



Self Management Fund – Special Report Neurological Conditions

February 2011

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Overview and Background

'Gaun Yersel' the Self Management Strategy for Scotland¹ recognises that people living with long term conditions, and their unpaid carers, should be involved in the design, development, implementation and evaluation of the services that are intended to support them.

This became a key criteria of the Self Management Fund, and the 81 successful projects all have the lived experience of people living with long term conditions, and their unpaid carers, at their heart.

The Self Management Fund has been available to voluntary organisations and community groups throughout Scotland since March 2009. The Self Management Fund has been set-up and administered by Long Term Conditions Alliance Scotland (LTCAS).

The Self Management Fund has been made possible through funding from the Scottish Government. £4 million was available over two financial years - £2 million across 2009/10 and £2 million across 2010/2011.

The aim has been to improve work to expand the capacity of people living with long term conditions to learn more about the management of their conditions and to become active partners in their own care.

Neurological Conditions

The Self Management Fund supports projects and organisations across Scotland which encourage people living with long term conditions, and their unpaid carers, to work in partnership with health and social care professionals.

This Special Report looks at how the Self Management Fund has encouraged approaches to self management for a wide variety of neurological conditions.

23% of the projects look specifically at neurological conditions, and many other generic projects involve people living with neurological conditions.

This report is the third of a series of Special Reports which highlight some of the key themes of the Interim Evaluation Report launched in October 2010². A full evaluation report will be produced at the end of the current funding period, June 2011.

¹ http://www.ltcas.org.uk/self_man_gaun.html

² http://www.ltcas.org.uk/self_basics.html

Neurological conditions in context

What is a Neurological Condition?

Neurological conditions are caused by damage to the nervous system, often as a result of illness or injury. Problems of the nervous system usually affect the brain and spinal cord and the nerves and muscles in the body.

The cause of many neurological conditions is not yet known and there is much research invested in trying to understand more about the environmental and genetic factors involved.

Neurological conditions can affect all ages and can begin at any time in a person's life. Not all are serious. Some neurological conditions are life-long and may be present from birth, such as Spina Bifida or cerebral palsy. Other conditions such as Alzheimer's and Parkinson's disease will affect mainly older people.

Neurological conditions account for one in five emergency hospital admissions, one in eight general practice consultations and a high proportion of disability, particularly severe and progressive disability, in the population. (see appendix 2 for more details)

Principles of Self Management

The Principles of Self Management (see appendix 1) were developed by LTCAS to encapsulate the core messages of the Self Management Strategy. The Principles provide a useful tool for underpinning any work being done to support self management.

The Principles reflect the approach people need from services and practitioners to enable them to take on the responsibility of self management.

The third Principle is;

'I am the leading partner in management of my health'

The Principles also form the basic criteria of the Self Management Fund for Scotland, and as such underpin each project.

Self Management Fund

The inclusion of peoples' experience in the design, development, implementation and evaluation of the 81 Self Management Fund

projects has been a key to their success. Working in a person-centred way to promote self management, all the projects have used the experiences of people to inspire and encourage others to become involved.

Neurological conditions have been reflected in the projects in a variety of ways;

- by involving peers in delivery and support
- by encouraging people to share information
- by encouraging people to develop new skills
- by working in partnership with other services

The 81 funded projects, and other examples of self management support across partnerships within the voluntary, health and social care sectors, have illustrated the value of maximising experience when designing and delivering services.

Neurological Alliance of Scotland

The Neurological Alliance of Scotland is an umbrella body of organisations and groups representing people living with or affected by a neurological condition. The Alliance was launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning.

Alliance members work together to support people affected by neurological conditions in Scotland to achieve the best quality of life through influencing policy, raising awareness and promoting the development of services.

The Alliance is interested in hearing experiences of what really matters to people when they receive services from health, social services or the voluntary sector or self manage your condition. They work to ensure the views and experiences of people affected by neurological conditions are fed back to the professionals delivering services.

