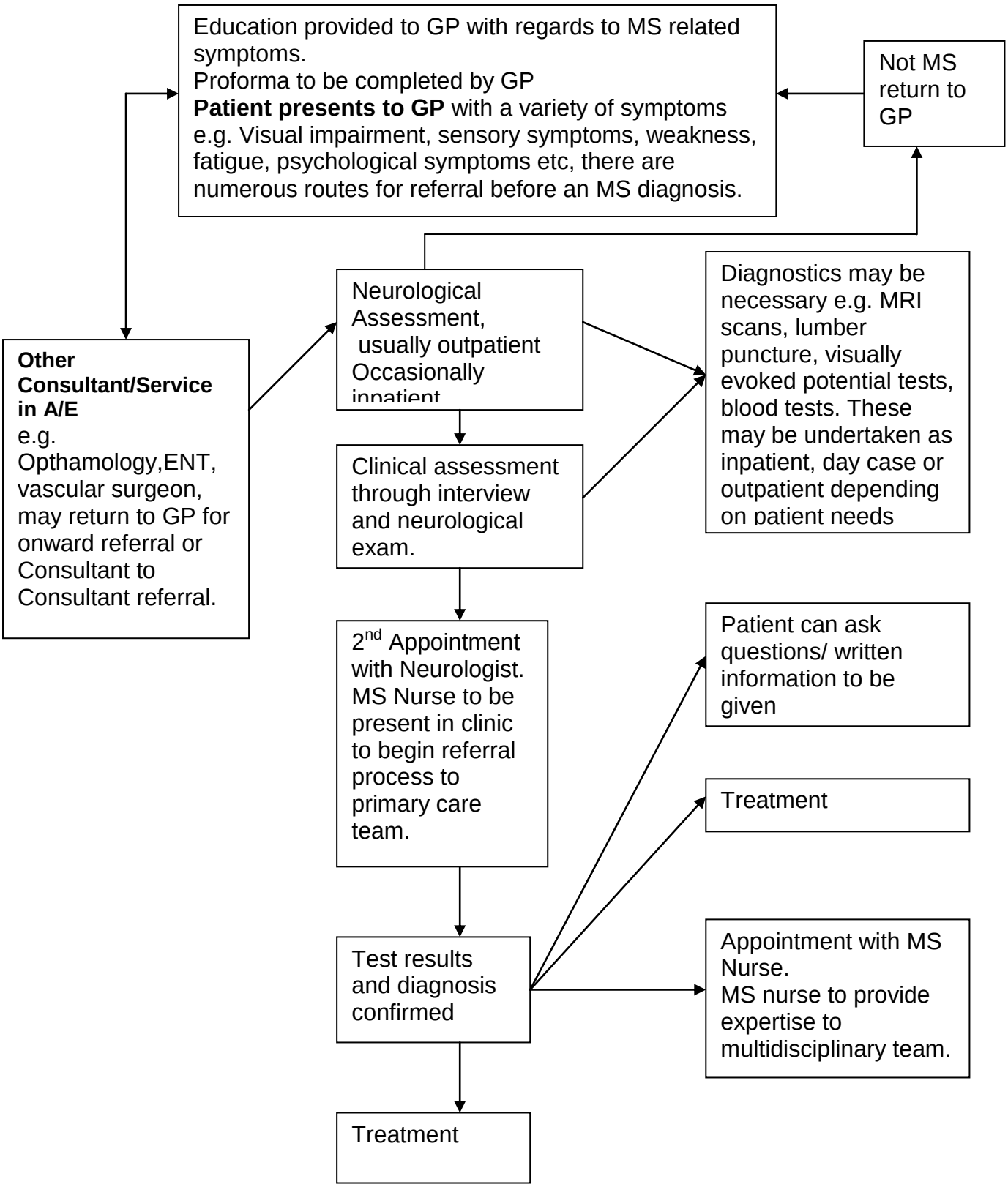
	Epilepsy Action Wolverhampton and District Branch The National Centre for Young People with Epilepsy NCYPE	National Epilepsy Action local branch National	www.epilepsy.org.uk Tel number:0113 210 8800 Local volunteer contact tel number: 01902 398713 www.ncpye.org.uk Tel contact: 01342 832243
Huntington's disease	The Huntington's Disease Association	National	www.hda.org.uk For Birmingham and West Midlands area contact: 01527 576044
Migraine (England)	The Migraine Trust	National	www.migrainetrust.org Helpline: 020 7462 6601
Motor neurone disease	Motor Neurone Disease Association	National	www.mndassociation.org. mnd connect helpline: 08457 626262 WM Branch Contact Tel 01922 746682
Multiple sclerosis	Multiple Sclerosis Society West Midlands Region: Dudley and District Branch	National	www.mssociety.org.uk (search for local groups) Helpline 0808 800 8000 Local Dudley contact listed as: 01384 8300995
Muscular dystrophy	Muscular Dystrophy Campaign Stourbridge Branch	National Dudley and District	www.muscular-dystrophy.org Contact line : 0800 652 6352 Local contact tel: 01384 836571
Parkinson's disease	Parkinson's Disease Society	National Dudley and District Branch	www.parkinsons.org.uk (search under local to you) Helpline:0808 800 0303 For local details first contact: 0844 225 3644
Post-polio syndrome	British Polio Fellowship	National	www.britishpolio.org.uk for local groups contact 0800 0180586
Spina bifida and congenital hydrocephalus	Association for Spina Bifida and Hydrocephalus Association for Spina Bifida and	National Dudley District	www.asbah.org helpline : 0845 450 7755 Local contact tel: 01902 738724

