

# "Gawn Yersel!"

The phrase "Gawn Yersel!" is used to cheer a person on as they embark on a challenge. It is a vote of confidence and a message that the person has your support.



## The Self Management Strategy for Long Term Conditions in Scotland



**LTCAS**  
LONG-TERM CONDITIONS  
ALLIANCE SCOTLAND  
people not patients



**The Scottish  
Government**

# The Self Management Strategy for Long Term Conditions in Scotland

“The draft strategy feels like someone’s actually been inside my head and reflects exactly what I’ve been through at different times and gives real practical advice and guidance of the kind of staffing and support required to make life easier for people living with a long term condition”

Respondent to consultation on the draft Self Management Strategy

## Acknowledgements

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The strategy builds on the work of many voluntary organisations over many years to promote self management and support people to live well with long term conditions.

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The Self Management Strategy that follows is a unique document, in that it has been developed not, as you might expect, by the Scottish Government, but by the Long Term Conditions Alliance Scotland. This was a deliberate decision, in keeping with our overall approach to long term conditions management, where we want to learn from people's own experience of living with these conditions. The strategy is, as it says, driven not by policy makers but by people themselves.

There should be no doubt, though, about our commitment to the concept of self management. It is at the very centre of our long term conditions work, as we have made clear in Better Health, Better Care. Partnership with the individual is central to the self management agenda. Where people can access timely and appropriate information and support, they are more able to make well-informed decisions about their life.

The individual case studies illustrating each of the key stages where people are looking for support bring home very vividly just how life could be better for people living with long term conditions, and their families and carers. We endorse the strategy's view that life is for living, and for living well, not for enduring.

In a sense, nothing in the strategy is new, and the examples of local initiatives are indicative of the extent to which NHSScotland and its partners have already embraced the self management approach. What the creation of the strategy makes very clear, though, is that we must get on and embed self management in a systematic way across the whole country, and in partnership with the third sector and local authorities. The Scottish Government fully accepts its responsibility, as highlighted in the strategy, for changing attitudes and culture, so that

by Nicola Sturgeon MSP, Deputy First Minister and  
Cabinet Secretary for Health and Wellbeing

the ethos of self management is integral to our care systems. The Long Term Conditions Delivery Plan promised in Better Health, Better Care, which the Chief Medical Officer's Steering Group is currently developing, will set out our joint thinking on the range of specific actions needed to implement the Strategy.



**Nicola Sturgeon MSP**

Deputy First Minister and Cabinet Secretary  
for Health and Wellbeing



This strategy sets out a challenge to each of us as individuals and organisations. In this, the 60th anniversary of the NHS (and for many years more in the case of so many voluntary organisations) we need to be willing to review our practice and offer a truly person-centred service. If we keep the needs of "people, not patients" at the heart of our work, and shape our services including information, education and support (both physical and psychological), with them we will respond to that ambitious vision.

Understanding we need to be the change we want to see in the world, the development of the strategy by people with long term conditions embodies the approach for all of us.

As someone living with a long term condition and having worked in both healthcare and the voluntary sector I am really excited by this challenge and confident we can make a real difference... gaun yersels!

**Audrey Birt**

LTCAS Chair and Chair of Chief Medical Officer's Self Management Subgroup



# Executive Summary

**Self management is the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term condition.**

The Long Term Conditions Alliance Scotland (LTCAS) was asked by the Scottish Government to develop a strategy for self management. This reflects recognition both of the considerable contribution self management can make and of self management as a movement driven not by policy makers but by people themselves. Self management is the key to meeting the growing challenge of long term conditions and this strategy harnesses the motivation, commitment and creativity of those at the heart of this agenda – people who themselves live with long term conditions.

## **Aim of the strategy**

Living with a condition for which there is no cure can have a devastating effect on a person. The impact can extend to social, economic, psychological, physical, cognitive and cultural aspects of a person's life. People cope as well as they can with the support they have but frequently do not have the information or skills to develop healthy responses to their condition, or make well informed decisions about their life. This strategy aims to work towards a situation in which people living with long term conditions have access to the support they need to successfully manage their condition. This could include: information leaflets; courses run by others with similar conditions; one to one support; structured education; and self management courses. All of these will empower people to learn about their condition, acknowledge the impact on their life, make changes and identify areas where they need support.

## Cost of long term conditions

The economic and social cost of long term conditions in Scotland is not known. It is estimated that for mental health problems alone this stands at around £8.6b or 9% of GDP<sup>1</sup>.

Evidence suggests that self management can reduce the impact of long term conditions on NHS services. However, this is not a cost-free option. It means that resources must be redirected into self management with a focus on developing social capital through, and within, the voluntary sector. LTCAS recommends the establishment of a new fund of £2m per year for three years to support expansion, development and innovation of support for self management.

<sup>1</sup> What's It Worth? The Social and Economic Costs of Mental Health Problems in Scotland published in 2006 by SAMH Glasgow. Available at <http://www.samh.org.uk/assets/files/112.pdf>



## Key stages where people need support

Key stage	Issues	Impact of self management
<b>Diagnosis</b>	<ul style="list-style-type: none"> <li>• By this point someone's life and ability to manage may already have been seriously affected by symptoms.</li> <li>• People feel challenged about their place in the world and the reality of their situation.</li> </ul>	<ul style="list-style-type: none"> <li>• Helps people come to terms with diagnosis.</li> <li>• Key to helping people reconnect with themselves and others.</li> <li>• Helps people make better decisions about treatment options.</li> </ul>
<b>Living for today</b>	<ul style="list-style-type: none"> <li>• People need information and skills to maintain optimum wellbeing.</li> <li>• Serious risk of social exclusion.</li> </ul>	<ul style="list-style-type: none"> <li>• Supports people to navigate an often difficult journey.</li> <li>• Challenges social exclusion by helping build bridges back into society and social roles.</li> </ul>
<b>Progression</b>	<ul style="list-style-type: none"> <li>• Cycle of illness and wellbeing arising from fluctuations in condition.</li> <li>• Increasing severity of symptoms.</li> <li>• Struggle to get additional support during flare-ups.</li> <li>• Possible loss of capacity.</li> </ul>	<ul style="list-style-type: none"> <li>• Helps to avoid (or minimise the extent of) flare-ups.</li> <li>• Enables people to recognise early warning signs and react effectively.</li> <li>• Tackles psychological impact of flare-ups or progression.</li> <li>• Supports changing needs.</li> </ul>
<b>Transitions</b>	<ul style="list-style-type: none"> <li>• Moving between services, sometimes to different levels/types of support.</li> <li>• Dealing with multiple needs/conditions and therefore a range of services.</li> <li>• Often a stressful time and this can have serious impact, including on person's condition.</li> </ul>	<ul style="list-style-type: none"> <li>• Supports person to manage transition processes.</li> <li>• Maintains focus on person's needs ensuring services are organised around these.</li> <li>• Provides person with control at a time when this can be undermined.</li> </ul>
<b>End of life</b>	<ul style="list-style-type: none"> <li>• Difficult time involving complex challenges.</li> <li>• Death may be premature.</li> <li>• Person may have to cope with symptoms of condition alongside additional challenges of end of life.</li> </ul>	<ul style="list-style-type: none"> <li>• Supports person to meet range of challenges and maintain control.</li> <li>• Addresses broader needs e.g. emotional, family and lifestyle.</li> </ul>

## Making it happen

Self management is the responsibility of individuals. However, this does not mean people doing it alone. Successful self management relies on people having access to the right information, education, support and services. It also depends on professionals understanding and embracing a person-centred, empowering approach in which the individual is the leading partner in managing their own life and condition(s).

# Background

People with long term conditions are major users of health and care support services in both the statutory and voluntary sectors. Often these services are driven by external and internal pressures rather than by placing people and their direct needs at the centre. By adopting and implementing a self management strategy and person centred philosophy, LTCAS believes that a transformative approach can be developed. Person centred approaches would become a reality for many of us who live with long term conditions or who work in these services. Such a strategy needs to enable people with long term conditions to live well and empower us to realise and heighten our personal goals. A low expectation of self and others prevents the concept of wellness being associated with those living with long term conditions.

Self care and self management form a key strand in the successful implementation of the Better Health, Better Care agenda in Scotland. People are living longer with long term conditions and the current structures and practices within health and social care are not adequately supporting people to cope effectively. As a result, in November 2006, LTCAS held the 'Gaun Yersel' conference. This brought together key health and social care professionals and voluntary organisations with an interest in promoting and developing the self management agenda across Scotland.

The terms self care and self management are often used interchangeably. LTCAS uses the following to clarify these terms:

- Self care is what each person does on an everyday basis. This is often compromised for a person living their life with long term conditions.
- Self management is the process each person develops to manage their conditions.
- Support for self care and self management is the responsibility of health and social care providers and unpaid carers.

LTCAS believes that the term self management encompasses the broad perspective of an agenda which not only places people at the centre of services but puts them in the driving seat. It is a broad church and includes partnership with a wide range of agencies, carers and health professionals. Most importantly we believe self management as a term is dynamic, not passive, and reflects an ethos of empowerment.

# What is Self Management?



## Key messages

- Self management is a person-centred approach in which the individual is empowered and has ownership over the management of their life and conditions.
- The role of health and social care professionals, services and treatment is to support the person's journey towards living well in the presence or absence of symptoms.
- The approach must be properly resourced.

Self management is a concept where the person takes ownership and is central. It is a process of becoming empowered to manage life with long term conditions. It is not an individual action, a specific treatment or service; neither can it be delivered by a single organisation. Self management is the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of their life with one or more long term condition.

Self management has to be a central component of the approach to working with people experiencing long term conditions and as such requires to be properly resourced. It is important to recognise that agencies such as the NHS and local authorities continue to be responsible for providing appropriate interventions such as care, support and treatment when needed.

## NHS Borders

NHS Borders' Long Term Conditions Team Lead is also lead for the Managed Clinical Networks. This aids coordination and communication of activities. The team are developing a Long Terms Conditions model based on the patient pathway. It refers to the many different local and national resources, agencies and support required at different parts of the pathway. NHS Borders has close links with Borders Voluntary

Community Care Forum which brings together a range of voluntary sector organisations such as the Princes Royal Carers Trust and the Red Cross.

## **NHS Tayside**

NHS Tayside has a 'self management framework for long term conditions' which aims to develop community-based, sustainable programmes across the region. The framework was devised by reviewing the evidence base for self care, using key themes which emerged from public focus groups and through consultation with stakeholders. NHS Tayside also has a 'long term conditions IT clinical system'. This encourages communication and sharing of data between primary and secondary care. The system currently works for diabetes, cardiology and Chronic Obstructive Pulmonary Disease (COPD) and will be extended to more conditions in the future.

Enablement and empathy go hand in hand with self management. People must not be expected to manage on their own without some level of support. This support is on a continuum and for some will be very little, for others 24 hours a day, seven days a week. Support levels will change depending on each individual's life stage and the nature of their condition. It is critical that the self management agenda takes account of the structural issues which serve to exclude people and the support needed to overcome these.

It is not a new concept. People with long term conditions currently self manage and do so with the skills and the abilities they currently have. However, this is often with great difficulty as services are not aligned to the concept. Not everyone has the same ability to learn and to manage and some groups face greater, or multiple barriers to self management. The impact of the range of health inequality issues such as poverty, unemployment, exclusion on grounds of ethnicity, refugee status, gender and sexual orientation all play a significant part in people's abilities to cope. This means that self management

interventions and individuals who determine and provide services need to be sensitive to barriers to participation in order to maximise their effectiveness.

