Emotional Support Matters

Emotional and psychological support needs of people with long term conditions

Report of the Open Space Events

held in Inverness 15 September 2010
and Glasgow 19 October 2010
This report stems from a commitment the Government gave in *Better Health, Better Care* to enhance the level of emotional and psychological support provided to people with long term conditions. It’s an issue that we know is of central importance to the two million or so people in Scotland who live with one or more long term condition. That’s why the issue was included as an action in our Long Term Conditions Action Plan we published in June 2009.

I’m grateful to the Long Term Conditions Alliance Scotland (LTCAS) for taking this action forward, in partnership with the Scottish Government Health Directorates. On this issue above all, we have to make sure that the voice and experience of people living with long term conditions, and those who support them, are not only heard, but heeded.

For me, perhaps the most striking message in the report is that if
we take opportunities to meet people’s emotional and psychological needs along their journey, then it’s much less likely that they’ll need to have recourse to formal psychological interventions. The overwhelming message is about how listening and compassion can promote people’s inherent capacity for self-healing. As the report says, the ability to ask questions about feelings is seen as essential. That’s probably one of the biggest challenges we face as Scots – to learn how to talk more freely about our feelings.

I’m pleased that the report acknowledges the range of work we already have under way. That includes the Self Management Fund; the long term conditions module of ‘Better Together’; the ‘Living Better’ project, which aims to improve the mental health and wellbeing of people with diabetes, coronary heart disease and chronic obstructive pulmonary disease; the ALISS (Access to Local Information to Support Self Management) project; our support for integrative care; and the use of telehealthcare to support independent living. The reference in our Quality Strategy to the use of the CARE (Consultation and Relational Empathy) measure reflects the value we attach to empathy and listening as a fundamental part of all healthcare contacts.

I therefore share the report’s assessment that Scotland is now well placed to make the changes outlined in it. As a Government, we are committed, through implementation of our Quality Strategy, to making sure the messages in this report will be acted on not just across NHSScotland, but also in partnership with social care and the third sector. Publication of the report will allow us all to focus on solutions developed from people’s own thoughts about what they want from life, so they are not just living, but living well, with long term conditions.

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

Chief Professional Officers’ Endorsement

We commend this report to all of our colleagues who have responsibility for delivering healthcare in Scotland. The report clearly highlights the importance that people with long term conditions attach to the need for holistic approaches that include skilled and empathic emotional and psychological support. The report rightly highlights the need to develop the skills of the workforce in communication and partnership working, for example through emotional intelligence development. This will make a valuable contribution to enabling people to manage their own conditions, and to live well with them. We therefore look forward to working with everyone concerned in taking forward this important area of work.

Harry Burns, Chief Medical Officer
Ros Moore, Chief Nursing Officer
Bill Scott, Chief Pharmaceutical Officer
Margie Taylor, Chief Dental Officer
Jacqui Lunday, Chief Health Professions Officer
Introduction by Professor Craig White and Susan Douglas-Scott

It is an established fact that living with a long term condition can have a significant impact on emotional and psychological wellbeing.

More and more is now known about the factors that contribute to positive emotional and psychological adjustment; and there is an increasingly effective range of approaches that have been developed to meet emotional and psychological support needs.

Health and social care staff may not always be aware of these needs and when they are, many are not sure how to respond. In many cases staff do not have the knowledge, skill or confidence and may feel that they have not been supported to develop the necessary skills to identify and support people. This can also apply to addressing their own emotional and psychological care needs.

It has been recognised that there is significant variation in the extent to which NHS services are currently able to identify and support these needs. Many voluntary sector organisations in Scotland provide vital emotional and psychological care services. Some people living with long term conditions are fortunate to have had their psychological care needs identified by clinical or voluntary services staff and can access specialist supportive and psychological care services when these are needed. All too often conversations about emotional and psychological care responses have concentrated on the necessary, but not sufficient, actions in relation to training and employment of specialist clinical staff.

The NHSScotland Healthcare Quality ambitions outline the importance of ensuring that services are delivered in a manner that supports the development of mutually beneficial partnerships, reduces the presence of wasteful or harmful variation across services and ensures that effective care, treatment and support are available to all who will benefit. Scotland’s health, social and voluntary sector services have vast potential to ensure that we become recognised across the world as having a comprehensive and truly integrated approach to emotional and psychological support.

Professor Craig A. White
Clinical Lead,
Long Term Conditions Unit,
Scottish Government Health Directorates

“Sharing knowledge develops capacity of all which impacts on understanding and emotional capacity to live with condition(s)”
Living with long term conditions can and often does have a serious impact on the emotional and psychological health and wellbeing. It can also have a detrimental effect on the emotional and psychological health and wellbeing of others in the family, especially unpaid carers.

The stresses and strain of certain symptoms, in particular pain, fatigue, sleeplessness, disorientation, breathlessness, low energy are all recognised as potential triggers for anxiety and depression.

Social issues can also lead to poorer emotional and psychological health and wellbeing. This is because living with long term conditions and the barriers that prevent full inclusion can affect people’s ability to work and to enjoy the full range of social activities they desire. The loss of income affects the whole household and is a challenge that many struggle to cope with.

This is an issue that is well understood, much research has identified it as a problem for many people with long term conditions. Despite this knowledge, emotional and psychological health and wellbeing is often seen as less of a priority than the other treatments and support for specific conditions.

We know that around one in three people with heart failure and diabetes and one in five people with coronary heart disease and chronic pain will experience depression. Mental health conditions can also become long term and potentially life altering. Prolonged stress alters immunity, making illness more likely and recovery more difficult, especially for those who are already unwell.

Better awareness of long term conditions helps people understand their symptoms and experiences. It is now accepted that this can improve people’s long term health and wellbeing.

The national strategy (Gaun Yersel 2008) says that part of the role of care professionals is to encourage self confidence and capacity for people to self manage their conditions. Self management also aims to support people to have more control of their conditions and their lives and promote their emotional health and wellbeing.

This means having an approach to setting goals and problem solving that is meaningful to the individual. This can include signposting people to the type of support and information they need. It also means having a more solutions focused approach to planning and reviewing their individual situation.

These solutions need to be developed from the person’s own thoughts about what they want from life living with long term conditions. It should take account, too, of people’s inherent ability for look after themselves and for recovery of their sense of wellbeing.

Susan Douglas-Scott
Consultant, Long Term Conditions Alliance Scotland
The Scottish Government action plan for health and wellbeing, Better Health, Better Care, was published in December 2007. It stated a commitment to enhance the level of emotional support provided to people with long term conditions. The action plan outlined that this would be achieved by:

- ensuring that people with long term conditions are treated as people, not a collection of symptoms
- making sure people are aware of the full range of information and support available to them, particularly from the voluntary sector, especially around the time of diagnosis.
- recognising the psychological dimension to long term conditions management and providing better support through counselling and techniques to raise self-esteem.

There is a significant body of evidence demonstrating the two way link between long term physical conditions and mental health.

