Self Management of Long Term Conditions

Introduction

There are an estimated two million people living with long term conditions in Scotland. A long-term condition can be defined as one of prolonged duration that may affect any aspect of the person’s life. These can be life threatening, affecting people physically, mentally and emotionally.

Some people are born with long term conditions; others will be affected at different ages and stages of life. Symptoms may come and go and may progress. Many people have more than one long term condition. Usually there is no cure but there are often things that can be done to maintain and improve quality of life.

Scotland’s life expectancy is improving and evidence suggests that people are living longer with long-term conditions. In most industrialised nations and in many developing countries, long-term conditions are now the most common cause of death. They are also strongly associated with social deprivation.

The Long Term Conditions Alliance Scotland (LTCAS) aims to bring together hundreds of voluntary and community organisations across Scotland to give a national voice to ensure the interests and needs of people living with long term conditions are addressed.

Why is the long term conditions agenda important?
- People are people, with lives and families, not just patients.
- Quality support and services means quality for life.
- Life is for living not enduring.
- There needs to be a reduction on the burden of long term conditions on individuals, families and society.
Culture of Health Care

A key driver of cultural change for the NHS is the move away from acute care to dealing with long term conditions. It is the main challenge facing health care providers. We believe that as people with long term conditions have to live with their condition over a long period of time, they can become experts in what is best for them. Many people and their unpaid carers want to continue to develop their knowledge and skills about how to manage their condition. LTCAS believes this process needs to be invested in and supported.

Self Management

LTCAS describes self management as a process where people living with long term conditions can achieve and maintain optimum wellbeing. Part of this will be managing their conditions and its impact on their lives. Where there is an unpaid carer, their involvement in this process is critical. The commitment of health and social care professionals is vital.

This process will vary according to both the person’s condition and their circumstances. Peer based initiatives have evolved from the experiences of people living with long term conditions. These are an important element of the process of learning to self manage.

Policy

The Scottish Executive states its vision for self management in ‘Delivering for Health’:

“Supporting self care and self management means more than giving patients information about their condition. It also means that health care professionals must empower patients (and involve their family carers) to take greater control over their own care.”

It goes on to say that it will work with the LTCAS to support self-management in order to:

- ensure that patients and their carers have the skills and knowledge they need, and someone they can contact if required
- develop mentors and ‘expert patients’ to act as advisers and role models
- pilot home-based information technology to support self management at home.
The LTCAS welcomes the opportunity to drive forward the self-management agenda in Scotland’s healthcare system.

**Voluntary Sector**

The voluntary sector is in an ideal position to provide self-management support for people with long term conditions. Many voluntary organisations working in the health sector in Scotland have been delivering or facilitating self-management programmes since the mid 1990s. During that time many hundreds of people with a long term condition and their carers have been supported to find ways to manage their condition effectively. **The valuable role of the voluntary sector in developing and providing self-management programmes must be recognised and supported by the statutory sector.**

**Peer-based support**

We believe that one of the ways in which services for people with long term conditions could be improved is through peer-based initiatives. Experience in delivering these courses has shown that participants identify realistic goals and develop action plans for employing new approaches learned from their peers. Experience has also shown that the same people go on to manage their condition more effectively and that this has positive outcomes for overall health and wellbeing. **Peer-based initiatives should be recognised as part of mainstream, self-management activity and should be properly supported and resourced.**

**Support for health and social care staff**

Another important way that services could be improved is to train health and social care professionals to work with service users and carers as partners in care. The voluntary sector is in an ideal position to be able to work with health and social care professionals in achieving this. **Health service and social care staff, including senior managers, practitioners and clinicians should commit to awareness raising and empowerment training approaches to encourage a person centred focus to service delivery. LTCAS would like to see the development of approaches which empower people in managing long term conditions.**
Information

LTCAS would like to see the ‘care pathway’ (the route taken from first contact with an NHS member of staff, usually the GP, through referral, to treatment) improved. One simple way of doing this is to provide accurate, accessible, and relevant information to support self care for people following discharge from hospital or following diagnosis. Information to support self management could be included, for example, as part of the care pathway for people. **Timely and accessible information is a key part of the process of self-management and should be built into local NHS strategies supporting self care.** LTCAS would like to see recognition for the value the voluntary sector brings in providing support in self management issues.

