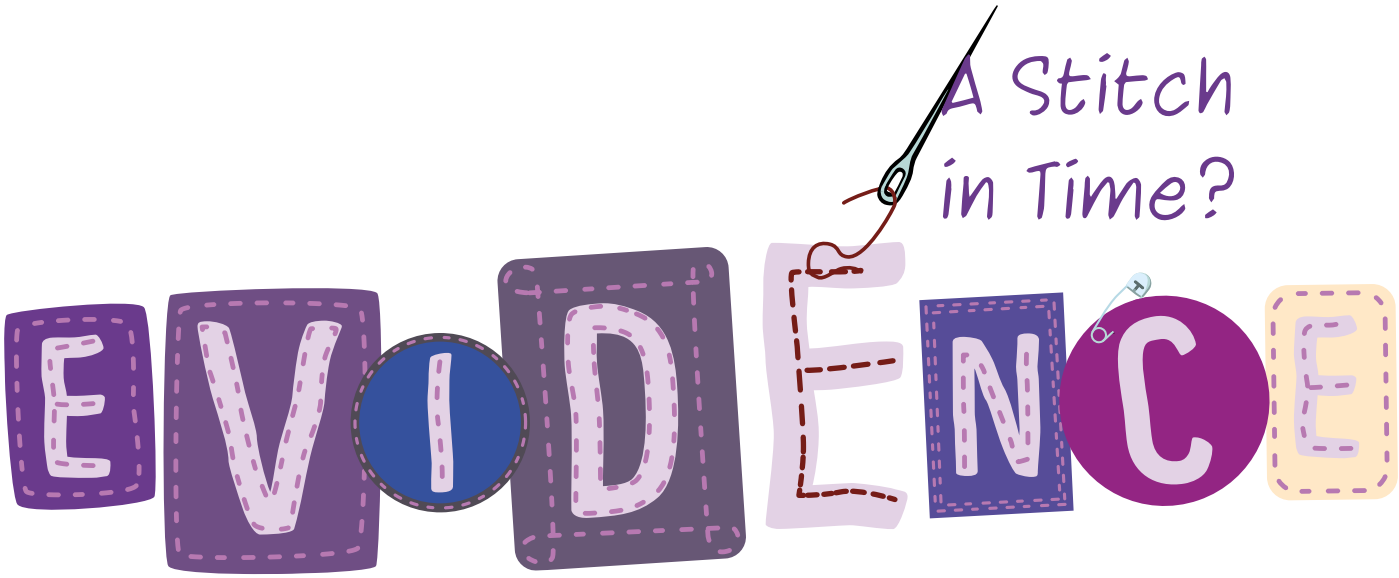

A review of the evidence around third sector's support to older people with degenerative neurological conditions in Lothian

neurological alliance of scotland

Evaluation Support Scotland

joint improvement team
creativity, collaboration and continuous improvement

The Scottish Government

The Role of the Neurological Alliance of Scotland's 3rd sector member organisations in providing support to older people in Lothian with degenerative neurological conditions.

The Neurological Alliance of Scotland
Funded by Evaluation Support Scotland through the '*A Stitch in Time?*' project

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1. Background and Introduction

1.1 Background to the Neurological Alliance of Scotland

The Neurological Alliance of Scotland (NAoS) is a forum of not-for-profit organisations and groups representing many thousands of people affected by neurological conditions in Scotland. The Alliance was launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning. The Alliance enables third sector neurological organisations and groups to campaign together and speak with an influential voice.

The Alliance has three main aims:

1. *Influencing Policy*

   To inform and influence policy by bringing the needs of people with neurological conditions to the attention of health and social policy makers and strategists.
2. *Raising Awareness*

   To raise awareness and disseminate information about neurological conditions and their impact on individuals and society.
3. *Improvements in care*

   To promote improvements in care for people with neurological conditions

The Alliance has the vision that 'People living with neurological conditions will have access to the best care possible, have control over their lives and be able to live free from ignorance and injustice.'

1.2 Background to neurological conditions

An estimated one million people in Scotland are living with a neurological condition which has a significant impact upon their lives. Most neurological conditions affect people's quality of life and require ongoing treatment and care. Neurological conditions account for one in five emergency hospital admissions and one in eight GP consultations in Scotland.

A quarter of all disabled adults of working age have a neurological condition, and the prevalence of neurological conditions is highest amongst older people, reflecting the fact that some conditions are lifelong, and other conditions particularly affect older people.[1] As a result of our increasing aging population, the numbers of people with neurological conditions will grow sharply in the next two decades.

Neurological conditions are caused by damage to the nervous system, often as a result of illness or injury. Some have a genetic basis and are inherited. For most others, the cause of

[1] http://www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

the condition is not known. Problems of the nervous system usually affect the brain and spinal cord and the nerves and muscles in the body.

With neurodegenerative disorders, neurons in the brain and spinal cord begin to deteriorate. Changes in these cells cause them to function abnormally and eventually result in the cells' demise. As neurons deteriorate, an individual may first experience relatively mild symptoms — for example, problems with coordination or mild cognitive changes. But as greater numbers of neurons die, symptoms progressively worsen and additional symptoms develop, resulting in health and care needs becoming increasingly complex and having a profound impact on individuals and families. Ultimately, many of these diseases are fatal.

1.3 Scope of the work

The focus of the demonstration project 'A Stitch in Time' is older people, and its aim is to gather and present evidence to explain, measure and prove how the third sector in Lothian:

- prevents avoidable future use of health and social care services and
- optimises older people's independence and well-being.

Evidence to date presented by A Stitch in Time has typically been upon preventative activities delivered by third sector organisations which enable older people to keep better in the community for longer. In the latter stages of the project, the role of the third sector in end of life care, support of older people with complex health and care needs or more advanced dementia became identified as a gap and NAoS attended a meeting in August 2014 with Evaluation Support Scotland to discuss how this may be addressed. It was agreed that it would be a missed opportunity to not gather evidence on the unique contribution third sector organisations make to older people included in these categories.

NAoS currently has 38 member charities who represent a wide range of neurological conditions which affect people of all ages from birth to old age. Following the discussion in August 2014, NAoS subsequently proposed to undertake work with a selection of its relevant member organisations who provide significant support and services in Lothian to older people with complex health needs, as a result of living with a neurodegenerative condition. The aim was to gather collective evidence on how these organisations support older people and their families who are affected by a degenerative neurological illness.

There were 5 objectives of this work:

- To identify and discuss the range and impact of the complex health and care needs older people living with a neurodegenerative disorder have and how this is located within the Reshaping Care for Older People agenda.
- To illustrate how the Alliance member organisations support older people with complex health and care needs via logic modelling.
- To identify the range of activities provided by these organisations and what the outputs and longer term outcomes are.

- To discuss the contribution made by the member organisations regarding the coordination of care, provision of therapeutic care, support for self-management, provision of integrated services and respite and carer support.
- To discuss some of the identified challenges faced by member organisations and any gaps in provision.