	Hydrocephalus (Dudley & Wolverhampton)		
Traumatic brain injury leading to long-term problems	Headway Headway Black Country Brain Injury Rehabilitation Trust (BIRT)	National Local area National and West midlands	www.headway.org.uk Helpline: 0808 8002244 www.headwayblackcountry.com Tel contact: 01384 869961 www.birt.co.uk Tel 0121 459 0909

Appendix 12

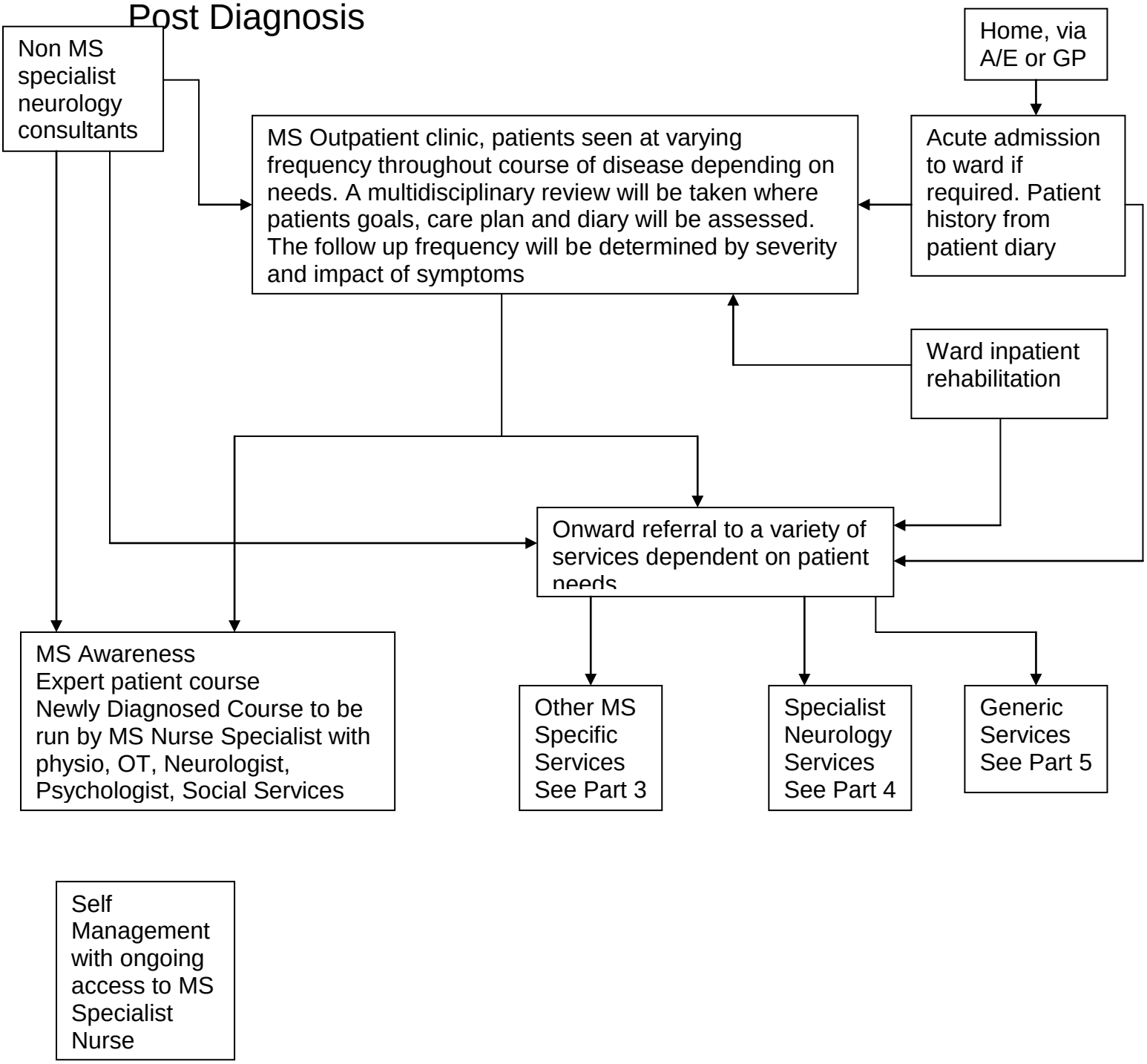
Dudley Multiple Sclerosis (MS) DRAFT Pathway