It is clear that responsibility for providing effective health and social care services remains firmly with professional organisations. People with long term conditions need services to assist them on their journey. However, by using a philosophy of self management we hope this journey can be a healing one.

People with long term conditions need nurture and respect so that their journey can lead to different levels of recovery. This can be recovery of spirit; of emotional wellbeing. It can be a journey that leads the person to live well in the presence or absence of symptoms. It will be different for each individual. Mental wellbeing and the interaction of mind, body and spirit is increasingly recognised as an important aspect of individual happiness. Personal worth and high self esteem are key elements to successful self management. The personal relationship the individual has with health and social care professionals, with unpaid carers and with their family is also key to success.

## Helping HIV positive people help themselves

Since October 2007 Terrence Higgins Trust Scotland – Highland Services and Highland Sexual Health (Raigmore Hospital, Inverness) have set up an HIV positive support project for people living within the NHS Highland area.

The project aims to:

- Help people gain more knowledge and skills around managing HIV as a long term condition
- Increase the level of health and understanding of HIV treatment
- Reduce the social isolation in which HIV+ people are living
- Offer support



Raigmore hospital offers the clinical services, informs people of, and refers people to Terrence Higgins Trust's support services. Once clients contact Terrence Higgins Trust a one to one meeting is organised. This first meeting is very important. Mostly it is face to face and happens where the client feels most comfortable. During that meeting their needs are discussed, Terrence Higgins Trust's support services are explained, and very often basic HIV information is given, brochures are distributed. Weekly or fortnightly contacts are then set up (via phone, e-mail or in person) and in December 2007 the first group support evening was held. On request of the clients, this now happens on a monthly basis.

As a result Terrence Higgins Trust has an ongoing two parallel stream of support: one to one and group support. Support may include: emotional support, education about HIV, counselling and welfare rights support (housing, work, legal advice).

Collaboration between Highland Sexual Health and Terrence Higgins Trust has great benefit. The integration of health and social care through this collaboration has had a positive impact on the lives of people accessing the service. They are becoming more empowered; feelings of isolation and exclusion diminish; adherence levels to medication improve; people understand and manage their condition and their lives better.

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## Why is self management important?



## Key messages

- The key to successful management of long term conditions lies in the hands of the person who lives with the conditions.
- People need the right information and skills to develop healthy responses to their conditions.

Being told you have a condition for which there is no cure can have a devastating effect on a person, their values and beliefs. Individual people respond in individual ways and the impact of diagnosis will vary according to the effect of the symptoms on the person's life circumstances. This includes social, economic, psychological, cognitive and cultural issues for that person, as well as the physical aspects of the condition.

All of these factors can have a profound impact on a person's well-being and self-esteem. People cope as best they can with the support they have; but frequently they do not have the information or skills to develop healthy responses to their condition, or make well informed decisions about their life; let alone make plans for the future.

To treat the medical condition in isolation from what is a much more complex human picture is reductive. It ignores the fact that ultimately the key to the successful management of long term conditions lies in the hands of the person who lives with the condition and their desire and ability to care about themselves.

## NHS Lanarkshire

Chronic pain self management groups have been provided throughout NHS Lanarkshire by The Pain Association for over 10 years. The 'Living with Pain' programmes are professionally led and offer structured training to people to facilitate coping with chronic pain and its impact. The course runs over a seven- week period and is based on bio psychosocial principles to maximise quality of life for the person with

pain and their family. The 'Living with Pain' programme offers a follow-on support to people from the Lanarkshire Chronic Pain Service.

## **Thistle Lifestyle Management Service**

Since 2001 the Thistle Foundation has delivered self management support to people with long-term conditions. This is focused particularly in its main base in Edinburgh but also in East Lothian, Aberdeen and the Borders.

The Thistle Foundation delivers a person-centred, solution focused and generic approach to supporting people at key stages and transitions in life. Programmes have been designed using best practice from fields such as cardiac and pulmonary rehabilitation, chronic pain and fatigue management, integrated with user involvement and person centred values.

It does this by working alongside and beyond any existing medical support. They work with the whole person who lives with the condition, not the condition itself. The programme builds on the individual's own strengths, skills, resources, hopes and recovery strategies. The aim of this is to empower people to increase their control, coping and confidence to move on in life.

People can self refer or be referred from any agency. They are offered a menu of therapeutic options. This includes a 10 week programme of group based sessions; individual consultations on lifestyle management; exercise, relaxation and fitness groups.

Topics such as sleep, stress, activity and time management, communication skills; mindfulness; managing relapse and forward planning are included.

The service has six members of staff, three of whom have a long-term condition. The organisation is training up to 15 past participants annually to become Peer Support Facilitators enabling greater involvement and increasing the capacity of the service.

Participant-led maintenance groups are supported by the service. Participants also have access to the wider services of the Thistle Foundation such as employment and volunteering support, supervised gym.

In 2007/8, 300 people attended one of 24 courses. 74% of the starting participants successfully completed the 10-week programme.

The service now offers training and consultancy in relation to the Thistle model. It has also a participative research and development strategy in relation their Lifestyle Management Service.

# How does self management help?

Self management includes a whole spectrum of mechanisms to support people to learn about their condition, acknowledge the impact it has on their life, make changes/adapt and identify areas where they require support. Whether an information leaflet about a specific condition, a course run by people with similar conditions or a series of one to one support sessions; all are proven effective in providing people with the knowledge and tools they need to cope effectively.

Some interventions will be very specific due to the complexity of the issue, for example understanding diet and insulin balance for people living with diabetes. Other interventions will be broader and can apply to a wide range of long term conditions such as the Stanford model of self management courses introduced into Scotland by Arthritis Care . Best practice suggests that all self management interventions should help people feel more in control and become less stressed. This is why many self management courses include aspects of meditation and other stress relieving techniques.

## Arthritis Care in Scotland

One in five people in Scotland live with arthritis. So the chances are that if you don't have the condition yourself, someone you know does. Arthritis Care, the largest UK-wide voluntary organisation working with and for people with arthritis, offers a variety of tools to help people with arthritis to manage their condition.

Arthritis Care in Scotland aims to provide information and support to anybody with arthritis. They make sure this is appropriate to the person's own experience of living with their condition. This ranges from one to one support on diagnosis to information on the latest medical treatments. It also offers a range of support and coping techniques for leading a full life. Workshops lasting 6 weeks, or a few hours, depending on an individual's time commitments, are presented by trained volunteers who themselves have arthritis. Acting as role

<sup>2</sup> <http://www.arthritiscare.org.uk/InyourArea/Scotland/>

models, they support people to develop the tools and confidence to live an active life with arthritis.

Volunteers play a very important part in the work of Arthritis Care in Scotland. The organisation makes sure that the support and services they provide remain focussed on the needs of the person with arthritis. Volunteers give as much time as they can commit. They get involved with the organisation at many different levels and in a range of different ways. For example providing information via hospital information points, clinics and giving talks on exercise, healthy eating and coping with pain. All information is written by and for people with arthritis. The organisation also provides volunteers with training and skills to help them campaign at local and national level for services and awareness for people with arthritis.

Arthritis Care has a BMJ award for its website, where visitors are able to participate in a discussion forum, access printed information and find out what is happening in their area. Within the local community Arthritis Care in Scotland has a network of branches and groups run by dedicated volunteer committees. The branches and groups promote the work of Arthritis Care. They also provide opportunities for people with arthritis to meet together and share their experiences and self management techniques.

Arthritis Care in Scotland is all about people. Being a user led organisation, people with arthritis inform and direct its work. Staff and volunteers meet regularly to make sure the needs of people with arthritis are being fully met.





## Key messages

- Self management contributes to a healthier, safer, stronger, fairer, wealthier, greener and smarter Scotland.
- Long term conditions are now recognised world-wide as a key challenge.
- The social and economic costs of mental health problems alone are estimated to be around £8.6b. The figure for all long term conditions will be far higher.
- Evidence suggests that people who receive self management support are significantly less likely to experience complications associated with their condition and therefore to require NHS services.
- As part of supporting the infrastructure of the voluntary and community sector LTCAS recommends the establishment of a long term conditions hub.
- LTCAS proposes new funding of £2m per year for three years to develop self management. This equates to £1 per person living with one or more long term condition.

## Cost of Long Term Conditions

The cost of long term conditions for Scotland is not easy to capture. Definition of cost – and assessment of effectiveness of interventions – cannot be based solely on financial measures. These must also take into account quality of life. With around two million people living with long term conditions, the economic argument for improving people’s health and wellbeing and enabling them to work where possible, is strong on all of these grounds. The Scottish Government is committed to policies which will enable Scotland to be healthier, safer, stronger, fairer, wealthier, greener and smarter. LTCAS believes self management contributes to all of these areas.

There is nothing documented that reflects the full social and economic cost of long term conditions. However, internationally the global burden of disease is well documented and addressed by the World Health

Organisation (WHO). WHO initially focussed mainly on communicable disease but now recognises that issues relating to long term conditions are key, especially in the face of ageing populations. One example of the predicted growth in age-related long term conditions is dementia; the number of people with dementia in Scotland is projected to increase by 75% within the next 25 years<sup>3</sup>.

Figures for the cost of all long term conditions are not currently available. However, the Scottish Association for Mental Health looked at the high costs of mental health problems. Their research<sup>4</sup> shows that in 2005, the social and economic costs were equivalent to £8.6 billion, some 9% of Scotland's gross domestic product. While mental health problems constitute the largest number of people living with long term conditions and predominate highly for people living with more than one condition, this figure will be significantly higher if all conditions were included.

## Economic impact of self management

A study<sup>5</sup> on the effectiveness of self care interventions in diabetes shows the benefits of education for self management in diabetes. It concludes that these programmes are highly effective but are not sufficiently widely available. Importantly it also highlights that people who have no such intervention are at a fourfold increased risk of complications, which result in huge cost to the NHS.

If self management is to work as outlined in this document and in the Living Well report, spending needs to be redirected. This applies to the NHS, local authorities and the voluntary sector. Each organisation needs to consider how they can influence culture and service provision, where training is needed and how services can be redesigned.

<sup>3</sup> Alzheimer Scotland (2007) The Dementia Epidemic.  
<http://www.alzscot.org/pages/policy/dementiaepidemic.htm>

<sup>4</sup> What's It Worth? The Social and Economic Costs of Mental Health Problems in Scotland published in 2006 by SAMH Glasgow. Available at <http://www.samh.org.uk/assets/files/112.pdf>

<sup>5</sup> Nicolucci et al, 1996 A comprehensive assessment of the avoidability of long-term complications of diabetes, *Diabetes Care*, 19: 927-933

## Citizens Advice Bureaux

Citizens Advice Bureaux provide a wide range of information and support to people many of whom are living with long term health conditions. They assist people to understand what help is available to them and their families if their health condition stops them from carrying out their usual daily functions. This could include helping people who can no longer work or who need extra help because of disability to apply for benefits. People might want help to cope with financial problems that have arisen due to loss of income or to know what rights they have to return to a previous job on reduced hours or with changes to the working environment. A person may need to have adaptations to their home or to move to a more suitable house. Again CAB would assist them to understand what can be done and provide support if required.

