# IMPACT

an evaluation of the

Self Management Fund for Scotland 2009-2011







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### Foreword

The Service Fund was expressed and service Fund was expressed

The Self Management
Fund for Scotland
was established in
2009 and was a key
recommendation in
Gaun Yersel, the
Self Management
Strategy for Long

Strategy for Long
Term Conditions
in Scotland. The
Fund was taken
forward through
the National
Long Term

Conditions Action Plan. The Long Term Conditions Alliance Scotland (LTCAS) consulted widely with voluntary and community groups prior to establishing the Fund, strengthening and promoting the criteria that people with long term conditions were to be included in the design, delivery and evaluation of all projects. Eighty one projects across Scotland were successful in sharing the £4million initial allocation.

I am delighted to support the publication of this report, coming at the end of the first allocation of the Self Management Fund for Scotland. I am grateful to the Long Term Conditions Alliance Scotland, in partnership with the Scottish Government, for developing such an innovative fund that has ultimately supported such a vibrant and inspirational set of projects, initiatives and approaches to self management from all across Scotland.

Supporting Self Management is, and remains, a priority for the Scottish Government. It is clear from this report that the Self Management funded projects also contribute to achieving many aspects of the Healthcare Quality Strategy. I am

impressed how the funded projects have been able to demonstrate a measurable impact on each outcome and act as a key indicator for improvement.

I am especially pleased that the report shows clearly the involvement of people living with long term conditions, and their carers, in the design, delivery, implementation and evaluation of services and approaches that are intended to improve their lives.

There is more work to be done, but thanks to the organisations and individuals highlighted in this report, we are well on our way. I look forward to continued partnership working and developing innovation in self management which will support people with long term conditions to live the lives they want to, and deserve.



#### Nicola Sturgeon MSP

Deputy First Minister and Cabinet Secretary for Health, Wellbeing and Cities Strategy



# Overview and Background

The Self Management Fund has been available to voluntary organisations and community groups throughout Scotland since March 2009. 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 be become active partners in their own care – see **Scottish Government** Case Study (Will Scott).

The voluntary sector has an excellent track record in supporting communities, and the Self Management Fund has built upon this. In challenging times, economically and socially, this has never been more important.

The Self Management Fund aimed to support projects and organisations which

maximise the experience of people living with long term conditions, and their unpaid carers, to work in partnership with health and social care professionals.

The Self Management Fund has been set-up and administered by Long Term Conditions Alliance Scotland (LTCAS). The process has been supported and managed by the Director of Self Management and one Grants Officer, with additional support from the Finance and Admin team. An independent Grant Allocation Panel was formed to assess the applications – see **Grant Allocation Panel** case study.

The Self Management Fund was launched, following extensive consultation with LTCAS members and other stakeholders, in March 2009.

ROUND	OPENED	DEADLINE	DECISIONS	ALLOCATED
One	March 2009	May 2009	July 2009	September 2009
Two	August 2009	October 2009	January 2010	February 2010
Three	January 2010	March 2010	May 2010	July 2010

This Evaluation Report looks at how the aims and objectives of the Self Management Fund have been realised, and focuses on the processes involved. The Evaluation Report will also look at the impact the Fund has had – focusing on the outcomes, benefits and learning from the projects. The collective, common themes and ideas from the projects are included with this report.



## What did we do?

#### **Projects**

The Self Management Fund supported **81 projects** across three funding rounds, allocating the full **£4 million** available.

ROUND	APPLICATIONS	£REQUESTED	SUCCESSFUL	£ALLOCATED
One	67	£7.6 million	16	£1,311,843
Two	90	£4.8 million	40	£1,973,762
Three	62	£1.75 million	25	£714,394
total	219	£14.15 million	81	£3,999,999

## Aims of the fund 2009 - 2011



#### Aim of the Self Management Fund

The Self Management Fund was established by LTCAS and funded by the Scottish Government. The fund was seen as a crucial part of LTCAS taking forward the Self Management Strategy - Gaun Yersel. The aim of the strategy and hence the Fund was:

to stimulate change across Scotland so that people with long term conditions have access to the support they need to successfully manage their lives

The Self Management Fund was 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.

Prior to the Self Management Fund, voluntary organisations like Arthritis Care UK and the MS Society developed and pioneered lay-led self management programmes based on the Stanford Model. Diabetes UK developed a clinician-led condition specific programme.

(http://patienteducation.stanford.edu/
programs)

#### Objectives of the Self Management Fund

The Self Management Fund has provided a unique opportunity for community and voluntary organisations. The fund set out to strengthen new ideas, developments and existing approaches in self management. The Self Management Fund had the following core criteria:

- To fund projects that will build the capacity of people with long term conditions to effectively self manage
- To fund projects which encourage new approaches to self management
- To fund projects which enable people with long term conditions to take a leadership role in delivering and promoting self management
- To fund projects that work together with public services to support the principles of the Self Management Strategy



The Self Management Fund has supported **132,789 people** across Scotland to learn more about their long term condition, and work in partnership with health and social care professionals to improve the quality of their lives.

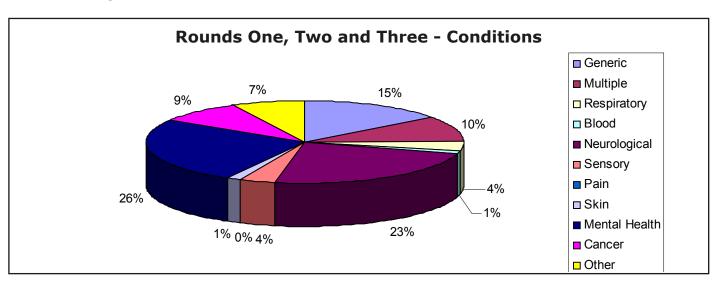
The Self Management Fund also

- Created **104 jobs** in the Third Sector
- Created at least **386 volunteering opportunities** throughout Scotland

#### **Conditions**

The Self Management Fund has funded projects expanding support for a wide **range of conditions.** 26% of the projects deal with mental health conditions. 23% of the projects deal with neurological conditions.

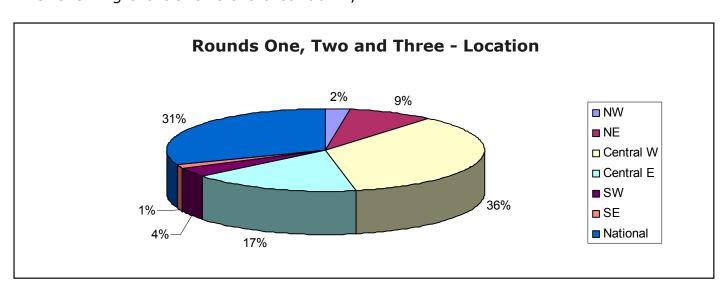
The following chart shows the breakdown;



#### Location

The Self Management Fund has increased projects with a **geographical spread** all over Scotland, including a third of projects with a national perspective.

The following chart shows the breakdown;

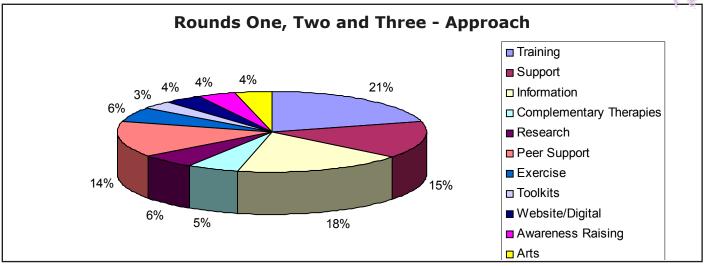


#### **Approaches**

The Self Management Fund has increased projects which have developed a **range of approaches** to self management. 21% of projects developed training programmes. 18% looked at the provision of information.

The following chart shows the breakdown;

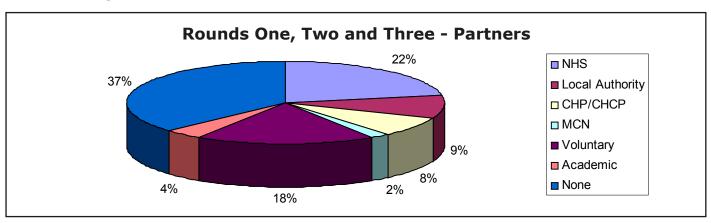




#### **Partnerships**

The Self Management Fund has expanded projects based in the voluntary and community sector, which have **worked in partnership** with others to achieve their goals. 63% of projects have worked with at least one partner.

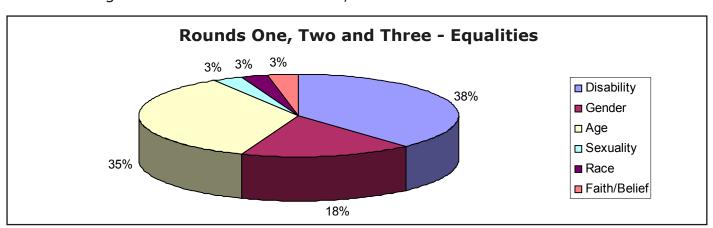
The following chart shows the breakdown;



#### **Equalities**

The Self Management Fund has improved the range of projects covering all of the six **equalities** areas. 38% of projects deal with disability. 35% of projects deal with age.

The following chart shows the breakdown;



A full list of projects funded, giving more detail on the areas highlighted above, can be found in Appendix 1.



# What difference did we make?

#### **Impact**

The 81 projects across Scotland represent a diverse range of ideas, conditions, equalities groups, locations and partnerships. Strategic Projects have generally worked to influence a change in culture to support self management. Main and Small Projects have generally developed and supported resources and services to improve people's access to and use of self management.

## Collectively the projects have demonstrated;

- increased self management support available
- increased self management information available
- increased involvement of people living with long term conditions and their unpaid carers
- increased partnerships across sectors to support self management
- increased peoples abilities to self manage
- increased resources to support self management
- decreased dependence on traditional services and support

#### To fund projects that will build the capacity of people with long term conditions to effectively self manage

The Self Management Fund has **increased** the range of projects which improve the capacity of people living with long term conditions to effectively self manage. This is the overall aim of all 81 projects. However, several key Strategic Projects have worked towards building capacity in different areas.