As the focus of the Stitch in Time project is the health and care needs of older people, not all NAoS member organisations were relevant. Following consultation with the NAoS Executive Committee it was agreed that only a limited number of member organisations would meet the inclusion criteria listed below and should be included in the scope of this work:

- The organisation provides support to people affected by neurological conditions which have increasing prevalence rates in late adulthood or old age.
- The organisation provides support to people affected by conditions which are neurodegenerative and thus result in increasingly complex health and care needs as the disease progresses.
- The organisation provides support and services in Lothian

NAoS subsequently approached a number of member organisations who met these criteria and the following organisations (with associate condition) agreed to participate:

- MND Scotland - Motor Neurone Disease (MND)
- Parkinson's UK – Parkinson's Disease (PD)
- Scottish Huntington's Association - Huntington's Disease (HD)
- PSP Association - Progressive Supranuclear Palsy (PSP)
- MSA Trust - Multiple System Atrophy (MSA)
- Leuchie House – Respite Care residential & day centre for neurodegenerative conditions

A further Alliance member organisation, Bobath Scotland, who provide services to people with Cerebral Palsy, also expressed an interest in participating in this work. Cerebral Palsy is a lifelong neurological condition, usually diagnosed during pregnancy, at birth or in very early childhood. Cerebral Palsy is not typically a progressive condition and thus the characteristics of the work delivered by Bobath Scotland did not meet all of the inclusion criteria set out for this project. However, as a result of increasing life expectancy, people with cerebral palsy are living into old age when their health and care needs become increasingly complex and the condition takes a degenerative course due to secondary aging. Bobath Scotland have identified significant gaps in service provision for older people with cerebral palsy which leads to a decrease in their health and wellbeing. Their experiences and concerns are therefore included in Section 4 of this report which discusses some of the gaps in services for people with neurodegenerative disorders.

Alzheimer's disease is a neurodegenerative condition which also meets the inclusion criteria set out. However, as Dementia was a specifically identified gap in the overall Stitch in Time programme and Alzheimer Scotland were present at the initial discussion meeting and

provide a wide range of care and support for people with dementia in Lothian, it was felt that they would be best gathering evidence for this group of older people should they wish to do so. Dementia is a symptom of some of the neurodegenerative disorders included in this work and so is only included in this context.

1.4 Process & Timescale

NAoS successfully submitted a proposal to Evaluation Support Scotland in October 2014 to undertake the project. The timescale of the project work is therefore October 2014 – January 2015 with the final written report being submitted on 30th January 2015.

The methods of gathering evidence for this project has comprised:

- Initial meeting of Stakeholders
- One to one consultation with several member organisations involved (Parkinson's UK, MND Scotland, Leuchie House)
- Regular telephone and email communication with all stakeholders to gather systematic information on service inputs, activities and outcomes.
- Gathering of in-depth case study information and evaluation data regarding two member organisations (Scottish Huntington's Association – Assessment of the Specialist Huntington's Disease Service in Lothian) & Parkinson's UK
- Service visit (Leuchie House)
- Desk research – literature review

1.5 Reshaping Care for Older People (RCOP)

The next 20 years will see an ageing Scottish population and a continuing shift in the pattern of disease towards long-term conditions as well as growing numbers of older people with multiple conditions and complex needs. By 2032 the population aged 65 and over is expected to increase by almost half (49%). The incidence of many of the neurodegenerative conditions increases with advancing age bringing greater demand for highly specialised care and support services[2]. In addition, those who have already been diagnosed with a neurodegenerative condition will have increasingly complex health and care needs as they age and their health progressively deteriorates as a result of the condition.

These increases bring with them a huge impact on both people living with the condition and their carers and wider family. There will be more older family carers -- many of whom will have their own health needs who struggle to cope with the demands of caring for a loved one with a neurodegenerative condition and the wide range of complex symptoms and needs that are present.

[2] http://www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

There will also be increasing numbers of people with complex conditions who live alone, - the number of people aged over 65 who live alone is expected to increase by more than half over the next 25 years, and the numbers of adults aged over 85 who live alone is expected to be two and a half times greater.[3]

The demographic changes and associated shifts in the pattern of ill-health will increase the demands on the whole healthcare system by older people in general but the cost of providing care for neurodegenerative conditions is likely to grow substantially.

Reshaping Care for Older People: A Programme for Change 2011-2021 sets out the national framework to address the challenges of supporting and caring for Scotland's growing older population into the next decade and beyond. It supports the delivery of other strategies including Self-Directed Support, Health & Social Care Integration and Joint Strategic Commissioning.

The key messages of the RCOP policy are that older people are an asset not a burden and should be supported by a wide range of agencies and partners to shift care to home based and community based settings. There needs to be a shift in philosophy, attitudes and approaches. Greater investment in preventative approaches is adding healthy years to life and reducing unnecessary hospital admissions.

For people with neurodegenerative conditions, the focus on adding healthy years to life is challenging and in some cases is not possible. The complex needs arising from degenerative conditions will inevitably become worse over time as a result of the disease. This is particularly the case in conditions such as MND, PSP and MSA which are rapidly degenerative, but also in conditions which usually have a slower progression or may be fluctuating (Parkinson's disease, Huntington's disease).

Likewise, the aspiration to reduce hospital admissions is also complicated as many people in the latter stages of neurodegenerative disease will inevitably – and appropriately - require in-patient hospital care at times. However, services delivered by multidisciplinary partnerships which include the third sector can make a real difference to outcomes for people with these conditions. Person centred, community based services and support are crucial in minimising length of stay in hospital, reducing unnecessary admissions and supporting self-management in the community and at home.

People affected by the five neurodegenerative conditions include in this work have a wide range of symptoms often affecting all parts of the nervous system. Symptoms worsen as the disease progresses and new symptoms develop. Whilst not everyone will experience all of

[3] http://www.gro-scotland.gov.uk/files2/stats/household-projections/2012-based/2012-house-proj-publication.pdf

the symptoms possible, people will inevitably experience impairment in motor skills, cognitive function, and mental health and in the latter stages of disease will be severely disabled. Whilst symptomatic treatment is available for some of the neurodegenerative conditions there is no disease modifying treatment and no cure. The table in Appendix 1 provides an overview of the neurodegenerative conditions included in this report and associated symptoms, average age of onset and average life expectancy.

The third sector organisations included in this report all provide crucial services and support to enable older people with these increasingly complex needs to maximise their quality of life. They play a vital role in the care pathway and illustrate real examples of integration of health and social care, using a holistic and person centred approach. They are important partners in the overall management of the condition and have a key role in providing support and training to health professionals and paid carers, enabling them to provide appropriate, informed care and to signpost to community based organisations and groups. Finally they provide support to the whole family, particularly carers, helping them to adjust to their caring role, cope with the demands of caring, provide advocacy, emotional support and information and can either offer or facilitate access to respite care.

2 The Role of the third sector member organisations in supporting people with neurodegenerative conditions in Lothian.

Individuals with neurodegenerative disorders require ongoing multidisciplinary health and social care management of their condition which will include palliative and end of life care. Their care pathway will typically have input from a wide range of professionals including Neurologists, Care of the Elderly consultants, Specialist nurses, Allied health professionals, GPs and a range of community based care staff.

The third sector member organisations are crucial partners in their care pathway and provide people affected, with expertise and a wide range of activities and support services; as well as informing, advising and supporting statutory health and care services. They often coordinate care for the individual and their carers and families and have a strong role in enabling choice, supporting self-management and signposting to other community based services.