Aims of the Alliance

The Neurological Alliance of Scotland 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.

They have three core aims:

1. To influence public policy in order to achieve the best outcomes for people affected by neurological conditions.
2. To raise awareness of neurological conditions in Scotland and their impact.
3. To work closely with member organisations, key stakeholders, healthcare professionals, national and local Government and others to improve the overall care of people affected by neurological conditions.

NHS QIS

NHS Quality Improvement Scotland (QIS) are a Special Health Board. They advise, support and assess NHS boards to help improve the quality of healthcare for the people of Scotland.

They have a lead role in supporting NHS boards and their staff in achieving their goals by:

- providing advice and guidance on effective clinical practice, including setting standards
- driving and supporting implementation and improvements in quality
- assessing the performance of the NHS, reporting and publishing our findings
- providing guidance on effective clinical practice, including setting standards
- driving and supporting implementation and improvement
- assessing the performance of the NHS and reporting our findings

NHS Quality Improvement Scotland is committed to an on-going work programme which began in 2007 and continuing over five years, to support continuous quality improvement within Neurological Services across Scotland (see appendix 3). This covers the three elements of the integrated cycle for improvement:

- advice and guidance,
- implementation and improvement support,
- assessment, monitoring and reporting.

Healthcare Improvement Scotland, a new improvement and scrutiny organisation will be launched on 1 April 2011. It will take over the current responsibilities of NHS Quality Improvement Scotland.

Learning from the Self Management Fund

Peer Support

'It's great to be in a group with others who understand – I'm not the 'only one' living with this' – Revive MS Support course participant

The value of peer led support, education and awareness raising can be seen directly and indirectly in the majority of projects. Although 14% of current projects are involved in formal direct peer support to encourage self management through sharing experiences, many others are reporting on the benefits of peer support informally in their programmes – see **PASDA, Alzheimer Scotland, Momentum and Revive MS Support** case studies.

Some further examples of are;

- **Headway Glasgow** have developed a self management programme for people living with Acquired Brain Injury (ABI). It is also running awareness raising workshops aimed at healthcare professionals. The organisation has worked with people affected by ABI to create the courses and plans to train interested participants as course facilitators so that the project will be sustainable
- **Carers of West Lothian** have developed a falls management programme for people with progressive neurological long-term conditions and their unpaid carers
- **Stammering Association Scotland** are working with people living with a stammer to support them to devise their own strategies for managing it - offering a monthly self management group by telephone, video conferencing or Skype for those who are unable to attend a self management group

Information

'Being one of the hub editors has been such a great experience for me. It's given me hope and built my confidence in my own ability, I am learning new skills and hope to use my new experiences to help me return to work'. – Rebecca Young, Action for M.E. project participant

The value of sharing information to encourage others to become involved in self management, to raise awareness of conditions and approaches and to increase understanding of the impact of self management can be seen in a number of the projects – see **PASDA, Momentum and Action for M.E.** case studies.

Some further examples are;

- **The Dystonia Society** have created a Dystonia specific self management programme
- **Confer** who are working with young people living with Neurofibromatosis to develop and facilitate an online resource and peer support network
- **Child Brain Injury Trust** are working with a group of young people with ABI to produce “hot topic” information resources. The information contained in the resources is that which young people and their families felt they needed

Developing skills

‘We realised we needed to adapt our programmes - the lived experiences of young men is a more powerful and effective tool for self management’ – Dorothy Strachan, Momentum

The value of capitalising on the personal, lived experience of people living with long term conditions, and their unpaid carers, as the starting point for developing new skills can be seen in many projects - see **Momentum, Alzheimer Scotland and PASDA** case studies.