Bureaux act as resource hubs and will give people information about local sources of support as well as generic information. CAB provides services to all people. This means that no one should be unable to access help if they contact a bureau. In addition some have specific services that are tailored to particular groups of people with certain health conditions. The service may be provided in a particular venue e.g. a psychiatric hospital or Resource Centre for people with a mental health condition. The bureau may take referrals from particular health specialist staff or charities, e.g. Macmillan / Chest Heart Stroke. In these projects the bureau staff and other partners work together to meet a wide range of needs of people coping with perhaps a change in circumstances due to the onset or worsening of a health condition.

Many bureaux will form ongoing relationships with clients so that they will return to seek help if a change occurs. This support can be vital at times of crisis when people may be unable to cope alone and there may be no other support readily available. This support can be crucial in helping people to cope with issues so that their health is not affected adversely.

In addition many people who can not engage in paid employment may volunteer in their local bureau helping to maintain their health and well being. With some people this can then lead back into education or employment.

## Supporting the voluntary sector to deliver

With regard to the voluntary sector, LTCAS recommends that funds are established for organisations to expand or develop self management programmes. The voluntary sector's biggest strength is its ability to reach people living with long term conditions. While self management is, in essence at the heart of the sector, not all voluntary and community organisations have had the opportunity or resources to develop formal and dedicated approaches. We have a vision of a sea change in the expectations of people living with long term conditions. However, the sector needs resources to build capacity and develop social capital to respond to rising expectations.

## Breast Cancer Care

Breast Cancer Care helps support people affected by breast cancer by: providing information, emotional and practical support services.

The organisation's Health & Wellbeing programme provides structured events and forums. This helps bring people with breast cancer together to gain information and support from each other. This programme includes a "Living with breast cancer" two day programme, half day informal Information Sessions and residential Younger Women's forum. Each service is tailored for the group involved and provides a supportive environment with time for discussion. Participants register with staff to make sure the programme is relevant and people are sign posted to other services where appropriate.

The programme is facilitated by trained staff and features guest speakers with expertise on the specific topic. It is delivered with input from trained volunteers who have personal experience of breast cancer. Participants evaluate their experience and this feedback allows Breast Cancer Care to ensure the programme is appropriate to client needs.

The Health & Wellbeing programme has been created to improve coping skills and reduce isolation post-diagnosis. It provides a group work intervention that operates in tandem with a 1-1 peer support service offered by trained volunteers with personal experience of breast cancer. These services are part of Breast Cancer Care's portfolio of national and local support.

## **Epilepsy Scotland**

Epilepsy Scotland provides information across Scotland to people living with epilepsy as part of its approach to self management. A recent example of partnership work with NHS colleagues is that Epilepsy Scotland's information has been included in a new electronic referral system being piloted in Tayside, Ayrshire and Arran, Grampian and Fife. This is for referrals from primary and secondary care to first seizure clinics run by epilepsy specialists. The aim of this programme, funded by the Health Foundation, is that it will eventually be available across all GP surgeries and Accident and Emergency services in Scotland. When making a referral to a first seizure clinic, the doctor is directed to complete the referral electronically. Part of this includes a check list of information that the person may benefit from. When the doctor clicks on these a link is made to Epilepsy Scotland's website. To make it easy, Epilepsy Scotland has adapted its user friendly leaflets to make them quick and easy to print off during the appointment with the doctor. This information includes explanations of epilepsy, lifestyle issues and details of how to get in touch with Epilepsy Scotland via its freephone helpline. Epilepsy Scotland believes this offers an early approach to self management and access to further support on the person's journey with epilepsy.

The contribution of community and voluntary groups will be different depending on size and existing capacity. This means consideration will need to be given to the different roles and definitions of support for self management. Some organisations will be in a position to offer established self management courses and/or person centred support that helps individuals along the self management path. Others may need funding to develop information leaflets or websites.

In order to develop and support self management within the sector, LTCAS supports the concept of a long term conditions hub. This would be a place where smaller and newly established organisations can be supported alongside other more established ones. This hub could offer office accommodation, shared facilities for administration, training and hot desk facilities. This too needs funding to establish and run.

## Self Management Fund for Scotland

To begin to establish the self management agenda, initially LTCAS seeks £2 million per year<sup>6</sup> for a period of three years. This equates to one pound per head for each person living with long term conditions in Scotland. This funding should be new money for the sector and not resourced from existing grants available to voluntary organisations and community groups. We believe the suggested period of three years would offer a basis to develop the capacity within organisations and individuals and enable innovative practice to emerge. As Better Health Better Care suggests, this is a long term plan and this outline proposal offers a starting point for development over the next two decades.

We suggest that the agreed budget is set up in a fund, to be managed by LTCAS. Organisations will then be supported to make bids for self management initiatives set against criteria agreed with LTCAS and the Scottish Government. An advisory board of LTCAS members with representation from the Scottish Government would be established to oversee the fund. LTCAS' structure and capacity would need to be developed to support the administration of this.

<sup>6</sup> Exclusive of long term conditions hub development for which costs are given separately.

# Key stages where people need support



## Diagnosis

Timely diagnosis is critical and how someone is supported at diagnosis can affect how well they deal with their condition for the rest of their life. For many people, diagnosis with a long term condition can feel like being given a life sentence. However, for people who have been living with symptoms without a diagnosis, it can be the start of getting on with the rest of their life. Often by the time a diagnosis is confirmed, a person's life and ability to manage it may already have been seriously affected by the symptoms associated with their condition.

Appropriate input and support to self manage at this stage can help people to come to terms with the reality of their situation. This can enable them to work towards becoming empowered to feel more in control of their life and condition. At this critical time many people are challenged about their place in the world. Do they fit in any more? Are they capable of maintaining relationships, of loving and being loved? Can they keep doing their job or providing for their family?

Self management can be the key to helping people reconnect with themselves and others. It can help them make better decisions about the variety of treatment options available for their particular condition(s). This is critical to feeling more in control of medical interventions.

To highlight issues within this document we have used people's stories to illustrate key points.

### Jane

After 2 years of symptoms Jane was finally given a diagnosis of rheumatoid arthritis, and it was such a relief to have proof that she wasn't imagining all her symptoms. The pain and stiffness in her joints, and the fatigue and flu like symptoms had been coming and going since she was 22. Jane had married young and was living on a low income



with her husband and new baby. Regular visits to her GP during that time produced a variety of prescriptions, for a range of possible conditions; including post natal depression and a touch of rheumatism.

Jane didn't have much support at home; her husband worked long inflexible hours in the building trade, and her extended family all worked full-time. The family budget would not extend to the option of childcare.

In the 2 years leading up to her diagnosis Jane's husband would return from work almost every other day to Jane's complaints of a new pain in a different place. The demands of coping with a young child with little respite from her symptoms left her feeling so tired and unwell; yet her doctor didn't seem to be overly concerned.

She tried to explain to her husband and family how she felt, but could often see their eyes glaze over as she bemoaned every new pain. With no conclusive medical diagnosis, the family consensus was that this must indeed be some type of post-natal depression and therefore the pain she was experiencing must be emotional in nature. Jane began to wonder if they were perhaps right.

In an attempt to give herself an interest outside of the family Jane took on a part-time job in a local supermarket. The time she was required to spend on her feet led to her symptoms getting worse. The situation was brought to a head when one day on a busy street, Jane's now mischievous toddler escaped from her grip and started to run away. All Jane had the strength to do was put out her foot and purposely trip the toddler up. She realised then she needed to make someone listen to her.

**Jane's life could be better than this. Read on to see how appropriate information and support tailored to an individual's need and aspirations can help someone like Jane develop skills to manage their life with a long term condition.**

With the support of a friend, Jane made an appointment with another

GP within the same practice. She described her symptoms, blood tests were taken, an x-ray appointment was arranged and the doctor confirmed a diagnosis of Rheumatoid Arthritis within a week.

Jane was referred to a Rheumatology specialist 30 miles away. However, she had to wait 6 months for the first appointment. As her GP had a particular interest in arthritis and an understanding of the impact on Jane, he started her on a range of medication immediately. He also spent time finding out about the key factors within her life that she needed immediate support with.

Over the next few weeks, Jane had a visit from a social worker who organised childcare for Jane at the local authority nursery nearby. This allowed Jane some free time to rest and get her strength back. She also arranged for a home help to call once a week to assist with those tasks around the house that she could no longer manage on her own.

An occupational therapist (OT) came to visit Jane at home and provided helpful aids and adaptations. This enabled her to get round some of the limitations that her condition was placing on her.

Jane's GP advised her that she may be entitled to some benefits and recommended that her local Citizens' Advice Bureau would be able to advise her and assist her to apply. Incapacity Benefit took some pressure off the family finances, and Disability Living Allowance enabled Jane to learn to drive and lease a car; making life much easier for herself and the whole family.

Jane's OT referred her onto a self management course which was being run in her community by a voluntary organisation for people with arthritis. The course leaders had arthritis too, and for the first time in years Jane felt that she was understood.

Over the course of 6 weeks Jane learned more about her condition; about managing pain, the importance of diet and exercise, and problem solving

techniques. She was supported to identify small goals and developed action plans to achieve them. With the additional resources and support, Jane was now able to devote some time to learning how to deal with her condition and to plan for a different, perhaps better, future.

Jane went on to study for a degree and her interest in social policy led her back into work full-time for the voluntary sector, using her experience of her condition to provide support for others.

## Living for today

Self management opportunities need to be developed in order to support people living with long term conditions on a daily basis. For some people this will mean helping them gather information and skills about how to maintain optimum wellbeing in the presence or absence of symptoms. Others will need ongoing support to help them maintain this. Again engagement, effective communication and empathy are key. There is no magic pill or solution; it is simply about helping people navigate what is often a challenging journey.

We need to grasp the social justice aspect of long term conditions. Too many people in Scotland are excluded at many levels because of their conditions and this is unfair and unjust. Self management offers the opportunity to build bridges back into society and social roles.

## George

George is 41 and lives on his own in one of the tower blocks in north Glasgow. He is in receipt of benefits having lost his job a year ago. George smokes 30 cigarettes a day. His flat is often the subject of minor vandalism. George has had no contact with his family for 20 years. He does have a small circle of close friends and his social life revolves around them. They meet up mostly at the weekends and drink to excess.

George was sexually abused as a child by his father but he has never disclosed this to anyone. He came out as a gay man at the age of 20 and was disowned by his family. He was diagnosed as HIV positive 5 years ago and more recently was diagnosed as having bi-polar affective disorder following referral by his GP to a psychiatrist 12 months ago. He lost his job when he disclosed his HIV status to his employer.

For the past 3 months he has been receiving support from a local voluntary organisation in the form of a support worker who visits twice a week for an hour and a half each time. Initially George welcomed the contact with the support worker but is finding it increasingly challenging. The support work encourages George to think about his drinking and smoking and social isolation. The support worker is concerned that he seems generally disinterested in 'looking after himself'. George would like to do more, starts with great conviction and then quickly returns to his previous behaviours. When this happens, he feels like a failure and is concerned that the support worker thinks he is not serious about taking care of himself and that he is not making an effort.

**George's life could be better than this. Read on and see how the implementation of a strategy for long term conditions can help someone like George.**

George has lived on the margins of society for most of his adult life. When he was diagnosed as having a bipolar affective disorder at 40 he was given support and information and referred to an outreach support service provided by a voluntary organisation.