Staffing varies with each organisation and funding of these staff posts is sourced differently. The staffing for the six organisations who provide support and services to older people with neurodegenerative disease within Lothian is as follows:

Parkinson's UK	2 Information and Support Workers • one covering Edinburgh, Mid Lothian and East Lothian • One covering West Lothian, parts of NHS Forth Valley and parts of NHS Lanarkshire 1 Branch and Volunteer Support Officer • covering Lothian as part of South Scotland 1 Influence and Service Development Officer • 10 hours a week, mapping Parkinson's services in NHS Lothian 1 Scotland-wide Credit Rated Learning Programme Manager There are also 3 Parkinson's Nurse Specialists in NHS Lothian. Parkinson's UK provided pump-prime funding for two of these posts for two years, but they are currently funded by the NHS.
MND Scotland	2 PT Clinical Specialist based at the Western General Hospital • Employed by NHS Lothian but fully funded by MND Scotland • Cover Lothian but also Borders and Part of Fife Welfare & Benefits Officer (South Scotland) Volunteer Development Officer (Scotland wide)
Scottish Huntington's Association	2 HD Specialists based at Western General Hospital • Funded by the 4 LA's and SHA Will soon also provide specialist financial advice on employment of Financial Wellbeing Officer (early 2015)
PSP Association	1 Specialist Care Adviser • Covers all of Scotland
MSA Trust	1 Nurse Specialist

	• Covers North of England, Scotland, Northern Ireland and Eire)
Leuchie House	18 members of staff based in residential centre • 2 physiotherapists • 1 clinical nurse manager • 2 charge Nurses • 6 registered nurses • 7 care, housekeeping and facilities staff Residential service is available Scotland wide Day respite service is available to people in Lothian

There is no systematic method of gathering data across conditions and interrogating existing data systems within the NHS or Local Authorities to accurately determine the number of older people affected by neurodegenerative conditions currently in the Lothian area. Some of the third sector organisations gather their own data and some have therefore been able to provide approximate numbers regarding older people in Lothian currently affected by that condition.

- Huntington's Disease - 35
- PSP - 48
- MND – 54 aged 60+
- Parkinson's Disease - 1700 with over 90% aged 60+ and 38% aged 80+

The current total number of older people living with neurodegenerative disease in Lothian is therefore significantly lower than those with other more common long term conditions such as ischaemic heart disease, COPD and cancer. However the disease trajectory of these lower prevalence and in some cases rare neurodegenerative conditions, means that those affected will inevitably and often quickly develop extremely complex health and care needs which require high economic investment. The contribution made by the third sector organisations in adding resources, building capacity and directly providing services & support to families is crucial in ensuring appropriate coordinated management of these complex conditions, proving support for individuals and their families and ultimately in maximising quality of life for those affected.

The evidence gathered from the six organisations included in this report demonstrate the wide range of activities delivered and illustrate the third sectors ability to provide truly integrated and holistic care. Organisations are able to identify and demonstrate the wide range of outcomes both short and long term that are achieved and which contribute to optimising quality of life for people with neurodegenerative conditions. The collective information and evidence gathered can be broadly grouped into the following four areas:

- Provision of accurate and accessible information
- Care Coordination and Assessment
- Training and Education for statutory health and social care staff
- Provision of health and non-health related practical help and support

2.1 Provision of accurate and accessible information.

All of the third sector organisations provide a range of information to people affected by that condition via a variety of means. They provide needs based information to individuals and families affected as well as specialist disease and care management information to health and social care professionals. This may be via telephone and email support as well as via social media channels. In some cases the organisation employs a dedicated information worker with this specific remit who will meet with people on a one to one basis (Parkinson's UK) whereas for others this will be provided by the organisation's central office and via the specialist care staff who are the families' key contact (MND Scotland, SHA). Parkinson's UK also offers a dedicated UK-wide phone based peer support service, enabling people with Parkinson's to contact others in a similar situation.

The condition specific organisations all provide high quality written hard copy and web based information and fact sheets about the disorder and its ongoing management. These cover all aspects of the condition such as medical information, advice on care, equipment, treatment, support for carers, information on respite services, financial planning and many other relevant issues.

All of the organisations are also are able to make links and provide information about and signpost people to health and care services across Lothian and other relevant third sector organisations which may offer specific support. These can include counselling and mental health services, complementary therapy services, welfare and benefits information and advice and specific support for carers via a range of Carer support organisations in the region. (E.g. VOCAL - Voices of Carers across Lothian).

Organisations often also take on an advocacy role themselves or will signpost to independent advocacy services in the area. They may provide direct information and advice regarding the condition via family information meetings which are supported by a member of staff or volunteers and be a mixture of informal discussion and Q&As or perhaps bring along guest speakers to pass on information about particular issues of interest.

Example: PSP Association (PSPA)

PSPA disseminates publications free of charge to individuals, their carers and families and to health and social care professionals about the disease and its management. These publications are funded by the organisation via its fundraising activities. Specialist PSP guides aimed solely at health and social care professionals are provided by the association as they are not available directly from the NHS. PSP specialist guides aim to improve practice and ultimately enhance patients' experience of health services.

PSPA and the Specialist Care Adviser will offer help and advice to patients, carers and Health and Social care professionals during weekdays and evenings via a helpline service. This ameliorates anxiety resulting from unfamiliarity or lack of experience of what is a rare disease, reduces isolation and frees up time for clinical staff. Social media is also utilised to provide quick signposting information and to answer queries as quickly as possible which are sensitive to capacity and communication issues.

2.2 Care Coordination and Assessment

All of the third sector organisations have a role in coordinating care for people with that condition though some have a greater responsibility for this than others (e.g. MND, HD Specialists). In the case of MND and HD, the specialists work closely in partnership with other health and social care professionals and are usually the key contact for that family from diagnosis (or on becoming symptomatic) until end of life. They will be the key person to coordinate all care for individuals with that condition from diagnosis to end of life and will also provide support and information on a wide range of support services such as complementary therapies, accessing equipment and aids as well as carer support and respite care.

Other organisations will also take a care coordination role working in partnership with statutory health and social care staff. They may provide direct support to families to assist with securing appropriate care packages and signpost to appropriate health and care services (Parkinson's UK). They may have a specific remit such as Leuchie House who providing intensive holistic coordinated care via their respite services both on a residential and day basis.

Organisations are also key in assessing and regularly reviewing the individual's needs. This can be done in a variety of ways to identify gaps in essential services and assess the stage of any given individuals condition, enabling them to make informed choices about their care where possible.

Example 1: MND Scotland

On diagnosis one of the MND Clinical Specialists in Lothian will visit the person at home, pass on an information pack and begin the coordination of their care. They will send information to the GP and other health and social care professionals who are involved with that person's care ensuring that care delivered is coordinated and appropriate.

The MND Specialist will give ongoing support to individuals, family and health and social care professionals. They coordinate other professionals and also act as a resource for them, providing expertise about a rare condition that many professionals such as GPs will have little experience in dealing with. The MND Specialist will also carry out clinical assessments on function, nutrition and respiration, referring to other health and social care professionals as required (e.g. Speech and Language therapy).

Individuals may be seen in clinic, in their own home, in a care home or in a hospice. The MND Specialist is the point of contact for them from diagnosis to end of life. They are recognised by all partners as the experts in this field and are a crucial resource.

Example 2: Scottish Huntington's Association (SHA)

The HD Specialists in Lothian are the key contact for the family and will undertake care planning, care coordination and whole person assessments of an individuals' health and social care needs. They will attend case conferences, community programme approach meetings and reviews. The HD Specialists use a person centred approach to promote and enable choice, supporting people to have as much control over their life as possible. They will give advice and support regarding a range of issues such as symptom management, emotional support and will coordinate other support from Speech and Language Therapists, Dieticians, Physiotherapists and Occupational Therapists in response to the needs of the person.

The HD Specialists will carry out joint visits with other health and social care staff to assess, plan and monitor care, including monitoring medication and reporting efficacy to the responsible clinician. They will identify and assess the needs of those who may be at risk of suicide or mental ill health ensuring that the appropriate agencies are involved. They are also able to undertake assessments and make referrals to social work to assist with independent living.

As HD is a particularly complex genetic degenerative neuropsychiatric illness, the HD specialists are a support for not just the older people but also other generations of that family who may be living with or at risk of the disease.

2.3 Training and education for statutory health and social care staff

All condition specific organisations have an important role in providing expertise and in depth advice regarding all aspects of the disease to health and social care professionals. It is likely that for some of the low incidence conditions, non-specialist staff such as GP's, general nurses, and community based care staff will have extremely limited, if any, experience of supporting an person affected by that condition.