Some examples of these are;

- SAMH have worked to improve mental health and wellbeing through physical activity and sport. SAMH have worked with four partner organisations, supporting 512 participants to improve their mood, sleep better, improve confidence, improve relationships, increase engagement and decrease stigma – see SAMH case studies
- People First have worked with 130 people living with a learning disability to investigate what self management means for them resulting in wider consultation and policy development see People First case study
- Thistle Foundation have developed an inter-disciplinary, cross sector learning community for self management, aimed at changing the culture through the promotion of Change Champions. Thistle worked with 15 partners to train 263 practitioners and support 11 Change Champions – see Thistle Foundation case study
- Men's Health Forum Scotland –
  have supported 285 delegates in 45
  training days to increase the capacity
  of a range of agencies supporting self
  management to engage with men, and
  to respond to the specific needs of
  men

# To fund projects which encourage new approaches to self management

The Self Management Fund has increased the number of projects which look at support for self management in a new way, or develop an existing approach for a new condition or group – see COMAS, Pink Ladies, Carr-Gomm Scotland and SKS Scotland case studies Some further examples of these are;



- EdMEsh have trained 8 therapists to deliver 119 sessions of complementary therapies to 36 members of EdMEsh, increasing their confidence to self manage, improving peer support and reducing isolation
- No Strings Attached have developed the skills and understanding of 10 young people living with asthma through music based activities, resulting in an 100% increase in average peak flow readings, 50% decrease in coughing/wheezing, 40% increase in confidence resulting in taking part in other activities, increased attendance at clinic appointments and a decrease in time taken off school
- Deafblind Scotland have empowered 9 deafblind people to learn self management techniques from each other through drama group exercises, peer support, writing and performance
- Community Health Shop –
  have delivered 615 sessions of
  complementary therapies to 35 people
  increasing flexibility, mobility relaxation
  and decreasing pain
- Glasgow West Regeneration
   Agency explored the use of arts as a
   medium for self management of mental
   health conditions, supporting 20 people
   to write 53 poems, 4 short stories,
   42 pieces of art and 8 songs to build
   confidence, self esteem and wellbeing,
   and reducing social isolation

To fund projects which enable people with long term conditions to take a leadership role in delivering and promoting self management

The Self Management Fund has **increased** the number of projects

which have people living with long term conditions at the heart of their design, delivery, evaluation and implementation. Many projects have been led by people living with long term conditions, and the experience and insight they bring – see Diabetes UK Scotland, Parkinson's UK, Action for M.E. and Momentum case studies

Some further examples of these are;

- Strathclyde Lupus Group have raised awareness and increased knowledge of Lupus and self management among medical professionals in training
- Clydeside Action on Asbestos have developed self management support groups in Aberdeen and Ayrshire supporting 33 people to increase their confidence, improve their breathing and decrease their social isolation
- Breast Cancer Care have supported 199 women to learn more about the management of their condition, increasing confidence, increasing the use of self management strategies, increasing awareness of side-effects of medication, increasing awareness of symptoms of recurrence and increasing knowledge of where to find additional support
- Speakability have supported 26 participants living with aphasia to increase their use of computers and share their knowledge, skills and experiences with others
- The Dystonia Society trained 4 peer trainers to deliver a condition specific self management course to 54 participants, improving access to information, improved ability to cope with pain and fatigue and an increased ability to plan



# What difference did we make?

# To fund projects that work together with public services to support the Principles of the Self Management Strategy

(Gaun Yersel – The Self Management Strategy for Scotland, see also Appendix 2)

The Principles of Self Management were developed by people living with long term conditions, and their unpaid carers, to illustrate the five most important aspects of self management support from their perspectives. The Self Management Fund has **increased** the number of voluntary organisations working in partnership with other public services to bring the Principles of Self Management to life – see **Post Natal Depression Support Network, PSALV, Alzheimer Scotland and IntoWork West Lothian** case studies

Some further examples of these are;

Be accountable to me and value my experience

Ayrshire Cancer Support – have delivered 16 workshop sessions, with 3 aimed soley at NHS staff, with 115 attendees teaching relaxation and hypnotherapy techniques which have increased the ability to relax, reduced anxiety, improved sleep and reduced stress

**Crichton Hale and Hearty** – have worked with local NHS staff to improve self management for their heart failure group, increasing peer support and reducing social isolation

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

Asthma UK Scotland – have worked in partnership with Asthma Nurses and schools to increase awareness of asthma and self management among 119,000 people, resulting in an increase in self management plans, 75% of participants attending for a asthma review and 95% of schools implementing an Asthma Plan

**Cornerstone** – have developed toolkits to support people living with a learning disability who additionally have epilepsy or diabetes to support self management, with 67% of participants reporting an increase in understanding, with 52% reporting increase skills and knowledge

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

**Penumbra** – have worked to increase self management for people with mental health conditions through the promotion of self directed support to 1000 people and training 235 social care staff to increase Self Directed Support Champions and influence the culture of self directed support

Waverley Care – have developed a self management and life coaching programme for 110 people living with HIV and Hepatitis C, with 34% decreasing demand on NHS services, 63% decrease in missing work due to poor health and 49% having increased emotional and mental health



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

Clear information helps me make decisions that are right for me

Promoting A More Inclusive
Society (PAMIS) – who have worked closely with education, social work and health professionals to bridge the transitions gap between Children and Families services to Adult services for 53 families of people living with profound and multiple learning disabilities, resulting in 84% of carers feeling better able to cope

British Lung Foundation - have enabled 116 people across 5 health boards to access self management support through telehealthcare, with 95% of people being more able to control their breathing and 81% feeling comfortable using the technology.

**PBC Foundation** – have led 15 self management workshops, supporting 191 participants to gain information and support to improve self management, enable positive decisions to be made, increasing confidence and decreasing isolation among people living with the condition. PBC have also visited 115 GP's to distribute their self management information pack.

Action for Sick Children Scotland – have supported 276 young people in Lanarkshire to access information and support which has increased awareness of self management and knowledge of long term conditions.

# Challenges and Changes



As a new initiative, the Self Management Fund has increased the opportunities for people living with long term conditions in Scotland to engage with self management support. However, many of the successful organisations have found common challenges in delivering their ideas in practice.

#### **Timings**

The timescales for funding rounds, and delivery of individual project outcomes have been tight. Although money has been available over two funding years, in reality funds have been available to organisations for less time. The first round of projects received their funding in September 2009 and were required to complete their project by March 2011.

This meant a total of 19 months of funding was available. Timescales for the second round were tighter, again projects were required to be completed by March 2011.

To increase the capacity of projects in the third round to deliver successful outcomes, the timescales for completion were extended to June 2011.



## Challenges and Changes

#### Recruitment

Many organisations faced difficulties in recruiting specialist staff to lead their projects. The nature of the fund recognises that people living with long term conditions themselves have a wealth of knowledge, skills and experience to bring to self management support. However in seeking to harness this experience, many organisations have taken longer to recruit than usual.

To expand the range of people living with long term conditions who are involved in self management projects, projects worked with LTCAS to revise their project plans and timescales to accommodate recruitment issues.

#### **Planning**

Many organisations seemed well planned on paper, but faced issues on getting their projects started, often due to the issues highlighted above. This was particularly true of projects in the initial rounds of the fund.

Two of the projects originally allocated funding returned the full amount as a result of not being able to deliver following issues internally.

To decrease the number of projects varying from their plan, LTCAS worked with organisations to find solutions and alternatives which still supported the outcomes of the projects to be sustained.

To support organisations who were struggling financially, LTCAS administered a Top-Up Fund allocation to 19 projects using the returned funds from projects unable to deliver.

#### **Partnerships**

Many of the projects have reported a lack of interest or support from partners across the NHS and Social Care to engage

with them on their projects, resulting in a change of direction or emphasis for some projects.

To support organisations to form partnerships and collaborations, LTCAS hosted a number of networking and showcase days to raise awareness of the individual projects and the benefits their work could bring.

#### **Funding**

Several projects faced reduced funding, or lost their core funding completely, during the period of the Self Management Fund, impacting on their ability to deliver or sustain their project.

To support projects facing difficulty, LTCAS administered a Top-Up Fund opportunity, agreed to extension periods and supported organisations to secure additional funds.



## Learning and Unexpected Outcomes



#### **Themes**

In addition to the overall objectives of the Self Management Fund, several key themes have emerged from the collective projects which expand the overall aim;

to stimulate change across Scotland so that people with long term conditions have access to the support they need to successfully manage their lives

This report highlights the common themes that have emerged from funded projects as well as some key learning points.

Common themes across all 81 projects have been

- an increase in capacity to self manage
- an increase in confidence
- an increase in understanding of condition
- a decrease in social isolation

This section looks at some of the main themes in more detail.

#### **Learning and Sharing**

A key feature of the Self Management Fund has been sharing and spreading the learning generated from the projects. The projects have also been encouraged to work together and learn from each other.

LTCAS has increased the opportunities for organisations to learn and share with each other by providing shared training, networking and Showcase sessions to bring the diverse projects together.

LTCAS, in partnership with Evaluation Support Scotland, provided Evaluation Workshops for the successful projects. These projects increased the organisations understanding and capability to evaluate their individual projects, but also improved their capacity to learn and share with other organisations working in a 'Self Management Community' – see **Hearing Link** case study.

#### Capacity/Sustainability

Organisations have had positive and negative experiences of developing their capacity to deliver self management support, and sustaining their ideas beyond the life of the fund.

- Organisations such as MS Society have been asked by service providers and NHS partners to expand their delivery beyond their current resources
- Parkinson's UK have been asked to share their positive experiences with other groups and organisations across the UK – see Parkinson's UK case study
- Pink Ladies have established a long waiting list to join their group, and are uncertain if they will be able to secure future funding to enable them to continue – see Pink Ladies case study
- Some organisations, such as
   Mental Health Aberdeen and the
   Castlemilk Stress Centre have
   seen their core funding cut severely.
   They have both worked with LTCAS
   to find alternative models to deliver
   their project outcomes, which has
   helped not only to sustain the
   project, but also the future of the
   organisation

#### **Personal Experience**

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 a project, idea or service can be seen in the majority of the 81 projects – see Parkinson's UK, Pink Ladies, PSALV, Momentum, Moray Carers and Action for M.E case studies.



## Learning and Unexpected Outcomes

#### **Peer Support**

The value of peer led support, education and awareness raising can be seen directly and indirectly in many projects. 14% of projects have a direct peer support element, but the majority of others have reported on the benefits of peer support in their programmes - see Pink Ladies, PASDA, Momentum and Revive MS Support case studies.

#### **Exercise and Activity**

Several projects have demonstrated the importance of exercise, movement and activity in self management support – see Revive MS Support, Angus Cardiac Group, Active4All case studies.

- Spina Bifida have supported 30 people and carers to attend fitness sessions, health checks, gym facilities and exercise programmes, with 88% reporting that they have benefited from exercise
- Drumchapel Disabled Action 2
   have supported 14 people to attend
   music and movement sessions
   to improve co-ordination, self
   esteem and confidence to aid self
   management
- Braveheart have supported 141 people across 12 peer support groups living with Coronary Heart Disease and Type 2 Diabetes to make improvements to their health and wellbeing, increasing confidence and promoting a positive attitude towards a 'healthier lifestyle'

## Emotional and Psychological Issues

Many projects have highlighted the emotional and psychological impact that living with a long term condition can bring, and some alternative solutions that they have developed – see LCIL, Parkinson's UK, SKS Scotland, Pink Ladies, PSALV and Hearing Link case studies.

- Tagsa Uibhist supported 14
   people in the community to manage
   their mental health and wellbeing,
   reducing social isolation, increasing
   mental and emotional wellbeing and
   increasing awareness of where to
   find help
- Healthy Valleys have supported 57 people to increase their ability to manage stress, reporting a 34% reduction in recorded stress levels
- Glasgow Association for Mental Health (GAMH) have supported 198 people to learn about complementary therapies and mindfulness to improve mental health and wellbeing, resulting in a 71% improvement in physical ability, 63% people feeling more able to cope in a caring role and 91% people reporting an improvement in being mindful
- Health in Mind have supported 50 people to develop Wellness Recovery Action Plans (WRAP) to decrease feelings of isolation and increase feelings of hope and participation



#### Choice

The Self Management Fund has increased the range of choice of support for self management. As an example, organisations working with people living with M.E. have developed different approaches to support their self management.

- EdMEsh have expanded skills and capacity to deliver complementary therapies to support health and wellbeing
- Action for M.E. have developed information resources to enable people living with the condition to self manage more effectively – see Action for M.E case study
- SKS Scotland have explored models of employment that reduce the likelihood of people living with the condition having to give up work – see SKS Scotland case study

#### **Information**

Several projects focused on improving access to high quality information to support self management – see **Action for M.E.** case study.