However, despite this, support for people’s emotional and psychological health is not consistent across Scotland. How do we know this? Well, people with long term conditions and the voluntary sector organisations that support them continue to tell us that the emotional and psychological support needs of people with long term conditions are not well enough met.

For goodness sake turn rhetoric into reality!

This is why this issue was specifically outlined as an action point in Improving Health & Wellbeing of People with Long Term Conditions in Scotland: a National Action Plan published by the Scottish Government in 2009. The overall aim of this plan is to encourage NHS boards to work in partnership - with people with long term conditions, local authorities, the voluntary sector - to ensure that
people receive the best services possible to improve their health and wellbeing. The specific recommendation relating to emotional and psychological support is as follows:

Produce guidance and resources for NHS Boards to support the adoption of models and approaches which offer a range of emotional and psychological support to people living with a long term condition at different stages of their condition.

Emotional and psychological issues have most recently been highlighted as key to people’s experience of health care services in the Healthcare Quality Strategy for NHS Scotland published in May 2010. This strategy underpins the importance of people’s need for care, compassion, clear communication and collaboration. All of these form the basis for support beyond a diagnostic label and if implemented would support emotional and psychological wellbeing, setting a foundation for better outcomes for the future mental health of the person concerned.

“People who feel involved from day one feel more able to cope with their journey”

So to begin the process of how to make sure people with long term conditions get the best possible emotional and psychological support throughout their journey, the Long Term Conditions Alliance Scotland (LTCAS) was asked by the Scottish Government to find out what the key issues are and to make suggestions for action.

We asked people with long term conditions and those who support them what needs to change to improve emotional and psychological support. This report outlines what people said and what they think needs to happen to see real change in this area.

“what it’s like for me and me and me”

This report also adds to the evidence and learning that is emerging from the Living Better Project. Refer to Appendix 4 for a summary of findings. The key themes are similar and together these two pieces of work should provide a clear route for improving people’s experiences.
How did LTCAS go about speaking to people?

In partnership with the Scottish Government, LTCAS held two discussion events with the aim of speaking to as many people interested in this agenda as possible. LTCAS and the Scottish Government already know that one solution will not suit everyone so want to hear all the thoughts that people with long term conditions, their unpaid carers and professionals supporting them have on this agenda. This is why these sessions invited people to talk about “the good, the bad and the ugly”!

The aim of these events and this report is to enable ideas to be shared. Through this we hope to highlight and share the service changes and improvements needed to support the emotional and psychological support needs of people with long term conditions across Scotland.

The events were held in Inverness on 15 September 2010 and in Glasgow on 19 October. They were designed to be interactive and encourage people to talk about the emotional and psychological support needs of people with long term conditions.

Overall 275 people came along and participated across the two events. Those involved were people living with long term conditions, unpaid carers, professionals from health, social care and voluntary organisations and policy makers. We were delighted with this level of support and feel that everyone’s participation was crucial. This involvement helps our commitment to making sure that the voice and experiences of people with long term conditions and those who support them is heard.

Discussions took place in small groups to try to make sure everyone was able to have their say and share their thoughts and ideas.

Here’s how it worked...

When people arrived at each event they were welcomed with a delegate pack and asked to join a round table.

All the tables were set out in a café style with pens, paper and post it notes. People worked in small groups with the others at their table. Each group was asked to select a ‘table host’ and each person was invited to write down their thoughts.
The day was divided into five sessions:

- **Session One** – the groups at each table were asked to identify the issues they thought were important and needed to be discussed. They were asked to write these ideas on post it notes. These post it notes were collected by the organisers and sorted into themes.

- **Session Two** - people were invited to look at the range of stands and information on services currently offering emotional and psychological support to people with long term conditions. Many organisations had stands and people at the event could get information in person or by taking away leaflets, booklets or DVDs.

- **Session Three** – each table was set up with a different theme and participants were asked to sit at the table where they felt they could make their best contribution. Each table was asked to nominate a table host who would be prepared to stay with that table for the rest of the day. The others were invited to move tables if they wanted to join a different discussion at any point.

- **Session Four** – After lunch participants were invited to join another table and pick up the discussion through feedback from the table host and by reading the notes left by others. They were asked to contribute their thoughts to this theme by writing down their ideas.

- **Session Five** – the last part of the afternoon was spent identifying the key issue that had emerged from the table discussion. The one thing that seemed really important and should be considered first because it would make the most difference.

- The facilitators encouraged tables to take notes of their discussions and a conference photographer captured key points. People could also record their thoughts and ideas in writing at a variety of locations throughout the events. All of these were used to produce this report.
What did people say?

The themes people chose to talk about allowed them to cover a lot of ground. Although the key topic of the day was the emotional and psychological needs of people with long term conditions, the discussions were far reaching. This underpins the fact that every interaction, every encounter has a potential impact on emotional and psychological wellbeing.

The discussions included looking at the infrastructures that need to change in order to make sure this type of support is available. They also included broad ideas of what emotional and psychological support can look like for people with long term conditions.

“Emotional and psychological support is core service not an add on”

“human kindness goes a long way”

Overall the discussions covered the following areas:

1. Planning
2. Carers
3. Holistic support
4. Staff/professional issues
5. Attitudes/stigma/discrimination
6. Self management
7. Services
8. Information
9. Communication & understanding
10. Multiple conditions
11. Challenging isolation
12. Support services
13. Emotional support
14. Training
15. Transitions
16. Person centred approaches
17. Service redesign
18. Finance and Resources

In this report we have tried to summarise everything that was talked about into main headings. These are:

- Holistic emotional support
- Involving people
- Communication
- Professional support and development
- Service design and delivery

The final section of the report is about suggestions for action, development and change. These ideas came from the people living with long term conditions, unpaid carers, professionals and policy makers who came along. They believe that if these things happen they will make a big difference to the emotional and psychological support needs of people living with long term conditions.

It was interesting that in both Glasgow and Inverness, people talked about similar things and identified common issues.
Holistic support was talked about in many groups and emphasised as a great contributor to emotional and psychological wellbeing. Through holistic support, practitioners could offer empathy, support for self-management, share knowledge and skills and support the use of the widest range of therapies that work for each individual. People need access to support that considers their needs and respects their values.

“Do no harm – harm can be emotional”

Many people at the events talked about how important ordinary human caring is. They believe it supports health and social care and is inseparable from the care needed to support emotional and psychological wellbeing. People were clear that listening to someone who is distressed by their condition(s) and helping them find some direction through that distress is good care.

People were also clear that those with long term conditions, even when there is no cure or treatment available, can benefit from support with any distress they are experiencing. No matter what issue an individual talks about, there is an emotional and psychological response that can be considered. Supporting emotional and psychological wellbeing can therefore always be addressed.