Part 1 Establishing a Diagnosis



Dudley Multiple Sclerosis (MS) Pathway

Post Diagnosis



Self Management with ongoing access to MS Specialist Nurse

On going liaison, joint working and referral between services dependent on patients needs and service availability/resources.

Dudley Multiple Sclerosis (MS) Pathway

Part 3 MS Specific Services

Reason for referral

Severe impairment, multiple needs	Community MS team, OT and psychology input to improve quality of life. Assessment and treatment of difficulties with day to day activities, concentration and memory , ways of coping with emotional problems presented by severe MS
Assessment for access to social Services	MS Specialist Social Worker/link worker. Assessment and care planning of needs, referral for service provision e.g community support, respite. Support for non specialist social work teams. Work in homes, community settings.
Mobility and spasticity problems falls	MS Specialist physiotherapist
Acute treatment and Disease Modifying treatment	MS treatment clinic and MS relapse clinic
Variety of issues throughout disease course	MS Specialist Nurse
Access to information and updates on MS treatment and local services	Dudley MS register
	Referral and liaison with local specialist and generic services

Dudley Multiple Sclerosis (MS) Pathway

Part 3 a Medical Specific Services

MS Specific: Acute Treatment and Disease Modifying Therapy

MS Treatment Clinic
Led by Consultant Neurologist with specialist interest in MS. Assessment for treatment with Disease Modifying drugs e.g interferon , glatiramer acetate, mitoxantrone.

↓

MS Specialist Nurse
Provides training and support with injections and regular outpatients review.

↓

Annual review by neurologist with specialist interest in MS to determine response to treatment.

Relapse Clinic
Led by Consultant with specialist interest in MS. To provide speedy response in case of relapse. Patients can self refer or via other healthcare professionals.

↓

MS Specialist Nurse co-ordinates admission to day case ward for treatment.

Non Dudley patients referred to local services where available .

Dudley Multiple Sclerosis (MS) Pathway

Part 3 MS Specific Services

MS Specific Services: Voluntary and Community Sector

- MS Society Dudley Branch. Social activities, information sharing and news letter.

- MS Therapy Centre at Wolverhampton. Hyperbaric Oxygen Therapy, social activities, support groups.