Some further examples are;

- **EdMEsh** who are developing a programme in which people living with M.E. in Lothian are trained to deliver complementary therapies which are known to benefit people with the condition. These individuals then use their new skills to provide therapy sessions to others living with the condition
- **Drumchapel Disabled Action 2** are running a music self management programme for those living with stroke, MS and Parkinson’s. The course supports participants to see how they can use music technology to help manage certain aspects of their condition

- **Momentum** have developed an ABI self management programme aimed at young men living with an ABI in Grampian who do not engage with existing services. The course has been developed, implemented and delivered by young men from the area who are successfully self-managing

Partnership working

'I have learnt so much about the effects of lack of good sleep for people living with Parkinson's and their families – it was invaluable to be there from the start' – Parkinsons Consultant

Many projects are working in partnership to develop, implement and evaluate their projects – see **Parkinson's UK** case study.

Some further examples are;

- **Speakability** have developed a programme which supports people living with Aphasia to communicate effectively using computers. The organisation has worked collaboratively with technology and speech therapy experts from Queen Margaret University to create the programme. The course enables those with little or no communication abilities, as the result of a stroke, to self manage using specialised technology
- **Cornerstone** are working with members living with a learning disability to develop and launch two accessible toolkits providing self management information for those living with Epilepsy and Diabetes
- **Spina Bifida Scotland** are running a pilot health and fitness programme for those living with Spina Bifida

More details of all the improvement tools used by the funded projects, and the results they produce, will be available in the Final Evaluation Report for this allocation of the Self Management Fund after June 2011.

Conclusions

The Self Management Fund for Scotland has enabled projects to incorporate the experience of people living with neurological and neuro-developmental conditions, and those that care for them, throughout all aspects of their projects. The Fund is capturing the learning from these experiences, and has so far shown the value of;

- involving peers in delivery and support
- encouraging people to share information about their conditions
- encouraging people to develop new skills
- working in partnership

Projects supporting people living with neurological conditions are as varied and diverse as the range of projects supported by the fund in general. Projects are developing new ways to support people living with neurological conditions, and encouraging people to think differently about self management.

LTCAS will continue to work with partners, including the Neurological Alliance of Scotland and NHS QIS to promote and develop self management support for people living with neurological conditions.

For further information about LTCAS - our work and our membership – the Self Management Projects and the continued development of the Self Management Fund for Scotland, please see our website www.ltcas.org.uk

For further information about the Neurological Alliance of Scotland, please visit www.scottishneurological.org.uk

Case Studies



The following Case Studies illustrate the impact, emerging themes and learning points from the Self Management Fund in relation to neurological conditions.

- Action for M.E.
- Parents of Autistic Spectrum Disorder Adults (PASDA)
- Alzheimer Scotland
- Momentum
- Parkinson's UK
- Revive MS Support

The Case Studies also demonstrate the impact that LTCAS has had on shaping, expanding and sustaining these themes.

Action for M.E



Action for M.E. is the UK's leading charity dedicated to improving the lives of people with M.E. - providing information and support to people living with M.E.

Susan Webster, Project Co-ordinator, Action for M.E. Scotland

M.E. (Myalgic Encephalomyelitis/Encephalopathy), also known as Chronic Fatigue Syndrome (CFS), is a long term condition which affects many parts of the body, such as the nervous and immune systems. Common symptoms include persistent exhaustion or fatigue, muscle and/or joint pain, sleep disturbance and problems with memory and concentration.

Action for M.E received £42240 from the Self Management Fund for Scotland to develop an online 'hub' as an information and support resource for those living with M.E. The hub will be developed and maintained with and by people living with M.E., building on their experiences and including vital information that they themselves know will be valuable.

People living with M.E. who participated in a scoping exercise clearly identified their need for a centralised source of information and support that would support them to manage their condition. It was clear to Action for M.E. that being able to access this information and support online was essential for people living with M.E. So the organisation worked to respond to this need through creation of their resource.

'Our hub gives people the opportunity to overcome some of the barriers they face independently and in a way that works for them' – Susan Webster, Action for M.E.

For many people living with M.E., isolation is a huge barrier to effective self management, not just geographically but also in social, economical, emotional, educational and physical terms. The

online hub will contain the first searchable directory of services so that people can easily and simply find services that exist for them locally.