“Communication skills are paramount”

Health and social care practitioners can succeed technically or medically and miss the fact that people have care needs beyond this. Most NHS complaints reflect this. Technical care without positive human care can be an over-mechanical, depersonalised experience. Ignoring the negative impact of emotional and psychological distress on physical and mental health and healing is unscientific and misses the potential of working with an individual’s full potential. There are benefits in this way of relating for both “patient” and “practitioner”.

Positive relationships can help everyone involved, giving rise to people identifying that “healing is healing”. This is not about forced caring, or sympathy but about being open to compassion. Offering support in a non-judgmental way that hopes for the best for the other can both help the person with long term conditions and enhance the practitioner’s own wellbeing.

“not about employing more psychologists but about innovation and thinking outside the box”

Good human engagement without technical excellence is unbalanced, limited and less effective. Together they are integrativevii.
3.1 Holistic, emotional support

The challenge is that this integrative approach of evidenced based medicine, person centred support and addressing emotional and psychological issues is not always included in the training of health and social care practitioners. When it is addressed, for some professionals, time, pressure of waiting lists and uncertainties of new and different approaches can cause barriers to truly holistic care and support.

The ideas that emerged from people focused on being holistic, seeing the whole person and really listening to people then acting on what they feel is needed.

“can we make sure the giving and receiving of support is truly holistic?”

“patient centred holistic and integrative care approach that concentrates on active listening – giving time not rationing it – validating what is important to patient”
3.2 Involving people

Self management was highlighted as a very important element of emotional and psychological wellbeing. People described how this can contribute to sustained improvement for people with long term conditions.

The discussions outlined how, for effective self management, people need information but that is often not enough. People with long term conditions can also need support if they are to successfully self manage their conditions.

It was also recognised that self management can be challenging and often is helped by a caring listener. People concluded that there is no easy answer on how to self manage any emotional and psychological aspects of long term conditions. They emphasised that a range of options need to be available for people so that they can find the approach that suits them.

There was recognition of support beyond health and social care professionals and peer support was identified as a useful approach for many. This was not seen as something that needs to be condition specific, rather a generic approach would work just as well. In order to support this model there is a need for raising awareness in all layers of communities. Voluntary sector organisations and faith organisations have useful roles to play here.

The important role of unpaid carers in supporting the emotional and psychological wellbeing of people with long term conditions was discussed at both events. The vulnerability of both groups was considered and their support needs explored. It was suggested that both groups may need support in different ways.
People with long term conditions need their families and unpaid carers to have enlightened, realistic expectations of their needs. Unpaid carers in turn identified their need to be listened to and have their own emotional and psychological needs identified and addressed.

Help with intercommunication with both groups should be considered along with the importance of developing shared empathy.

The issue of paid carers was also discussed. People with long term conditions have very intimate working relationships with paid carers and these relationships can impact on emotional and psychological wellbeing.

This can be affected by turnover of staff and having to begin again with training new workers and building effective relationships with them.

Concerns were raised at both events that there is a lack of understanding that emotional and psychological support needs often need to be part of people’s care packages and resourced with the same level of importance as physical needs.

“mental health issues must be recognised as part and parcel of all health conditions with no stigma attached”

“training and turn over of paid carers is a problem”

“being a carer am I allowed a life?”
The ideas that emerged around communication covered interpersonal communication and relationships and the importance of these being right every time for every person. Information on emotional and psychological support for people living with long term conditions was also thought to be critical to accessing effective services.

Communication with health and social care professionals was talked about a lot across many tables. The emphasis of these discussions was on listening and acting on the needs of the person with the long term conditions.

Body language and approach was also emphasised as critical. As humans we can at times feel the other person’s intention more than we hear their words. We are also quick to pick up if people’s faces and bodies are not backing up the words they are saying.

People at the events thought that if the art of communication improved, people with long term conditions would be able to make better connections across health and social care services. Linked to this, people thought that everyone involved would recognise a common purpose more effectively if everyone’s communication and relationship skills improved. This includes embracing the person centred model, moving away from entrenched models of care, sharing good practice, trust in self referral, better use of technology, shared information, interdisciplinary training and development and shifting attitudes to truly support self management.

A skill that was seen as lacking is the ability of professionals to make sure that the person they are supporting feels heard. Phrases such as “time to talk” and “listening for life” were discussed and related to the importance of the interpersonal relationships that underpin all health and social care interventions.
People identified that **information** on emotional and psychological wellbeing and related support is important. Information needs to be accessible and available in different ways. While many people use the internet for information, many others cannot. Accessible information needs to be available online, printed, by telephone or at drop in facilities to reach as many people as possible. People stressed how important it is for people with long term conditions to be able to really understand what is available to them.

**Services** that can offer a central point of contact and accessible information were identified as gaps. This is because it is often challenging for people with long term conditions to find out where to go in their local communities to either get support or to access information.

A **one stop shop** for signposting was talked about as ideal. Frustration levels are high among people with long term conditions, unpaid carers and professionals with how challenging it can be to find out what is available quickly and easily. Good practice was not always effectively shared and again a central point where this could be found would really help.

This navigational role was also identified at the Living Well events in 2007 and remains important to both people with long term conditions and practitioners.

People with long term conditions identified **symptoms** such as pain and fatigue interfering with their ability to have the energy to access information on all aspects of their needs, including emotional and psychological support. This is made worse by the way information is available at present with an apparent scatter gun approach that is good in pockets and poor for many. As all Scots should benefit from good practice, this is not yet good enough across enough of Scotland.

Professionals said they are pressed for time and as identified in current policy and reiterated by those attending these events, they need to focus their efforts on active listening and developing a positive relationship with people with long term conditions. Therefore, ready access to **clear, simple information**, can be a very useful tool that they could quickly and easily pass on to the people they are supporting.

The use of telehealth and electronic records were also raised as ways of effectively using IT to support people. Concerns were expressed that these are areas that are well documented internationally as effective but are not yet being made best use of in Scotland. Again there are pockets of good practice but this needs to be **shared** more effectively.
Staff and professional issues were discussed at both events. People from all backgrounds talked about the importance of working in partnership. This included the full range of NHS practitioners involved in the care and support of people living with long term conditions. It was considered an issue that needs leadership and champions.

Due to the fact that offering emotional and psychological support is so interpersonal, participants identified the need for support for practitioners. They too need to self manage their own emotional and psychological wellbeing so that a sense of balance will come through when supporting others. Real answers for people with long term conditions about their emotional life will only come when the person feels safe with the “other” who is supporting them.

The emotional intelligence of practitioners and people with long term conditions was highlighted as an issue and support around developing this could help with emotional and psychological wellbeing.

“Emotional intelligence, ability to empathise, ability to open yourself and protect yourself”

The discussion also covered the potential “straight jacket” approach of evidence based medicine. How effectiveness is defined is often narrow and by definition medical model in approach. Participants believed that while this has a clear and important role, complementary therapies, including creative interventions, that are reported by people with long term conditions to add value should be embraced.