- RNIB have delivered 30 awareness raising sessions and distributed 600 information packs to educate and inform peers and professionals about life for young people who are blind or partially sighted
- Disability Information and Support In Perth (DISIP) have supported 32 people to attend a self management course and access local information which signposts them to relevant supports to improve self

management, increase individuals ability to deal with challenges and increase a sense of control and empowerment

- Scottish Huntingtons Association have created a Road Map resource to support individuals and families who have received a diagnosis of Huntingtons, or who have lived with their diagnosis for some time but are now experiencing symptoms
- Target Ovarian Cancer have distributed 831 copies of their self management guide and supported 75 women at 3 events across Scotland to increase knowledge, increase sharing of experiences and increase awareness of other services that are available to support self management

#### **Cost Effective**

The Self Management projects have been able to demonstrate significant outcomes for people living with long term conditions and their unpaid carers, with a relatively small investment. £4 million has been invested over 2 years, supporting 81 projects to develop self management support, and share their learning.

The 79 projects (2 returned their funds to LTCAS) who completed in June 2011 have supported **132,789 people** to learn more about self management, with an investment of just under £4 million. This represents an average investment of £29.61 over the life of the projects per person who have directly benefited.

# Conclusion

The Self Management Fund for Scotland has been successful in meeting its aims and objectives to;

- To fund projects that will build the capacity of people with long term conditions to effectively self manage
- To fund projects which encourage new approaches to self management
- To fund projects which enable people with long term conditions to take a leadership role in delivering and promoting self management
- To fund projects that work together with public services to support the principles of the Self Management Strategy

LTCAS has been further able to demonstrate an impact in making a significant difference towards;

- Enhancing awareness of the Self Management Fund
- Improving the quality and range of applications
- Expanding networking and sharing opportunities
- Increasing the partnerships between the voluntary, health and social care sectors

#### **Future**

To capitalise on the sharing and learning that the Fund has so far produced, future projects could develop the common themes that are showcased in this report which show the value of:

- peer support
- co-production of services
- exercise and activity
- appropriate emotional and psychological support
- support to develop skills and employability

LTCAS has produced a discussion paper for the Future of the Self Management Fund and would welcome continued support from the Scottish Government to fund self management activities and developments – see **Scottish Government** case study (Tim Warren).

These themes and developments will continue to support the person-centred, effective and safe ambitions of the NHS Scotland Quality Strategy.

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







The following Case Studies illustrate the impact, themes and learning points that the Self Management Fund has increased.

- Scottish Government –
   Will Scott
- Scottish Government Tim Warren
- Diabetes UK Scotland
- Pink Ladies
- Parkinson's UK
- PSALV
- Action for M.E.
- SKS Scotland
- Momentum
- Revive MS Support
- Hearing LINK
- COMAS
- Post Natal Depression Support Network
- Moray Carers
- Lothian Centre for Inclusive Living
- PASDA
- Alzheimer Scotland
- IntoWork West Lothian
- Carr-Gomm Scotland
- Angus Cardiac Group
- Active4All
- SAMH Get Active
  - o Get Active Aberdeen Foyer
  - o Get Active Street Soccer
  - o Get Active Branching Out
  - o Get Active Ayr United Football Academy
- Thistle Foundation
- People First
- Grant Allocation Panel

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







# Scottish Government – Long Term Conditions Unit



Will Scott, Former Head of the Long Term Conditions Unit

The Long Term Conditions Unit, part of the Health Directorate, is working in partnership with LTCAS to implement the Quality Strategy, Long Term Conditions Action Plan and the Self Management Strategy.

As Head of the Long Term Conditions Unit within the Scottish Government Health Directorates during the time the Self Management Fund was being established, Will Scott was passionate about supporting ways to ensure that people living with long term conditions had more control over and confidence in managing their conditions. Will was involved in supporting the setting up of LTCAS, the publication of Gaun Yersel' and making sure its key recommendations on self management were reflected in the Government's Long Term Conditions Action Plan (June 2009). Will was a member of the Grant Allocation Panel that had responsibility for selecting successful projects to fund.



Self management for me is about making life better for people - Will Scott

Will recognised that as a membership organisation LTCAS had the ability to look at using the Self Management Fund to extend established approaches across a wider range of conditions, as well as opening the doors to real innovation. The partnership between LTCAS and the Government around the Fund was unusual, but represented a very good example of the Government's policy on working with the Third Sector.

It was important for the LTC Unit not to have any preconceived ideas for the Fund, and LTCAS were able to be innovative in designing it

- Will Scott

Working as part of the Grant Allocation Panel, Will was keen to ensure that collaboration and partnership with the statutory sector were at the heart of the proposals that were supported. Will was keen that projects had robust evaluation plans that would help to support the learning that would emerge to spread and be sustained, no matter what level of grant was awarded.

Self management is not a one-way street, and I was keen that funded projects reflected genuine partnerships recognising the work of the Third Sector - Will Scott

Overall, Will hoped that his role in the process had been a positive one. He recognised the role of LTCAS in supporting organisations to submit strong applications as an essential element of the Funds success. Will was pleased that the Fund was able to support such a high quality of projects, covering a broad range of conditions and approaches across both physical and mental health in all areas of Scotland, reflecting National and Local priorities.

We've started to
demonstrate a process of
continuous improvement with
self management in Scotland
that others will be envious
about - Will Scott

Will also hoped he had been able to provide a valuable and helpful role in making connections between ideas, partners and strategies while at the same time bringing objectivity to the Grant Allocation Panel. The process also helped to boost Will's own understanding of how the Third Sector worked, which in turn benefited his work and role within the Panel.

The successes of the Fund should be seen as part of wider changes and initiatives, continuing to change relationships and raise awareness - Will Scott

Will had shared with LTCAS some thoughts about ways in which the grant application process might be improved, and is optimistic about the future for self management in Scotland, recognising that there is still much work to be done to spread the message across all sectors, and that the Government has a responsibility here, as an aspect of its contribution to the partnership with LTCAS.



# Scottish Government – Long Term Conditions Unit



Tim Warren, Policy Lead for Self Management, Scottish Government

The Long Term Conditions Unit, part of the Health Directorate, is working in partnership with LTCAS to implement the Quality Strategy, Long Term Conditions Action Plan and the Self Management Strategy.

Tim Warren joined the Long Term Conditions Unit as Policy Lead for Self Management in 2011, taking over from Will Scott in 'sponsoring' LTCAS and the Self Management Fund for the Scottish Government. Tim was acutely aware of the importance of self management throughout all levels of health and social care and support in Scotland, especially in the light of the changing demographics, which indicate that services delivered as they have traditionally will not be sustainable.

Traditional models of support miss out on the assets that people bring to the situation - Tim Warren

Tim was immediately impressed by many of the projects supported through the Self Management Fund for Scotland, which he saw built upon people's strengths, to respect and advance capacity. For Tim, the self management approach seemed 'right', working with people, in partnership with professionals, to achieve shared goals.

Relationships are at the core of making sure self management works – people need respect and understanding to be effective - Tim Warren

Tim is aware that in order to sustain the good work that the funded projects have been able to deliver, systems need to be in place to capture the information and support that people need locally, and in line with their health literacy levels. Tim was really interested to learn about the range of projects, conditions, approaches, locations and partnerships that the fund has supported.

I've been impressed with the engagement LTCAS have had with our team, demonstrating the impact that the projects were having as they went along - Tim Warren

Tim has been able to see that the projects have been enabling and empowering for people living with long

term conditions, but has also been encouraged by the change in culture that the projects have fostered. Tim would like to see measures in place to demonstrate the value that the interventions like those delivered by these projects can bring, to act as a lever for further and additional support.

Self management is not a luxury, an extra support to make people feel happier – it's essential to making sure that services in Scotland continue to improve – I want services that my family will be able to access to be better than those in my parents generation had access to - Tim Warren

Tim's vision for the future is that people who are newly diagnosed with a long term condition are supported to experience high quality services and support, provided seamlessly, to sustain them in managing their conditions. Tim recognises that there needs to be a focus on the core organisations and partnerships that are involved to sustain this, working together. Tim sees communication and information as key – with health and social care professionals working in partnership with people and a range of community organisations, to support people to live fuller lives.

Tim is clear that LTCAS and the Self Management Fund projects are showing the way forward with self management support, and realises that on-going funding will be required to continue to develop and improve systems and services in Scotland.

# Diabetes UK Scotland

**Diabetes UK is the largest** organisation in the UK working for people with diabetes, funding research, campaigning and Diabetes helping people UK live with the condition. In Scotland **Scotland, Diabetes UK** aim to influence healthcare provision and improve services for people with diabetes at a local level.

Diabetes UK Scotland applied to the Self Management Fund to develop their work with BME communities in the South of Glasgow. BME communities have a higher risk and prevalence rate of diabetes but a lower than usual take-up of services and support. In order to raise understanding of self management within BME communities there would need to be a more intensive and direct engagement with the community.

The Self Management Fund gave us the opportunity to work in a more intensive way with the community - Sara Ward

Building on existing knowledge, links and contacts within the communities, Diabetes UK Scotland were looking for opportunities to involve the community in the provision of information and support. They wanted to engage with 'champions' within the communities to build a self management support network that would benefit people living with diabetes, and those that supported them.



Sara Ward, Diabetes UK Scotland

We knew we had to approach things differently, spending time to build up the trust with the community - Sara Ward

The approach was successful. The communities valued the localised and responsive presence of a large charity. They appreciated that the approach was not NHS led, and allowed the norms within the communities to become part of the project – linking information and knowledge with other activities to build capacity and standing within the communities.

There are now local community groups, meeting regularly to talk about Diabetes, using our resources and building on the access to healthcare professionals

- Sara Ward

Diabetes UK Scotland worked closely with specialist contractors who were able to engage with the communities to raise the profile of the project, and encourage people to come along to sessions. Emphasis was placed on the fun aspects of the sessions and activities and good use was made of opportunities like the Mela and Radio Awaz to spread the message about the sessions.

We've made great progress, but only just scratched the surface in engaging with communities across Scotland - Sara Ward

Diabetes UK Scotland have found that with time they have been able to make good links and connections with the BME communities in Glasgow, but that they have had to work in different ways. The project wasn't just about developing resources and information that were culturally appropriate for the communities they aimed to support, but about looking at sustainable ways of working in partnership with those communities.

Diabetes UK Scotland would like to look at developing their community links further through more training and support for volunteer group leaders. Diabetes UK Scotland will continue to work with the groups to develop schedules of activity that will help to sustain their good work and engagement with BME communities.



For more information please visit www.diabetes.org.uk/ Scotland

# Pink Ladies Scotland

Pink Ladies Scotland is a constituted Voluntary body, working presently in Midlothian with women experiencing stress, anxiety and depression.

Pink Ladies Scotland provide motivation workshops and group meetings to empower and enable women to take charge of their lives.

Pink Ladies Scotland – giving women a springboard for change.



Maria, Margaret and Sheila - Pink Ladies

Pink Ladies Scotland knew when they started that existing information and support available did not meet the needs of women like themselves. They recognised that women needed to be comfortable and have access to on-going support from others who had also experienced stress, anxiety and depression. Receiving £19,280 from the Self Management Fund allowed Pink Ladies Scotland to deliver a series of ten week courses in Midlothian.

It's great to see people opening up and discussing things, I suffered a few years back from anxiety following the sudden death of my mother and I wish I had Pink Ladies to help me then - course participant

'When we saw the fund advertised we thought – that's us! Self management is what we are about - it's what we've been doing for years. We wanted to use our personal experience to pass on tools and techniques to help women to manage better. We take a very personcentred approach, asking women what they themselves want to happen.' Sheila Peaston, co-founder of Pink Ladies Scotland.