- Peer Support Groups

Dudley Multiple Sclerosis (MS) Pathway

Part 4 Neuro Specific services

Neuro Specific Services

Reason for referral

Multiple and complex needs able to Engage and benefit from intensive Rehab.	Community Rehabilitation.Multidisciplinary input to address rehab goals. E.g. mobility, spasticity management, continence, activities.
Rehabilitation needs whilst Inpatient.	Neurorehabilitation Team – multidisciplinary input (PT, OT,Medical) will pick up people admitted to non-neuro wards and provide advice and support to patient and staff.
New treatment regimes, lumber puncture, relapse.	Neuro acute day case ward
Fatigue memory and vocational rehab	Specialist neuro occupational therapy out patient basis.
Mobility, spasticity, falls	Specialist neuro physiotherapist out patient basis
Cognitive assessment, psychological adjustment, coping with impact of MS	Specialist neuro psychologist assessment and treatment.
Swallowing and speech problems	Specialist neuro speech and language therapy
Nutrition assessment and treatment	Specialist neuro dietetics treatment

Dudley Multiple Sclerosis (MS) Pathway

Part 5 Generic Services

Specific interventions

- Continence service
- Liaison psychiatry
- Gastroenterology – PEG insertion
- Social services – respite, telecare,adaptions and equipment
- Orthotics
- Wheelchair Services
- Medical Equipment Services
- Palliative Care service – Hospice, community, hospital

Generic services often provided/used

- District Nursing services
- Housing services
- Vocational services
- Direct payments
- Community Physiotherapy
- Community Occupational therapy

Appendix 13
Consultation: Questions & Responses

Question1 – Do you agree with the vision?

Consultation Response	Strategic Group Response
• Agreed to principles of coordinating and improving services, but concerned if achievable without extra funding	The PCT are committed to additional funding to take forward the neurological team. See actions page 13
• We agree with the vision for Dudley as a positive strategy for supporting the long term needs of people affected by MS. With additional reference to support the needs of the person affected by MS, their carers and family	The vision of the strategy is to be inclusive of the needs and care of all people and their carers affected by neurological conditions
• Agree with the vision – should it include the support of informal carers and the availability of respite	The support of informal carers is a key priority to be addressed and is reflected in the strategy (page……)
• Agree with vision, particularly supporting people in their own home and supportive living accommodation, also supporting carers. Recognising gap in provision of services currently, particularly for Parkinson's. Need to address speed of delivery to accommodate needs from referral time, e.g. OT adaptations. Also young stroke victims, there is lack of services and should be included	The neurological strategy does not include ''young stroke victims'' as there is a separate service and strategy for stroke. In 2007 the average time waiting for the work order to be placed / grant approval was 47 weeks. Based on current performance in 2008/09 this will be reduced to an average of 37 weeks closer to the West Midlands average. This has been achieved by a variety of measures to speed up the process and build in efficiencies and increased investment.

Question 2 – Do you think the workshop outcomes reflected experiences (see page 10 for summary)?

Consultation Response	Strategic Group Response
Service Users Experiences (coordinated by Dudley CVS)	The Strategy has been guided by the responses from

• Several of those present had contributed to the list of experiences set out in the strategy. Most of the others who had read it said that they had had similar experiences at some time. One of those present said he had a more positive experience that most of those set out in the document. Overall service users and carers felt that they had had experiences similar to those set out at some point in their journey through the health service.	the service users experiences to improve and develop neurological conditions.
Clinicians and Voluntary sector were asked if this was their perception of the user experience • Agree. No specific neurology ward from hospital point, tend to be treated as/with stroke patients often limited understanding of condition from staff (fatigue management, handling, perception and cognition)	
• The results from the Stakeholder group reflect the experiences of our members of the MS Society. Feedback from local members is that the length of time taken for diagnosis has historically taken a long time but it has improved in more recent years. More support for carers and family is required as well as access to timely support and information	
• Generally reflects own perceptions. Diagnosis cannot always be quick but information is required to explain the necessary delays.	

Question 3 – Do you think the proposals will meet the needs of people with neurological conditions and their families and carers?