“respond to the wants and needs of people with long term conditions”

This is another area where the value of people’s stories and their successes should be used to support the sharing of good practice. By focussing on positive outcomes experienced by people with long term conditions, ideas on how we can all learn and progress can spread. This was seen as an essential part of the move from fixing people to supporting people’s own goals. An approach advocated by the UK wide co-creating health programme and many LTCAS members.

“professionals not scared to ask feeling questions”

“use patient stories to enable others to appreciate the whole of a person”

Conversations with people are seen as the key here. The ability to ask questions about feelings is seen as essential. Sometimes this calls for consultation and/ or counselling approaches, but mostly not. It is a skill that, while often lacking, can be gained through professional development. Contact and community with others on similar journeys can also be invaluable.

“valuing and respecting the person and what they share with you”
3.5 Service design and delivery

Those at the events identified a need to invest in emotional and psychological support in communities and stressed that equality and diversity issues need to be addressed.

People with long term conditions need the creation of safe, accessible, balanced support based on empathy, personal choice and the ability to build a chain of support. Often there are barriers to a wide range of people accessing support to these need to be addressed.

A wide range of emotional and psychological support was identified as being needed. This includes counselling services, occupational therapy, pain clinics and ongoing psychological support. Many felt that we need to think beyond traditional ways of accessing and offering support as there needs to be more on offer. Use of complementary therapies and accessing community based and college based services need to be embraced.

Early intervention was identified as necessary to prevent further emotional and psychological distress. This was preferred by all as it could help avoid flare ups of severe episodes of anxiety and depression.

Post diagnostic support was also discussed as critical to ongoing emotional and psychological wellbeing and needs to be embedded in the way everyone works. People were clear that it is better if these services are available from a wide range of agencies as this will in turn reach a wider range of people.

Discussions on planning of services focussed on the need to ensure that better emotional and psychological support emerges with better use of multi disciplinary partnerships. It was felt that there have been a number of pilots and that there needs to be a comprehensive and robust approach to gathering this kind of information and disseminating it.

Flexible services are called for and these in turn demand different approaches and skill mix of those delivering them. It was strongly felt that there is a need for a culture change in services in order to truly address the needs of people with long term conditions.

Where there are barriers to planning, these need to be addressed and removed. People with long term conditions and local practitioners want to see transparency and involvement/empowerment of people with long term conditions. People worry that the real voice of people with long term conditions is still not heard, particularly at a local level. True interagency working needs support and effort if it is to move beyond policy papers and rhetoric.
The value of **multi agency** emotional and psychological support reflects a person centred approach and is advocated by participants at these events.

People are concerned about the **waiting times** for accessing specialist psychology and psychiatric services.

While these services have a very important role for some people with long term conditions, a **better range** of less specialist but equally supportive services can and would meet their needs.

People with long term conditions and their unpaid carers feel that earlier, **simpler interventions** based on a wide range of options could help free up these specialised services for those who really need them. The voluntary sector in particular fulfils and welcomes this support role assisting people with long term conditions to maintain their emotional and psychological wellbeing.

The strong message about services and service planning and redesign is that there are many great ideas and projects already working but they fail due to lack of a shared investment in their future.

One of the tables came up with this chart:

<table>
<thead>
<tr>
<th>The challenges of partnership working – the courage to try! “Wellbeing in Partnership”</th>
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<tbody>
<tr>
<td><strong>Communication</strong></td>
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<tr>
<td>- Services don’t talk to each other (IT or otherwise)</td>
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<tr>
<td>Accessible, open, trusting, clear, two way, co-ordinated, compatible, reflective</td>
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<tr>
<td><strong>Connections</strong></td>
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<td>- People falling between services</td>
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<tr>
<td>- Services can be protectionist</td>
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<tr>
<td>Better referral pathways, education &amp; awareness of all sector roles</td>
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<tr>
<td><strong>Quality &amp; Consistency</strong></td>
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<tr>
<td>- Lack of responsibility</td>
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<tr>
<td>- Lack of follow up</td>
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<td>- Lack of evidence base</td>
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<td>Better signposting</td>
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<tr>
<td>Collegiate working</td>
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<tr>
<td>Shared responsibility &amp; willingness to accept responsibility</td>
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<tr>
<td>Consistent messages</td>
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<tr>
<td><strong>Common Purpose</strong></td>
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<tr>
<td>- ‘Politics’</td>
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<tr>
<td>- Outdated, entrenched models of care</td>
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<tr>
<td>Attitude shift – person centred</td>
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<td>Shared vision (to support to live with a LTC)</td>
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<td>Someone to drive this (LTCAS?)</td>
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<td>Upskilling</td>
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<tr>
<td>Capacity building</td>
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<tr>
<td><strong>Currency</strong></td>
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<td>- No money</td>
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<tr>
<td>Resource programmes that work to hold on to and share good ideas</td>
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Through the discussions outlined in this report, people at both events made suggestions for action, developments or change they feel will improve emotional and psychological support for people with long term conditions.

This section outlines what people identified:

- Raise the profile of the need for emotional and psychological support to be integrated into all services for people with long term conditions.
- All health and social care professionals need to understand their important role and contribute to the emotional and psychological health and well being of people with long term conditions.
- Emotional and psychological support to include a wide range of interventions from simple to complex.
- Develop the jigsaw of self management opportunities across Scotland. These should:
  - Consider people with long term conditions as policy makers and create meaningful ways for inclusion. Widening out programmes to empower people with long term conditions, for example the Voices Programme, is one way to address this.
  - Develop training and support for unpaid carers on emotional and psychological issues – needs to recognise the challenge of accessing this due to demands of the caring role. Use of web based/email/phone services may be useful here.
  - Improve support for unpaid carers when bereaved – recognition of their contribution and loss
  - Increase training on managing paid carers through self directed support budgets.
  - Better access to services that have an impact on emotional and psychological wellbeing such as transport, chaplaincy services and advocacy services.
  - Training for information providers in how to produce information that is easy to get and easy to understand. This includes issues such as how to set up accessible websites, how to write and print accessible leaflets, how to effectively share information and how to use volunteers in this area.
  - Participants at both events identified a role for an umbrella group, in particular LTCAS, to act as informers, as a route map of self management opportunities and services for people with long term conditions across Scotland.
Healthy living spaces were suggested as a way of supporting people. People suggested a network of these across Scotland in a variety of formats to suit communities. For example mobile units, community centres, online communities. These could be built into existing services but need to be explicit about recognising the need for and actively contributing to emotional and psychological wellbeing for people with long term conditions.

Use of, and support for, complementary therapies as a positive contribution to emotional and psychological wellbeing for people with long term conditions.

Ring fenced funding for multi agency partnership in the delivery of emotional and psychological support services.

Move beyond short term funding for all agencies.

Understanding by budget holders and managers of the need for paid support with emotional and psychological support needs.

Health, social service and education services need to work as planning partners and jointly deliver services that support people with their emotional and psychological health. To achieve this they need to identify ways of pooling resources to support these types of services. In doing so they need to be transparent and explicit about their agreed development so people using the services understand who, why and what is being delivered.