'There are many small support groups but they often don't have the resources to advertise locally or online, however they can publicise the brilliant work they do via the hub' – Susan Webster, Action for M.E.

As well as information, the online hub also provides virtual peer support through a forum for those who are often housebound by the condition. The forum enables people to share experiences, opinions and tips on self management in a way that is accessible and comfortable for them. This allows people to engage in a way that previous services perhaps were unable to.

'The forum has attracted people we've had no previous contact with' – Susan Webster, Action for M.E.

Action for M.E contacted LTCAS for some advice and support prior to submitting their application. Although their idea for the online hub was strong, they realised through discussion with the Grants Officer that the process of developing the idea for funding was not a 'pass or fail' test based on idea alone, instead it was a question of allowing the project to be developed and led by the needs of those living with M.E.

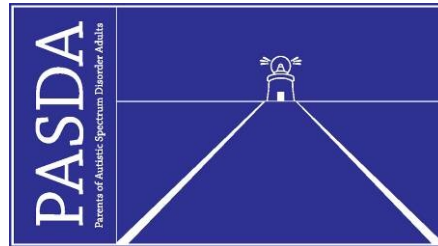
Through involvement of people living with M.E. at all stages of the design and development of the resource they are sure it will be a valuable resource. Action for M.E. hope that their online hub will become the first port of call for people all over Scotland looking for information and support about self management when living with this condition.

In addition, the project volunteers are gaining new skills and experiences which will in turn support their own self management.

'Being one of the hub editors has been such a great experience for me. Its given me hope and built my confidence in my own ability, I am learning new skills and hope to use my new experiences to help me return to work'. – Rebecca Young, project participant

For more information please visit www.afme.org.uk

Parents of Autistic Spectrum Disorder Adults



PASDA is a support organisation for parents and carers of adults on the autistic spectrum who live in Edinburgh and the Lothians. PASDA are also involved in promotional work to raise awareness among professionals and the public.

Karina Williams, Development Worker, PASDA

Parents of Autistic Spectrum Disorder Adults (PASDA) have been a constituted group since 2005, providing peer support and campaigning for service change. PASDA recognised however that they needed some professional support to develop, and applied to the Self Management Fund to employ a development worker.

'Nothing was changing for the PASDA parents, they were too busy and stressed with life to focus on developing the service' – Karina Williams

Some of the parents had experience of accessing complementary therapies to help reduce feelings of anxiety for their adult sons and daughters. They knew that aromatherapy sessions had previously allowed some people to open up more, feel more confident, build up relationships and learn new skills. All these are hard for people living with autism. They decided to create a project to develop support for complementary therapies, in addition to an A-Z support and information guide.

'At one point my daughter, who was in her twenties, was so anxious she wasn't speaking at all – the sessions were really positive and helped her to build up her confidence again' – parent

Originally, the aim of the sessions was to equip parents with skills in complementary therapies that they could then use with their sons and daughters. However it soon became clear that the sessions also enabled the parents to support each other. Through bonding and interacting in this way, parents were able to decrease their own anxieties, and increase their understanding of autism through sharing information with each other.

'You see the relief in people's faces when they meet other people in the same situation, often talking about the impact autism has on the whole family for the very first time' – course participant

Karina has worked hard to link with other professionals across Edinburgh and the Lothians, recognising the impact that the condition has on all aspects of people's lives – family, work, social, relationships and health. PASDA have included this type of information in their A-Z guide and on their website. The website has enabled new people to get in contact with the service, many of whom were not aware of PASDA or the support they could offer. PASDA would like to build upon the developments they have started, and are well aware that if they were in the position to grow they could support so many more people.

'It's been a great opportunity to network and link with other people and organisations – we've been able to achieve so much more as a result' – Karina Williams

PASDA are applying for additional funding to continue their work on self management, and to develop ideas that have come through from this initial project. Parents are asking for more training themselves on autism and some of the barriers to employment and relationships that it can bring. They are also keen to look at the impact of the condition on the mental health of people living with autism, their siblings and those that care for them.