Consultation Response	**Strategic Group Response**
Clinicians and Voluntary sector responses • Not all patients have access or ability to use internet pathways can only be achieved with appropriate staff to guide journey Information prescriptions – what does this mean?	All the information on the local website will be produced in a hard copy format that will be available on request via the neurological team facilitator. Information prescriptions will contain a series of links or signposts to guide people to sources of information about their health and care – for example information

	about conditions and treatments, care services, benefits advice and support groups. Information prescriptions will let people know where to get advice, where to get support and where to network with others with a similar condition. They will include addresses, telephone numbers and website addresses that people may find helpful, and show where they can go to find out more. They will help people to access information when they need it and in the ways that they prefer.
• Why have separate teams – should be integrated team providing seamless service. This team should case manage and seek other services as required to meet individual needs e.g. Corbett rehab.	The new neurological primary care team will be an integrated team to provide a seamless service and that will work/support with other teams.
• Respite: should include emergency, planned and adhoc education for carers' very important providing empowerment. Specialist day care required.	Support for carers will be addressed via assessment in the new team (see also section on carers and respite care)
• No mention of day care which is presently provided near end stage by Mary Stevens Hospice. Respite and Nursing/residential homes need to take into consideration needs of younger people. Also access to specialist equipment which is good but needs to be more timely, especially if major adaptations are required.	Day Services is included in the current service provision section. The strategy and issues raised for example re younger people will be a guide for commissioners and providers to address. Please see question 1 response for adaptations
• Early diagnosis is needed. There is gap in access to services for patients without a diagnosis. Providing services when problems occur. Specialist advice immediately and at point of need of client. Specialised respite provision and rehabilitation. Gap in services when only one specialist nurse is in post, need to arrange cover when on leave etc. Need information pack with telephone numbers for contacts. Support for carers and recognition for psychological care as well as es physical.	The neurological team will be taking new referrals and provide support and cover when their annual leave/sickness. A psychologist is in post for the neurological team. Additional clinicians are being appointed at the acute hospital to support access and diagnosis. Please see proposals section for taking forward information. Please see carers section for support for carers.

Redesign of new resources • Proposed team should be one integrated team and with current case load needs more than one therapist for each discipline and support workers. In addition, specialist therapists are required. More investment will be required in addition to clinical leadership and specialist pharmacist.	The new neurological primary care team will be an integrated team to provide a seamless service and that will work/support with other teams. The team is including new appointments of clinicians.

Service Users Responses (coordinated by Dudley CVS)

6. The patient will have knowledge and information about what is going to happen to them throughout their journey:-

Actions:

a. Development of Dudley Neurological website to support information sharing and a central database
b. Development of Information prescriptions,
c. Development of care pathways and protocols

Consultation Response	**Strategic Group Response**
The themes which come out from the service user/carer comments on information are: • People are individuals; some may need more information than others. It may need to be layers of information/support.	Information can be tailored as appropriate to requirements.
• Not everyone has access to the internet for information especially older people- PCT needs to ensure information gets to them as well. How can this be done? It needs to be in accessible format as well e.g. large print and audio.	Hard copies of information in relevant formats will be made available.

	Information will be available via libraries.
• There is a general welcome for more information including a web site BUT a couple of queries were raised: - The service user/carer still needs one to one contact as well as information; they may need explanation of the information given. - There could be danger of people becoming anxious or stressed by long term prospects if they do not have support as well. - Will it be kept up to date? - A comment that carers need information as well.	Support will be available via the neurological primary care team. Information will be kept up to date. Information and specific information for carers will be available. Also via the Carers Network.
• Care Pathways – there is a general welcome for this. Comments are that it may need to be accompanied by more training for professionals and more support at each step.	A key part of the neurological team will be to provide education and training.
• There was high praise for the support that Integrated Living Team gives to those service users who are eligible to access their services.	

7. Every patient with a Long term neurological condition will have a personalised, individual care plan:-

Actions:

- **To ensure all neurological patients have a patient held record**
- **To develop a multidisciplinary neurological primary care team aligned with a neurological rehabilitation team that have the right workforce skills, with the main focus in Primary Care and providing care closer to home.**

Consultation Response	**Strategic Group Response**
It's a good idea BUT • Will professionals keep them up to date • What if people forget them, they may have memory problems • NHS should keep records up to date – not patients responsibility	Care records will be kept up to date and the location agreed between the patient and practitioner. It will not be the patient's responsibility.