Increase/continue the financial support to voluntary sector programmes that are already providing emotional and psychological support.

Embed information about the range of different services available into NHS practitioners systems to make sure this is passed on to people with long term conditions and their families.

There needs to be mandatory professional development for health and social care professionals in communication. This includes:

- Interpersonal skills for consultants and senior physicians
- Active listening for life
- Openness about taboo subjects
- Skills for breaking bad news with empathy
- Person centred practice training
- Time to talk and listen
- Raise professionals’ awareness of what is possible
- Long term support for long term conditions
- Flexibility of communication styles
- Support to develop emotional intelligence
- Real time feedback on interactions and how to improve
- Involvement of people with long term conditions and their unpaid carers in delivering some of this development
- Involvement of the voluntary sector
- Centrally co-ordinated and delivered in every NHS area across Scotland
- Helps professionals see beyond conditions to the wider aspects of life
- Develops an understanding of the impact of living with life long issues
- Raises awareness and helps professionals make fewer assumptions
- Helps professionals ask “feeling” questions
- Increases professionals’ confidence in dealing with people’s emotional functioning
5 Conclusion

There is nothing in this report that has not been said before, often many times. However, everything in this report has come from the mix of people with long term conditions, their unpaid carers, their families and the professionals that support them. Collectively these people are telling us that today in Scotland, not enough is being done. They go beyond that and tell us what can be done about it.

These are powerful messages from people who know what it is like to live with or work with people with long term conditions. People are currently getting inadequate support with their emotional and psychological wellbeing.

These events have told us what it is like, good, bad and even ugly. The commitment from all of us working in Scottish Government, NHS, local authorities, voluntary sector and people with long term conditions themselves along with their unpaid carers and families will be the driver for change.

As people’s stories have been used to powerful effect in the past to make documents like this come alive there are some examples in the appendices. These explore the realities and aspirations of real people who have a vision for what future services could look like if the ideas in this report were to be made a reality across Scotland.

The simple question we asked at these events – what do people with long term conditions need to best support their emotional and psychological health – has been answered. Interestingly people tell us that taking opportunities to meet people’s emotional and psychological needs on their “patient journey” means that formal psychological interventions are less likely to be needed. The overpowering message coming back at us is about listening and compassion.

This sounds simple but as we can see from the issues raised in this report it is not. The positive thing is that we know there is commitment for the culture change needed. This commitment is seen in policy, in practice and in the lives of some people with long term conditions. The Scottish Government give their assurance that the messages in this report will not be lost but will be acted upon. This leadership is vital to progress as they work with partners across the NHS, social care and the voluntary sector.
The recommendations of this report must be a priority for all organisations involved in supporting people living with long term conditions. The report should help to deliver on the Quality Strategy’s commitment that the NHS will listen to people’s views and use them to further improve care. Its recommendations sit firmly within the Quality Strategy’s ambitions for:

- Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making.

- There will be no avoidable injury or harm to people from healthcare they receive.

- The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated.

At a time when public services are facing budget constraints it is even more important than ever that investment is made to prevent health issues from developing. In relation to long term conditions, mental health problems are the most common complication and, if implemented, the recommendations of this report will help to reduce longer-term costs to NHS Boards and Local Authorities.

Most importantly, the recommendations must be acted upon in order to reduce the harmful impact of mental health problems on the lives of many people living with long term conditions and their families.
People’s stories

These stories have been included as a way of highlighting some of the issues raised in the report. They are from real people living with long term conditions in Scotland today.

May’s story

These words express how May felt on diagnosis with type 2 diabetes. She had been attending her GP with symptoms of abdominal discomfort, itchy feet and hands, fatigue and weight loss. The latter she had put down to exercising her dog.

Diabetes, the first three weeks

"I received the phone call from the doctor just as I was about to bite my last bit of teacake! My blood test earlier that week suggested to her that I was ‘diabetic’. If I’d had cancer would she have phoned me at home? Don’t think so. But then how could she know the emotional downward spiral that the call initiated never mind the anticipation of the physical implications.

When I was at school (I left in 1973), the ‘diabetics’ were isolated in another room to have their lunch. There was a smell in there, stale school canteen smell, and no one ever opened a window. These girls were seen as different, ill, smelly and they were isolated and lonely, never part of the crowd. My GP could never know what her news had triggered in me. How could she? I was shocked, even traumatised, the old memories kicking in where they weren’t expected.

I am aware that I am at the very beginning of living with diabetes and have a long journey ahead. I was keen to get started on the big changes that I need to make, so had high hopes of my first nurse appointment at the Practice.

It began with her calling me the male equivalent of my quite unusual first name. My partner came with me and when we arrived despite her walking in with her walking stick, we had to ask for another chair. Otherwise she would have been left standing! I was upset with that. She was ignored the rest of the time which I thought was a bit unhelpful as she does much of the food preparation in our house. It made me wonder if that would that have happened if I had been a man. I don’t know.

I had lots of questions because for the past two weeks I had been reading quite in depth stuff about diabetes. I wanted to know all my blood results, but was only given the HBA1a, not the longer term levels (HBA1c).

When I asked for my cholesterol levels the nurse noticed that the Lab had not measured the HDL (good lipids). She dismissed that saying it didn’t matter because I was high risk for heart disease so I should be taking statins. I explained that if possible I would like to try managing my condition by diet and supplements such as omega 3. She reiterated that statins were the recommended treatment plan for ‘diabetics’.

I know all that, I have a back ground in public health and understand the science but emotional and psychologically it is important for me to try avoiding drugs unless they are a last resort. I explained that and asked if these blood results can be requested. She said no, it needs another sample being taken. That means another fasting blood test next week.

I wasn’t weighed, I didn’t have my blood pressure taken and she didn’t...
ask if I smoked. I thought these were pretty basic things to provide a baseline for future lifestyle risks and changes. She did however offer me a 5 year old Pharmaceutical published leaflet that I felt was a bit of an insult. Person-centred – don’t make me laugh. I am not blaming this nurse, she’s a nice woman, but the NHS has a million miles to go if they think that “being nice” is enough.

I have put aside those thoughts about diabetes being somehow smelly and isolating, thank goodness, but only because I have been able to speak to an empathic, person-centred counsellor. I am measuring carbs accurately and trying my best to get started on a sensible eating plan, even though the advice I’ve been given so far is just to ‘watch my sugars’. What the heck does THAT mean? Maybe I’m impatient? I go to my first ‘Diabetic Clinic’ 6 weeks after my phone diagnosis. Seems a long delay to start changing things.”

So how is May feeling with regards to her emotional and psychological wellbeing?

“Emotionally I am tired and weary. I am lucky to have a knowledgeable partner who is cherishing and supportive and can empathise with what I am going through. It’s not even the diet thing, it’s the thought of the much higher risk of heart disease and stroke that is very scary indeed. I don’t want to leave her or my children prematurely if it can be avoided.”