'We'd like to have access to the same training that professionals have – it's often assumed that simply by living with someone on the autistic spectrum in your house you'll know everything' – parent

For more information please visit www.pasda.org.uk

Alzheimer Scotland



Alzheimer Scotland
Action on Dementia

Alzheimer Scotland helps people with dementia, their carers and families. Their members include carers, relatives, people with dementia, professionals, groups and organisations. Alzheimer Scotland provide local services all over Scotland for people with dementia and their carers.

Catherine Thomas, Fundraising Manager, Alzheimer Scotland

Alzheimer Scotland recognised that the Self Management Fund was a fantastic match with their work with people living with dementia and their families. Alzheimer Scotland had been working to promote the personalisation agenda. Personalisation is where people are empowered to direct their own support and families effectively combine state resources around their own natural supports – creating truly personalised support.

Alzheimer Scotland knew that some of the barriers to this way of working were around information and social support. However, the organisation knew from their experience that a standard training course wasn't the best way to go. They knew that they had to do things differently for different people to allow them to translate self management and personalisation into their everyday lives. Alzheimer Scotland wanted to set-up a 'Dementia Café' to allow carers and those living with the condition to share information and support in a more accessible and informal way.

'Each family has different needs so we look at how we can meet those needs and provide information according to their situation' – Claire Armstrong, Alzheimer Scotland

Alzheimer Scotland received some valuable support from the LTCAS team prior to submitting their application. There was so much they wanted to achieve to work towards the personalisation agenda. They were able to submit an application with clear aims and achievable outcomes, which showed the impact that they wanted to make, and how they had informed their idea by the experiences of people living with dementia and their carers.

'We wouldn't have been able to get where we are today without the support of LTCAS' – Catherine Thomas

Their self management project in West Lothian has encouraged people to take more control over their condition, to think differently about their support and to ultimately feel better with their lives. Using some of the tools and techniques that are shared, people have been able to make big changes to their lives and realise social benefits.

Carers too have been able to increase the information that they have at their fingertips. By learning about Memory Management carers are encouraged to use the techniques to make life easier. Carers have also benefitted from getting a regular break – really appreciating an hour or so with peers to talk about the condition and its impact, often for the first time.

'We have tried to encourage participation by offering a variety of environments and styles for the self management training' – Catherine Thomas

Through the project, Alzheimer Scotland have been able to raise their profile in West Lothian, and raise awareness of the condition. More local people are now fundraising for the organisation, and sharing information to let the local community know about their services and support

'The project has allowed us to significantly increase our presence and profile in West Lothian. We have built up new contacts and volunteers, and identified new areas of work' – Catherine Thomas

Alzheimer Scotland are keen to develop their work in West Lothian focusing on self management. Looking at alternative funding sources, they hope to link the learning from this programme with self directed support to continue to provide personalised support to people and their families.

For more information please visit www.alzscot.org

Momentum

momentum

Working with people to build an **equal** future



Momentum delivers a range of programmes supporting people living with Acquired Brain Injury (ABI) throughout Scotland to rebuild their lives following an injury or illness, while others will be aiming to gain employment for the first time.

Momentum has more than 50 years of experience assisting disabled and excluded people to realise their goals and achieve their potential.

Dorothy Strachan, National Brain Injury Manager

Momentum recognised that there were a high number of young men in Grampian living with an Acquired Brain Injury (ABI), often as a result of road traffic accidents on rural roads. Although the organisation provided a variety of rehabilitation services, many young men affected often found it difficult to engage with the programmes. Momentum recognised that in order to address this, staff would have to adapt their way of working. Momentum received £45,325 from the Self Management Fund to pilot a peer led ABI self management programme for young men in Grampian.

'We were surprised to find that what we as an organisation felt was "self management" was completely different to what the young men felt they needed to self manage' – Dorothy Strachan

Momentum's ABI services have always aimed to support individuals build skills and independence however, working through the process of applying for the fund, and getting valuable feedback on their idea and application from the Long Term Conditions Alliance Scotland Grants Officer, Momentum realised that, at times, they were promoting what they felt young men needed from their services rather than promoting individual self-management.