Building both knowledge and capacity with wider health and social care staff within the Lothian area is undertaken in a variety of ways. All organisations provide written guides or educational publications aimed specifically at clinical and non-clinical care staff in both hospital and community settings. These publications aim to improve knowledge, share expertise and foster best practice. Subjects covered are extremely wide ranging addressing symptom management, treatment issues and care management amongst others and there are often specific publications for different professionals, for example, community pharmacists or care home staff. The third sector organisations are recognised as the experts in their condition and all produce extremely high quality, accurate information for professionals which is widely used. Information and guidance regarding integrated care pathways and a range of tools for assessment and review are also produced. All of the third sector organisations also link to the Clinical Standards for Neurological Health Services[4].

As well as publishing education materials, most organisations provide training or teaching sessions and hold study days for a range of health and social care professionals to attend. Some work in partnership with educational establishments to provide accredited courses aimed at specific staff.

Training delivered by the third sector organisations is underpinned by the person centred and holistic approach from which these organisations deliver their services. Training content is therefore within the context of overall care management and is not limited to clinical input on disease management. It will address the role of health and care staff in supporting both people with the condition but also carers and family. The third sector organisations are also closely linked to current research into the condition both in terms of funding research but also support people who are participating in clinical trials or research projects.

As all of the condition specific organisations provide training and education materials for health and social care professionals, the following includes a summary of all organisations giving examples of what they deliver.

[4] http://www.scottishneurological.org.uk/content/res/final_QIS_standards.pdf

Example: Training and Education provided by condition specific organisations

MSA Trust

- information leaflets on symptom management and daily living with MSA; information about aids and equipment; information for carers; taking holidays; accessing respite etc.
- MSA Trust nurse specialist provides teaching sessions and 1:1 guidance and advice to professionals working with people with MSA and to hospices, residential and respite care facilities and care agencies.

PSP Association

- Free specialist guides to GPs, District nurses, AHP's, Social care professionals on a range of issues including cognition and PEG guidance which enables people to stay at home for longer
- Free training delivered to health and social care professionals – two events delivered in Lothian in 2014 with 129 staff attending.

Parkinson's UK

- A wide range of specialist guides and assessment tools for all health and social care professionals.
- Have developed a SQA accredited learning programme for health and social care professionals which was piloted in care homes in Edinburgh and West Lothian.
- Works with Parkinson's nurse specialists to deliver educational activities to health and care professionals

Scottish Huntington's Association (SHA)

- CPD course in Huntington's disease: an enabling approach to supporting families, delivered in association with the University of Stirling but for all practitioners working in Scotland.
- Lothian HD Specialists provide training and education to health and social care agencies including nursing home staff, home care staff and allied health professionals.

MND Scotland

- Education service provides education to health and social care professionals at their place of work.
- Run study days on the condition throughout the year at various locations across Scotland

2.4 Provision of health and non-health related practical help and support

Practical help and support is provided by all of the third sector organisations who have many dimensions and deliver a wide range of services both health and welfare related. The organisations all have an expert understanding of the needs of older people with neurodegenerative conditions and their carers and families and as such are able to develop innovative ways of providing support. They are also able to ensure that practical services are tailored and responsive and able to cope with the complex needs people are likely to have.

The organisations all provide support and advice regarding self-management of the condition. This may be tips and techniques to help people cope with symptoms themselves which can be passed on by the specialist staff member supporting that older person and their carer. The organisation may also deliver more structured group run activities such as singing groups, art classes and advice on nutrition and stress management amongst others.

Volunteer support and peer support is usually a feature and is particularly valuable as many neurodegenerative conditions have low awareness in the community, leading to stigma and isolation. Some of the third sector organisations run support groups in Lothian which will meet, often on a regular basis, allowing people to socialize and share experiences on all aspects of living with the condition (MND Scotland, SHA, Parkinson's UK and MSA Trust to establish a Lothian group in 2015).

Some organisations either provide themselves or facilitate access to therapeutic activities and complementary therapies to relieve stress, promote relaxation, ease tension and reduce anxiety. Therapies including Aromatherapy, Reiki, Reflexology, and Indian Head Massage may be delivered at the organisations premises or in the person's home.

Older people with a neurodegenerative condition will inevitably require significant adaptations to housing and a range of aids and specialist equipment. As the condition progresses people become severely disabled requiring a suitable wheelchair and perhaps sophisticated and expensive technological equipment to facilitate communication. Many of the organisations have an advocacy role in ensuring that people are able to access the equipment they require from social services. Equipment may also be provided by the organisation itself if statutory services are not able, or would take too long to provide it (MND Scotland) or can be funded through a small grants scheme (Parkinson's UK). Wheelchair assessment may also be undertaken and repairs done in house or referrals made (Leuchie House).

Financial issues and advice on welfare and benefits is an important part of providing practical help to older people and their families. Organisations may carry out financial assessments and use their specialist knowledge to help people to complete benefit applications, provide advice on Self-Directed Support packages or refer people to other services in Lothian such as money advice agencies who can give financial advice. They often

have a role in working with older people and their carers regarding advance care planning, covering issues such as living wills, power of attorney and wills and testaments.

All of the organisations provide practical help to carers, understanding the particularly complex difficulties and pressures that carers' face. The complexity of caring for a person with a neurodegenerative illness makes it impossible to cope without access to emotional support and respite care services that are appropriate for older people with complex needs. In addition to providing support directly via their specialist staff in Lothian, organisations will all signpost carers to a range of third sector carer organisations operating in the Lothian region. One of the organisations included in this report is a dedicated respite care service (Leuchie House) and MND Scotland also run a holiday service for families and have a fully adapted chalet and wheelchair accessible caravan, enabling families to take a holiday together.

Example: Parkinson's UK

Parkinson's UK provides a wide range of practical health and welfare activities in the Lothian region. There are 3 local groups offering friendship and support in Edinburgh City, East Lothian and West Lothian. The local groups run self-management activities including popular singing groups, dance classes, art classes and gentle exercise. They also run carers support courses and have a research interest group.

The Edinburgh Branch also works with the Thistle Foundation to provide a self-management course for people affected by Parkinson's where people are supported with movement to music and relaxation. Other therapeutic interventions such as relaxation sessions, sleep management and physiotherapy are promoted by the Edinburgh branch and delivered by health professional partners.

A self-management weekend has also been hosted in Edinburgh whereby people could access a host of complementary therapies.

Example: Leuchie House

Leuchie House in East Lothian provides respite breaks with 24 hour nursing care and day respite. They provide a host of activities such as reiki, aromatherapy, Indian head massage and reflexology which promote relaxation and reduce stress. Leuchie provides onsite physiotherapy on an individual and group led basis to improve peoples' range, motion and flexibility. They provide high quality home cooked meals which accommodate all diets and have specialised vehicles to enable people to take regular outdoor excursions to places of interest.

Leuchie undertake wheelchair assessments and repairs. They also offer a range of beauty treatments and hairdressing and social activities such as film nights, quizzes and concerts.

2.5 Logic Model

This logic model aims to show the range of activities and outcomes from all of the third sector member organisations included in this report. It captures the contribution made by the organisations' in the overall management of older people with complex health and care needs arising from their neurodegenerative condition. The model has been created from evidence gathered from all organisations regarding their practice delivery in Lothian and from self-evaluation of their services. It sets out the inputs, activities and system, person and strategic outcomes achieved by the organisations.