Rather than "chew the fat" over the past and go over and over old problems, we spoke about our experiences in a positive way and I found that I could laugh about half of it already - course participant

Pink Ladies Scotland promoted their sessions by delivering information to health centres, giving presentations to Mental Health teams and through word of mouth locally. The sessions promote a sense of belonging, taking away the stigma often associated with mental health. Pink Ladies Scotland provide a space where it is alright to talk about it, and give women a choice for their future that does not necessarily involve pills and potions.

Pink Ladies have truly impressed me with their genuineness and willingness to 'walk that extra mile' with me, on more than one occasion. Little by little my faith in myself and other people is being restored - course participant

As a relatively small community based organisation, Pink Ladies Scotland have benefited from a great deal of support from Long Term Conditions Alliance Scotland. 'We've met lots of other groups and inspiring people through LTCAS networking events. It's been great talking to others involved in self management and sharing their enthusiasm. LTCAS have always been extremely approachable as funders, and by encouraging us to speak at conferences and events we feel that we are really part it. Their enthusiasm and support has inspired us to keep going' Maria Martin, co-founder Pink Ladies Scotland.

I began to refer suitable clients of Midlothian substance misuse services and found that they had a remarkable impact on these clients lives

- Community Psychiatric Nurse

The work of Pink Ladies Scotland has only just begun – they are keen to build upon their success and expand their services across Edinburgh and eventually across Scotland. Future funding is required to enable them to develop their approach, introduce new skills, interests, tools and techniques and be available more for the women they support.

Pink Ladies has helped me in so many ways to find the strength and confidence in me to rebuild my life. I have learnt that it is ok to be myself and have actually begun to really like the person I am

- course participant

For more information please visit www.pinkladiesscotland.com

## Parkinson's UK

# PARKINSON'S" CHANGE ATTITUDES.



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.

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



# FIND A CURE. JOIN US.

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

# Psoriasis Scotland Arthritis Link Volunteers (PSALV) Provision Scotland

PSALV is the only Scottish Charity supporting people living with the skin condition Psoriasis and associated Psoriatic Arthritis. PSALV was launched in 2004. PSALV provide support,



Janice Johnson, Founder and Trustee PSALV

information and campaign.
Psoriasis is a common condition
affecting 2-3 in a 100, but still has
an extremely low profile, and is
much misunderstood.

PSALV recognised that although fairly common, the condition was not well understood by GP's who had limited training in dermatology. This meant a lack of good information being available to people on diagnosis – including information on how to manage the condition effectively. PSALV knew that there were no condition specific self management courses available, and applied to the Self Management Fund to pilot a new course.



I now feel I am not alone

course participant

# <u>Case Studies</u>

Working with a range of partners, Janice Johnson from PSALV used her experience of living with the condition, and over 12 years of supporting others, to design, develop and deliver this innovative course. Janice used her networks to identify clinicians, leading dermatology nursing academics and pharmaceutical experts to work with her and trainers from Arthritis Care in Scotland to support the development of the course.

My knowledge has increased and I am more able to state my opinions to medical services.

I feel self empowered – course participant

PSALV publicised the course nationally, particularly targeting dermatology and rheumatology clinics, to recruit participants. PSALV identified three people living with the condition themselves who were keen to become lay-trainers, and twelve people who signed up to be the first course participants.

Working with the network of experts, including people living with the condition, PSALV developed a six-week course, and a manual with information to support participants to become more confident in managing and understanding their condition.

I thoroughly enjoyed the course - it was the best thing that has happened to me.
It was great and enlightening and I learnt more in 6 weeks than 40 years of having psoriasis - course participant

The course was run over six evenings from the Long Term Conditions

Alliance Scotland Hub in Glasgow. Different aspects of managing the condition were explored, with input on different evenings from a range of professionals in addition to the laytrainers. Course participants were asked to rate their confidence and expertise in understanding and managing their condition at the beginning and end of the course. All ten participants completed the course, and eight reported an increase in their confidence following the course.

The main benefit that participants reported was sharing information with others living with the condition, and also having the time to discuss informally with health professionals the questions that they felt could not be answered at clinics.

I am more confident, have gained knowledge and shared concerns and ideas – course participant

PSALV hope to build upon the success of this pilot course, and identify further funding to use their expertise to roll-out their course to other people across Scotland living with the condition.

Our pilot course was unique, bringing together health professionals and experts with people living with the condition to learn and share together – Janice Johnson, PSALV Founder and Trustee



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

## **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 £42,240 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. 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 me

project participant

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

#### **SKS Scotland**

SKS Scotland is an independent social enterprise supporting the

third sector to achieve its goals, promoting joint working across sectors. The objective of **SKS Scotland** is to be able to provide employment options for people living with M.E and other long term conditions.



Shona Sinclair, Director, SKS Scotland

Shona Sinclair set up SKS Scotland building on her own experience of living with M.E. since 2002. SKS Scotland provides a wide range of business support services to the third sector on a contract and project led basis. The delivery of the work allows for people to work flexibly in terms of when and how they do it, a large part of their work can often be carried out in a home environment at times that suit the individual. This meets the needs of people with M.E. in self managing their condition.

I felt emotional when I saw the Self Management Fund details – this is what I'd been doing for years without any recognition –

Shona Sinclair, SKS Scotland

Shona knew from her own experience, and from talking to members of M.E. groups around the country, that people living with M.E were aware of self management skills such as pacing and planning, but these approaches were not easy to employ in the work environment.

In employability terms, people living with ME became invisible – if employers can't understand the issues they can't support anyone – Shona Sinclair, SKS Scotland

97% of people diagnosed with M.E have their employment affected as a result of their condition, with 69% having to stop working altogether. SKS Scotland found that even when people successfully engage with self management strategies to allow them to return to work, their current working practices may not support their self management. Their action research project looks at the barriers and potential solutions to these to allow flexibility in work and working patterns which will enable successful employment outcomes.

How can you engage socially again if you've been sleeping for 20 hours a day? I just wasn't sure how to build myself up again

- project participant

Shona contacted the LTCAS Grants
Officer for some advice and support
prior to submitting the application.
Although the core idea was strong,
Shona realised through discussion with
the Grants Officer that she needed to
take a step back, engage with local M.E.

groups and organisations and clarify the steps she proposed to take to achieve her goals.

I knew what I wanted to achieve, but without Jen's help I could never have found a clear pathway – she helped me to see the bigger picture and supported me to get there – Shona Sinclair, SKS Scotland

In addition to demonstrating that a more flexible, person-centred model of employment can work for people living with M.E. and other long term conditions, SKS Scotland want to influence the attitudes of employers. If the model can be shown to work in a realistic way for both, SKS Scotland will be able to provide a beneficial vehicle for work opportunities, and a learning platform to share good practice linked to employability. SKS are committed to demonstrating that people living with long term conditions can be productive employees, remaining in control of the management of their condition and outputs at work.

I feel strongly that we should look at issues from a personal experience viewpoint – I really want to lead an organisation that can truly support people at the end of the day – Shona Sinclair, SKS Scotland

For more information please visit www.sksscotland.co.uk



## **Momentum**

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.



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



Dorothy Strachan, National Brain Injury Manager

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 good to know that we can talk about anythingeven 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



# Revive MS Support

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

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.

# <u>Case Studies</u>

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 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



Members of a Revive MS Support exercise group in Maryhill

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' – 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



# **Hearing Link**

Hearing Link provide support and information for people living with a hearing loss and their families. Hearing Link aim to increase awareness and understanding about hearing loss and its impact on life, to inform, enable and empower people to manage their hearing loss with appropriate services.

Hearing Link had an established track record in delivering some self management sessions for people living with a hearing loss, but they were finding it more and more difficult to find support to develop this and roll it out further. Hearing Link applied to the Self Management Fund and were delighted to be awarded £78,949 to develop their capacity to deliver self management programmes across Scotland.

As a funder, LTCAS 'get it' – they recognise that there are a wide range of long term conditions, not just physical – Linda Sharkey, Scotland Manager

In addition to being able to develop their self management sessions, Hearing Link has benefited from other opportunities LTCAS were able to offer. They found the training programme provided free to funded projects from Evaluation Support Scotland invaluable. This has ensured that their own evaluation and resources are robust and appropriate, and that they are well connected with other organisations providing self management support.

Being part of the evaluation support sessions confirmed that they were on the right track, but enabled them to look more carefully at their supporting information and the positive value of being able to tell their story more effectively.

## Hearing Link



Linda Sharkey, Scotland Manager, Hearing Link

Hearing Link found that despite being well networked with other organisations supporting deaf people, those organisations were not involved in self management. Working with other organisations involved in providing self management support has enabled them to learn from others and share their experiences, as well as having a wider feel for what is happening generally. They have also been able to take the opportunity to discuss deaf issues with other organisations to raise awareness.

We really feel 'plugged in' and connected to the bigger arena now – Linda Sharkey, Scotland Manager

Hearing Link have also been involved in some LTCAS events around Scotland, which has given them the opportunity to consolidate and share their learning from the delivery of the self management programme. Events like these have enabled Hearing Link to involve people living with long term conditions in showcasing the benefits they have received from attending a self management programme. This has helped Hearing Link to learn more about how to support people to best 'tell their stories'.

My circumstances may change, but my condition remains – the self management programme gives me coping strategies that I can adapt as my life changes – course participant

Hearing Link would like to build upon their success with their self management programme, specifically targeted for people living with hearing loss. They know that people benefit greatly from the support. Although many people stay in touch to support each other after a course ends, they know that by nature long term conditions are on-going, and support should be available at different stages of life.

We feel there needs to be a shift in approach and support which reflects this, which as a voluntary sector organisation we are well placed to provide' – Linda Sharkey, Scotland Manager



For more information please visit www.hearinglink.org

## **COMAS**



Comas is a community development organisation working to promote recovery and resilience amongst individuals, helping them to create community connections.

Comas began working with people recovering from addiction and learned from them that there was limited support for them to look at their whole life, beyond their addiction. Existing addiction treatment programmes, once completed, could only provide limited ongoing support. Comas knew that many people who encountered a problem after a treatment programme returned to their substance misuse as a way of coping because they lacked the tools to cope in other ways.

Recovery is life long, not something that ends when the treatment ends – Ruth Campbell, Chief Officer, Comas

Comas was not initially familiar with the term 'self management', but soon realised the links between this and the work they were doing on recovery. Comas was relieved that LTCAS saw addiction as a long term condition, as this allowed the opportunity to look at recovery holistically, rather than in isolation from the rest of life – many health services look at one small aspect of a condition, not the bigger picture. Comas applied to the Self Management Fund to support the development of their peer support initiative within their Serenity Café project in Edinburgh.

The Serenity Café is a co-produced project, people in recovery lead the



Volunteers with the Serenity Café, Comas

project and Comas facilitates their learning and development. They have been able to offer peer support through life coaching, developing a unique course called 'Recovery Coaching' with the help of the Self Management Grant. Recovery coaches are people in recovery, and their training as coaches is person-centred, based on learning from each other. The course has been adapted to respond to people's individual learning styles and their stage of recovery.

The Recovery Coaching model is based on the learning from people in recovery that people want to find ways to occupy their time and think positively about the future, as well as learning to manage their addiction.

Life can look big and daunting to people – addictive patterns of behaviour gnaw away at the back of people's minds – Ruth Campbell

The Serenity Café has supported people on the Recovery Coaching course to learn about emotional intelligence and brain recovery, encouraging people to understand how the brain can build pathways to support positive new behaviours. This provides people with a context and an explanation for certain behaviours. Participants learn about themselves in a safe environment, as well as learning skills in coaching others. Being coached by a Recovery Coach helps people to clarify their goals and plan the steps that they can take towards their goals.