What support have you had?

“I am so lucky that I have a life partner who really supports me and who happens to live with a long term condition herself. I have other family members and friends who are health professionals and they have been so supportive too, sharing their knowledge and time.

Thank goodness, because the last three weeks have been a challenge in many ways, not least psychologically and emotionally.

I organised for myself a couple of sessions with a person centred counsellor and that has really helped. It does make me think though about what people feel like who don’t have access to friends and family to support them.”

What would have helped May with the emotional impact of her recent diagnosis?

“If the nurse had just said ‘Well May, the tests are show that you do have type 2 diabetes. What is the best thing I can do for you today?’ That would have made all the difference in the world. I would have just said ‘Tell me the blood results and what happens next please’. Instead we both came out of the consultation and I burst into tears..and lit up a fag!! (I promise they will go very soon!)”

Frank’s story

My experience

I went to my doctor last summer complaining of headaches and unusual sensations down the left side of my body. He seemed convinced I was suffering from migraine but sent me for some tests. I had a CT scan very quickly and a number of other tests all organised quite quickly and efficiently.

On all occasions I would go back to my GP for the results and to discuss what next. Although my GP was very good I always got the feeling that he had not prepared for our meeting and that he was reading letters and reports etc from his computer screen during the meeting
to remind him of why I was there. Although he had requested tests it seem I always had to tell him when they were taking place.

Eventually I had a meeting with a locum who was standing in for the neurologist at my local district general hospital. She took my history and again seemed convinced that I had some form of migraine.

Despite no positive diagnosis other than migraine it was suggested on a number of occasions that I should stop driving. This I resisted as the implications of being unable to drive would be immense both personally and professionally.

**Specialist services**

Eventually I got to see Dr Smith the consultant neurologist. He immediately dismissed the idea of migraine and suggested I have an MRI scan. This I duly did. I met with Dr Smith to review the scan and at this point it was suggested that I might have a form of epilepsy although it was not a definite diagnosis so I declined the offer of any medication, concerned about the impact it would have regarding driving. In December I had filled in a lengthy form for the DVLA and I was determined to keep driving until they told me otherwise. The scan was inconclusive so the doctor suggested I have another scan, which I did.

I think I was in denial, resisting the diagnosis of epilepsy and thinking that was the worst possible thing.

At the follow up appointment on reviewing the scan I was told there were some slight abnormalities which might be lesions which might require further investigation.

I was advised me he was going to discuss the scan with colleagues in Edinburgh and would like to see me again.

About a week later I received a phone call from my neurologists secretary who advised me that he had had a cancellation and could I come to see him the following day. This seemed strange at the time but all was soon to become clear. I took my wife Carol with me to this appointment. We were advised that brain lesions were a possible sign of low grade brain tumours and that there was nothing he could do for me at the local hospital and he would refer us to Dr Goode in Edinburgh.

I was advised at this point that the epileptic symptoms were being caused by these lesions. Stop driving.

**Triple whammy - no longer able to drive, diagnosed with epilepsy and brain tumours**

**What support did you get?**

We left this meeting both a little stunned and had to sit in the car for 10 minutes to make sense of it and get our heads round it.

Throughout the process the care I had been given as a patient has been good. No long waits, prompt appointments etc

However, I feel that very little consideration was given to me as a person and no thought was given to the impact of my diagnosis to me as a person or to us as a couple.

Before going into the meeting with my doctor I was a person with a job and a life with mild symptoms.

Afterwards I was a person with epilepsy, a brain tumour, who couldn’t drive who might not have a job, wondering how I was going to manage my life from now on.
How did you manage to deal with the changes in your life?

It has taken us four months to come to terms with this and I have to say we have done it on our own. Follow up appointments in Edinburgh have had to be chased and it just feels that nobody really cares about your mental well being.

Appointments in Edinburgh have been arranged at difficult times requiring overnight stays. It is as if no one thinks about the impact of their decisions on you as an individual.

This has tested us as a couple and as individuals. So four months to work out that its not as bad as it sounds, four months to work out that you can change your medication to something with less side effects, four months to work out that you can get your prescriptions free (nobody tells you this), four months to get all your consultants’ secretaries’ phone numbers so you can chase them for appointments. Four months to learn how to manage your GP to get him to do the best for you.

Four months to completely re organise your life.

I have had to negotiate a more flexible approach to work with my boss – working from home for example.

I have had to put in place a network of individuals to get me to and from work, to meetings as there is no public transport where I live.

I have had to change the way in which I work – to be truthful I am probably less effective now as I am unable to respond to clients in the same way.

What about the future?

We are having to moving house. There is no realistic prospect of getting my driving license back. If I am to have any independence as an individual we need to live in the town. There I can walk to work, access leisure and other facilities independently. It also relieves Carol from the responsibility of having to take me everywhere. However, this means leaving our friends and neighbours behind to start all over again somewhere new.

So going forward – I may have to live with this condition – benign brain tumours and associated symptoms for the rest of my life. This depresses me as clearly my life will never be the same again. I am an articulate, assertive person, how on earth would some one less equipped manage this situation?

At a follow up appointment with Dr Smith we raised the matter of support as this was a very big thing to deal with. He agreed that there should be support but said I should raise this with my GP.

My overall impression of this entire experience is that no health professional has the full picture of what is happening to me. I would expect my GP to fulfil this role. I do also expect each health professional to relate to me Frank the person with these conditions and experiences. Sadly this had not been my experience.

The only person who has the full picture is me. I have to tell my GP what is happening. This is a very big responsibility especially when you are feeling vulnerable as you just want some one to deal with it all. You don’t want to have to try and make it all happen yourself.

The health service is a process driven, bureaucratic nightmare and I think I have had a relatively positive experience. When my younger daughter was diagnosed with epilepsy whilst living in London her experience was much worse!
Laura’s story

Laura is 40 years old and was diagnosed with epilepsy when she was 25. “I did have blackouts as a child when I was 6 or 7 but I was never told that was epilepsy. I suppose it was looking back.” She goes on to describe how isolated she feels. Her epilepsy is not well controlled and when she has seizures they cause disturbances in her consciousness and affect the way she behaves. Socially she finds this very distressing and the pattern of high seizure frequency over a two week period and then relative seizure freedom is challenging for her and others.

How do you deal with having seizures?

It does get me down and when it’s bad I sit in the house crying asking why have I got it? I see my pals going out and doing things but when I’m feeling bad I’m too scared in case I take a turn. Sometimes when I was right bad I felt like running at a wall and banging my head. I just end up bottling it up saying to myself, here we go again.

I try and hide that I’ve got epilepsy but since I take a lot of turns its hard to do that. People don’t understand – they just think I’m stupid or something. If I hadn’t my husband Tom and my daughter Lynn I wouldn’t have anyone. They are really there for me but the rest of my family and my neighbours don’t understand.

What support do you get?