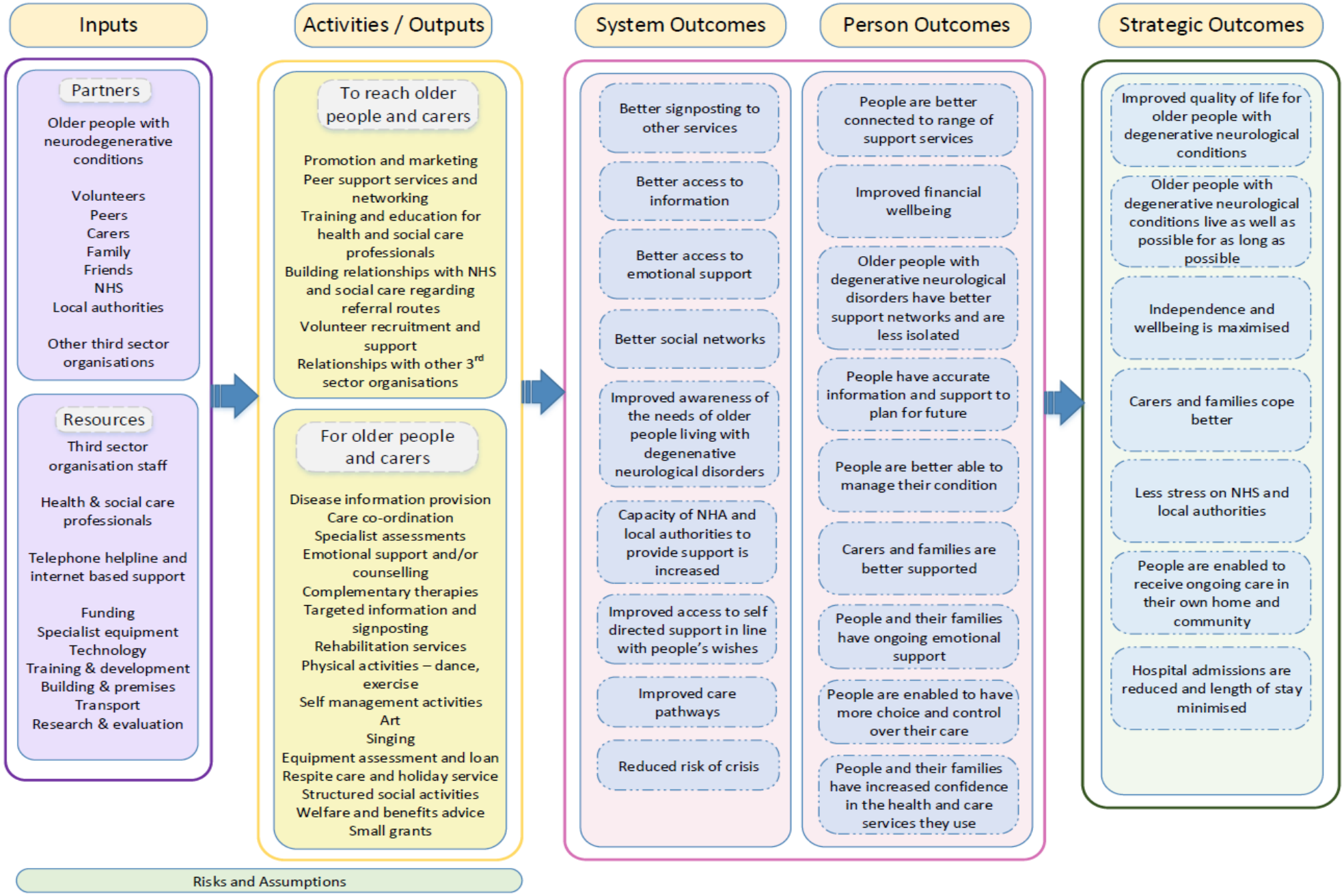
Across all of the organisations are a number of shared assumptions which underpin their work. There are also a number of commonly identified external factors which may impact on the ability of the organisations to achieve the outcomes set out.

Assumptions

- Organisations have a shared set of values underpinning services.
- People with neurodegenerative conditions are not a homogenous group and services may not be appropriate or accessible to all.
- Organisations provide the highest quality and most comprehensive written materials about living with that degenerative neurological condition.
- Older people with neurodegenerative conditions have complex needs and NAoS member organisations support and services in partnership with specialist multidisciplinary support is essential.
- Organisations are experts in their conditions and key in providing accurate and consistent training and development to statutory partners.
- Organisations are person centred and responsive to the needs of the older person as well as their carers and wider family.
- Carers and family of older people with neurodegenerative conditions benefit from peer support which reduces isolation.
- Self-management of the condition is facilitated by activities provided by organisations allowing people to better manage their symptoms for longer
- Complex needs arising from neuro degenerative conditions will increase over time and disease management and best quality of life rather than prevention is the goal.

External factors

- Loss of funding for organisations provision of services.
- Effective partnerships with and referrals from statutory services are not consistent
- Family and carer support changes, e.g. older persons carer becomes ill or dies
- Pathways for people living with rare conditions are not always given sufficient priority or appropriate resources.
- There may be increased demand for services and/or increasing expectations
- Changes in National and local Prioritiesand practice around key areas of work may lead to additional demands.
- Loss of funding to partner third sector organisations reduces opportunities to access complementary services


Inputs
Activities / Outputs
System Outcomes
Person Outcomes
Strategic Outcomes
Partners
Older people with neurodegenerative conditions
Volunteers
Peers
Carers
Family
Friends
NHS
Local authorities
Other third sector organisations
Resources
Third sector organisation staff
Health & social care professionals
Telephone helpline and internet based support
Funding
Specialist equipment
Technology
Training & development
Building & premises
Transport
Research & evaluation
To reach older people and carers
Promotion and marketing
Peer support services and networking
Training and education for health and social care professionals
Building relationships with NHS and social care regarding referral routes
Volunteer recruitment and support
Relationships with other 3rd sector organisations
For older people and carers
Disease information provision
Care co-ordination
Specialist assessments
Emotional support and/or counselling
Complementary therapies
Targeted information and signposting
Rehabilitation services
Physical activities – dance, exercise
Self management activities
Art
Singing
Equipment assessment and loan
Respite care and holiday service
Structured social activities
Welfare and benefits advice
Small grants
Better signposting to other services
Better access to information
Better access to emotional support
Better social networks
Improved awareness of the needs of older people living with degenenative neurological disorders
Capacity of NHA and local authorities to provide support is increased
Improved access to self directed support in line with people's wishes
Improved care pathways
Reduced risk of crisis
People are better connected to range of support services
Improved financial wellbeing
Older people with degenerative neurological disorders have better support networks and are less isolated
People have accurate information and support to plan for future
People are better able to manage their condition
Carers and families are better supported
People and their families have ongoing emotional support
People are enabled to have more choice and control over their care
People and their families have increased confidence in the health and care services they use
Improved quality of life for older people with degenerative neurological conditions
Older people with degenerative neurological conditions live as well as possible for as long as possible
Independence and wellbeing is maximised
Carers and families cope better
Less stress on NHS and local authorities
People are enabled to receive ongoing care in their own home and community
Hospital admissions are reduced and length of stay minimised
Risks and Assumptions

3 Evidence and discussion of outcomes of third sector organisations

Due to the ageing population there is a clear need for effective home based and community based support for older people with complex health care needs. For those with neurodegenerative conditions, ongoing specialist management is critical and is typically delivered via a partnership between statutory health and social care agencies and the third sector organisations who provide support and services for people affected by that condition.

The third sector organisations all gather evidence supporting the system and person outcomes included in the logic model via ongoing self-evaluation of their activities. This may be accompanied by service reviews and assessment as well as formal and informal research with the individuals and families they support, in order to identify service benefits regarding peoples' quality of life and to detect areas of concern or challenge.