Many people regard recovery from addiction as an event rather than something that needs on-going self management – we were really pleased that LTCAS understood – Ruth Campbell

Comas and the Serenity Café are accessible to the community they support, it is free to attend and no referral is required. The benefits of the project are multiplying – Recovery Coaches are adding to the capacity of the community to help each other, and people coming forward for coaching are able to access support. This is often during the hours that other services are closed, because this support is now available from within the community.

Comas has found that the strongest promotional tool is people in recovery themselves, spreading the news about the Serenity Café widely and positively throughout the recovery community. Comas would like to develop their Recovery Coaching programme nationally with other local communities, training peer coaches and continuing to provide recovery courses.

For more information please visit www.comas.org.uk and www.serenitycafe.org.uk



# Post Natal Depression Support Network

PND Support Network provide a 24 hour Virtual Support Network. PND

support people to identify individual needs explore and develop individual coping strategies and self help tools, leading to self management of their post natal depression.

Before the PND Support Network was established, there was very little specific help that women could access. Services that were around were closing, partly as result of the geography of the area and the difficulties women faced in accessing public transport to get to these services. Aberdeenshire CVS knew that because of the size and rurality of the area they covered, it was important to enable women to help themselves without relying on services that they might not be able to access. Talking to women they realised that self management could be effective in supporting women to recognise trigger and crisis points, and also equipping women with the tools to manage these themselves.

I found the hardest time to cope was actually when I felt I was beginning to recover and all the normal forms of support were pulling back and gradually being withdrawn – PND Support Network participant

They focused on the main barriers that women themselves identified - which were isolation, location of services, time to attend and the associated costs - to provide flexible solutions. Women were able to access one-to-one time with a support worker, and also to access an

Karen Nicoll,
Project
Co-ordinator,
Post Natal
Depression
Support
Network



on-line resource and forum to share information and support at times that suited them.

The PND Support Network benefits women themselves, and also healthcare professionals and others who support women with post natal depression. The network have seen an increase in people's mental health and wellbeing resulting in increased attendance at appointments as confidence levels rise. At the same time, there has been a reduction in appointments overall, and the length of time that professionals have spent with women as they develop their own individual coping strategies.

In the longer term, by helping women to progress beyond individual crisis points, there is less chance that they will deteriorate to the point where more medical intervention is required – healthcare professional

The benefits filter into every aspect of the women's lives, including work and family. The Network encourages women to find the information and support that they need rather than feeling like decisions are being made for them. They support women to feel less isolated and to realise that what they are feeling is 'normal' for someone living with this condition. Realising that despite their geographical isolation they are not alone is crucial to support the management of their condition.

Before this support, I felt a huge sense of insecurity and mistrust in my own ability to make decisions rationally and look objectively at problems - PND Support Network participant

The work of the PND Support Network has led to an increase of general health and wellbeing of local residents, and an increase in social activity within communities. Women they support are now using more community groups and facilities locally, which is helping to reduce social isolation.

We made sure we were offering a service which enables rather than takes over, offering support to deal with problems and issues rather than "taking them away" for women – Karen Nicoll

The PND Support Network would like to expand into other geographical communities, as well as looking at other developments such as a volunteer led buddy system.

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

#### **Moray Carers**



Moray Carers Project

Moray Carers Project works with carers of all ages throughout Moray to ensure they are recognised, valued and supported to manage the impact of caring on their lives.

Moray Carers Project realised that many services available to carers focused on the needs of the person they cared for. They often failed to recognise the importance of responding to the individual needs of the carer in relation to health and well-being. This represented a significant gap in local service provision, and support for self management.

Carers are key partners in self management. Effective self management means recognising the needs of the carer and the cared for. The wellbeing of both parties must be considered - Chryssy Gibbs

Local carers began expressing a desire to be heard and to have an opportunity to share their stories. With funding from LTCAS, Moray Carers began working with carers to create a library of digital stories. These short films aim to give carers the opportunity to share their experiences and raise awareness of issues that matter to them, by portraying both the challenging and positive aspects of caring.

Moray Carers Project knew that in order to achieve these aims they had to develop a person centred method of production. The team recognised



Liz Thomson, Will Burgess, Chryssy Gibbs - Moray Carers

that the carer was the expert therefore each film became a consultative process, shaped around the carer's situation.

Our role was to listen and respond to the needs of the carer. We learned from them and helped them communicate the experiences they wanted to share - Will Burgess, Digital Stories Project Co-ordinator

Many carers have found the filmmaking process therapeutic. Voicing their experiences has become an important emotional outlet for feelings of isolation and stress. So much so that many carers can make stories for themselves and their families rather than for distribution. Those who have been comfortable sharing their stories understand that they are a remote peer support tool, not only giving the carers the opportunity to speak out for themselves but also for other carers in similar situations.

These honest and personal insights have become an affirmation of the carer's value. Many people who have watched the films, as well as those who participated in making them, have reported an increase in self confidence.

As carers become more confident they become more effective in their ability to support the cared-for in their self management journey

The stories are also used as a tool to communicate with family and friends, who often don't fully realise the complexities of caring. After watching a film, one family member commented:

I was hugely moved by your film. It gave a deeply moving insight into what full time care involves and how your needs are just as important as the needs of the person you care for

This work has enabled Moray Carers to effectively demonstrate the importance of supporting the carer and the how their wellbeing impacts on the person they care for.

You are allowing us a voice and that gives us a sense of worth. It makes us stronger and more effective in our caring roles

- Val Ireland, Carer

The stories are currently being promoted widely, with great feedback. Moray Carers Project want to continue to develop this resource by widening dissemination to include websites, community screenings and even festivals. The team aim to collaborate with other organisations that support those living with long term conditions to promote digital stories as an effective medium for raising awareness and sharing experiences to support self management.

# Lothian Centre for Inclusive Living



Lothian Centre for Inclusive
Living (LCiL) is a usercontrolled organisation which
supports disabled people to live
independently.'Your Call' is a free
telephone counselling service led
by disabled people themselves
who work as volunteers, and are
trained to a professional standard
in counselling.

'Your Call' was developed in response to feedback from LCiL service users who felt that telephone counselling would increase the accessibility of counselling provision for disabled people and those living with long term conditions.

Difficulties encountered by disabled people who were looking for counselling included accessibility, expense, transport and a lack of understanding among non-disabled counsellors of the issues and challenges which disabled people meet on a day-to-day basis.

LCiL felt that a telephone counselling service would have many advantages in terms of accessibility. It would also allow the counsellors to work in a flexible way which would also support their own self management.

A telephone service means that you can access counselling even if you aren't well enough to get out. You don't have to exacerbate your symptoms unnecessarily

- LCIL Counsellor

LCiL also identified a lack of joined up working around counselling for disabled



Pauline and Katrina, Your Call Counsellors

people. Statutory services tended to medicalise a person's physical condition, but provide no support for associated psychological and emotional issues. Your Call's aim was to link these for disabled people across the whole of Scotland.

The success of the Your Call pilot demonstrated the importance of peer counselling and the value of emotional and mental support for people with long term conditions. The Self Management Fund presented an opportunity to expand the service.

The experience of already professionally trained LCiL counsellors was integral to the design of the new national service. They have become project consultants advising on every aspect of the service from the technology used to the need for flexible working practices.

Your Call used the experience of those living with long term physical disabilities to combine peer support with emotional support in a package that was accessible and appropriate - Ian Fuller, Counselling Coordinator

LCiL believes that the success of the service is based upon the mutual understanding between counsellor and client of what it means to live as a person with long term conditions. The counsellors personal experience is strengthened by the counsellors holding professional qualifications.

A disabled counsellor is better able to understand your situation and what it is to be disabled and physically unwell. The support from the Your Call counsellors has helped me to make positive changes in my life - Service user

The benefits that have arisen from the service are specific to each individual. However, initial evaluation found that 95% of those who have engaged with Your Call have reported an increase in their sense of wellbeing.

Your Call has made me stronger. It has helped me deal with emotional issues and overcome my fears. It has boosted to my confidence – service user

Looking to the future, the Your Call team are keen to work towards the provision of diploma level counselling training for disabled people and to investigate new approaches to service delivery using technology for those people who have difficulty in using the telephone.

For more information please visit http://www.lothiancil.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.

Parents of Austistic Spectrum Disorder Adults (PASDA) have been a consitituted 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 wesbite. 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 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.

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



Catherine Thomas, Fundraising Manager, 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 benefited 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

# IntoWork West Lothian

#### INTOWORK

Intowork West Lothian offers support to people with mental health issues, autistic spectrum disorders and acquired brain injuries. Using the Supported Employment model, the project is able to assist people significantly distanced from the labour market move into employment, or to offer support to individuals who become ill whilst in employment.



Anne Reid, Jim Campbell, Lorna Wood, IntoWork West Lothian

IntoWork West Lothian support people with complex needs to realise their potential, recover their quality lives and employment. IntoWork West Lothian had identified that 'wellbeing' was much more than an absence of symptoms, and more about people having the tools themselves to take part in their care. They applied to the Self Management Fund for their 'Getting Started'

course which looks at self management techniques and employability related skills over eleven weeks.

Within minutes of realising that the people in the room were in the same position as I was the nerves lessened – course participant

The funding has allowed IntoWork West Lothian to address the overall needs of the person, by bringing a mental health specialist, an Occupational Therapist and previous participants as volunteers into the team. Together they researched tools and techniques that would support people to feel less isolated, less negative and to combat feelings of despair.

I now don't feel like an outcast, I learnt how to communicate in a group again – course participant

Throughout the project, participants have been supported to identify new skills, and to value transferable skills that they possess already. IntoWork West Lothian offers ongoing support to encourage people to learn coping strategies to overcome barriers to progression. These barriers range from continued education and money management to advocacy and job search skills.

I'm a lot more confident than before, I feel I am able to reach my goals and I know I am ready to start looking for work – course participant

IntoWork West Lothian have found that having an Occupational Therapist as part of the team gives participants an instant access to clinical interventions, as opposed to joining lengthy NHS waiting lists. Participants are supported to make decisions for themselves and to access other services which are integrated, flexible, proactive and responsive to their needs.

I've found goal setting and not being too ambitious most helpful, maybe previously it has been too stressful jobs that have brought on ill health – course participant

Participants have benefited from having a basic structure to their day or week, as well as being able to interact socially with a group of people in a similar situation. Sharing these experiences has encouraged participants to feel more confident, to raise their expectations, to feel that they 'are worth something' again and to understand themselves, and their conditions, better.

During the project, IntoWork West Lothian have seen an increase in demand. As a result of the links made by the Occupational Therapist, there has been greater 'buy-in' from the NHS. This strong, integrated partnership has given the course more credibility and ultimately more benefits to the people they support.

IntoWork West Lothian would like to build on the success of their project by developing their ideas and taking forward their learning to continue to support their 'harder to reach' group.

I now work 16 hours a week and I still have the added bonus of being able to call the team when I falter, when anxiety creeps in or I feel down – previous course participant





## Carr-Gomm Scotland

Carr-Gomm Scotland is a person-centred organisation that supports people to lead their lives safely and to do the things they want to do: in day-to-day living, in planning for the future and in realising dreams. Carr-Gomm Scotland do this by providing support at home and in supported services.