When I’m run down with it I go to the practice nurse. She’s easier to speak to than the doctors. But she’s busy and I don’t like to bother her as she’s got better things to do than to listen to me. They gave me anti depressants but I wanted to fight through it as I’m on enough medication with the epilepsy drugs.

I’ve seen a neurologist a few times but he just says keep a diary but often I don’t even know I’ve had a turn so I don’t see how that can help. The last time I saw him I came out crying as he asked me questions and then didn’t listen to me – he was answering the questions himself. He wasn’t interested in what I was saying or what I wanted to know. He wrote to my GP and they keep giving me more and more medicine but it doesn’t seem to help.

I did get counselling a while back but it was only for 3 sessions for 25 minutes a time. At the third time I felt I was starting to open up more and was frustrated when I was told that it had to finish there. There was no follow up. That’s not what I need, I need support for longer. I think it would help.

What else would help?

Well I wouldn’t know what to do without Tom and Lynn – I wouldn’t be coping as there is nobody else, they are the only ones I can speak to. But it would be good for them to have someone to talk to for support. Also my other daughter can’t handle it so if there was someone who could explain it to her that would really help. And if I had a group I could go to where other people also had things wrong with them then that would help. It doesn’t need to be the same as me but they would know how it feels having something like me. It would mean mixing with folk rather than sitting frightened on my own.

On good days I do get out and I text
Lynn every 15 minutes so she doesn’t worry. But then I worry that she’s just young and needs her own life.

I don’t like telling other people but when I do it helps. I joined the bowling and explained to the other ladies about my turns and how I can’t do anything if they are happening or that I might act funny. They just said right if it’s your turn for the bowls and you’re not ok then we’ll take our turn and you can go when you come out of it. It feels safe with them as they know me. Oh and I won the ladies cup this year!

What changes need to happen to support May, Frank and Laura’s emotional and psychological wellbeing?

In particular, what changes do NHS and other professionals need to make? How best can we support and empower people with long term conditions to engage with their conditions and to embrace self management? Outlined in this report are a few simple suggestions.
### This table highlights the key points made in chapter 4 Actions, Development and Change and outlines possible ways to achieve them.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Lead Responsibility</th>
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<th>Key Actions</th>
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| Raise the profile of the need for emotional and psychological support to be integrated into all services for people with long term conditions. | • LTCAS  
• Scottish Government Long Term Conditions Unit | • Health Directorates Scottish Government  
• NHS boards  
• Managed Clinical Networks  
• Local authorities  
• Third sector | • Promote this report, findings of Living Better project and the findings of evaluation of the self management fund to key decision makers across Scottish Government, NHS, COSLA, local authorities, third sector and political parties  
• Reflect emotional health within ‘My Conditions, My Terms, My Life’ self management awareness campaign | Integrated, consistent approach to emotional and psychological support for people with long term conditions. |
| All health and social care professionals need to understand their important role and contribute to the emotional and psychological health and wellbeing of people with long term conditions. | • NES  
• LTCAS | • NHS boards  
• Local authorities  
• Third sector  
• Professional bodies  
• Quality Alliance Board ‘person centredness’ delivery group | • Integrate into existing programmes of professional development and undergraduate/vocational training  
• Use opportunities through implementation of Quality Strategy, particularly the ‘person centredness’ strand | More effective, holistic support for people with long term conditions.  
Practitioners feel empowered and confident in addressing people’s emotional needs and signposting appropriately. |
| Emotional and psychological support to include a wide range of interventions from simple to complex. | • CHPs  
• Managed Clinical Networks  
• NHS Boards  
• Local authorities  
• Third sector  
• Chief Health Professions Officers | • LTCAS  
• Scottish Government Long Term Conditions Unit | • Support work by third sector organisations including self management projects and peer support  
• Build on work / pathways / infrastructure developed through Living Better project  
• Address shortages of counselling and psychological services across Scotland | People provided with support from an early stage (including post diagnosis of a long term condition).  
Prevention of more serious mental health problems.  
Increased access to psychological services for those who need it. |
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<td>Raise the profile of the need for emotional and psychological support to be integrated into all services for people with long term conditions.</td>
<td>• LTCAS • Scottish Government Long Term Conditions Unit • Quality Alliance Board ‘person centredness’ delivery group</td>
<td>• Share, and build on, learning from the Self Management Fund for Scotland. • Improve connections across sectors and across geographical areas of Scotland so that a more comprehensive picture of self management provision emerges. • Work to sustain existing good practice and to build capacity for local development of self management support. • Highlight positive practice development such as Co-Creating Health, The Edinburgh Crisis Centre and the WEL programme.</td>
<td>Better choice for people with long term conditions and their families. Avoids the one size fits all approach which we know does not work.</td>
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<td>Integrated, consistent approach to emotional and psychological support for people with long term conditions.</td>
<td>• NES • LTCAS • NHS boards • CHPs • Third sector • Local authorities</td>
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<td>• CHPs • Managed Clinical Networks • NHS boards • Local authorities • Third sector • Chief Health Professions Officers • LTCAS • Scottish Government Long Term Conditions Unit • Quality Alliance Board ‘person centredness’ delivery group</td>
<td>• Support work by third sector organisations including self management projects and peer support • Build on work / pathways / infrastructure developed through Living Better project • Address shortages of counselling and psychological services across Scotland</td>
<td>People with long term conditions and their unpaid carers are increasingly involved in ways which help to deliver real improvements to policy and services. Contributes to Quality Strategy ambitions.</td>
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<td>People provided with support from an early stage (including post diagnosis of a long term condition). Prevention of more serious mental health problems. Increased access to psychological services for those who need it.</td>
<td>• LTCAS • Scottish Government Long Term Conditions Unit • Quality Alliance Board ‘person centredness’ delivery group</td>
<td>• Take forward work of Better Together Long Term Conditions Module as part of implementation of Quality Strategy • Build on, and continue to support, existing good practice such as Voices Scotland • Support work of voluntary sector organisations who are building the capacity of their members to influence policy and practice such as The Thistle Foundation and the British Lung Foundation</td>
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<td>Develop the jigsaw of self management opportunities across Scotland.</td>
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<td>Consider people with long term conditions as policy makers and create meaningful ways for inclusion. Widening out programmes to empower people with long term conditions.</td>
<td>• Quality Alliance Board • LTCAS • Third sector • Scottish Government Long Term Conditions Unit • NHS Boards • Managed Clinical Networks • Local authorities • CHPs</td>
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<td>Training on managing paid carers through self directed support budgets.</td>
<td>• Centres for Inclusive Living • Other disability led organisations</td>
<td>• Scottish Government • Local authorities • NHS Boards</td>
<td>• Build on and develop existing programmes as part of implementation of 'Self-directed Support: National Strategy for Scotland' (published October 2010).</td>
<td>Disabled people and people with long term conditions feel more empowered as employers and at directing their own support.</td>
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<tr>
<td>Better access to services that have an impact on emotional and psychological wellbeing such as transport, chaplaincy services and advocacy services.</td>
<td>• Local authorities • NHS boards • Community Planning Partnerships</td>
<td>• Third sector • Religious and spiritual organisations</td>
<td>• Build on and develop existing programmes.</td>
<td>People with long term conditions less isolated and more able to access services, communities and society.</td>
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<td>Training for information providers in how to produce information that is easy to get and easy to understand. This includes issues such as how to set up accessible websites, how to write and print accessible leaflets, how to effectively share information and how to use volunteers in this area.</td>
<td>• Scottish Accessible Information Forum • LTCAS • NHS Inform • Health Rights Information Scotland</td>
<td>• Third sector • NHS boards • Local Authorities • IT specialists • Volunteer centres</td>
<td>• Immediate action to ensure compliance with the Equality Act 2010 and people’s rights to access information. • Work to spread good practice and increase skills across sectors. • NHS Inform to work with LTCAS to ensure voluntary sector information is available through online, phone and face-to-face information services.</td>
<td>People with long term conditions and their unpaid carers feel more informed and understand the information they receive. People with long term conditions involved in the design, delivery and evaluation of information.</td>
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<td>People with long term conditions involved in the design, delivery and evaluation of information.</td>
<td>• LTCAS • Scottish Government Long Term Conditions Unit • Third sector • CHPs • NHS boards • Local authorities • ALISS • NHS Inform</td>
<td>• Build into LTCAS’ 2011-14 work plan. • Further develop support directory on <a href="http://www.myconditionmylife.org">www.myconditionmylife.org</a> • Development of networks across sectors and individuals, including use of social media.</td>
<td>People with long term conditions and their unpaid carers and those who support them know where to go for information and how to access support for self management.</td>
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<tr>
<td>Healthy living spaces were suggested as a way of supporting people. People suggested a network of these across Scotland in variety of formats to suit communities. For example mobile units, community centres, online communities. These could be built into existing services but need to be explicit about recognising the need for and actively contributing to emotional and psychological wellbeing for people with long term conditions.</td>
<td>• NHS boards • Local authorities • CHPs • Third sector</td>
<td>• Reframing of existing services to have explicit role on offering a wide range of support services that in turn offer emotional and psychological support to people with long term conditions.</td>
<td>People with long term conditions and their unpaid carers will feel better supported.</td>
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### Appendix 2