Issues such as having better control over their treatment and care, having support in accessing aids and equipment and most particularly having a key person who can pass on information, signpost to other services and community support and who can coordinate care are key to maximising people's quality of life. Services delivered by the third sector organisations are personalised, needs led and underpinned by expertise in the management of the wide range of complex needs arising from a neurodegenerative condition. There is also the added benefit of third sector organisations having strong links and regularly working in partnership with other third sector agencies in the community, ensuring that specific support services, e.g. carer support are accessible.

Older people with neurodegenerative conditions will inevitably see a decline in health due to the disease progression and the focus must therefore be on tertiary prevention. Evaluation of the third sector organisations contribution to their health and wellbeing is concerned with examining people's quality of life rather than reducing physical deterioration. Hospital admissions at times may indeed be inevitable for older people as the disease progresses and they become more vulnerable. However, the third sector organisations' believe their role in anticipatory care, coordination of care and delivery of integrated services may have some impact on reducing hospital admissions or avoiding unnecessary emergency admissions and minimising length of stay for those who are admitted. Some of the organisations' identify a goal of reduction in avoidable emergency hospital admissions being supported via the delivery of self-management interventions which may prevent falls, increase mobility and avoid problems with medication.

Measuring impact of any health intervention is challenging particularly when upstream, primary and secondary prevention strategies are typically not possible. Additionally, gathering of evidence is further complicated by the person's possible impairment in cognitive function, the onset of disease related dementia or where there is a short life expectancy from diagnosis.

The following two case studies have been included in this report to give two different examples of the contribution that organisations have made to the management of older people and their families affected by neurodegenerative disease.

The first case study has been provided by Scottish Huntington's Association and provides an overview of their assessment of the Lothian specialist service and work they undertook in late 2013 to develop a Lothian wide care pathway for people with Huntington's disease.

The second case study has been provided by Parkinson's UK and illustrates a wide range of evidence gathered from people affected by Parkinson's disease in regard to the delivery of their services and activities for people affected by Parkinson's in Lothian.

3.1 Case Study: Scottish Huntington's Association (SHA)

There are an estimated 35 older people directly affected by Huntington's disease in Lothian. People with the condition are often frail and vulnerable and face multiple health and social care challenges. The management of the disease is typically very complex and requires well-coordinated care across both health and social care systems in order to respond to the progressive and unpredictable changes in physical, mental health and cognitive function. The role of the HD Specialists in providing consistent, proactive and well-coordinated management is vital and is an effective approach in both reducing the number of crisis admissions to acute hospital beads and decreasing the need for outpatient visits as well as reducing demand for GP appointments.[5]

As part of an overall assessment of the Specialist Huntington's disease service in Lothian, SHA gathered data from people affected, asking them to rate their experience of the support given by the HD Specialist and areas in which this had been particularly effective. Some of the reported outcomes were as follows:

- Better able to manage with behaviour changes
- Reduction in symptoms of depression and anxiety
- Increase in emotional support
- Package of care received was well coordinated
- Needed information, emotional support and advice for carers was provided
- Signposted to services for financial advice

Towards the end of 2013 SHA undertook work to develop a Lothian wide Care pathway for people with HD. The overall aim of the care pathway was to support people living with HD in community settings for the majority if not the entirety of the period during which they are living with their condition.

SHA examined IRF (integrated resource framework) data in order to understand more clearly current resource use across health and social care for people in Lothian with

[5] Assessment of the Specialist Huntington's disease service in Lothian (Scottish Huntington's Association)

Huntington's disease. The IRF data gathered had limitations, for example it did not include GP costs, but overall was consistent with the trajectory of Huntington's disease where hospital admission was only necessary in the advanced stages of the condition and where social care costs were higher.

SHA also held a series of meetings with agencies across Lothian and hosted two stakeholder days with health and social care staff and for families living with Huntington's disease. They identified a significant number of elements of the Lothian care pathway that were working well:

- The HD Specialists provide effective information services
- The HD Specialists carry out accurate assessment of cognitive function and capacity which is essential in development person centred care plans.
- The HD Specialists effectively signpost to appropriate money advice services
- The HD specialists are a consistent and accessible point of regular emotional support and also play a key role in helping individuals to strengthen their social and support networks.
- There was a strong network of carer support services in Lothian
- The HD Specialists provide full support for people wishing to make future plans
- Care coordination was being effectively met by the HD Specialists

Various recommendations have also been made by SHA regarding the changes and improvements necessary to ensure that there is an integrated care pathway for people affected by HD in Lothian. These recommendations include:

- Setting out how community based mental health support will be effectively delivered between community mental health teams and the specialist unit (Lanfine Unit) and HD Specialists.
- Provision of ongoing training and education provided across health and social care activities – SHA have subsequently developed a CPD course in Huntington's disease
- Offering an annual assessment to people with Huntington's disease

Scottish Huntington's Association makes a critical contribution to the support and management of people with Huntington's disease and their carers across the Lothian region. They have a strong person centred care coordination role and the HD specialists are best placed to anticipate and coordinate integrated care for the person throughout the trajectory of the illness.

3.2 Case Study: Parkinson's UK

There are at least 1700 people with Parkinson's in Lothian, a large proportion of whom will be over 65 years and some over 80 years.

Across Lothian, Parkinson's UK have three volunteer led local groups offering a vast range of activities that support people with Parkinson's and carers to live as well as possible with Parkinson's.

Group activities are highly relevant to the communities they serve, and have evolved out of the lived experience of what has helped people affected by Parkinson's to live better with their condition. All group activities are open to anyone who wishes to take part, and are not restricted to a single geographical area, or to charity members. Edinburgh Branch activities, in particular, draw people from across NHS Lothian.

Opportunities to socialise and to meet other people who have similar issues can help people with Parkinson's and carers feel less isolated. It also normalises the experience of living with Parkinson's, and gives people opportunities to share their experiences in a way that can be difficult with people who don't know about the condition.

A good example is the Edinburgh Branch Carers' Group which provides an open, safe and welcoming space for carers to talk about the issues that they face. About 10 – 15 people attend monthly meetings. Typically they care for people with very advanced Parkinson's, where symptoms are very challenging and there are very high levels of health and social care involvement. Those who attend gain the support and understanding of others, enabling them to continue to care.

The range of physical and creative activities offered also have tangible outcomes. Regular exercise sessions, ranging from bowls to hydrotherapy and gentle exercise to dance, cater to a wide range of tastes. Research suggests that regular exercise has particular benefits for people with Parkinson's, and may even slow the progression of the condition.

The Singing 4 Fun community choir offers two sessions a week, and more than 50 people with Parkinson's and carers are involved. People participate because they enjoy it, and identify benefits in terms of improved mood and symptoms.

The two dedicated Information and Support Workers which cover the Lothian area offer free, confidential one-to-one information and emotional support to people with Parkinson's, their families and carers. In 2014, these workers provided support to over 100 people with Parkinson's and carers in Lothian. In almost every situation, they provided information about Parkinson's and emotional support, and signposted to other forms of support in the statutory and third sectors.

A significant area of work related to financial and benefits matters – supporting people with Parkinson's and carers to claim a total of £108,000 in benefits. Work with carers accounted for about half of their work, although about a quarter of clients were people with Parkinson's who live alone.

Client feedback from Lothian demonstrates positive outcomes for individuals and their families, covering a wide range of areas.