George and his support worker spent weeks developing the relationship and discussing how George feels about his diagnosis and other major issues in his life. He gradually tells the support worker that he is gay and is HIV positive, has no contact with his family and relies on a small group of supportive friends. He feels worthless much of the time and feels that he has failed to live the life he should have.

They agree to focus on developing George's self-esteem. The worker arranges for him to attend an informal peer support group attended by a number of gay men who have a mental health problem. Being gay is discussed positively and without stigma and George is greatly encouraged by this. Despite initial reservations, George finds it a safe place to talk about his situation and hear other people's experiences. He appreciates the non-judgemental atmosphere and the sense of belonging.

While attending this group George hears about recovery for the first time and begins to understand that it is possible to live a fulfilling life, regardless of the problems or difficulties he may be facing. He begins to feel some hope for the future.

George's support worker continues to work with him individually. She reflects back to him that accepting the loss he feels for the life he believes he should have had could be thought of as the start of his recovery journey. She reinforces positive messages about George's sexual orientation and challenges his internalised homophobia. George no longer talks in despairing terms all the time and is starting to pay more attention to his own and his home's appearance.

The support worker suggests that George considers a mindfulness based stress reduction course run for both members of staff and people who use the service. George struggles at first but his self-acceptance grows as his confidence in his mindfulness practice increases. He is able to commit to both completing the course and carrying on his practice afterwards.

George is surprised by how far he has come. Both professionals and friends are reporting changes that they see – his appearance and positive attitude, the fact that he has stopped smoking and doesn't drink as much as he did. He also finds it easier to take all the drugs he is prescribed for his HIV and has started talking to his psychiatrist about reducing the drugs he takes for depression. Through his daily mindfulness practice, George has begun to experience a strong feeling

that 'he' is more than his condition and that the HIV isn't actually killing him in this moment. This has helped to motivate him to focus on what is right with him rather than what is wrong.

After 9 months the support worker floats the idea of George attending a further course to help him develop the skills to get back to work. George feels that this is probably over ambitious at the moment but agrees to become involved in a user involvement group.

At his annual review meeting George is able to speak with confidence about the progress he has made. He can see his darker days in the context of his overall progress and is committed to working towards his recovery – whatever that may be for him. At the meeting George is assured that the support from the service will continue. All agree to review pre-vocational training in 3 months time.

George leaves the meeting with a sense of pride in the progress he has made. Because of this and the trust and connection he has developed with his support worker, he also resolves to think about talking to her about the abuse he experienced as a child. Maybe.

### Progression

The fluctuating cycle of illness and wellbeing for people with long term conditions can be a major challenge and can follow on from a social, personal or health crisis. Other conditions are progressive and the person's symptoms will become increasingly severe. This clearly impacts on the person's health and wellbeing and it is often the lack of crisis services or early intervention that leads to these becoming acute health crises.

The emotional and psychological impact of a flare up of symptoms cannot be underestimated. This often comes with a sense of failure and loss of confidence. During these periods, people often struggle to get the

additional support they need because the current system is too inflexible. Again self management techniques can help and may often help people avoid such crises in the first place. This can be achieved by understanding their condition fully and managing it effectively; thus avoiding becoming ill again. Or it might mean learning to recognise the signs and symptoms of a pending health crisis and seeking help at an early stage. To make this work, these interventions must be there and accessible or the situation will deteriorate.

For progressive conditions, early intervention with the right information, support and help which can adjust to changing needs, can help avoid difficulties and crises.

## Isa

Isa was in her 70s and living alone when she started to have difficulties with day-to-day activities. Her daughter Joan lived 80 miles away, but kept in close contact, phoning daily and visiting at weekends.

Joan was anxious that her mother seemed not to be eating properly, was forgetful and constantly losing things. This was of particular concern as Isa was diagnosed with diabetes four years ago and manages this through her diet. Joan was so worried she suggested Isa see the doctor. The GP was sympathetic and arranged for Isa to see an old age psychiatrist for tests. The appointment was for a day Joan had to be at work, so Isa went on her own. The psychiatrist told her that she had dementia. She said some other things as well, but Isa was in a state of shock and couldn't remember anything beyond the bad news and that a social worker would be in touch. She went home with a prescription, but she wasn't sure what the tablets were for.

Joan heard the news from Isa. She had only a vague idea of what the diagnosis meant and didn't know where to turn for information. The

social worker did an assessment but Isa didn't like to admit to what she wasn't managing. Sometimes she was not getting to the toilet on time so occasionally wet her chair and bed. The social worker arranged for meals on wheels. Isa forgot to tell the social worker that she was on a controlled diet for diabetes.

Isa struggled to cope. For months Joan was on the phone to her five or six times a day, sometimes in the middle of the night, and visiting several times a week. It put a huge strain on her and her family. Isa kept forgetting to take her medication and she didn't think it was helping. Isa's GP prescribed some treatment for her diabetes but she didn't understand when to take it either and found it made her feel ill and shaky, so she stopped taking it. Joan asked the social worker for more help but Isa refused it because she preferred Joan to help.

Eventually the travelling got too much and Isa moved in with Joan, who gave up work to care for her full time. It was not a success. Isa felt she'd lost her independence and got frustrated very easily. Joan found herself losing patience because Isa was slow. It was easier just to do things herself. She was often angry with her mother and felt bad about it afterwards. Isa felt useless and ignored and spent a lot of time sitting doing nothing. New difficulties came up every week. Neither Isa nor Joan felt they had anyone they could talk to about how to cope with the symptoms or with the effect Isa's dementia was having on their lives. Things came to a head when Isa had an accident in the kitchen and there was a fire. Luckily no-one was hurt but Joan decided she couldn't carry on. Isa moved into a care home. It wasn't what she wanted but she didn't feel she had a choice.

**Isa's life could be better than this. Read on and see how the implementation of a strategy for long term conditions can help someone like Isa, and her family.**

When Isa started to have difficulties coping with day-to-day life after her husband's death, her daughter Joan suggested she see her GP. The GP was helpful and explained some of the possible diagnoses.



He arranged for Isa to see an old age psychiatrist. Isa asked for an appointment at a time when Joan could come with her, which was no problem as the clinic had evening sessions.

After some tests, the psychiatrist sat down with them both to explain the diagnosis of dementia. She said that she knew it would be a shock and that they might not remember everything. She gave them clear information to take away. She made a follow-up appointment for them with a link worker at the clinic, so that they could ask more questions and work out what to do next. She prescribed some tablets for Isa and explained what they were for. She also explained that Isa needed to stick to her diet to control her diabetes as high blood sugar would increase her level of confusion and forgetfulness and make her need to go to the toilet more often.

Isa and Joan went home and read the leaflets together. One was for a helpline and over the next week each of them phoned it to ask more questions, and to talk about how they were feeling.

At the follow-up appointment the link worker explained again some of the things they couldn't remember from what the psychiatrist had said. She told them about services that could help and arranged an appointment with a social worker for an assessment. She promised to make sure the social worker had all Isa's details so they wouldn't have to start from square one. The link worker also told Isa about ways she could plan for the future and make sure she had maximum say in what decisions were taken if she couldn't take them herself. The link worker told Isa and Joan that they could contact her whenever they needed more information.

A few weeks later she got in touch about a new group that was starting for people with dementia. The group would provide information about dementia and strategies for coping with the memory loss and other problems it could bring. It would help her plan her future. It would also let Isa meet up with other people with the same condition and

she agreed to join. There was a parallel group for carers, which Joan joined.

The social worker arranged some services which helped a lot. The meals on wheels service were happy to provide meals that helped Isa balance her blood sugar levels. This also meant that Joan didn't have to worry about whether Isa was eating or if she was safe. Isa's dementia did get worse but because they understood the condition, she and Joan found ways to cope with each new challenge. Sometimes they spoke to their link worker for help, and sometimes they called the helpline.

Both Isa and Joan were given the opportunity to have their say about the services in their area and how they could be improved. Joan couldn't think of anything, but Isa said she'd like to walk to her day centre instead of going by taxi, for a wee bit of exercise. She had remembered that she had been advised to maintain regular exercise when she was diagnosed with diabetes. The day centre arranged for someone to accompany her twice a week, and she felt much better for it.

Whenever Isa's needs changed the social worker would adjust the services. Joan reduced her hours at work because she wanted to spend more time with her mother. However, she was able to do this on her own terms and keep working because Isa loved going to her day centre or going out with her home support worker. Isa was able to stay at home for several years despite the progression of her condition.

## Transitions

Additional support is essential during those key life stages when people living with long term conditions have to move between services. The way services are organised and the levels of support offered in paediatric, adult and older people's services is very different. Also, the links between different condition specific services are critical and can be very stressful. The current system has some models of good practice in

this but often lets people down. Within a self management model, living with more than one condition is recognised and support extended to the person to look at ways to manage everything they are faced with. This is not an exact science and can and does change for people over time. A rigid model of care focused on evidence-based medicine alone is not effective in achieving a sense of wellbeing for individuals faced with such complex challenges. All of the life stories we have outlined demonstrate this as does this one about a young person with complex needs.

## Fiona

Fiona left residential school and is back living with her mum and dad. Her folks are great but they fuss a lot. Fiona would like to develop skills to work and live more independently so she goes to a resource centre for disabled people.

Although she is learning some new things, she finds the centre very different from school. The staff are not as supportive as her teachers and they don't always take time to understand what she is saying. She remembers her communication methods being talked about at a review meeting before she left school. At this stage it was agreed that the staff at the resource centre would have training. None of this seems to have happened and often Fiona thinks staff are pretending to understand her rather than taking time to get to know her.

Other support in terms of personal care is fine except when she has a bad seizure. The minor ones are ok, no one seems to panic about them. Sometimes they don't even notice. The panic happens when Fiona needs to get her emergency medicine. This doesn't happen often but when it does staff don't follow her care plan and phone her mum instead. If they can't get a hold of her mum they phone an ambulance. This is worse as Fiona hates going into hospital. She especially hates it if there is no need to be there in the first place.

All of this is making her mum worried, which Fiona also hates as she fusses even more. No one seems to treat Fiona as a young adult. She thinks there is no point in telling anyone what her dreams for her future are as no one seems to listen.

Another thing that is happening for Fiona is that she needs to change her hospital care from the children's hospital to adult services. She's been waiting months for an appointment. Fiona thinks they have forgotten about her.

**Fiona's life could be better than this. Read on to see how better communication and collaborative work can help people like Fiona live well with long term conditions.**

When Fiona is planning to leave school and go to a resource centre, staff from the resource centre begin working with her during her last six months in school. They come to visit her and spend time with her and her teachers learning about how Fiona communicates. They also learn about the best ways to approach Fiona's personal care. Part of this includes training on administration of her emergency medication. The support staff at school show the resource centre staff Fiona's emergency care plan. They talk about Fiona's seizures and describe what a serious seizure needing emergency medication looks like. The resource centre staff then understand the nature of Fiona's seizures and how to deal with them.

Back at the resource centre, staff still feel anxious about dealing with Fiona's seizures. To help with this the manager organises for the voluntary sector to offer epilepsy awareness training to the whole team. Everyone on the team learns a lot about the complex and diverse nature of seizures. The speech therapist also comes with Fiona and trains staff on the best way to communicate with her.