Carr-Gomm Scotland provide support for people to find self management strategies which suit them best, encouraging people to take control of their own lives. They received feedback through focus groups and forums that people wanted to learn more about food and cookery. Carr-Gomm applied to the Self Management Fund for £9,710 to deliver their 'Healthy Kitchen' project to support people to increase their food knowledge and cookery skills in Glasgow.

I feel this has done a lot for my confidence, mixing with other people and getting out of the house – project participant

Carr-Gomm Scotland wanted the course to be as peer-led as possible. They identified someone that they supported to be the chef on this project – supporting his own self management and employability. The chef was able to use his own lived experience in a real job opportunity. Carr-Gomm Scotland knew



Kevin Fullerton, Community Development Worker, Carr-Gomm Scotland

that by showing people how to cook the types of food they wanted to eat, there would be a higher chance of them using the skills at home. So, the types of food that the chef supported people to learn to prepare were decided by the group themselves.

Before becoming involved in the Healthy Kitchen I just stayed in bed all day – I felt very self-conscious about meeting people and talking to them – I have now joined other workshops and have things to do every day – project participant

People involved in the project have reported that they have made positive changes to their diet, and that they have felt confident to cook at home for themselves, and for other people. Many of those involved have had issues with social anxiety. People involved in the project have developed a sense of camaraderie, which has in turn led to people choosing to participate in other activities together.

## <u>Case Studies</u>

The Healthy Kitchen was promoted through the local CHCP's in Glasgow and other mental health networks that Carr-Gomm Scotland are linked to. The project has offered people the opportunity to increase their cookery skills. During a regular slot each week, participants feedback to the group about what they have cooked at home. This builds on their team work, decision making and group discussions as part of the course. Carr-Gomm Scotland have been able to see the benefits for people re-acquainting themselves with social situations and building personal confidence.

The Healthy Kitchen is important to me because it builds up my confidence and communication with others – this social anxiety has been a big part of my life

- project participant

The Healthy Kitchen has attracted interest from other parts of Glasgow and around the country. Carr-Gomm Scotland are looking at funding options to deliver their project in other locations. Carr-Gomm Scotland are looking to develop their learning from this project by investigating the possibility of creating a food based social enterprise. This project has helped them to understand how best to involve the people they support in future ventures.

This project has opened up possibilities for people – in employment or volunteering and in developing their skills and confidence. The group support each other to get through their anxieties – Kevin Fullerton, Community Development Worker

For more information please visit www.carr-gommscotland.org.uk

Carr-Gomm Scotland

## Angus Cardiac Group



Angus Cardiac Group support cardiac care and rehabilitation in Angus.

The Angus Cardiac Group, in partnership with local support groups, Angus CHP and Angus Council, already had a very successful heart disease exercise programme and applied to the Self Management Fund to extend that to include other long term conditions. The group aimed to develop some lighter exercise opportunities for people living with all long term conditions who are physically unable to manage their current programme. The group were also keen to ensure that partners, carers and family members would be able to be included in the exercise classes.

Participants feel fitter, healthier and more able to manage their condition

- Angus Cardiac Group

Angus Cardiac Group really wanted to encourage people to develop exercise opportunities in the community. They have been supporting local community initiatives to establish long term condition support and activity groups to create an appropriate environment to encourage physical fitness and self management.

Angus Cardiac Group wanted to include a range of appropriate activities for people to choose from. These include

chair-based or other lighter exercise, which Angus Cardiac Group have found to be particularly useful for people with restricted or poor mobility who may not be able to stand during exercise. They have also developed their existing circuit-based activity and included some gym-based activities for people who are able to use some or all of the basic gym equipment. The group also wanted to encourage support for walking and cycling activities.

Angus Cardiac Group see wide ranging benefits of exercise and activity for people living with long term conditions, and their families. Their sessions support people to maintain their physical fitness, to live well with their condition and generally be happier, healthier and more confident. They also are aware that people have been able to learn through exercise

techniques and social interaction how to manage specific symptoms of their conditions.

Joining the exercise programme has really helped my husband, and myself, to deal with his condition – wife of participant

The group also hoped that additionally, partners, family members and carers would become more confident in the role they play in supporting self management. They were also interested to see volunteers, health practioners and exercise instructors increase their skills and knowledge in supporting people living with long term conditions to exercise and be active.



Angus Cardiac Group members

## <u>Case Studies</u>

Since joining the Angus
Cardiac Group sessions I
have been able to stop taking
my medication for depression
and I really feel more confident
as a result – programme
participant

Angus Cardiac Group ultimately wanted to demonstrate that through participation in exercise and activity, those involved in the programme would develop an increased 'community spirit'. This, together with the clear benefits of exercising, should lead to a reduction in people accessing community services, and decrease the burden on NHS services in particular.

I couldn't manage the gym-based exercise through the referral scheme, but once I joined the seated programme with Angus Cardiac Group it's been great and I WILL continue to go! – programme participant

Angus Cardiac Group sessions have proved to be extremely popular, they have exceeded their initial targets for their groups. The group feel that they now have some evidence of the benefits that they can develop further for people with a range of long term conditions, and varying levels of ability in exercise. The group would particularly like to develop their one-to-one sessions for people who are housebound, which they are currently piloting.

For more information please visit www.anguscardiacgroup.co.uk



#### **Active 4 All**

Active 4 All are based in Lanarkshire and aim to provide community and sports activities to people of all abilities, in an environment of respect and friendliness.

Active 4 All knew that public interest in disability sport expanded quickly following the British team's outstanding success at the Beijing Paralympics in 2008. They also knew however that facilities and other support for disability sport in Scotland were still very limited. Scottish disability sport is still relatively poorly resourced and there is no national centre for disabled track and field sport. Local councils and others have invested heavily in improving disabled access to sport and community facilities, but some buildings have limited potential for being fully accessible. Developing disability sport requires extensive training for staff and volunteers, with long term support for clubs, teams and leagues, which is rare.

If successful, this approach has the potential to move self management to the centre of discussions about health and deprivation – Active 4 All

Active 4 All want to develop a disability sports centre to serve all of Scotland, supporting development of competitive disability sport at every level in Scotland. They want to support expansion of leisure sport among disabled people as well as healthy living and general wellbeing. Active 4 All applied to the Self Management Fund to research and develop a





Participants in exercise and activity

greater understanding of the benefits of participation in disability sports, identify links and possible areas of co-operation which start to improve the long term infrastructure for disability sport.

Active 4 All argue that designing or modifying community and sports facilities to improve disabled access is not enough to make them disabled-friendly or disabled-centred. Active 4 All feel that they need disabled design input and disabled staff. They also need able-bodied staff who understand and like working on equal terms with disabled people. Active 4 All believe that managers and users of services should be open to new ideas and be keen to experiment.

Self management can provide a strong indication of the direction of change by showing what service users see as desirable and prioritise accordingly

- Active 4 All

Active 4 All have concluded that in the West of Scotland, there are high levels of long term illness which are linked to poverty, stress and the experience of de-industrialisation. Many years of regeneration investment have brought huge improvements in housing and other concrete assets, but large scale poverty persists and numbers of people living with long term conditions continues to increase. Many people live with more than one long term condition. Active 4 All feel that inflexibility and a conservative approach to health and care provision are likely to hamper development of any future project to improve people living with long term conditions health and wellbeing.

LTCAS has made substantial efforts to develop its members' capacities and strengthen alliances between members and others – Active 4 All

Active 4 All recommend establishing an initiative to increase participation in sports and exercise by people living with long term conditions which are known to benefit from this. They would like to see a volunteering programme to be developed to provide more opportunities for buddying, coaching and other support work. Active 4 All would like to see strong local roots for this work, developing initiatives in co-operation with community organisations and groups representing people living with long term conditions and carers.

For more information please visit www.active4all.info

#### SAMH

**Scottish Association** for Mental Health (SAMH) are Scotland's leading mental health charity, dedicated to providing help, information and support; to campaign on behalf of people with mental health problems and to raise money to fund their vital work.



Get Active members, SAMH

The Scottish Association for Mental Health (SAMH) is Scotland's leading Mental Health Charity, which provides a range of mental health services across Scotland. In 2010 SAMH secured funding from the Long Term Conditions Alliance Scotland (LTCAS) to run four pilot projects as part of the Get Active National Programme, on the mental health and wellbeing benefits of physical activity and sport.

The link between physical activity and physical health has long been known, but the link between physical activity and mental health has been less explored, until now.

We want to ensure that everyone, regardless of where they live, their age or income, is aware of ways to improve their mental health by participating in physical activity and sport - SAMH

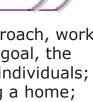
'Get Active' is a 5 year national programme with a community engagement programme at the heart of achieving this goal. For years Scotland has hit the headlines for all the wrong reasons such as high levels of anti-depressant prescribing, poor health, high mortality and appalling diets.

It's time for us to turn the tide and become recognised as a nation that takes pride in our physical and mental health - SAMH

The four community engagement projects which are part of the SAMH project not only show the positive impact sport and physical activity can have on people who have long term conditions but demonstrate the transformation that occurs in people's lives when you create opportunities that focuses on their strengths.



It's what they can do, not what they can't



When you create the right approach, work in partnership with a common goal, the outcomes become evident for individuals; from homelessness to securing a home; from living chaotic lives to stability; from unemployment to employment; from not seeing a future to coaching young kids, securing a university place, to reclaiming your life back.

The support of LTCAS has been central to the success of the four community engagement projects. They recognised the value of what we aimed to do and also recognised the real potential for people to better manage their long term mental health problem as a direct result of participating with the community engagement project - SAMH

The results are excellent; there are real improvements in how individuals self manage and in their quality of life. Get Active delivers, the success of the four projects is testimony and we should all be considering how we progress this valuable work so that others can also experience the positive impact of getting active.

The four Get Active projects are showcased in the following case studies;

- Get Active Aberdeen Foyer
- Get Active Street Soccer
- Get Active Branching Out
- Get Active Ayr United Football Academy

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

#### **Get Active - Aberdeen Foyer**

Aberdeen Foyer is a successful local charitable organisation working to prevent and alleviate youth homelessness and unemployment.



As part of their range of projects, Aberdeen Foyer offers access to health and

wellbeing



assessments for people who access
Aberdeen Foyer projects and
accommodation. The health and wellbeing
assessments are one-to-one brief
interventions where people can talk about
their health and lifestyle and any concerns
they may have. They can receive advice
and information based on how they would
like to address these concerns or put
them on a pathway to positive behaviour
change.

The focus of the intervention is choice and so if someone is not ready to address a particular issue, Aberdeen Foyer wouldn't push them. They would instead provide them with more information on the topic and make them aware of organisations or interventions where they could get

support if they decide to make changes in the future.

I think we're really fortunate in Aberdeen
Foyer because we have a health team, we have a support network there for people to tie into other programmes - Aberdeen Foyer, project lead

The health and wellbeing assessments gave Aberdeen Foyer the idea for the Get Active pilot project which took the same one-to-one approach but focused on physical activity. The assessments looked at where someone currently was regarding physical activity and if they

were active at all, and whether there were any changes to their level of activity



they would like to make. The consultation also looked at whether the individual was experiencing any barriers to becoming more physically active e.g. cost, knowledge of activities available, weight, medication.

For more information please visit www.aberdeenfoyer.com

#### **Get Active - Street Soccer**

Street Soccer was set up in 2009 as a social enterprise with the aim to engage with socially disadvantaged adults and young people through the power of football.

Street Soccer was developed to help engage people through football and use it as a tool to help them make positive changes to their lives.

