





Self Management Fund – Special Report – Exercise and Activity

April 2011

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Overview and Background

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

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

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

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

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

Exercise and Activity

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

This Special Report looks at how the Self Management Fund has encouraged positive approaches to self management across Scotland focusing on the benefits of exercise and activity.

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

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

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

Exercise and Activity in context

Exercise and activity are widely recognised to promote wellbeing, physical and mental health, prevent disease, improve social integration, belonging and quality of life.

However, physical inactivity remains one of Scotland's major public health issues, with at least 63% of Scottish adults and 35% of Scottish children failing to meet the minimum recommendations for physical activity³.

Principles of Self Management

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

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

The fifth Principle is;

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

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

Self Management Fund

The inclusion of people's experience in the design, development, implementation and evaluation of the 81 Self Management Fund projects has been a key to their success.

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

Exercise and Activity have been reflected in the projects in a variety of ways;

³ The Scottish Government (2010). The Scottish Health Survey: Volume 1: Main Report http://www.scotland.gov.uk/Publications/2010/09/23154223/107

- by involving peers in delivery and support
- by encouraging appropriate and accessible exercise
- by encouraging walking
- by encouraging other activities

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

Scottish Physical Activity and Health Alliance

Scottish Physical Activity and Health Alliance is a network that engages a variety of people from different sectors and professions who are involved in the promotion of physical activity and health in Scotland. It helps to inform people, connect people with others and to aid policy development and implementation.

The Scottish Physical Activity and Health Alliance supports the physical activity health improvement workforce in implementing the national physical activity strategy Let's Make Scotland More Active (Scottish Executive, 2003)⁴.

The strategy is a 20 year plan and set targets to achieve 50% of all adults (aged over 16) and 80% of all children (aged 16 and under) to meet the minimum recommended levels of physical activity by 2022.

The workforce includes all those with a role to play in the promotion of physical activity within national and local government, NHS health boards, community health partnerships, community planning, voluntary and community organisations, research and academia, media, local enterprise companies and businesses.

The aim of supporting the implementation of national physical activity and health strategy will be achieved by:

- Effective communication between all stakeholders involved in physical activity and health
- Providing opportunities for debate

⁴ http://www.scotland.gov.uk/Publications/2003/02/16324/17895

- Sharing physical activity and health evidence and information, for example promoting good practice
- Learning and development opportunities

Active Scotland

Active Scotland has been developed by NHS Health Scotland as a tool to support the physical activity workforce, primarily primary care staff and allied health professionals working with people to answer the question 'where do I go to be active'?

Active Scotland has created a dataset of national and local physical activity infrastructure, including opportunities and mechanisms of support from the public, private, and voluntary sectors. Active Scotland aims to make this information easy to use and accessible to help the people of Scotland become more active.

All primary and community care staff including doctors, nurses, physiotherapists, dieticians, psychiatric nurses and pharmacy staff play a key role in helping people to understand the value of physical activity for their health. Active Scotland provides access to local information that will help people locate social support networks and opportunities to engage in physical activity in their neighbourhood.

Equally, Active Scotland can signpost those working in communities, schools and workplaces to local physical activity opportunities and networks.

Paths for All

Founded as a Scottish charity in 1996, Paths for All is a partnership of more than twenty national organisations committed to promoting walking for health and the development of multi-use path networks in Scotland.

Paths for All are leading the way to a happier, healthier, greener, more active Scotland through their work and provision of advice, resources and support to others.

Their priorities are:

- to reduce the proportion of the population who are physically inactive through a national walking programme
- to promote an increase in the number, quality, and accessibility of paths for everyone

Learning from the Self Management Fund

Peer Support

'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' - PASDA course participant

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

Some further examples of are;

- Scottish Association for Mental Health (SAMH) who are running a nationwide project to empower people to manage their mental health and wellbeing through participation in physical activity
- No Strings Attached are developing and delivering a music self management programme for young people living with Asthma from a deprived area. The course teaches participants about their Asthma and how playing wind instruments can be used to help manage their condition
- Speakeasy have developed self management workshops for people living with head and neck cancer. The workshops cover a variety of topics including stoma management and appropriate exercise for those living with head and neck cancer

Appropriate and accessible exercise

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

The value of encouraging people to become involved in appropriate and accessible exercise to support their self management, to raise awareness of conditions and approaches and to increase understanding of the impact of self management can be seen in a number of the projects – see **Revive MS Support, and Angus Cardiac Group** case studies.