Just before Fiona leaves school, everyone involved in her care and support from the children's hospital and school meet with Fiona and her

parents. They invite all the new staff who will be working with her in her adult life. Together with a facilitator from the voluntary sector, they help Fiona develop a person centred plan. For the first time she is able to say that she wants her own home at some point.

Fiona's plan is drawn up showing her goal of her own flat, a boyfriend and going to college. Next year she is going to talk about her longer term goal of work. She would also like to have a baby. Fiona feels confident that she can get help to build up to telling her mum that one day; especially now that people are listening to her.

After this meeting Fiona's Mum and Dad feel reassured that there is support there for their daughter with her health and social care needs. The main thing for Fiona's mum is the reassurance that she will get emergency medication in time.

## End of Life

People with long term conditions can face complex challenges at the end of their lives. Some people live with conditions that lead to premature death. For others life expectancy can be reduced by lifestyle factors such as poor diet, smoking, alcohol misuse, lack of exercise and the consequences of the potent drugs many receive to alleviate the symptoms of their condition. Some medicines lead to other long term conditions such as diabetes, coronary heart disease and stroke.

It is therefore important that individuals and families have access to physical, practical, psychological, emotional, financial and spiritual support based upon their identified needs.

Patterns of care delivery and support must be sensitive to individuals' needs and preferences whilst being available on an equitable basis. Enabling decision making and empowerment for individuals and their families must be a central pillar of care towards the end of life.

Individuals and families need open and honest communication regarding available options and choices for care and services based upon the practical realities of the person's daily life.

Adopting a person centred approach to communication and information based on what, and how much, the individual and their family wish to know is crucial in identifying their needs and ways to meet these. All identified health and social care requirements should be delivered in a co-ordinated way with no barriers between, or across, care sectors.

**This case study shows key stress factors at the end of life and how they can be dealt with in an empowering way, placing the dying person and their family at the centre of services.**

### Diane

Diane was 28 when she was diagnosed with cervical cancer. This was when she was pregnant with her second child. Following the pregnancy she underwent two years of chemotherapy and radiotherapy, both of which proved unable to stop or limit the spread of the disease. Diane was told at this stage that there was no further treatment that could offer her a cure.

As a young woman and the mother of two young boys she was keen to try to maintain a level of independence and normality, even though this was proving to be extremely difficult. Diane's husband was unable to cope with her diagnosis and they separated. To help her cope Diane's mother moved into the house to help care for her daughter and grandsons.

Diane wanted to stay at home where it was easier to be with her boys and she could control her routine to suit her needs. She wanted to be able to play her own music and have the odd glass of wine in the evening when the boys had gone to bed. However, because of her poor mobility she couldn't get up and down the stairs so felt trapped in her bedroom.

She sought support from a cancer organisation and went into their local hospice for some active rehabilitation to try to improve her mobility. At the hospice there were no restrictions on visiting times and Diane was given a single room which allowed the boys to make as much noise as they wanted and to visit when it suited Diane. This made them all much more relaxed about it and they were able to enjoy visiting times.

The medical team made several adjustments to Diane's pain control medication and within 4 days her pain was well controlled, without her being too sleepy.

The nurses helped her to develop ways to self manage the personal care issues associated with her illness which really helped her feel better about herself.

A physiotherapist started a programme of rehabilitation for Diane with the aim of getting her able to manage up and down the stairs.

An occupational therapist (OT) visited her at home and ordered a few pieces of equipment that would help Diane cope better. Diane really welcomed the bath hoist as she loved to relax in a bubble bath with candles and a gin and tonic. The OT talked to Diane about a range of ways to maximise her independence.

The social worker sat with Diane and worked out what benefits she was getting and helped her to apply for some that she hadn't known she was entitled to, including a grant from a cancer relief charity.

Diane quickly established a trusting relationship with all of the hospice staff, including the counsellor, and was able to talk about her anger and fears for the first time.

By the time Diane left the hospice two weeks later she was able to manage very slowly up and down the stairs, was pain free, able to move around the house and was managing her personal care. Life felt less like

she was in a black hole. She was beginning to come to terms with her diagnosis and prognosis. However, she was still not sleeping well and this seemed to be mainly due to her anxiety about the future. To help her get her head round this she was offered the opportunity to come back to the hospice's day unit to talk about which complementary therapies might be suitable for her.

Because Diane was embarrassed about her body image it was agreed that a no-touch therapy like Reiki might be helpful, as this is done wearing clothes. Diane found this enormously relaxing and said that it helped her to sleep much better.

By this time Diane's hair was starting to grow in again but she didn't want to go to her previous hairdresser as she was too embarrassed. At the day unit she was able to have her hair done by the volunteer hairdresser and this really boosted her self esteem. While she was at the day unit she could also see the physiotherapist to help keep her on her feet, a social worker and a counsellor, with whom she had established good relationships. All of this empowered her to talk about her death and what might happen after it.

Diane asked for help to get up and dressed in the mornings, so that her mum could concentrate on getting the boys to school and nursery.

A Community Nurse Specialist (CNS) started to visit Diane at home and they agreed that she would visit weekly. Diane could also call her in between times if she needed anything. Initially the visits focused on Diane's physical symptoms but as the weeks progressed and Diane learned to trust her, she talked more about her fears for the boys. One of her biggest fears was that they would soon forget her. She wanted them to be able to remember her, so the CNS started working with her to produce a "memory box" for each of the boys which included photographs of them together and stories that they enjoyed, some of Diane's things and a letter from Diane telling them how much she loved them and what her hopes were for them.



Diane was keen that her boys regain a relationship with their father and the CNS helped her to come to terms with her feelings about what he had done to her and to work out a way of getting in touch with him. He responded positively and soon began to have some contact with the boys.

Six months later Diane's condition deteriorated. Her pain became less well controlled and again she struggled to get up and down the stairs. She decided that she would get the support she needed in the hospice.

Her drugs were adjusted to bring her pain under control and the physiotherapist worked with her to improve her mobility. This time it did not improve enough for her to walk up and down the stairs but she learned how to get up and down on her bottom, using her arms, which were a bit stronger than her legs.

After two weeks she was at home again with a District Nurse going in every evening to help her get to bed as well as in the mornings to get her up and dressed.

Throughout this ordeal Diane's mum was struggling with the situation. She was stressed, not sleeping well and trying to hide her anxiety from Diane. She and Diane had never spoken about how they were feeling and that Diane was soon going to die.

The CNS arranged for Diane's mum to attend a drop-in group for carers at the hospice and referred her for hypnotherapy to help her relax and sleep better at night. These supports made her feel less stressed and allowed her to open up and talk about how she was feeling with Diane. This helped them both to come to terms with what was going to happen.

By then the boys' father was seeing them more regularly and taking them out for a couple of hours at the weekend. Diane was very relieved about this and was hopeful that this would continue after she died.

## Key stages where people need support

It was not long before Diane was very weak and needed much more help, particularly at night, which was proving exhausting for her mum. Diane and her mum discussed what options they had with their CNS and they both preferred that, if she could, Diane should die at home rather than at the hospice. Together with the District Nurse and GP a plan of care was worked out and cancer specialist care nurses started to come to stay overnight with Diane, attending to her needs and allowing her mum to get some sleep.

It became apparent to the CNS that the boys had no idea how ill their mum was and they were not at all prepared for her death. Experience had taught her that children are more likely to have problems after a parent's death if they are not prepared for it so she encouraged Diane and her mum to start talking to the boys. With the CNS's help the boys started to understand that mummy was going to die and what this would mean for her and them. A month later Diane's condition was very poor and it was clear to the nurse caring for her that her death was imminent. She sat with Diane's mum and the two boys and helped them say goodbye. Diane's mum sat up with her daughter and just after 2am Diane died peacefully in her own home holding her mum's hand.

# Whose responsibility is self management?



## Key messages

- Self management is an individual's responsibility but they must be given the information, skills, confidence and support to self manage successfully.
- Those responsible for supporting self management include: unpaid carers; voluntary sector; NHSScotland (including individual health professionals); local authorities; and the Scottish Government.

Self management is an individual's responsibility and supporting this process, ensuring effective care and support is in place is everyone's responsibility.

To suggest that people should look after themselves may seem like stating the obvious. However, many people either do not have the necessary information and skills to make well informed decisions about their life or they choose not to. Whatever the reason, successful management of life with a long term condition also requires a degree of self awareness.

People need to be realistic about their condition and any limitations it may place on them, as well as how their life choices impact upon it. They also need to be aware of the positive steps they can take to manage their condition and expand their life choices. This is why partnership with the individual is central to the self management agenda. Where people can access timely and appropriate information and support they will be more able to make well informed decisions about their life.

Part of this is therefore about enabling everyone, individuals and organisations, to develop an understanding of recovery as a possibility for us all. That may mean at different levels with regards to the challenges faced. Recovery needs to be adopted as a concept relating to self respect, spirit, self esteem and sense of self. While people are generally unlikely to recover from the condition itself, effective management of symptoms balanced with increased autonomy and independence can help recover optimum wellbeing. Quality of life is

critical with a key factor being the ability to live well in the presence or absence of the difficulties long term conditions present.

## The individual

Self management is not about having to do everything yourself. It can be broken down into four distinct aspects:

- ▶ Working out what you want to achieve.
- ▶ Working out what you want to or are able to achieve alone.
- ▶ Working out what you might need intermittent or occasional help with.
- ▶ Working out where you need ongoing support.

## Aims for individuals

- People with long term conditions are supported to identify the above issues and to develop personal action plans to address them. There is no one way of achieving this and some people will need more support than others.
- People with long term conditions are encouraged to participate in, and where possible lead, the process by health and social care practitioners and unpaid carers.
- Individuals learn how to manage their own independent health and wellness budget<sup>7</sup>. Part of this process will be working out which self management courses/supports suit their needs. It may also mean identifying complementary therapies to help gain wellbeing, for example yoga, massage, tai chi or counselling. This type of support is intended to complement, not replace, necessary medical treatment.
- Shifting people's vision about what transformations can and should happen can enable them to achieve a better quality of life. Life is for living, and for living well, not enduring.

<sup>7</sup> 'Independent health and wellness budgets' are a suggestion that LTCAS would like to see developed where people have access to an independent fund that means they can purchase complementary health care at the right time and right place for them. This idea is generated from feedback at the Living Well consultation events held in 2007.

## Unpaid carers

For many people with long term conditions the role of the unpaid carer is vital to achieving a good quality of life. This is particularly critical where individuals lack capacity to make decisions for themselves. The unpaid carer's role is also vital to the ability of people with long term conditions to self manage. Where the person is unable to fully achieve this, unpaid carers may need support to make sure the person gains independence as far as is possible. Assisting people to achieve optimum independence and well-being, and ensuring unpaid carers have the support they need, is in everyone's interests.

## Aims for unpaid carers

- Training and education alongside effective support from health and social care enables unpaid carers to maintain their caring role. Without this support, particularly for those unpaid carers providing continuous support, the caring role may break down. This can undermine the support the unpaid carer provides in enabling the individual to self manage.
- Unpaid carers have their own needs, desires and dreams for life and relationships. Whilst these may be closely interlinked with those of the individual with long term conditions, they must be seen as separate and distinct and addressed as part of the development of a person centred plan for the individual. This includes identifying any health problems experienced by the unpaid carer.