Service users summary of comments on multi disciplinary primary care team**:**

Consultation Response	Strategic Group Response
It's a good idea BUT: • What about cover for sickness and leave? – It seems a small team (note- recent problems with Parkinson's Disease Nurse being on sick leave and cover issues)	The plans for the neurological team are to share the workloads and provide support to each other. It is envisaged the team will develop over the next few years.
• Will there be someone to talk to at the end of the phone? People find this aspect of Integrated Living team very helpful. Don't always need to speak to the Doctor.	There will be full time administration to support the team.
• It's no good if you can't access them quickly.	See above
• Would they have knowledge of all conditions?	Staff knowledge will increase over time
• What about support for conditions with no specialist nurse e.g. epilepsy?	The team will expand their skills to provide support for all neurological conditions.
• It should include support for everyday tasks as well e.g. chiropody	The team would refer to the wider multi-disciplinary team e.g. podiatry as appropriate.
• Planning of local services to avoid travelling across Borough	The team will cover whole of the Borough.
• Include a point of contact for carers on the team.	A point of contact and support for carers will be addressed

3. Carers needs are addressed:-

Actions:

- **The development of access to respite.**
- **Carers have input into the care plan and their needs are taken into account.**

Consultation Response	Strategic Group Response
Service Users comments on respite provision increased respite provision was welcomed BUT	

• Who will pay for it?	A review of respite provision will be undertaken
• Need respite beds just for neurological condition so staff understand conditions.	Staff who provide care for people with neurological conditions will receive specific education and training relating to neurological conditions.
• More help for carers on their own health needs.	Support for carers will be addressed and carers assessments undertaken
General comments on Carer input into care plan: • Carers felt they need to have more input into care plan BUT some service users views are that they should have a choice over this; some people might not want this.	Carers input into the care plan will be optional and this agreed with the carer

4. Every patient has access to specialist/expert advice when it is required. Either in an acute emergency or as part of the progress of the disease:-

Actions:

- **To model the demand and develop a specification for specialist bed based provision.**
- **Development of care pathways (see appendix 12** for draft pathway of Multiple Sclerosis in the main strategy document**)**

Consultation Response	**Strategic Group Response**
Service Users comments on specialist beds: • Very welcome – there is a feeling that on general wards the conditions are not understood • Need to be local so not too much travel and carers/ family can access to reduce isolation	Further analysis will be undertaken

Acquired Brain Injury

Recommendations

- **Development of Acquired Brain Injury Pathway (see appendix 9)**
- **Designated beds for ABI patients**
- **Formal advice to be given for mild head injury patient in the form of a booklet.**
- **Time scale for referral to neurologist for timely advise and management**
- **Timely Care planning that is patient and carer/family centred**
- **Specialist nurse to flag and track patients through acute trust into primary care.**
- **Time scale for referral to rehabilitation team**
- **Time scale for referral to Neurological specialist units**

Community:

- **No dedicated Neurological out patient service in Dudley.**

Recommendations

3. **To have a Neurological consultant / specialist nurse / Consultant Nurse on a sessional basis, for those mild, moderate and severe patients who have been discharged and /or reintegrated into community.**
4. **To incorporate with other neurological conditions.**

Supportive Housing

Currently this is obtained out of area. There is no supportive living accommodation for the younger adults

Recommendations:

- **To develop Intermediate Care provision for ABI patients with access to rehabilitation therapists**
- **Availability of supportive living accommodation within Dudley closer to home**

Consultation Response	**Strategic Group Response**

The Service Users with ABI comments were:	
• It would be good to have a specialist ABI nurse	Further analysis at the roles of specialist nurses will be undertaken
• Need to reduce delays for access to rehabilitation	A review of rehabilitation is being undertaken
• There was great praise again for the Integrated Living Team and their work with people with ABI. – Needs extending.	The ILT will work closely & share their best practice with the new neurological team

Question 4 – Is there anything additional in the detailed proposals that you would like to see or anything not required?