Seven, eight, nine months ago I wouldn't have been confident, but coming here, for me... I think I built up a lot more confidence from what I was the first session I went to

- Street Soccer participant

Football can have a positive effect on people's lives whether it be homelessness, rehabilitation, mental health, and there wasn't enough...there was all these guys

and not being able to access regular training, regular football, so I think the main reason for Street Soccer being set up was to encourage more guys to get into football to try and provide regular access to football session and to spread it out, right across Scotland.

All our good work is done on promoting, building confidence, building communications on the pitch, giving people encouragement, making you feel part of a team... this is all the stuff that builds them up and it increases their mental health -

Street Soccer, project lead

Street Soccer saw Get Active as an opportunity to share learning with SAMH and develop a strong partnership.

For more information please visit www.streetsoccerscotland.org



## **Get Active - Branching Out**

Branching Out was set up by the Forestry Commission in 2007 to engage people experiencing mental health problems in woodland activities.

Branching Out aims to give people a chance to either get back into the outdoors if they hadn't been outdoors for a while, or introduce people to the outdoors if they'd never experienced woodlands before, to increase physical activity, develop team working and improve mental wellbeing.

Achieving different things that people think that they can't do... I think that gives people a big boost that they can do something - Branching Out, project lead

Branching Out look to try and get more people taking part in woodland-based activities. People with mental health issues are less likely to go into the woodlands, so that's a client group in general that they'd like to engage with. They've also got a health strategy which tries to promote use of the outdoors, and the woodlands in particular, to be more physically active, and for mental well-being as well. So it's really all three; mental, physical health and use of woodlands. And also, I suppose just knowledge and understanding of sort of conservation issues and, you know, not dropping litter and looking after the environment as well.

We find that the groups really bond over time, they help each other Branching Out, project lead

The ways in which Branching Out aim to improve mental health and wellbeing are multiple. For example, by building confidence and self-esteem in participants as they learn new skills and gain a sense of achievement in what they can do.

For more information please visit www.forestry.gov.uk/branchingout





Ayr United Football Academy work in partnership to develop sport, health and education for people as a community contribution to the aims of their partners and in the long-term interest of people of all ages.

The aim of the pilot project for participants was threefold: to increase physical activity and thus fitness; improve individual's football techniques; and improve the mental health and well-being of participants.

To measure whether participants had become fitter as a result of taking part in the project, Ayr United ran a fitness test at the beginning and at the end of the programme. Improved football skills were measured through observation by the coaching team. Finally, improved mental health and well-being of participants was mainly assessed by the observation of the coaching team focused on any changes in behaviour and attitude.

Their communication skills improve...from the first week and then leading up to the second last week, they would come and talk to you rather than you having to go talk to them - Ayr United, project lead

Ayr United reported that although the project was short, it was successful in achieving its outcomes. The coaching team observed lots of positive mental health and wellbeing outcomes in participants, including increased confidence and self-esteem which was illustrated in the changes in how participants communicated with the coaching team and each other.

#### **People First**

People First (Scotland) started in 1989. It is the independent self-advocacy organisation in Scotland. People First (Scotland) are run by and for people with learning difficulties. They aim to change individual and collective attitudes, policies and the law relating to learning difficulties.

People First set out to map views and opinions about the most pressing areas for change in the lives of people with learning disabilities. Their project aimed to prioritise issues and targets for lobbying and influence as well as looking at ways to involve members in the widest way possible.

I hope people listen to what we have to say.
We should get the same rights as other people - People First member

Members of People First aimed to write up the research on the methods used to increase the effectiveness of support to members with learning disabilities and to publish this. They also wanted to look at ways of demonstrating and explaining the processes involved and the thinking behind the processes, making these available to other organisations who support people with learning disabilities. In addition the members planned a Citizens' Grand Jury, where political figures and the most senior policy makers were 'summoned' and questioned publicly about their policies and implementation.

The Citizen's Grand Jury has produced a report of the event with recommendations for the future.





Members of People First (Scotland)

People First found that engaging with debates, and managing to understand complex issues increased people's confidence. This reinforced that people can have a grasp of difficult subjects, and can form an opinion that is valid and they can expect will be taken seriously. People First found this to be especially important in the context of independent (self-determining) living and to the idea of co-production.

And one of the things I've really learnt and I hadn't really encountered this situation much in my life before is that on the whole, the laws in this country are skewed against the community of people with learning difficulties – Richard Holloway, Grand Jury Questioner

Again, People First were able to demonstrate that being faced with a challenge, and having the opportunity to overcome that challenge, increases people's confidence and builds resilience, which are essential components of the capacity for self-management.

I'm going to make sure we have a conference in my area. It's important to speak up - People First member

People First have found it both rewarding and challenging to engage with LTCAS and the Self-Management Fund. They supported one of our senior members on the LTCAS Board for a time and contributed to and participated in most of the invitations received from LTCAS. People First's capacity to respond to more invitations from Government and other systems has been greatly enhanced by LTCAS funding during the funding period with an enhanced staff complement.

The motions we passed should get sent to the government now - People First member

However without the funding People First will have to refuse invitations due to staff capacity, even though members continue to be interested and willing. This does create a tension in the organisation and their members who have had raised expectations about support to be involved in a range of activities.



For more information please visit www.peoplefirstscotland.org



#### **Thistle**

Thistle Foundation is a boundary-pushing, pioneering charity supporting people with disabilities and long term health conditions. They support people to lead great lives where they are in control.

Central to the Thistle approach is its insistence that alongside optimal medical care, people, with the right support, can become empowered to actively live their life well, living with a long term condition. This 'right support' is generic - people can benefit from similar support regardless of their medical conditions and that a generic service design and set of competencies required to deliver this approach can be easily integrated into all sectors and levels of care.

I'll have a clearer picture of what clients want to achieve and how to achieve it by drawing on their past strengths and coping mechanisms – health professional

Thistle aimed to support the development of an inter-disciplinary, cross-sector learning community with identified leaders in health and social care professions who would actively cascade their learning within and beyond their areas of work.

Practitioners are learning more effective, empowering ways of interacting with people so that individuals are more aware of and motivated to use existing resources to move toward the outcomes they want in their lives – Ross Grieve, Thistle Foundation

#### **Foundation**

Thistle identified 11 professional Change Champions who were actively cascading their learning and influence. By supporting the development of cross sector networks and learning communities, there are indications that practitioners are now sharing good practice including practical changes to service design.

The 'ripple' effect was noted at increasingly higher levels of management which has resulted in formal requests for further training of the workforce.

When we orientate to what the person wants, then regardless of the health profession or agency we belong to, we're essentially doing the same thing –

health professional

This project demonstrates that a generic approach to supporting practitioners to work in a person-centred way to support the adoption of self-management strategies can be effective across sectors and across a wide range of client groups.

Thistle have demonstrated that considerable change is possible with modest inputs: even two days of training can be enough to provoke changes in practice, and further training results in improved confidence and openness to supporting others to change independently.

We anticipate more change champions will emerge and look forward to supporting a community of practice

Ross Grieve,Thistle Foundation



Thistle Foundation Course Participants

Thistle would like to continue to develop their leadership in the field of supported self management. To achieve this they intend to maintain an integration between their training service and lifestyle management service delivery.

This will ensure that as trainers, they stay active as practitioners and have the opportunity to offer learning experiences to other practitioners, be able to continue to deliver training and flexible support to interested partners and practitioners, including the delivery of more advanced training. They will also continue developing their web-learning resource.

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

### Self Management Fund Grant Allocation Panel

Long Term Conditions Alliance Scotland (LTCAS) recruited an independent Grant Allocation Panel to collectively make funding decisions on applications to the Self Management Fund.

Panel members were recruited from LTCAS membership organisations, LTCAS Board, Scottish Government and the NHS. All members had an interest in the self management agenda.

Kate Munro, Community Engagement Manager, NHS Greater Glasgow and Clyde

Kate Munro was delighted to be asked to join the Grant Allocation Panel. Her role as Community Engagement Manager with NHS Greater Glasgow and Clyde gave a vital background in working with diverse, non-clinical groups to encourage participation and influence in reviewing health services. This, together with Kate's own experience of living with a long term condition, and employing self management strategies, made her an ideal panel member.

The panel that came together had many different perspectives – but we shared a common philosophy – this was a huge strength – Kate Munro

The Grant Allocation Panel was involved in reviewing applications and making decisions in all three rounds of funding, with support from the LTCAS team. Kate felt that the panel had a positive role in being involved in developing the Self Management Agenda in Scotland.

It's been a totally enjoyable process to be part of – and so rewarding to recognise some of the great work going on out there – Kate Munro

Kate was able to see projects and ideas develop over the course of the funding rounds. As the process went on, and as the panel increased their own knowledge and understanding, patterns began to emerge making it easier to assess the applications.

You could see the benefits in the organisations that worked in a positive way with LTCAS – a great deal of work went in to develop good ideas into great projects – Kate Munro

It wasn't always an easy process for the Grant Allocation Panel. They were faced with hundreds of applications, and many



from organisations who were in need of funding to survive. However, Kate felt that the potential tensions were well managed, and the positive approach adopted by the panel meant that it was a safe, open environment to air views and consider the wide range of interests the panel represented.

Over time, Kate was able to recognise the value of the 'specialist advisor' role of the LTCAS team. She developed a great respect for the amount of work that they put in to turn good ideas into good applications, and her understanding of this vital role increased over the three funding rounds.

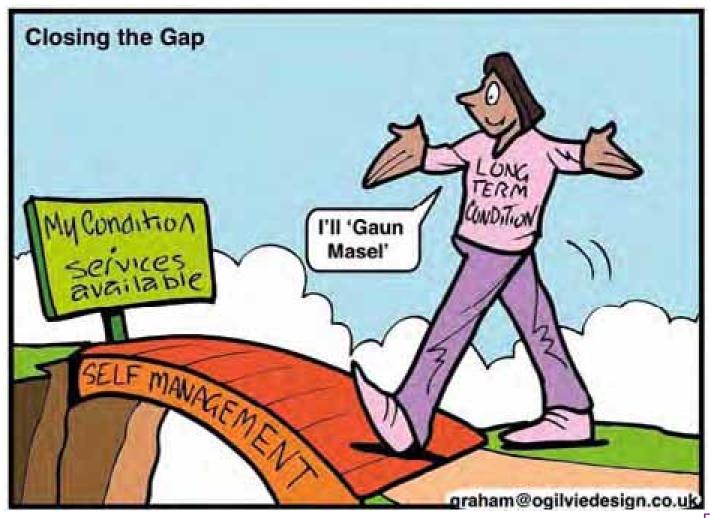
I never felt like I was working alone or in the dark - Kate Munro

Kate believes that the allocation process was not only the panel to allocate the

funding fairly, to recognise innovation and to provide value-for-money but also that it will have a great impact on the voluntary sector. The fund brought together a range of innovations in a 'creative forum' supporting people living with long term conditions.

Kate looks forward to seeing the difference that these projects make in developing the understanding of self management across the voluntary, health and social care sectors in Scotland. She sees this as her ultimate reward for being involved.