These describe a service that:

- increases self-confidence and wellbeing
- reduces social isolation
- enables people to access the information, support and services they need to live well with their condition
- identifies and addresses issues that are leading to anxiety and stress
- supports people with Parkinson's and / or families to make the changes they need to improve their lives

The support given to enable people to navigate the complexity of the welfare system and access the support they needed has been reported as extremely valuable:

"We were worried how we were going to cope after J's diagnosis with extra heating costs and aids for bathroom etc. the [Information and Support Worker] helped us apply for attendance allowance and where to phone for OT assessment, we would have been lost without her information"

"You have [given] my dad so much support. He didn't know where to turn and was about to sell his house to pay back the DWP an overpayment when we contacted you. You have taken all his worries off his plate while working with him. If you hadn't helped him he wouldn't have had the confidence to appeal and have the money all written off, he can go out now he has his blue badge …. He is less stressed and more confident and you have made such a difference by working with my parents they are so much happier"

Training for Health and Social Care Professionals

People with Parkinson's and their families say that it is vital that professionals who provide care understand the condition and how it affects them. Parkinson's is a very complex condition, and its symptoms can be misunderstood. Workers often do not appreciate the full range of symptoms that are caused by Parkinson's, or how they can support people to live well with the condition.

There are particular issues around medication management. If a person with Parkinson's is unable to take their prescribed medication at the right time, the balance of chemicals in their brains can become severely disrupted – leading to the symptoms of the condition becoming uncontrolled. In a care setting, missed medication could result in a preventable hospital admission, cause serious harm (e.g. falls, malnutrition, infection) or have a very significant impact on quality of life, so it is critical that care workers are aware of this issue.

Parkinson's UK provide a SQA credit rated qualification for the care of people with Parkinson's in Scotland and the UK. The programme cascades learning about Parkinson's

throughout the care home or care agency setting and has been developed in partnership with people with Parkinson's disease with some people training as facilitators.

The learning programme was piloted in late 2012, and is now being rolled out throughout Scotland. Care organisations from throughout Lothian have been involved from the pilot stage onwards. Since October 2012, Parkinson's UK have trained 16 facilitators in Lothian, and 74 care workers have participated in the training that they have delivered. As the programme progresses, these numbers will grow.

Comments from participants in Lothian demonstrate significant improvements in the care that workers can provide, improved relationships between workers and people who use services, and the potential to have a meaningful and sustained impact on quality of life.

"You feel like you are understanding Parkinson's more and I now know that the person we are working with is not just being awkward. Knowing that fluctuations happen has been really good to know, I've found the sessions really good and feel good about this course and what we have already learned."

3.3 Summary

The two case studies provide specific examples but this approach and many of these activities are also delivered by all of the third sector organisations. Organisations work at a strategic level, informing NHS board improvement plans for neurological health care services both locally and via the National Neurological Advisory Group. They often lead or are closely involved in developing integrated care pathways for people with conditions and provide high quality training and education for health and care professionals. They also deliver a wide range of expertise, information and practical support and activities to people affected by the conditions as well as their carers and wider families.

All of the third sector organisations have a critical role to play in the support of older people with complex needs as a result of a neurodegenerative condition and are key to coordinating integrated and person centred care for people which ultimately helps to improve quality of life for all affected and achieves a range of strategic outcomes - as listed in the logic model included this report.

4 Gaps in Service Provision

Despite the important contribution made by the third sector organisations in supporting older people affected by neurodegenerative conditions, there remain gaps in provision. There are often significant gaps in provision for adults and provision for older adults with older adults more likely to be placed in nursing care homes that don't necessarily have the skills and knowledge to manage the complex needs that occur with a neurodegenerative condition and are therefore not able to provide the level of support required.

The interfaces between services are not always clear which can result in gaps between services and sectors, inefficient and unreliable transitions and unnecessary delays for people getting the support they require. The development of integrated care pathways by some of the third sector organisations are helpful in supporting a more seamless system, particularly for rarer conditions such as MND and Huntington's disease where people are not always given sufficient priority or appropriate resources. The role of third sector specialist staff is crucial in coordinating care but effective support could be improved by a more integrated team approach across all sectors, particularly to symptom management and mental health issues.

Appropriate community based nursing care is often lacking, with inadequate provision to cope with the complex needs those with neurodegenerative conditions inevitably have and resulting in limited options for care homes. The third sector organisations all have an important role in providing advice, delivering training and support to community based care staff which helps to develop higher quality care.

The welfare and benefits system is increasingly complicated with access to financial benefits undergoing significant change. All of the third sector agencies play a key role in supporting people with welfare and benefit issues but are becoming increasingly stretched as demand for this area of support increases. Whilst the introduction of Self Directed Support has been helpful in enabling control for people in deciding their care, there is evidence that personal budgets are used less frequently for older people, that older people may experience poorer outcomes using personal budgets, and that often older people do not wish to have the responsibility of managing their budget and organising care and support themselves.[6] In the case of neurodegenerative conditions, older people may be even more reluctant to have this responsibility, but still wish to exercise choice and control over their care and support.

The following example illustrates a significant gap in service provision for a different neurological condition, Cerebral Palsy as identified by NAoS member organisation Bobath

[6] http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Care/Personalisation_in_practice-lessons_from_experience.pdf?dtrk=true

Scotland. As introduced in section 1 of this report, Cerebral Palsy is a lifelong condition with 65 – 90% of children with CP now having a normal or near normal life expectancy[7].

Example: Older Adults with Cerebral Palsy (CP)

Older people with CP are facing greater difficulties in their lives as a result of an inadequate provision of support services. CP has traditionally been viewed as a static condition but research shows that people with CP are living longer and experience accelerated secondary aging as the result of living with a lifelong condition. Lifelong musculoskeletal disuse or overuse by people with CP can result in pain, osteoarthritis, muscle tightness and urinary tract problems.

Access to physiotherapy, speech and language therapy and occupational therapy can make a huge difference to people affected in this way and even negate the need for surgery in some. However, Bobath Scotland have highlighted that there is a lack of provision of suitable aids and adaptations, a lack of specialist knowledge of CP and a lack of access to services from statutory health and social care providers who fail to understand the effects of secondary aging for people with CP and their subsequent rehabilitative support needs.

Within the Lothian area there are some private therapists who can work with older adults with CP. However access is limited by availability of funding.
Bobath Scotland offer support and advice to health and care professionals via telephone and can discuss issues relating to management and support for older people with CP. They believe however that older people with CP are being lost in the system resulting in avoidable personal and economic costs.

4.1 Conclusion

This report demonstrates the crucial role of the third sector organisations in not only providing services, coordinating care and delivering a wide range of activities but also in informing strategic planning for neurological services and developing guidance on management of conditions and integrated care pathways.

Some of the organisations services are commissioned by statutory providers and others work in partnership with health and social care professionals to ensure that people and their carers are able to access the wide range of support they require. The complex needs arising from neurodegenerative conditions will inevitably increase over time and the third

[7] Jones, GC (2009) Ageing with cerebral palsy and other disabilities: personal reflections and recommendations. Developmental Medicine and Child Neurology. Vol 51, Issue supplement s4

sectors role in supporting carers and families is crucial, an area of support often overlooked or under resourced in statutory service provision.

Organisations work to identify and address gaps in mainstream provision and are well placed to consult with and involve the people they support, to ensure that services are person centred and responsive to need. They provide training and education to health and social care professionals in a variety of ways and are key partners in the overall provision of integrated care for older people with complex needs.

4.2 Acknowledgements

The Neurological Alliance of Scotland would like to sincerely thank all of the member organisations who participated in this work, for their time and sharing of information and experience. We would also like to thank them for their support in both gathering the evidence for and reviewing the content of this report.

Appendix:
Summary of Neurodegenerative Conditions, average age of onset, typical life expectancy & associated early, mid and late stage symptoms.

The following table gives a summary of the characteristics of the neurodegenerative conditions included in this report.
Individuals with a neurodegenerative condition all experience the disease differently. Not everybody experiences all of the symptoms, and the order of onset and severity of symptoms vary considerably from person to person. Therefore the needs of individuals and families will vary according to their own experience of the condition.