## Caring with Confidence

The Scottish Government is funding a two year pilot through the Princess Royal Trust for Carers. This is to deliver and evaluate a range of training courses for unpaid carers across the Lothians. The courses are being delivered in a variety of ways by the four Carer Centres –

VOCAL, Carers of West Lothian, Carers of East Lothian and VOCAL Midlothian. The different approaches are being evaluated by Glasgow Caledonian University. The project aim is to develop a comprehensive programme of 'Caring with Confidence (expert carer)' training that is determined and delivered locally. It is aimed at those caring for 50 hours or more each week and those whose health is being adversely affected by their caring situation.

Caring with Confidence expert carer training offers learning opportunities for unpaid carers in a mutually supportive environment. This enables carers to build on their own expertise and gain further knowledge and confidence from health and social care professionals and through peer support. The courses are also designed to improve carers' ability and confidence to self manage their own situation and thus improve their quality of life and that of the person they care for.

## **Voluntary sector**

The role of voluntary and community organisations representing people with specific long term conditions is crucial to ensuring the care a person receives is in line with their identified needs. The voluntary sector is experienced in working in partnership with individuals and is therefore best placed to work alongside people on this agenda. Indeed the self management agenda is already well developed within parts of the sector and should be reflected throughout services.

Additionally, voluntary organisations have an important role in articulating people's needs to other service providers, both health and social care. This will help to ensure that statutory services also meet the aims of a self management approach. By working in partnership alongside the public sector the voluntary sector aims to ensure that everyone delivers support in a holistic way.

## Aims for the voluntary sector

- Engage with their constituent group to identify what they need.
- Raise awareness of identified needs with other service providers.
- Develop joint referral mechanisms with the statutory sector to ensure effective co-ordination of support and services.
- Develop support mechanisms to assist people to self manage, including goal setting and action planning for the future.
- Work in partnership with LTCAS on the development of the self management agenda.
- Build an evidence base for self management support and work to provide best practice.
- Identify barriers to self management and solutions to these thus supporting systems that enable participation and development of skills for self management.
- Ensure self management remains high on the Scottish Government's health policy agenda and that NHS practice reflects the partnership approaches needed to make it happen.

## Headway

Headway is a voluntary organisation dedicated to supporting people with acquired brain injury (ABI), their families and unpaid carers living in the community. Headway does this by listening to people and responding to their individual needs. Needs vary significantly as ABI is a highly complex and variable condition.



Headway offers a range of innovative support that brings together people who have shared similar experiences. To meet others similarly affected is often a revelation for people and their families. They have often felt socially isolated and let down by services. They liken this to a feeling of having been abandoned, not only by health and social work, but by friends and sometimes family members too.

From the humble beginnings of people coming together, they start to shift their positions as they grow in confidence. They start to feel better about themselves. Almost every member of Headway wants to be involved in raising awareness of ABI. This often entails partnership working with councils, for example to help train staff about the impact of ABI on the whole family or teaming up with road safety departments to talk to older school children about safe driving and drinking to help prevent ABI.

Headway organises a range of local activities including art classes, cooking, walking groups, computer classes and assists people to use coping strategies to improve their every day functioning. The organisation works with local colleges and leisure centres to arrange community-based social and educational activities.

Headway fosters a sense of belonging and offers people the opportunity to establish new social networks, become interested in doing things again. It helps to hear how others similarly affected have coped with difficult situations and to get involved in campaigning for better recognition and resources.

People who join Headway often say their lives have been transformed. They describe a huge sense of relief in finding an organisation made up of people who understand.

## NHSScotland

The issues concerning NHSScotland providing support to people with long term conditions are covered extensively within the Living Well report<sup>8</sup>. We have also highlighted the broad issues of partnership needed in this document. To address this the NHS will need to consider a range of targets and redirection of funds in the coming years in line with Better Health Better Care.

LTCAS would welcome an awareness raising campaign on the values and principles of self management to reach every NHS employee as we believe a whole service approach is needed. This needs to be followed up by training directed at health professionals in the detail of what needs to be developed.

Giving people better information about their conditions, including measurable data on their respiratory function, temperature, weight, pulse, blood pressure etc has been shown to modify their behaviour and support self management<sup>9</sup>. Telehealth can be used to support the whole spectrum of long term conditions and to develop, in partnership with clinicians and people living with long term conditions, potential areas for better self management. Technology can support individuals with better information and minimise unnecessary face-to-face contact with health services.

Our experience shows that health professionals are keen to learn more about self management and many projects and educational programmes are being developed to raise awareness.

## NHS Grampian

In 2007, a joint NHS Grampian and NHS24 four month pilot provided professionals with quality assured patient information to support self care verbal advice. The key recommendation was to develop the service throughout Grampian via, for instance, practice learning time, train the trainer conferences and pharmacy training programmes.

<sup>8</sup> Living Well with Long Term Conditions, LTCAS and Scottish Government 2007 [www.ltcas.org.uk](http://www.ltcas.org.uk)

<sup>9</sup> Department of Health 2005. Supporting people with Long Term Conditions to self care 2007 Jul;93(7):819-25. Epub 2006 Oct 25

"Supporting the Professional", is a Grampian service which enables health care professionals to adopt self care approaches. The service provides information and signposting to support such as health information and advice in the high street and other health settings. Grampian Caredata website, accessed by public and staff, provides information about health and social care, voluntary sector and local authority services.

## **NHS Dumfries and Galloway**

A local survey in NHS Dumfries and Galloway, of staff's perceptions and beliefs around self management was undertaken in January 2008. The results will be used to increase awareness and promote a bio-psychosocial approach to patient care and identify education and training needs.

In addition self help workers, trained by the clinical psychology team, are available in all GP practices to help people to manage anxiety and depression. Approved books on self-help topics are available in all libraries across Dumfries and Galloway and lists are available in all GP practices.

A Patient Information Centre, situated in the Dumfries and Galloway Royal Infirmary, provides paper leaflets as well as advice and support from the Benefits Maximisation Team, Pensions Service and the Princess Royal Trust for Carers. There is also a Cancer Advice Service, situated in the Alexander Unit, provided by the Citizens Advice Bureau. A wide range of general patient information leaflets can be ordered by GP practices from the Patient Information Centre in Crichton Hall. Disease specific specialist care information is provided by hospital departments prior to discharge and as part of the ongoing care for people.

## **Education**

In early 2008 NHS Education Scotland (NES) undertook a survey of Health Boards to build a picture of the educational needs and provision associated with long term conditions.

Abertay University, in partnership with NHS Tayside, delivered a Masters level module in management of long term conditions in 2006 for community nurses being trained as case co-ordinators. A new module entitled Managing Long Term Conditions is now also being delivered at degree level. Self management will be referenced in future pre-registration nursing degree in adult nursing.

## Aims for NHSScotland

- Health boards and Community Health Partnerships (CHPs) sign up to the approach set out in the Living Well Report<sup>10</sup> and the strategy set out by Scottish Government.
- An awareness raising campaign directed at all NHS practitioners and managers on the concepts of self management and the wishes outlined in the Living Well report.
- Education programmes developed for all health professionals to change the culture of their working environment, break down professional barriers and promote the self management approach; including accreditation for attendance. This should focus on how to support people living with long term conditions to navigate their condition, themselves and the system.
- Develop joint referral systems with other partners including the voluntary sector to ensure all aspects of support are co-ordinated effectively.
- Ensure all relevant NHS services, including telehealth, understand the particular needs and their role in contributing to successful self management for people living with long term conditions.
- Agree funding packages and support a broad range of national and local self management initiatives.

<sup>10</sup> Living Well with Long Term Conditions, LTCAS and Scottish Government 2007 [www.ltcas.org.uk](http://www.ltcas.org.uk)

- Encourage a culture within the NHS of effective communication between professionals and with people living with long term conditions and their unpaid carers.
- Enable self referral to services that do not require to be doctor-led, such as physiotherapy.

## **South East and Tayside Long Term Conditions Workforce Development**

The three NHS Boards within the South East and Tayside region of Scotland (NHS Lothian, NHS Borders and NHS Fife) are working with NHS Education for Scotland and the voluntary sector to develop a training and education framework that will ensure staff are skilled in supporting self management.

The project is working towards creating and piloting a cross-sector workforce development toolset. Pilots of work in each NHS board area will focus on:

- Scoping of different models of Supported Self Management.
- Adaptation of supported self management models to meet local requirements.
- Utilisation of service modernisation tools to enable new ways of working to become integral to the patient journey.

The project has also scoped and reviewed the core knowledge and competencies/capabilities required for delivery of support for self management. This will be complemented by the development and piloting of a training needs analysis tool for frontline staff in relation to supported self management. The tool will produce key insights into training and knowledge gaps. It is due to be piloted in August 2008.

The project team is also scoping current education provision relating to long term conditions in Scotland. The outcome of this will be a

comprehensive searchable database available on the NHS e-library. This will include education and training provided by the voluntary sector.

The project has been informed by local consultation events with people with long term conditions, unpaid carers and staff from voluntary and statutory sectors.

## Local Authorities

Local authorities have a key role in providing social care support to people with long term conditions. They also have a joint role with the NHS in supporting the Rehabilitation Framework<sup>11</sup>. Numerous pieces of work including Joint Futures and Community Planning have attempted to address some of the barriers to joined-up support. It is important that existing strategies are fully implemented in partnership with the health and voluntary sector.

## Aims for local authorities

- Local authorities sign up to the approach set out in the Living Well report<sup>12</sup>, Joint Futures, Better Health, Better Care and the Rehabilitation Framework.
- Education programmes developed for providers of social services, including social work, housing and education, to change the culture of their working environment, break down professional barriers and promote the self management approach; including accreditation for attendance.
- Implement existing strategies for ensuring support is effectively co-ordinated.
- Agree funding packages and support a broad range of national and local self management initiatives.

<sup>11</sup> <http://www.rehabilitationframework.scot.nhs.uk/Documents/reports/CoordIntandFitforPupose.pdf>

<sup>12</sup> Living Well with Long Term Conditions, LTCAS and Scottish Government 2007 [www.ltcas.org.uk](http://www.ltcas.org.uk)

- Develop occupational therapy services so individuals can gain direct access to their full range of skills in community settings.

## **The Scottish Government**

The Scottish Government has a role in ensuring the required culture and systems change takes place at all levels and across sectors. Part of this will involve redirecting resources appropriately.

The Scottish Government also has a broader responsibility for leadership in changing attitudes and culture. It is important that the issues are raised within wider society. Long term conditions do not just affect a minority of the population. Ultimately everyone is touched in some way by the effects of a long term condition. It is important that the ethos of self management is promoted more widely for change to be effective and sustainable in the longer term.

## **Aims for the Scottish Government**

- Set targets for mainstreaming the self management ethos throughout the health, social care and voluntary sectors.
- Provide resource incentives to all stakeholders to develop their capacity for promoting and developing the self management approach.
- Plan long term to support the sustainability of the voluntary sector to deliver on the self management agenda beyond the initial 3 year ask within this strategy.
- Awareness raising programmes aimed at employers; including flexible working and support required within the working environment, including from colleagues. The impact and cost of worklessness for people with long term conditions is huge.
- Set targets for establishing the resources to support people with long term conditions in the workplace, for example through occupational therapists and others for assessment. This may be from the beginning of a person's employment and/or if circumstances change and the individual or employer requires advice or support.