Consultation Response **Clinicians and Voluntary sector responses**	**Strategic Group Response**
• Perception/cognition and coping strategies very much part of the treatment plan, not addressed and can have implications for management and may increase hospital admissions. Emphasis appears to be on medical model	The neurological team includes a psychologist and in addition there will be access to and support via the EPP
• Education for social carers to support at home.	Carers needs will be assessed and support provided e.g. via the Expert Patient Programme
• Easier access to phycology services via community. Current levels are insufficient.	The appointment of a psychologist for neuro conditions to the team will improve access
• Needs to be seamless service (integrated) based on similar model to stroke team, neuro clinics at Q.E.	The team will be tackled with developing integrated care pathways
• The provision of specialists MS and Parkinson Disease Nurses will provide substantial support and information to people affected by MS and carers and family members. The co ordination of care will be improved with the implementation of the MS Care Pathway; however some consideration needs to be taken into account where people have more than one LTC. This will require	The team will provide E & T to the wider workforce and pathways to healthcare professionals who care for people with more than one long term condition

teams from different specialisms outside of Neurology to improve communication with other health professionals.	
• The Neurological Conditions website will improve the access to information and create links with Voluntary and Charitable Organisations locally.	
• Respite nationally is a key issue for our members and we are pleased to see Dudley actively addressing the concerns of people affected by MS in this area.	
• Clear links and referal pathways to specialist services and particularly wheelchair services and rehab. Centre in Selly Oak for environmental controls. Often untimely delays.	The development of integrated care pathways will include wheelchair rehabilitation and environmental controls
• Greater emphasis on needs of carers. Maybe a unit such as the White House or an extension of their service to cover neurological conditions. More information on services available given at the start. A helpline number and dedicated respite or sitting service.	Support for carers of neurological conditions is a high priority for the team coupled with the provision of appropriate information

Question 5 – Do you think the recommendations will meet the needs of people with Acquired Brain Injury and their families and carers and if not why not?

Consultation Response **Clinicians and Voluntary sector responses**	**Strategic Group Response**
• Why is ABI highlighted as separate condition, maybe emphasis should be on progressive and deteriorating conditions.	ABI was highlighted separately within the strategy as people who have an ABI do not necessarily have physical impairments and may also have issues relating to psychological and behavioural thus requiring different management and treatment. Further it may also be a hidden disability and unlike other neurological conditions may not deteriorate.
• Recommendations appear to be similar to other neurological conditions discussed	The recommendations doe reflect similar gaps and

in strategy.	issues in services
• No mention of work and help to work towards this – important for younger people with Acquired Brain Injury.	The ILT provide the links to work and employment and also via the Sure Trust, Rehab UK and Headway.
• Recommendations will meet needs of people. What is the timescale? How will teams be made up, i.e. types of staff and ratio to patients.	The neurological team will commence as a full team towards the end of 2009 and develop their activity in 2010. Please see page 20 for the staff involved

Question 6 – Are there any other comments that you would like to add?

Consultation Response **Clinicians and Voluntary sector responses**	**Strategic Group Response**
• Prioritisation to more progressive and deteriorating conditions maybe more appropriate.	The neurological team are developing their referral criteria and this will include team discussions of referrals and prioritisations on an individual basis
• The Directorate of Adults, Community and Housing support the recommendations in this strategy, we see these recommendations leading to improved outcomes for people and their carer's. We also see the potential for these recommendations to increase the expectations/demands on social care and therefore we would wish to ask that we are involved in planning/discussing the resource implications of raising awareness, and caring for more people in the community.	The neurological strategy group that includes the Directorate of Adults, Community and Housing will continue to meet and address the resource implications, raising awareness and care in the community
• There is a strong emphasis on rehabilitation in helping someone live with a neurological disease as independently as possible. The service needs a champion specifically for this range of conditions. This could be a nurse consultant or AHP consultant.	The PCT are appointing a team leader for neurological conditions that will be either a nurse or AHP. In addition a GP lead for neurology in the PCT is to be appointed

Acknowledgements

Neurology Strategic Group

Andrew Hindle	Chair Strategic Commissioning Lead: Older People & Long Term Conditions
Alison Matthews	Physiotherapy Manager
Ann Askew	Head of Service – DACHS
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Clair Huckerby	Pharmaceutical Adviser
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Sara Shreeve	Physical Health Psychology Manager
Sarah Little	Community Adult SLT Manager
Trudy Gaskin	Parkinson’s Disease Nurse