National strategy

Lastly, we would like to see the promised national strategy for long term conditions putting support for self management at the heart of developments. **The long term conditions strategy should be a lever to ensure that every person living with a long term condition in Scotland has access to information, support and education as required.**
Gaun Yersel

Being Human: 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

EXECUTIVE SUMMARY

BACKGROUND

WHAT IS SELF MANAGEMENT?

WHY IS SELF MANAGEMENT IMPORTANT?

HOW DOES SELF MANAGEMENT HELP?

THE ECONOMICS OF MANAGING LONG TERM CONDITIONS

KEY STAGES WHERE PEOPLE NEED SUPPORT

WHOSE RESPONSIBILITY IS SELF MANAGEMENT?

MAKING IT HAPPEN

PLANNING AND EVALUATION
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 costs of long term conditions in Scotland is not known. However it is estimated that for mental health problems alone this stands at around £8.6b or 9% of GDP¹.

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.

### Key stages where people need support

<table>
<thead>
<tr>
<th>Key stage</th>
<th>Issues</th>
<th>Impact of self management</th>
</tr>
</thead>
</table>
| **Diagnosis** | • By this point someone’s life and ability to manage may already have been seriously affected by symptoms.  
• People feel challenged about their place in the world and the reality of their situation. | • Helps people come to terms with diagnosis.  
• Key to helping people reconnect with themselves and others.  
• Helps people make better decisions about treatment options. |
| **Living for today** | • People need information and skills to maintain optimum wellbeing.  
• Serious risk of social exclusion. | • Supports people to navigate an often difficult journey.  
• Challenges social exclusion by helping build bridges back into society and social roles. |
| **Progression** | • Cycle of illness and wellbeing arising from fluctuations in condition.  
• Increasing severity of symptoms.  
• Struggle to get additional support during flare-ups.  
• Possible loss of capacity. | • Helps to avoid – or minimise extent of – flare-ups.  
• Enables people to recognise early warning signs and react effectively.  
• Tackles psychological impact of flare-ups or progression.  
• Supports changing needs. |
| **Transitions** | • Moving between services, sometimes to different levels/types of support.  
• Dealing with multiple needs/conditions and therefore a range of services.  
• Often a stressful time and this can have serious impact, including on person’s condition. | • Supports person to manage transition process(es).  
• Maintains focus on person’s needs ensuring services are organised around these.  
• Provides person with control at a time when this can be undermined. |
### End of life

- Difficult time involving complex challenges.
- Death may be premature.
- Person may have to cope with symptoms of condition alongside additional challenges of end of life.

- Supports person to meet range of challenges and maintain control.
- Addresses broader needs e.g. emotional, family and lifestyle.

### Making it happen

Self management is the responsibility of individuals. However this does not mean people doing it alone. Successful self management relies upon people having access to the right information, education, support and services. It also depends upon 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 and 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 Delivering for Health/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, the Long Term Conditions Alliance Scotland held the ‘Gaun Yersel’ conference, bringing 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.

- Self care is what each person does on a everyday basis but which is often compromised in a person living their life with a long term condition.
- Self management is the process each person develops to manage their condition.
- 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 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 condition.

• The role of health and social care professionals, services and treatments 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 working with all appropriate individuals and services working together and supporting a person 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.

Enablement and empathy go hand in hand with self management, and people will 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 seven days a week. Support levels will change depending on each individual’s life stage and the nature of their condition. Therefore it is critical that the self management agenda takes account of the structural issues which serve to exclude people.

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 this concept. Not everyone has the same ability to learn and to manage and all statistics show that people from poorer backgrounds do less well. The impact of the range of well documented health inequality issues such as poverty, unemployment, exclusion on grounds of ethnicity, refugee status 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.

With this in mind 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 carers and with their families is also key to success.

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 condition(s).

• People need the right information and skills to develop healthy responses to their condition(s).

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 impact 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(s) and their desire and ability to care about themselves.
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 support is required. 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 eg 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.

The Economics of managing long term conditions

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(s).