- Awareness raising targeted at schools, both the role of the teacher in supporting a child with a long term condition and support for peers. The model of health promoting schools means that health is already on the education agenda. Teaching self management values would enable young people to build life long resilience to coping with long term conditions in both themselves and others. LTCAS would like to see this agenda sit alongside and complement the prevention, promotion and early intervention messages already developed within education.
- Education departments and schools need to develop the resources to allow children to develop self management skills in school. This should include the right physical environment for independence and therapy aimed at reducing dependence on assistants where possible and encouraging resilience and problem solving.
- Awareness raising through colleges and universities, both educating future professionals in the self management approach, and also support for students with long term conditions and their peers.
- Awareness raising programmes aimed at community activities, leisure and recreation to ensure the inclusion of people with long term conditions. Provision should enable people to have the widest possible access to a choice of activities to benefit health and wellbeing.

## Employment

Employment is critical to many people's sense of self. Positive employee relationships have a direct effect on self esteem and people's perception of their usefulness. Often working gives people a sense of belonging, it is an expectation, a normal and ordinary thing to do. There are also issues in relation to the correlation between unemployment and poverty. This is more likely to impact on people with long term conditions as they are less likely to be employed, more likely to have lower occupational status and have lower household incomes than their non-disabled counterparts<sup>13</sup>.

<sup>13</sup> Characteristics of adults in Scotland with long term health conditions: An analysis of Scottish Household and Scottish Health Surveys' Wendy Loretto and Matt Taylor, University of Edinburgh, Scottish Executive Social Research 2007. <http://www.scotland.gov.uk/Publications/2007/10/29093311/0>



There is a growing awareness among employers that supporting people with long term conditions in employment makes good economic sense. Many people living with long term conditions want to remain or re-engage in work. The central government move to get people off welfare benefits and into work may create pressures to achieve unrealistic goals. It is important that employers understand how they can help through initiatives such as flexible working and reasonable adjustments.

## Grampian Pathway Pilots

Since October 2003, Pathway Pilots (based on the Department for Work and Pensions' Pathways to Work programme) have been set up across the UK. Grampian's Condition Management Programme has been developed to enable people with certain conditions claiming incapacity benefit to return to work. Condition Management Programmes deliver services using a mix of NHS, voluntary and private sector specialists. Incapacity Benefit Personal Advisors at participating Jobcentre offices refer people with conditions such as mild-to-moderate depression, back pain or cardio-respiratory conditions to the programmes.

## Aims for employers

- Networks of employers share good practice in supporting people with long term conditions in the work place. This can be informed by local self management initiatives operating locally though voluntary sector, local authority and NHS partners.
- Development of long term conditions and self management concepts through targeted learning packages utilising protected learning time, e-learning and other such developments.
- Identify local champions to liaise with employers and develop this agenda.

# Goals



1.

2.

3.

This is a challenging agenda in which everyone living with, or who works in the area of, long term conditions has a part to play.

LTCAS is a membership-based development organisation and does not provide direct services to people living with long term conditions. We are, therefore, in a good position to offer a brokerage role in the development of self management programmes across Scotland and to develop standards and promote best practice.

Some voluntary sector organisations have, and will, develop their own capacity in this area and LTCAS can support them to make links with other interested parties. Master trainer, mentoring and coaching are all possible options. Innovation needs to be maximised in how LTCAS makes links across Scotland. Remote and rural organisations need access to teleconferencing, up to date and interactive websites, online and e-learning opportunities. In particular LTCAS will promote and encourage robust development of self management programmes that address health inequalities.

However, for the self management agenda to progress in the ways outlined in this strategy, LTCAS needs to grow its infrastructure. The new infrastructure (outlined in a separate paper<sup>14</sup>) will allow us to act as the foundation for progress in self management across the country.

As outlined earlier in this document, LTCAS initially seeks £2m per year for three years. This funding would be used to help the voluntary sector across Scotland to develop a wide range of self management programmes.

To achieve this, LTCAS would employ a Director of Self Management and a Grants Officer. These staff would have developmental and reporting roles in the disbursement of funds. This includes marketing – informing organisations about the fund and the criteria for funding.

The Director of Self Management would map current self management provision in the voluntary sector, analyse gaps, capture learning and feed this learning back in order to develop and improve self management practice. The role would have a particular focus on capacity building in relation to projects which are aimed at tackling health inequalities.

<sup>14</sup> Beyond May 2008, Developing the Long Term Conditions Alliance Scotland – supporting implementation of the Self Management Strategy for Scotland, submitted to Scottish Government under separate cover.

The Grants Officer would support assessment of bids against agreed criteria and report to an Advisory Board of LTCAS members established to oversee the fund. The Advisory Board would have representation from the Scottish Government.

Funding criteria will be developed and consulted on widely. However, at this stage, LTCAS would expect the criteria to reflect some basic principles and approaches. As a basis we would expect that projects will:

- be person centred
- be holistic in approach
- maximise empowerment
- involve service users
- make a positive difference to people living with long term conditions

Additional criteria are likely to emerge, which reflect gaps in provision identified in the initial mapping exercise.

We also see the following as fundamental elements that will need to be reflected in any funding criteria:

- accountability is built into the programme through ongoing evaluation<sup>15</sup>
- the scope of the project is achievable, accessible and sustainable
- there are built-in links to working partners
- the project reflects the value base for self management outlined in this strategy
- the project has the potential for application to a wide range of audiences
- the programme supports the reduction of health inequalities

Other broader criteria will be applied selectively depending on the nature of the application. These might include:

- the project/programme is innovative
- promotes opportunities to develop new self management techniques
- promotes self directed and life long learning
- creates advocates for self management

<sup>15</sup> LTCAS recommends using LEAP as an evaluation framework. This is widely used across voluntary, community health and local authority programmes already and is therefore a tried and tested familiar model. See appendix 1 for details.

- is flexible enough to reach range of audiences across Scotland
- has built in infrastructure and links to working partners
- promotes partnership working within and across sectors
- builds capacity for voluntary sector organisations to work together
- takes a community development approach
- involves people with long term conditions as leaders
- supports volunteers effectively
- promotes self management approach to excluded groups

In conclusion, LTCAS want to see funds applied to programmes that will have the strongest impact and widest reach. We understand that organisations are likely to pilot projects with their specific target group. However, we will be looking for robust criteria that will enable programmes to be adapted to meet broader needs both in terms of conditions and geography.

LTCAS has experience of this approach working within its current membership. Arthritis Care Scotland introduced the Stanford model to Scotland and this is now adopted by a range of organisations and applied to mixed condition groups in rural settings<sup>16</sup>.

LTCAS will be looking for programmes that broadly address the need for information for people with long term conditions that include self management plans and educational programmes. LTCAS would expect that to achieve these broad aims, programmes will address issues of empowerment, make available psychological support, including talking therapies and self help techniques, and promote peer to peer support.

We anticipate that funding will support people with long term conditions to access self management programmes which have lifelong relevance and can be accessed at any stage of living with a long term condition.

LTCAS welcomes this opportunity to work in partnership with the Scottish Government in establishing real change for people living with long term conditions and their families across Scotland.

<sup>16</sup> This is also the model used by the Expert Patient Programme in England & Wales.  
Living Well with Long Term Conditions, LTCAS and Scottish Government 2007 [www.ltcas.org.uk](http://www.ltcas.org.uk)

# Appendix one - Principles of Self Management

These principles were developed by LTCAS to encapsulate the core messages of the Strategy for Self Management. They should be viewed alongside the full strategy document. It is hoped the principles may 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.

**“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.



**LTCAS**  
LONG-TERM CONDITIONS  
ALLIANCE SCOTLAND  
people not patients

**“I am the leading partner in management of my health”**

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

**“I am a whole person and this is for my whole life”**

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

**“Self management is not a replacement for services. Gaun yersel doesn’t mean going it alone”**

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

**“Clear information helps me make decisions that are right for me”**

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

# Appendix Two – Policy Context

## **Better Health, Better Care**

Better Health, Better Care sets out the Scottish Government's action plan for health in Scotland. It builds on the existing broad direction of health policy but also sets out a vision for going further over the next five years. Better Health, Better Care describes the aspiration of developing a 'mutual' NHS. This entails a move away from viewing people as 'patients' or 'service users' towards a new ethos that sees people and NHS staff as partners or co-owners in the NHS.

Long Term Conditions and self management are key priorities within the Better Health, Better Care Action Plan. In it the Scottish Government reflects the ethos and recommendations of the Self Management Strategy for Long Term Conditions in Scotland.

## **Chief Medical Officer (CMO)'s Long Term Conditions Steering Group**

A Long Term Conditions Steering Group, chaired by Chief Medical Officer (CMO) Dr Harry Burns, meets regularly. This group has strategic responsibility for taking forward the long term conditions agenda. Membership of the group includes Scottish Government Long Term Conditions Unit, NHSScotland, the Long Term Conditions Collaborative, NHS ISD (Information Services Division), NHS Quality Improvement Scotland, NHS Education Scotland and LTCAS.

## **Long Term Conditions Collaborative**

The Long Term Conditions Collaborative is one of three national improvement programmes others being Mental Health Collaborative and the 18 Weeks Referral to Treatment Time Programme. It was launched in April 2008 and is a national programme run by the Improvement and Support Team and hosted by NHS Tayside.

The Long Term Conditions Collaborative is designed to support NHS Boards and their partner agencies to deliver sustainable improvements in the management of long term conditions, including self management, specialist condition management and complex care/case management.

The programme aims to provide a platform for best practice, sharing ideas and innovation.

## **Mental Health Collaborative**

The Mental Health Collaborative was launched in April 2008. It will support NHS Boards to make the improvements needed to deliver against key national targets set out by the Scottish Government.

The objectives of the programme are:

- To identify where the use of improvement methodologies and techniques will lead to improved performance, and then to work with NHS Boards and other key partners to ensure effective application.
- Provide training for front line staff working in Mental Health services on the use of improvement methodologies.
- To enable NHS Boards to use information effectively to support improvement.
- To develop a culture of NHS Boards sharing information and knowledge about what works and what doesn't for improving mental health services.
- To support the development of a culture of continuous improvement across mental health services in Scotland.

## **Long Term Conditions CHP (Community Health Partnership) Toolkit**

In 2007, the Scottish Government requested that CHPs complete an annual self assessment exercise - known as a toolkit. When completed the toolkit gives an indication of the level of service being provided for people with long term conditions. The toolkit was not designed to be used for benchmarking against other CHPs but rather to support evaluation and improvement of services. Each CHP has the opportunity to identify and share areas of good practice, acknowledge service gaps and consider actions which can be taken to meet each criteria.

Action plans created from the toolkits by each CHP will be submitted to the Scottish Government Long Term Conditions Unit annually.



At the behest of the CMO Long Term Conditions Steering Group LTCAS identified 10 core priorities from the range of actions in the CHP toolkit. These were informed by LTCAS' work with its members including through the Living Well events.

## **Co-ordinated, integrated and fit for purpose, A Delivery Framework for Adult Rehabilitation in Scotland (published February 2007)**

The need for a successful, comprehensive rehabilitation service is described in "A Delivery Framework for Adult Rehabilitation in Scotland" (available at [www.scotland.gov.uk/Publications](http://www.scotland.gov.uk/Publications)). The report describes the development of models which identify opportunities for early intervention, with emphasis on self management and health promotion, utilising community culture, leisure centres, lifelong learning opportunities and voluntary agency services. It recommends development of a systematic approach to delivering rehabilitation to individuals by providing effective integrated services.