'We realised we needed to adapt our programmes - the lived experiences of young men is a more powerful and effective tool for self management' – Dorothy Strachan

Momentum recruited two young men living with ABI as peer leaders. They are working hard to connect with communities to incorporate information that the young men feel is important into the new course. The peer leaders have designed things to ensure that the content is adaptable and interchangeable so that the course can respond to individual needs in different rural areas. The main benefit that the young men are looking forward to is the opportunity to share information informally and talk about their experiences of living with the condition as well as sharing strategies and techniques for successful self management.

'The sessions before felt a bit like school, so in the end I didn't go back. Now there is going to be a course run by local guys my age telling me what I want to know and giving me tips that I will actually use. Its also be good to know that we can talk about anything- even sex!' – Course participant

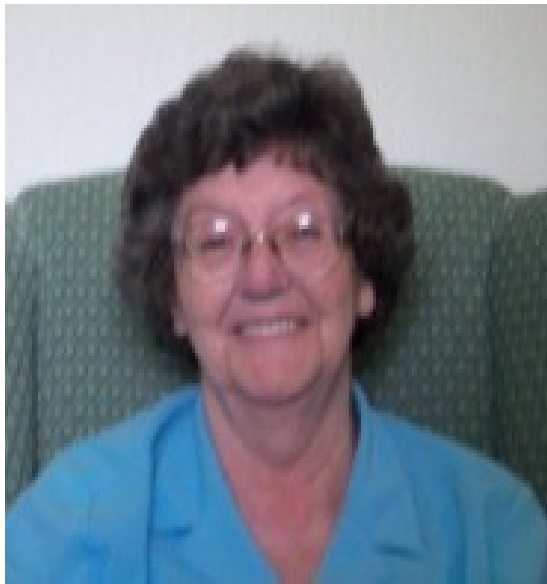
Momentum hopes to demonstrate the success of this type of model and share the learning from it widely. It hopes to build upon the success of this pilot course, and expand their peer-led course to other men across Scotland living with ABI or other conditions.

'This programme already has the potential to be a great success in Grampian. If this model works for young men in this area then there is no reason why it shouldn't work in other areas of Scotland' – Dorothy Strachan

For more information please visit www.momentumscotland.org

Parkinson's UK

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.



Parkinson's UK are the leading support and research charity for Parkinson's. For more than 40 years they have been working to find a cure and to improve life for everyone living with, or caring for someone with, Parkinson's. The Scotland team provide a range of support and information services as well as campaigning to raise the profile of Parkinson's.

Jean Ballantyne, Carer and Steering Group Member

Parkinson's UK knew that sleep had an impact on people's lives and that some specialist nurses felt confident to give support in sleep management – although this support often came in the form of a written information sheet. Jean Ballantyne, who cares for her husband Mel who lives with Parkinson's, suggested to Parkinson's UK that they apply for funding for a sleep project because of the hundreds of people they knew who are affected by little sleep.

Parkinson's UK were successful in their bid to the Self Management Fund to focus on this important area for 40% of people living with Parkinson's in Scotland and their families.

'In the 25 years since Mel was diagnosed, I could count on one hand the nights I'd had a 'good' nights sleep' – Jean Ballantyne

Gathering together a broad partnership of Nurse Specialists, Consultants, Sleep Counsellors, Psychologists, staff from Parkinson's UK and people with direct experience of Parkinson's, they set to work to find out more about the issue, and investigating the options for developing some standards for self management support in this area.

The different perspectives enriched the experience of the group. Jean was able to bring her practical experience, and that of many

other people who faced the daily battle that little or no sleep can bring, to highlight the emotional and psychological side of lack of good sleep and its impact on life with a long term condition.