The cost of long term conditions for Scotland is not easy to capture. Definition of cost cannot be based solely on financial cost but on quality of life and effectiveness of interventions. 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 addresses 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 years².

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 research³ 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.

A study⁴ 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 widely enough available. Importantly it also highlights that people who have no such intervention are at fourfold increased risk of complications which result in huge cost to 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 services modified.

With regard to the voluntary sector, LTCAS recommends that funds are established for organisations to either expand or develop self management programmes. The voluntary sector’s biggest strength is

---

⁴ Nicolucci et al, 1996 A comprehensive assessment of the avoidability of long-term complications of diabetes, Diabetes Care, 19: 927-933
their 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 that foresees a sea change in the expectations of people living with long term conditions. However, the sector needs resources to build capacity and to allow this social capital to develop.

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 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, where smaller and newly established organisations can be supported alongside other more established ones. This hub will offer office accommodation, shared facilities for administration, training and hot desk facilities. This too needs funding to establish and run.

To begin to establish the self management agenda, initially LTCAS seeks £2 million per year\(^5\) 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. Like the Kerr Report, Delivering for Health and Better Health Better Care suggest, 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 encouraged 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.

\(^5\) Exclusive of long term conditions hub development which is costed 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 and build on empowering themselves to feel more in control of their life and condition/s. 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, and 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 which 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 here, its 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 so many levels because of their conditions and this is simply 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 grows and he is able to commit to both completing the course and carrying on his practice afterwards.

George is surprised 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 then 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 cycle of illness and well-being for long term conditions that fluctuate 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 get 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; 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 either by understanding their condition fully and managing it effectively; thus avoiding becoming ill again or recognising the signs and symptoms of pending health crisis and seeking interventions at an early stage. These must however be there and accessible or the situation will deteriorate.

For progressive conditions, early intervention with the right information, support and flexible help which can adjust to suit changing needs, can help to 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 that 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 based only on evidence based medicine is not effective in achieving a sense of wellbeing for individuals faced with such complex challenges in life. All of the life stories we have outlined demonstrate this as does this one for 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 was planning to leave school and go to a resource centre, staff from the resource centre began working with her during her last six months in school. They came to visit her, spent time with her and her teachers learning about how Fiona communicates. They also learned about the best ways to approach Fiona’s personal care. Part of this included training on administration of her emergency medication. The support staff at school showed the resource centre staff Fiona’s emergency care plan. They talked about Fiona’s seizures and described what a serious seizure needing emergency medication looked like for her. The resource centre staff then understood the nature of Fiona’s seizures and how to deal with them.

Back at the resource centre, staff still felt anxious about dealing with Fiona’s seizures. To help with this the manager organised for the voluntary sector to offer epilepsy awareness training to the whole team. Everyone on the team learned a lot about the complex and diverse nature of seizures. The speech therapist also came with Fiona and trained staff on the best way to communicate with her.

Just before Fiona left school, everyone who is involved in her care and support from the children’s hospital and school met with Fiona and her parents. They invited all the new staff who would be working with her in her adult life. Together with a facilitator from the voluntary sector, they helped Fiona develop a person centred plan. For the first time she was 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.
As Fiona asked for help to reach her goals, further support is organised through a voluntary organisation. This support is community rather than centre based and focuses on helping Fiona gain independence in making decisions that will chart out her life path. This type of service is flexible and allows Fiona choose the areas where she needs to develop. As she is worried about the move to the adult hospital, her support worker gets an appointment sorted out. At this appointment they take away information about the service and work together to help Fiona ask all the questions she has at her next appointment.
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 people receive to alleviate the symptoms of their condition. Some 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 despite the condition requiring services. 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 persons daily life.

Adopting a person centred approach to communication and information regarding what and how much the individual and their family wishes 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 their service.

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 to be 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 at home. 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 wants 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 to have her walking up and down the stairs but she learnt 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 some hypnotherapy to help her to relax and sleep better at night. This helped to make 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 is 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.

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 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 has 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. Another 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 to their mummy. 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 seems a bit like stating the obvious, yet all statistics regarding human behaviour would suggest that it is not equally obvious to everyone. 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 on 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 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 for addressing them. There is no one way for achieving this and some people will need more support with this than others.