I thought I had a lot of knowledge about self management, but my own ideas were challenged by the innovative, constructive and dynamic proposals we've seen in the applications – Kate Munro



	Appendix	1

Organisation	Partners	Location	Condition	Equalities	Approach	£ allocated
Men's Health Forum Scotland ^	I	National	Generic	Gender	Training, support	256104
Lothian Centre for Inclusive Living ^	1	National	Generic	Disability	Telephone support	162722
PAMIS	1	Dundee/NE	Multiple - Learning Disability	Disability	Training, support	249555
Asthma UK ^	NHS CHP's MCN's Scottish Government – Education Local Authorities – Stirling, Clackmannanshire, Western Isles, Falkirk, Aberdeen	Lanarkshire	Respiratory - Asthma	Age	Training, support, information	131263
Waverley Care ^	NHS (Living Well)	Central	Blood - HIV, HCV	Sexuality, Gender, Race	Training	100000
MS Society ^	Voluntary – Arthritis Care	Highland	Generic	1	Training	41050
Action for Sick Children	NHS Lanarkshire	Lanarkshire	Generic	Age	Training, support, information	32749
EdMEsh ^	1	Lothian	Neurological - ME	ı	Complementary Therapies	23330

## 



							T-	7
43560	22105	56160	52762	34024	78949	19280	8230	1311843
Training, Research	Training	Training	Research, support	Training	Training	Peer support	Training	
Disability	1	Disability	ı	1	Disability, Age	Age	1	
Neurological - Aphasia	Neurological - Dystonia	Neurological - ABI	Neurological - Parkinsons	Diabetes, Coronary	Sensory	Mental Health	Skin – Psoriasis Pain	
Lothian	National	Glasgow	National	Falkirk	Central	East Lothian	Central	I (round one)
Academic – Queen Margaret University	Voluntary – Arthritis Care	1	NHS Voluntary – Sleep Scotland Academic – Loughborough University	ı	Voluntary – Deaf Connections, Lothian Deaf Counselling Local Authority – Lothian Lipreading	1	NHS Lanarkshire	Sub-total (rou
Speakability ^	Dystonia Society	Headway Glasgow ^	Parkinsons Disease Society	Braveheart	Hearing Concern Link ^	Pink Ladies ^	PSALV ^	

 $\ ^{\wedge}$  received support from LTCAS prior to submission



\*encouraged to re-apply following round one and received support from LTCAS prior to submission

Organisation	Partners	Location	Condition	Equalities	Approach	£ allocated
People First ^	ı	National	Multiple – Learning Disability	Disability	Research, training, support, information, peer support	172900
SAMH *	Voluntary - Street Soccer, Aberdeen Foyer Forestry Commission	National	Mental Health	I	Research, training, support, information, peer support, exercise	267095.70
The Thistle Foundation *	Lothian CHP tbc	Lothian tbc	Multiple	1	Research, training, support, information	193265
Cornerstone *	I	National	Multiple – Learning Disability, Epilepsy and Diabetes	Disability	Toolkits	23144
Alzheimers Scotland ^	ı	West Lothian	Neurological - Alzheimers	Age	Peer support, information	56037
Revive MS *	ı	Glasgow	Neurological - MS	1	Training, information, exercise	36238
Speakeasy ^	Voluntary – Macmillan Local Authority – North Lanarkshire	Lanarkshire	Cancer – Head and Neck	ı	Training, support, exercise	16579
Clydeside Action on Asbestos *	1	Central	Cancer – Pleural Plaque	Gender	Peer support, training, complementary therapies	48517
Action ME *	1	National	Neurological - ME	1	Website, information, peer support	42240

## Self Management Fund - Round Two



55000	49690	58333	37617	37867	39516	50005.56	26900	49940.60
Complementary therapies, exercise	Training, peer support	Training	Training	Information, support, peer support	Peer support	Digital stories	Research	Exercise, information, support
1	ı	1	I	ī	ı	ı	1	Age
Multiple - Generic	Generic	Mental Health	Neurological - Falls	Generic	Neurological - Autism	Generic	Mental Health	Neurological – Spina Bifida
Glasgow	Lanarkshire	Glasgow	West Lothian	Perth	Lothian	Moray	Glasgow	Lanarkshire
1	NHS Lanarkshire Local Authority – South Lanarkshire	Greater Glasgow CHCP	West Lothian CHCP	NHS Local Authority – Perth & Kinross Voluntary – Arthritis Care, Pain Association, Perth Association for Mental Health	Voluntary – Autism Initiatives	Voluntary – Princess Royal Trust for Carers	Academic – Strathclyde University NHS Greater Glasgow	NHS Social Care/Leisure Professionals Voluntary – Action for Sick Children
Community Health Shop ^	Healthy Valleys ^	WIN (What I Need) Project ^	Carers of West Lothian	Disability Information Support In Perth (DISIP) *	Parents of Autistic Spectrum Disorder Adults (PASDA) ^	Moray Carers ^	Mental Health Foundation *	Spina Bifida Association *



\*encouraged to re-apply following round one and received support from LTCAS prior to submission

Organisation	Partners	Location	Condition	Equalities	Approach	£ allocated
Health in Mind *	Local Authority - City of Edinburgh Council NHS Lothian	Lothian	Mental Health	ı	Peer support, training	38953
Diabetes UK *	Glasgow CHCP Diabetes MCN	Glasgow	Diabetes	Faith/Belief	Training, awareness raising	57550
Intowork West Lothian	West Lothian CHCP	West Lothian	Mental Health	1	Training	00009
Angus Cardiac Group *	Angus CHP	Angus	Coronary	ı	Exercise	63000
Gorbals Healthy Living Network ^	NHS Greater Glasgow	Glasgow	Generic	Age	Toolkit	60107.3
Glasgow Association Mental Health	Glasgow CHCP Voluntary - SEAL	Glasgow	Mental Health	ı	Complementary therapies	53426
Huntington's Disease Association	Voluntary – Outside the Box	National	Neurological - Huntingtons	ı	Toolkit	32600
Stammering Association Scotland ^	1	National	Neurological - Stammering	I	Telephone peer support	44000
PBC Foundation *	1	National	Auto-immune - PBC	1	Information, awareness raising	32000
TLC Borders ^	Local authority – Scottish Borders NHS Borders	Borders	Generic	ı	Peer support	53000
Scottish Development Centre for Mental Health	1	National	Mental Health	1	Research, Peer support	30156
Mental Health Aberdeen *	1	North East	Mental Health	1	Training, support	64324
Breast Cancer Care Scotland	NHS Aberdeen, Dundee, West Lothian	National	Cancer - Breast	Gender	Training, information	39274

## Self Management Fund - Round Two



3285605.54				one and two)	Running total (rounds	Ru
1973762.54				Sub-total (round two)	Sub-tota	
9920	Complementary Therapies	1	Multiple, Neurological	Lanarkshire	NHS Lanarkshire	The Haven *
9452	Toolkit, information	1	Cancer, Skin	National	1	Melanoma Action ^
9710	Training, support	ı	Mental Health	Glasgow	1	Carr Gomm *
9897.6	Website, information	Age	Neurological - NF	National	1	Confer ^
7500	Arts, training	Disability	Neurological - stroke, MS, Parkinsons	Glasgow	1	Drumchapel Disabled Action 2 ^
7500	Arts, training	Disability	Neurological - stroke, MS, Parkinsons	Glasgow	1	Drumchapel Disabled Action 2 ^
49940.60	Exercise, information, support	Age	Neurological – Spina Bifida	Lanarkshire	NHS Social Care/Leisure Professionals Voluntary – Action for Sick Children	Spina Bifida Association *
26900	Research	1	Mental Health	Glasgow	Academic – Strathclyde University NHS Greater Glasgow	Mental Health Foundation *
10000	Research, exercise	Disability	Multiple	Glasgow	ı	Active 4 All ^
10000	Arts	1	Mental Health	Glasgow	NHS Greater Glasgow	Glasgow West Regeneration Agency ^
9482.78	Toolkit, peer training	Disability Age	Sensory - Vision	National	-	RNIB *
8525	Peer support, complementary therapies, awareness raising	1	Cancer	Ayrshire	NHS Ayrshire and Arran	Ayshire Cancer Support

\*encouraged to re-apply following round one and received support from LTCAS prior to submission

Organisation	Partners	Location	Condition	Equalities	Approach	£ allocated
Momentum ^	Voluntary – Grampian Brain Injury Group	North East	Neurological - ABI	Gender	Training, Peer Support, Information	45825
Open Secret ^	Voluntary – Kingdom Survivors, Moira Anderson Foundation	Central West	Mental Health – survivors of sexual abuse	1	Complementary Therapies	48049
COMAS^	NHS Lothian, City of Edinburgh Council – Housing	Central East	Mental Health, Addiction – Drug and Alcohol	1	Peer Support, Training	48787
Aberdeenshire Signposting Project *	1	North East	Mental Health - Post-natal depression	Gender	Support, Information	49307
Castlemilk Stress Centre *	1	Central West	Mental Health, Addiction, Multiple	Disability	Support, Information	20782
Strathclyde Lupus Group ^	ı	Central West	Other -Auto- immune - Lupus	1	Information, Awareness raising	17969
Dunoon Link Club ^	1	Central West	Mental Health	1	Information, Support, Peer Support, Counselling	24212
East Dunbartonshire Association for Mental Health ^	1	Central West	Mental Health	1	Training - WRAP	49685
Marie Curie *	1	Central West	Cancer, Neurological - MS, Multiple Conditions	1	Complementary therapies	42895
Intrelate *	Voluntary – Thistle Foundation and Penumbra	National	Mental Health, Multiple – physical and learning disabilities	Disability	Technology, planning	20000

## Self Management Fund - Round Three



399999.54				two and three)	lotal (rounds one, t	
714394				(round three)	-tota	
9928	Drama/Theatre	Disability	Sensory - deafblind	National	Voluntary – Sense Scotland	Deafblind Scotland *
10000	Drama/Theatre	Age	Mental Health	Central West	1	Solar Bear ^
9920	Complementary Therapies	1	Multiple, Neurological	Lanarkshire	NHS Lanarkshire	The Haven *
10000	Exercise, support	1	Other - Cardiac	South West	NHS, Voluntary - CHSS	Crichton Hale & Hearty
2000	Information, support	1	Mental Health	North West	1	Tagsa Uibhist ^
10000	Information, awareness raising	1	Cancer - ovarian	National	NHS	Target Ovarian Cancer
9850	Exercise	1	Generic	South West	NHS	Nithsdale CVS ^
8050	Support, Information	1	Neurological - Epilepsy	North East	1	North East Epilepsy Group *
8852	Action research	1	Neurological – ME, Generic	National	1	SKS Scotland ^
24700	Support, Information	1	Multiple, Mental Health	Central West	NHS – Ayshire and Arran, Voluntary – Arthritis Care, AccessAbility	Fullarton Community Health House ^
20000	Support	1	Mental Health	National	1	Penumbra ^
40246	Information, peer support	1	Generic - carers	National	ı	Shared Care Scotland ^
28548	Information, peer support, Art/ Music Therapy	Age	Neurological - ABI	National	-	Child Brain Injury Trust *
20000	Technology, support, training, information	1	Respiratory - COPD	National	NHS, Scottish Centre for Telehealth, Voluntary	British Lung Foundation *
43311	Technology, awareness raising, information, peer	1	Generic – rare conditions	National	1	Genetic Interest Group *

#### **Principles of Self Management**

**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 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.

#### "I am the leading partner in managment 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.

#### "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.

**July 2008** 





#### **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/resources/library/search/gaun+yersel/

My Condition, My Terms, My Life campaign website and resources **www.myconditionmylife.org** 

Series of Special Reports linked to the Self Management Projects www.ltcas.org.uk/resources/library/search/special+reports/

Long Term Conditions Action Plan www.sehd.scot.nhs.uk/mels/CEL2009\_23.pdf

Long Term Conditions Community www.knowledge.scot.nhs.uk/ltc.aspx

NHSScotland Quality Strategy www.scotland.gov.uk/Publications/2010/05/10102307/0



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