Condition	Overview of condition	Average Age of onset	Average life expectancy following diagnosis	Early symptoms	Middle symptoms (in addition to early symptoms)	Late symptoms (in addition to early & middle symptoms)
Motor Neurone Disease	Motor Neurone Disease (MND) is the name given to a related group of diseases affecting the motor neurones. MND is a rapidly progressing and ultimately terminal neurological condition that currently affects over 400 people within Scotland. MND damages and destroys the neurones that carry the signals from the brain to the muscles leading to weakness and	Generally age at onset is from 40 years up to 70s and 80s In a few cases it can occur earlier. Average age at onset is 63years.	Life expectancy from diagnosis is 14 months	About two-thirds of people have limb onset: • a weakened grip • difficulties picking up or holding objects • difficulties in lifting the arm above the head • tripping up • Twitching of the muscles (fasciculations) and/or muscle cramps. About a third of people have Bulbar-	• Limbs become progressively weaker • muscles begin to waste away • Muscles can become unusually stiff. • About two-thirds of people will eventually find the ability to speak and swallow increasingly difficult. • Loss of weight and body mass. • Problems with reduced swallowing causing excessive or constant drooling of saliva. • Saliva may be hard to	• increasing body paralysis • Significant breathing difficulties. • Eventually, non-invasive breathing assistance won't be enough to compensate for the loss of normal lung function.

	paralysis. People with MND can quickly become severely disabled. 5%-10% of cases are familial. 15% of cases can have frontal temporal dementia with an additional 35% having some form of cognitive or behavioural impairment.			onset: • slurred speech (dysarthria) • difficulty swallowing	clear from the chest or throat because of weakened cough muscles. • Changes in the ability to control emotions such as uncontrollable crying or laughter. • Difficulties with planning, language and concentration (frontotemporal dementia). • Breathing will become increasingly difficult.	
Parkinson's Disease	About 10,000 people in Scotland people have Parkinson's. Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. There are also other issues such as tiredness, pain,	The risks of Parkinson's increase with age. Most people are aged over 60 when they are diagnosed, but people in their 30s, 40s and 50s can also develop Parkinson's. UK GP records suggest that over 90% of	With appropriate care and support, many people with Parkinson's can have a good quality of life for some years after diagnosis. Life expectancy depends on a number of	• Slowness of movement • Tremor (1/3 of people are unaffected by tremor) • Rigidity • Bladder and bowel problems • Eye problems • Fatigue • Restless legs syndrome • Skin, scalp and sweating problems • Drooling	• Falls and dizziness • Balance problems • Postural Hypotension • Gait disorder • Speech problems • Freezing • Weight loss • Hallucinations • Dementia • "Off" periods and immobility • Breathlessness • Dyskinesia(uncontrolled movements) • Dystonia • Pain	• Increased falls • Physical frailty • Swallowing problems (may need PEG) • Long periods of immobility • Pressure sores • Recurrent infections It is also very common for people with advanced Parkinson's to have other serious health conditions in addition to their Parkinson's. Both Parkinson's symptoms and other conditions

	depression, dementia, compulsive behavior's and continence problems which can have a huge impact. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'. There is no cure.	people living with Parkinson's are aged over 60, and about 38% are aged over 80.[i]	factors including age at diagnosis. People with Parkinson's typically live less long than people of the same age without the condition.	• Sleep problems • Mild Cognitive Impairment (planning and memory problems) • Apathy • Depression • Anxiety • Sexual dysfunction • Medication side effects, including Impulse Control Disorders		increase the risk that infections and other life-threatening situations can develop
Huntington's Disease	Huntington's disease is a progressive genetic neuro-psychiatric illness. A child who has a parent with the gene has a 50/50 chance of inheriting it. There is a wide range of physical symptoms, cognitive changes and psychiatric symptoms. Symptoms worsen over time and death usually occurs due to respiratory and other infections.	Symptoms can appear at any age but mean onset is between 35 and 44 years.	Life expectancy varies depending on age of onset but is between 10 and 30 years	• Jerky uncontrollable movements (Chorea) • Tics • Incoordination • Dysarthria • Fatigue • Communication problems • Incontinence • Concentration & memory problems • Visuspatial • Speed of Processing	• Swallowing problems • Increased falls /problems with balance • Sensory loss • Weight Loss • Oral/dental issues • Dystonia • Lack of Motivation	• Inability to swallow (PEG management) • Excessive secretion of saliva (Sialhorrea) • Pain • Epilepsy • Agitation • Dystonia/Contracture

	There is no cure.			• Self-Awareness • Planning & Organising • Problem Solving • Judgement • Depression & Anxiety • Psychosis • Irritability • Obsessive disorder		
Progressive Supranuclear Palsy (PSP)	Progressive Supranuclear Palsy is a progressive neurological condition caused by the death of nerve cells in the brain. There currently is no disease modifying treatment and there is no cure.	Mid 50s – 60s. UK average age of onset is 63	5 -9 years UK average is 6.4 years.	• Poor balance, unsteady gait • Reduced mobility and falls, often backwards: • Double, blurred vision • Reduced blink rate • Photophobia and Vertical Stare Palsy • Difficulty swallowing; • Change in personality and cognitive change. • Dystonia.	• Frequent falls, Deteriorating mobility with need of walking aid and later on use of wheelchair; Sialhorrea • Regular infections (Urinary and Chest) • Risk of aspiration • Blepharospasm and eye Apraxia • Nuchal rigidity/ Apathy • Bowel and Bladder problems	• Frequent infections, Pneumonia • Choking • Complete loss of mobility • Inability to communicate verbally • Use of PEG feeding: Contractures • Double incontinence:
Multiple System	A progressive neurological disorder	Commonly in Late 50s,	3 -9 years	• Erectile dysfunction	• increasing muscle weakness	• Loss of mobility

Atrophy	that affects adult men and women. It is caused by degeneration or atrophy of nerve cells in several (or multiple) areas of the brain which can result in problems with movement, balance and automatic functions of the body such as bladder and blood pressure control.	early 60s		• Bladder dysfunction • Unpredictable bowel function • Poor balance / slowing of movement • Fatigue • Impaired speech • Altered emotions - uncontrolled laughing / crying • Cold hands and feet.	• fatigue • stiffness only walk with aids in the house, wheelchair for outdoors • drops in blood pressure • increasing falls • swallow and speech increasingly difficult • changes in posture - side or forward head and body tilt • blurred / double vision • noisy breathing due to vocal cord spasm • weak cough and inability to clear secretions • poor sleep quality - restless legs / act out dreams • Require urinary catheterisation.	• no arm or leg strength / co-ordination • rigidity • muscle spasms • recurrent urinary and chest infections • inability to swallow and control oral saliva • Loss of communication capacity.

[i] Parkinson's UK (2012) Parkinson's prevalence in the United Kingdom (2009) Online at http://www.parkinsons.org.uk/sites/default/files/parkinsonsprevalenceuk_0.pdf

A Stitch in Time?

A Stitch in Time? is a partnership project to support the third sector to collect and present evidence about its contribution to Reshaping Care for Older People (RCOP). The programme runs from April 2013 to March 2015 and focuses on third sector organisations working with older people and carers in Lothian.

A Stitch in Time? publications

A model to explain the third sector contribution to Reshaping Care for Older People

Focus on third sector interventions that allow older people to stay positive and in control

Indicator Bank for third sector outcomes for older people

Focus on third sector interventions to enable older people to keep or be more financially and materially secure

Focus on third sector interventions that make the physical and social environment more age friendly

Focus on third sector interventions that make the system work better for older people

Focus on third sector interventions to enable older people to keep or be more socially connected

Focus on third sector interventions that ensure healthy and active ageing

To accompany this series there are **evaluation case studies** and a number of **evidence reviews**.
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