'I have learnt so much about the effects of lack of good sleep for people living with Parkinson's and their families – it was invaluable to be there from the start' – Consultant

The programme that the group developed was based on generic materials from the Sleep Research Centre at Loughborough University, adapting them to reflect some of the specific issues of living with Parkinson's. The structured, step-by-step approach allows people flexibility to develop new techniques to manage their sleep better. The '10 Rules of Sleep Hygiene' included in the programme support a change of attitude towards sleep, shifting to a focus on a better quality of sleep rather than the number of hours. This shift in behaviours has been found to also improve self esteem and decrease feelings of depression, allowing people to interact more with their families.

Specialist Nurses and other professionals working to support people living with Parkinson's have also reported that they feel more competent in their skills and ability to offer an additional service to the families they are working with. People living with Parkinson's, and their families, have been encouraged to share their experiences to support the knowledge and qualifications that the professionals have.

'We can all relate to the issues lack of sleep can bring, with or without a long term condition' – Anna Lynall, Parkinson's UK

Parkinson's UK feel that this project is only just the start of work in this area. They hope to make the programme available to other professionals and people across the UK as well as other organisations supporting people living with different long term conditions.

'It seemed natural to me to suggest to the Scotland team that an application for funding looking at the impact of sleep could improve the quality of life for people living with Parkinson's' – Jean Ballantyne

For more information please visit www.parkinsons.org.uk

Revive MS Support



Revive MS Support is dedicated to helping everyone affected by Multiple Sclerosis. Over 10,000 people in Scotland live with MS.

Members of a Revive MS Support exercise group in Maryhill

Revive MS Support knew from experience that people living with MS, and their families, look for a variety of tools and techniques to support their self management. MS can be a highly complex, individual and unpredictable long term condition. A person-centred approach to self management and therapy is essential. Revive MS Support used their experience of therapy, information and support to develop a successful application to the Self Management Fund for £36238 focused on developing their exercise sessions and peer support.

'Being part of the exercise group makes me feel great – I never thought I could do it' – course participant

Revive MS Support planned their programme with a range of partners, including physiotherapists, MS Specialist nurses and counsellors. Local MS Society branches helped to spread the word about the sessions, and set-up consultation and information events to let those interested know what would, or could, be involved.

'We are now able to offer people living with MS much more choice in their menu of support' – Angela Feherty, partnerships Development Manager, Revive MS Support

Around 80% of people living with MS experience problems with their mobility. Revive MS developed a series of classes which involved more active exercise than previous classes, to support people to remain mobile through movement. People learn exercises and techniques which can they can keep going with at home, improving

their movement, sustaining their mobility and supporting their self management.

'The groups give me coping strategies, not just for life with MS, but life in general' – course participant

By sharing information and experiences from people 'further down the road', people living with MS have reported that they feel more knowledgeable, more confident in social settings, and more relaxed in sessions with therapists. Coming together with people in a similar situation is a significant element of the success of the sessions. The collective understanding contained within the group, and the relaxed social setting, make a real difference to how people manage their conditions.

'I feel better energy-wise, I can now last all day!' – course participant

Revive MS Support now run successful support sessions in a variety of locations throughout the West of Scotland. This allows people to benefit from the services without having the additional stress of travelling to the main centre in Maryhill.

The exercise and peer support sessions are regularly supplemented with Information Evenings, where health professionals are invited to come and discuss different aspects of the condition. This valuable access to information in a less formal setting has proved to be particularly important to people newly diagnosed with the condition.

'It's great to be in a group with others who understand – I'm not the 'only one' living with this' – course participant

Revive MS Support have been able to demonstrate the benefits of exercise together with peer support and access to information and other services. They would very much like to continue to provide and develop these valuable support services beyond the funding period of this project.

'It's 50% social – I love the company while I exercise, going at my own pace feeling stronger and stronger' – course participant

For more information please visit www.revivemssupport.org.uk

Principles of Self Management

July 2008

Principles: Self Management Health, Social and Voluntary Sectors

"Be accountable to me and value my experience"

Evaluation systems should be ongoing and shaped by my experience. They should be non judgemental and focus on more than medical or financial outcomes.