Local rehabilitation coordinator posts are being established throughout Scotland to ensure the framework recommendations are implemented locally. The coordinators will work with the National Rehabilitation Implementation Group to provide leadership and direction and will facilitate the required organisational changes.

## **Towards a Mentally Flourishing Scotland**

Towards a Mentally Flourishing Scotland (available at [www.scotland.gov.uk/Publications](http://www.scotland.gov.uk/Publications)), a discussion paper on mental health improvement 2008-11 was published for consultation in late 2007. This sets out the Scottish Government's thinking on the next stage of activity to support mental health and wellbeing.

## **Delivering for Mental Health**

Delivering for Mental Health (available at [www.scotland.gov.uk/Publications](http://www.scotland.gov.uk/Publications)) was published in 2006 and sets out

a series of commitments to improve mental health services and support. The document was published by the previous Scottish administration but many of the commitments have been adopted by the new Government and are referred to in Better Health, Better Care.

## **eCare Framework**

The eCare Framework has been developed by the Scottish Government to enable information sharing between public sector agencies for the care and protection of citizens. It will enable professionals in different agencies (health, education, social care, housing, police etc) to share sensitive personal data, securely and electronically. Information is disclosed only with the explicit consent of the service user, unless a statutory duty of care allows for this to happen without consent, e.g. for child protection. From autumn 2007 the first Data Sharing Partnerships will begin sharing personal data via the eCare Framework.

## **Ehealth Strategy 2008-11**

The Ehealth Strategy (available on <http://www.show.scot.nhs.uk/>) aims to change the way in which information and technology is used within NHSScotland in order to improve services, quality of care and information intelligence. Aims and actions identified in the Strategy include:

- Contributing to 'health literacy' to ensure that all citizens have the necessary skills, knowledge and confidence to manage their own health.
- Building the platform for an electronic patient record that, in due course, will support patients' journeys through the NHS.
- Working to support the creation of a National Health information and Support Service (as detailed in Better Health, Better Care).
- Developing, in collaboration with LTCAS and the Long Term Conditions Collaborative, an action plan. This will build on progress already made with electronic records to support diabetes care and trials of home monitoring devices. It will also address eHealth support in areas such as education, shared care plans, condition monitoring, self care, and support for carers.

- Contributing to self management by giving patients the option to access their own records and care plan and the ability to add to the record, for example self monitoring information, via secure internet services.

## **Scottish Patient Safety Alliance**

NHSScotland is the first health service in the world to adopt a national approach to improving patient safety. Acute hospitals across the country are taking part in a dedicated drive to ensure that patients receive even safer care. By reliably introducing evidence-based changes to practice the aim is that patient safety in Scotland will be significantly improved.

## **Changing Lives, Report of the 21st Century Social Work Review**

The Changing Lives review began in 2004 and published its report in 2006 (available at [www.scotland.gov.uk/Publications](http://www.scotland.gov.uk/Publications)). The review drew three overriding conclusions to inform future direction of services:

- Doing more of the same won't work. Increasing demand, greater complexity and rising expectations mean that the current situation is not sustainable.
- Social work services don't have all of the answers. They need to work closely with other universal providers in all sectors to find ways to design and deliver services across the public sector.
- Social workers' skills are highly valued and increasingly relevant to the changing needs of society. Yet we are far from making the best use of these skills.

Many of the recommendations of the review echo the self management agenda. These include:

- Social work services must be designed and delivered around the needs of people who use services, their carers and communities.
- Social work services must build individual, family and community capacity to meet their own needs.

- Social work services must become an integral part of a whole public sector approach to supporting vulnerable people and promoting social wellbeing.
- Social work services should develop the capacity and capability for transformational change by focusing on re-designing services and organisational development.

## Single Shared Assessment (SSA)

SSA is a Joint Future initiative that promotes joint working and whole systems approaches in community care. The SSA aims to speed up delivery of services, sharing of information and avoid duplication of assessments. This is particularly useful for older people and those who require multiple services.

## Model of Supported Self Care in Cancer

This model has been developed based on findings from three national forums held throughout November 2006 and February 2007. The forums brought together people living with cancer, unpaid carers and clinicians from across Scotland to discuss what supported self care means for cancer services.

Key themes were very similar to those identified within this strategy and the Framework for Rehabilitation and relate to: information; communication; navigating the patient pathway; and building confidence to support people to self care. The model is person centred and includes the following components at different stages across a pathway of care:

- Prompts and questions to ask
- Who to contact
- Information and resources
- What can I do for myself?

## **Better Together – Scottish Patient Experience Programme**

Better Together was launched in summer of 2008 following a commitment in Better Health, Better Care to develop an NHS in Scotland that delivers a greater say for service users. The programme will support NHSScotland to make year-on-year improvements in the care people receive by helping NHS Boards to:

- Listen, in conjunction with staff views, to what patients and carers want.
- Compare patients' service experience to what patients want.
- Act on this information to improve services.

The focus of the programme for the first few years will be: inpatient care; long term conditions; and GP services. The aim is for the long term conditions element to begin in spring 2009.

## **Community Nurse Review**

The Community Nursing Review was set up to find out what community nurses, in partnership with fellow professionals, should be doing to give people the best possible care in or near their own homes. This review was carried out in response to the challenges facing the delivery of quality healthcare to the people of Scotland in forthcoming years. In particular it was to respond to the increasing numbers of people with long term conditions.

The report proposes a generic community health nurse model which will be tested in four development sites, NHS Borders, Highland, Lothian and Tayside. These sites were chosen as they reflect the diverse nature of Scotland's geography and health needs. Testing of the new model and other work streams will continue to allow an informed decision to be made about the future of community nursing services.

## NHS24

NHS24 is now expanding its scope by contributing to the health improvement and long term conditions agendas. There are several work streams being developed beyond the out of hours service traditionally associated with NHS24. For example:

- Using existing infrastructure NHS24 is developing a service to enhance the care in winter for people with COPD. This is done by providing telephone support and advice when the MET Office predicts that outside temperatures will drop. The project will focus on Dundee where people will be monitored to check their understanding and concordance with arranged treatments. They will be given strategies to maximise these. Early signs of deterioration will be detected and followed up. It is hoped this will improve quality of life for people and reduce hospital admissions.
- NHS24, in collaboration with Glasgow and Clyde, will provide a support service for the bowel screening programme currently being developed. NHS 24 is piloting the delivery of telephone based Cognitive Behavioural Therapy (CBT) by trained therapists to five Health Board areas. This will be offered to people referred by GPs in the first instance. If it is successful in the pilot stage the service will be made available across Scotland.

## Palliative Care

The Scottish Government and the Scottish Partnership for Palliative Care (SPPC) have worked in recent years to develop policy and practice in palliative care. It is now widely recognised, and acknowledged in a range of recent policy documents, that good palliative care should be available to anyone who needs it, regardless of their diagnosis. The Better Health, Better Care action plan for health and wellbeing includes a commitment by the Scottish Government to the production in 2008 of a national action plan which will for the first time introduce a single, comprehensive approach to the provision of palliative care across Scotland. The action plan will set out how the Scottish Government

intends to implement the recommendations of the 2007 Scottish Partnership for Palliative Care report Palliative and end of life care in Scotland: the case for a cohesive approach. This report and all other SPPC publications are available at [www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)

## **Keep Well**

A key priority for the Scottish Government is to strengthen and enhance primary care services in deprived areas to reduce health inequalities. To support this, the Keep Well programme is piloting an anticipatory care model within geographic communities of greatest need.

The Keep Well programme has provided extra resources for primary care services in deprived areas, primary for additional staff to identify, contact and offer health checks and risk assessment to those who may be at risk.

Keep Well is now entering its second phase and Well North has been established to extend and adapt the model to remote and rural Scotland. As part of wave two of Keep Well work will be targeted to specific populations including: homeless people; travelling communities; and prison populations.

## **Living Better**

The Living Better project aims to improve the mental health and wellbeing of people with diabetes and coronary heart disease. It is funded by the Scottish Government and runs from January 2008 to November 2010. The project is led by the Royal College of General Practitioners (RCGP), in partnership with the Scottish Development Centre for Mental Health and the University of Stirling. Other partners in the project include Diabetes UK Scotland, British Heart Foundation Scotland and Depression Alliance Scotland.

The project was established in response to evidence of the link between long term physical conditions and mental health problems and recognition that detection of such problems is currently low. Living Better starts from the position that people with diabetes and/or CHD

deserve a holistic assessment of their needs (mental and physical), matched by appropriate services to meet these needs.

To achieve this the project intends to work with GPs, Community Health Partnerships (CHPs), patients and their carers to improve detection of, and support for, mental health problems among these groups.

## **Workforce Plus – an Employability Framework for Scotland**

The Employability Framework (available at [www.scotland.gov.uk/Topics/Business-Industry/Employability](http://www.scotland.gov.uk/Topics/Business-Industry/Employability)) was launched in June 2006. The main aim of Workforce Plus is to increase the chances of employment for vulnerable and disadvantaged groups throughout Scotland including those who:

- Face many barriers to gaining employment and therefore require additional help.
- Only require some or minimal help.
- Are in low paid, low skilled jobs.
- Are already in work but whose health and related barriers put continued employment at risk.



# Appendix Three – Planning and Evaluation

Reproduced from <http://www.scdc.org.uk/our-services/training/planning-evaluation/> and <http://www.scdc.org.uk/leapinfo/>

## Introduction to the LEAP Framework

The LEAP (Learning, Evaluation and Planning) framework is in widespread use in community learning and development, health improvement, greenspace work, volunteering and regeneration settings across Scotland. LEAP poses key planning and evaluation questions including:

- How do we understand the needs or problems we are dealing with?
- What are we trying to achieve - what are our outcomes?
- How will we know if anything has changed - how will we measure progress towards outcomes?
- How do we action plan in relation to outcomes?
- How will we capture the lessons about what works, what doesn't work and why?

LEAP also poses critical questions about the process of planning and evaluation:

- Who has a stake in the issues we are trying to address?
- Who should be involved in identifying need, deciding what our outcomes should be and what action we should take?
- Who should be involved in deciding how we will judge success?

The LEAP framework was developed by SCDC and is designed to be a useful tool in all aspects of project, programme and policy development, planning and management. It can be used in different contexts and by people working in different sectors. It encourages us to ask critical questions about our work and to ensure that all those involved are working to the same agenda. The LEAP framework emphasises self-evaluation, encouraging shared responsibility for planning and evaluation throughout a project or programme.

Taking account of the interests of everyone who is involved, LEAP is equally applicable to all contexts for community development practice.

It seeks to support personal and shared learning and empowerment of participants, focusing on attention on key questions that it is in everyone's interests to answer.

The questions are:

- What is the need?
- What difference do we want to make?
- How will we know we made a difference?
- How will we go about making the difference?
  - o What resources will we use?
  - o What methods will we use?
  - o In what ways will we use them?
- How are we making sure it is happening?
- Have we made a difference?
- What are the lessons we have learned?
- What will we need to do now?

For more information and to view a diagram of the LEAP process please visit [www.scdc.org.uk/leapinfo](http://www.scdc.org.uk/leapinfo)

# "Gann Yersel!"

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