Some further examples are;

- **Scottish Spina Bifida Association** are running a pilot health and fitness programme for those living with Spina Bifida
- Community Health Shop are running a programme which supports people to manage the negative aspects of their condition using a range of complementary therapies and appropriate exercises. Once participants have found the therapy which works best for them they will be given the opportunity to learn how to practice the therapy
- Healthy Valleys has developed its stress management programme and has made it available to those living with any long term condition. On completion of the course participants will have three options; to be trained as course facilitators, join a regular tai chi course run by a local instructor from the centre or to attend peer support group

Walking

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

The value of joining a local walking group to support self management can be seen in many projects - see **Active 4 All** case study

Some further examples are;

- **Braveheart** are running a series of self management workshops and exercise programmes for those living with diabetes and coronary heart disease
- Nithsdale CVS are developing a formal referral system in order to increase the scope of their health walk programme. The organisation believes this will ensure that more people in the area, who live with a variety of conditions, will learn how to manage their condition more effectively through gentle exercise

 Crichton Hale and Hearty are creating an exercise peer support group for those living with heart failure, their families and carers. This will build on a successful local model of support which exists for those living with coronary heart disease and create a sustainable group, run by those living with the long term conditions

Other activities

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

Many projects are developing activities other than exercise to support self management – see **Active 4 All** case study.

Some further examples are;

- Drumchapel Disabled Action 2 are running a music and movement self management programme for those living with stroke, MS and Parkinson's. The course supports participants to see how they can use music technology and movement to help manage certain aspects of their condition
- Solar Bear are running a therapeutic theatre programme for young people living with mental health conditions, their friends and families
- Deafblind Scotland are running a drama self management programme for those who are deafblind

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

Conclusions

The Self Management Fund for Scotland has enabled projects to investigate the benefits of exercise and activity for people living with long term conditions, and those that care for them, in supporting self management. The Fund is capturing the learning from these experiences, and has so far been able to show the value of exercise and activity by;

- involving peers in delivery and support
- encouraging appropriate and accessible exercise
- encouraging walking
- encouraging other activities, which are not necessarily exercise-based

LTCAS will continue to work with partners to promote and develop exercise and activity based approaches to self management support for people living with long term conditions conditions.

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

Case Studies



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

- Revive MS Support
- Angus Cardiac Group
- Active 4 All

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

Revive MS Support





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

Members of a Revive MS Support exercise group in Maryhill

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

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

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

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

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

techniques which can they can keep going with at home, improving their movement, sustaining their mobility and supporting their self management.

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

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

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

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

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

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

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

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

For more information please visit <u>www.revivemssupport.org.uk</u>

Angus Cardiac Group





Angus Cardiac Group support cardiac care and rehabilitation in Angus.

Angus Cardiac Group members

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 practitioners and exercise instructors increase their skills and knowledge in supporting people living with long term conditions to exercise and be active.

'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.

Participants in exercise and activity

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 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 it's 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

Appendix 1

Principles of Self Management

July 2008

Principles: Self Management Health, Social and Voluntary Sectors

"Be accountable to me and value my experience"

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

"I am 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 management of my health"

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

"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.

Scottish Physical Activity and Health Alliance

About the Alliance

Scottish Physical Activity and Health Alliance is a network that engages a variety of people from different sectors and professions who are involved in the promotion of physical activity and health in Scotland. It helps to inform people, connect people with others and to aid policy development and implementation.

What does the Physical Activity and Health Alliance do?

- We connect people to information by keeping you up-to-date on physical activity and health issues, including evidence, policy and practice across a range settings, sectors and professions involved in physical activity in Scotland.
- We connect people with each other within and across a range of professions, sectors and settings. By bringing people together, we are able to share information and experiences. Through networking we are able to help you make the right connections in order to help you do your bit to make Scotland more active.
- We connect people to policy providing the opportunity for you to inform policy development and implementation through consultation and debate.

Contacting the Physical Activity and Health Alliance

The Physical Activity and Health Alliance is located within NHS Health Scotland, Thistle House, 91 Haymarket Terrace, Edinburgh, EH12 5HE.

You can contact us by emailing nhs.HealthScotland-PAHA@nhs.net or phoning 0131 313 7500

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

Appendix 3

Paths for All

Founded as a Scottish charity in 1996, Paths for All is a partnership of more than twenty national organisations committed to promoting walking for health and the development of multi-use path networks in Scotland.

Health Walks

Health walk groups have been established by Paths for All to create a supportive environment for people to start to enjoy the many benefits of being physically active. Walking is described as the perfect exercise by health professionals and has many benefits. Walking requires no special equipment or expense and is the ideal way for most people to become more active

Paths For All through its Walking For Health project is a leading delivery agent for the Physical Activity Strategy. The role of Walking For Health is to develop walking schemes in community settings as well as in workplaces. Through the projects Paths for All aim to increase the awareness of the benefits of being physically active as well as encourage more people to become active and stay active through walking.

Paths For All have supported over 200 community based schemes and over 100 workplaces to develop walks. Paths for All have approximately 20,000 people participating in the community programme alone and an additional large number participating in the workplace programme.

In addition Paths For All have trained over 3000 volunteers in delivering walks contributing a significant number of volunteer hours.

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

Appendix 3

Useful Links

Long Term Conditions Alliance Scotland

www.ltcas.org.uk

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

www.ltcas.org.uk/self man gaun.html

Scottish Physical Activity and Health Alliance

www.paha.org.uk

Active Scotland

www.activescotland.org.uk

Paths for All

www.pathsforall.org.uk

Long Term Conditions Action Plan

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

Long Term Conditions Community

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