"I am the leading partner in management of my health"

I am involved in my own care. I, those who care for me and organisations that represent me, shape new approaches to my care.

"I am a whole person and this is for my whole life"

My needs are met along my life journey with support aimed at improving my physical, emotional, social and spiritual wellbeing.

"Self management is not a replacement for services. Gaun yersel doesn't mean going it alone"

Self management does not mean managing my long term condition alone. It's about self determination in partnership with supporters.

"Clear information helps me make decisions that are right for me"

Professionals communicate with me effectively. They help ensure I have high quality, accessible information. They also support my right to make decisions.

What is a Neurological Condition?

There are an estimated one million people in Scotland living with a neurological condition that has a significant impact on their lives. The most common physically disabling condition affecting young people, multiple sclerosis (MS), has a particularly high prevalence in Scotland compared with the rest of the UK.

Neurological conditions account for a high proportion of disability, particularly severe and progressive disability, in the population.

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. Problems of the nervous system usually affect the brain and spinal cord and the nerves and muscles in the body.

An injury or illness, such as a head injury or stroke, meningitis, or cancers of the brain and spine can cause a neurological condition. Some neurodegenerative conditions, such as multiple sclerosis and motor neurone disease, occur mainly in adulthood and are progressive, causing deterioration over time. This means that a person's ability to live independently eventually becomes difficult and they will rely more on appropriate services to assist them.

Most neurological conditions affect people's quality of life and some will cause life-long disability. It is important that people affected by a neurological condition receive the right care and treatment at the right time. Many neurological conditions can be dealt with in primary care and in the community though some people will have to be referred to more specialist services for investigations. Diagnosis of a neurological condition is often made by a neurologist following diagnostic investigations. Sometimes, however, a diagnosis cannot be made.

In general, neurological conditions are not well understood by the general public. Levels of awareness are low even about some of the more common conditions such as epilepsy. As a result of this people with a neurological condition may face stigma and unhelpful attitudes from others.

Neurological Symptoms

Some people experience functional and dissociative neurological symptoms including functional weakness and dissociative (non-epileptic) attacks. These are neurological symptoms that are

genuine (and not imagined) but not due to a neurological disease. Instead they are due to a problem in the way the nervous system is working.

Symptoms like these are surprisingly common but can be difficult for patients and health professionals to understand.

www.neurosymptoms.org is a free self-help website written by a neurologist with a special interest in these problems which aims to give a better understanding of these symptoms. There are links, downloads and personal stories relevant to many different types of symptoms that can be experienced as part of these problems including pain, memory problems and abnormal movements.

(see www.scottishneurological.org.uk for more details)

Appendix 3

Neurological Services Standards Implementation Programme

NHS QIS published evidence-based Clinical Standards for Neurological Services in October 2009 and they were formally launched in January 2010. The development of these standards was the first part of this programme, and since this work first started, we have been reviewing our strategic direction and undertaking a shift in working functions by formally supporting the implementation of our advice and guidance as a fundamental part of our activities.

The Neurological Services Standards Implementation Programme is a two year programme in the first instance, which aims to build on the progress of the Standards so far and:

- support NHS Boards to improve neurological health services and achieve the clinical standards
- build improvement capacity and capability amongst frontline staff and managers
- work with key stakeholders to build a culture of improvement that will result in measurable improvements in neurological services for patients in Scotland

This project is led by:

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Appendix 4

Useful Links

Long Term Conditions Alliance Scotland

www.ltcas.org.uk

Gaun Yersel – the Self Management Strategy for Long Term Conditions in Scotland

www.ltcas.org.uk/self_man_gaun.html

Neurological Alliance of Scotland

www.scottishneurological.org.uk

NHS QIS

www.nhshealthquality.org

Long Term Conditions Action Plan

http://www.sehd.scot.nhs.uk/mels/CEL2009_23.pdf

Long Term Conditions Community

www.knowledge.scot.nhs.uk/ltc.aspx