People with long term conditions are encouraged to participate in, and where possible lead, the process by their health and social care professionals and carers.

Individuals learn how to manage their own independent health and wellness budget. Part of this process will be working out which self management courses/support sessions suit their needs. It may also mean identifying complementary therapies to help gain wellbeing eg yoga, massage, tai chi, counselling. This 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.

Note: ‘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

The role of the unpaid carer is vital to many people with long term conditions achieving a good quality of life. This is particularly critical where the individual lacks capacity to make decisions for themselves. Being a carer is a role that very few people would choose, yet most see themselves as having little choice in the matter. The carer’s role is also vital to the ability of people with long term conditions ability to self
manage. Where the person is unable to fully achieve this fully, carers may need support to make sure the person gains independence wherever possible. Assisting people to achieve optimum independence and well-being is in everyone’s interest.

**Aims for carers**

Training and education alongside effective support from health and social care enables carers to maintain their caring role. Without this support, particularly for those carers providing continuous care, the caring role may break down, including support the carer provides in enabling the individual to self manage their condition.

Carers have their own needs, desires and dreams for their life and relationships and, whilst these may be closely interlinked with those of the individual, 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 carer.

**Voluntary sector**

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

Additionally, they have an important role in articulating those needs to other service providers, both health and social care, to ensure that the services they provide 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 the identified needs with other service providers.

Develop joint referral mechanisms with the statutory sector to ensure effective co-ordination of support.

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 in order to support systems that enable participation and development of skills for self management.

Ensure that 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

**NHS Scotland**

The issues around NHS Scotland providing support to people with long term conditions are covered extensively within the Living Well report. We have also highlighted the broad issues of partnership needed in this paper. To address this there are a range of targets and redirection of funds that NHS will need to address in the coming years, in line with the Kerr report, Delivering for Health and 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 for success.

Giving patients 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. Telehealth can be used to support the entire 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. This can be achieved by using technology to support individuals with better information and minimise the amount of unnecessary contact that they would have with health care professionals in situations where their management is erratic and occasional.

**Aims for NHS in Scotland**

Health boards/CHPs sign up to the approach set out in Living Well Report and Scottish Government’s strategy.

---

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 report⁷.

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. People living with long term conditions are likely to need support 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 that all relevant NHS services understand the particular needs and their role in contributing to successful self management for people living with long term conditions, including Telehealth.

Agree funding packages and support a broad range of national and local self management initiatives.

Encourage a culture within the NHS of effective communication – between professionals and with people living with long term conditions and their carers.

Enable self referral to services that do not required to be doctor led such as physiotherapy.

**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 Framework⁸. 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 fully engaged.

---


Aims for local authorities

Local authorities sign up to the approach set out in the Living Well report, Joint Futures, Delivering for Health, Better Health, Better Care and the Rehabilitation Framework.

Education programmes developed for providers of social services eg social work, housing, 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.

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 that the required culture and system change takes place at all levels and across the sectors, and redirecting resources appropriately.

The Scottish Government also has responsibility for leadership in changing attitudes and culture. It is important that the issues are raised within the 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.

Long term plan to support the sustainability if the voluntary sector to deliver self management 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 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 such as occupational therapists and others for assessment. This may be from the beginning and/or if circumstances change and the individual or employer requires advice.

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.

Educations 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 peers of people with a long term condition.

Awareness raising programmes aimed at community activities, leisure and recreation to ensure the integration of people with long term conditions in their choice of community initiatives that both benefit their health and wellbeing alongside ensuring widest possible access.

**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’s 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\(^9\).

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 however 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.

**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.

---

\(^9\) 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

Making it happen

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 do 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) 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 Self Management Advisor 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 Self Management Advisor 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.

The Grants Officer would assess bids against agreed criteria and report these 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, which will need to be reflected in any funding criteria:

- Accountability is built into the programme though ongoing evaluation\(^{11}\)
- 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 must have 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
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

\(^{11}\) 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.
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.12

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.

---

12 This is also the model used by the expert patient programme in England & Wales
Appendix 1


Planning and Evaluation
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 development 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?
  - What resources will we use?
  - What methods will we use?
  - 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?