This table highlights the key points made in chapter 4 Actions, Development and Change and outlines possible ways to achieve them.

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<tr>
<td>People with long term conditions are able to get help with specific symptoms and a positive boost to their emotional and psychological wellbeing.</td>
<td>Promote models of good practice, including through learning from Self Management Fund projects.</td>
<td>Centre for Integrative Care, Scottish Government Long Term Conditions Unit, Third sector.</td>
<td>LTCAS Scottish Government Long Term Conditions Unit.</td>
</tr>
<tr>
<td>People with long term conditions less likely to fall between gaps in services.</td>
<td>Review of existing provision and identification of where changes could be implemented.</td>
<td>NHS boards, Local authorities, Third sector.</td>
<td>NHS boards Scottish Government, LTCAS.</td>
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<td>People with long term conditions and disabled people confident that their emotional and psychological needs are supported.</td>
<td>Formalise funding arrangements and service delivery mechanisms.</td>
<td>NHS boards, Local authorities, Third sector.</td>
<td>NHS boards Scottish Government, LTCAS, Scottish Government.</td>
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<tr>
<td>Better overall provision of emotional and psychological services for people with long term conditions.</td>
<td>Managers and budget holders review existing service provision and build in models of good practice.</td>
<td>NHS boards, Local authorities, Third sector.</td>
<td>NHS boards Scottish Government, LTCAS, Scottish Government.</td>
</tr>
<tr>
<td>Services are created which more effectively respond to people's needs, offer person centred support and deliver value for money for public funds.</td>
<td>Increase/continue the financial support to voluntary sector programmes that are already providing emotional and psychological support.</td>
<td>NHS Boards, Local authorities, CHPs, LTCAS Scottish Government Long Term Conditions Unit, Third sector.</td>
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<tr>
<td>People with long term conditions and their families are better informed about the range of support they can access.</td>
<td>Embed information about the range of different services available into NHS practitioners systems to make sure this is passed on to people with long term conditions and their families.</td>
<td>Scottish Government Directorate for Healthcare Policy and Strategy, NHS Inform, NHS Boards, Primary Care Services, Third sector.</td>
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**Key:**
- Holistic emotional support
- Involving people
### Holistic emotional support

Involving people

This table highlights the key points made in chapter 4 Actions, Development and Change and outlines possible ways to achieve them.

<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Lead Responsibility Partnerships</th>
<th>Key Actions</th>
<th>Outcomes</th>
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</table>
| Use of and support for complementary therapies as a positive contribution to emotional and psychological wellbeing for people with long term conditions. | - LTCAS  
- Scottish Government Long Term Conditions Unit  
- Centre for Integrative Care  
- Third sector | • Promote models of good practice, including through learning from Self Management Fund projects. | People with long term conditions are able to get help with specific symptoms and a positive boost to their emotional and psychological wellbeing. |
| Ring fenced funding for multi agency partnership in the delivery of emotional and psychological support services. | - Long term conditions unit in partnership with other Scottish Government directorates  
- LTCAS  
- NHS boards  
- Local authorities  
- Third sector | • Review of existing provision and identification of where changes could be implemented. | People with long term conditions less likely to fall between gaps in services. |
| Move beyond short term funding for all agencies. | - Scottish Government  
- NHS boards  
- Local authorities  
- Third sector | • Formalise funding arrangements and service delivery mechanisms | Better overall provision of emotional and psychological services for people with long term conditions. |
| Understanding by budget holders and managers of the need for paid support with emotional and psychological support needs. | - NHS boards  
- Managed Clinical Networks  
- Local authorities  
- Third sector | • Managers and budget holders review existing service provision and build in models of good practice | People with long term conditions and disabled people confident that their emotional and psychological needs are supported. |
| Health, social service and education services need to work as planning partners and identify ways of pooling resources to support services that enhance emotional and psychological wellbeing. They also need to be explicit about this. | - Relevant Scottish Government departments  
- CoSLA  
- Community Planning Partnerships | • Develop leadership initiatives and incentives to support this process.  
• Showcase good practice examples.  
• Develop as part of wider moves to increase integration of health and social care, including through work of the new £70m Change Fund | Services are created which more effectively respond to people’s needs, offer person centred support and deliver value for money for public funds. |
| Increase/continue the financial support to voluntary sector programmes that are already providing emotional and psychological support. | - NHS Boards  
- Local authorities  
- CHPs  
- LTCAS  
- Scottish Government Long Term Conditions Unit | • Encourage NHS Boards and local authorities to recognise, and invest in, the value of these programmes.  
• Develop work through continuation of the Self Management Fund for Scotland. | People with long term conditions benefit from continuity of emotional and psychological support. |
| Embed information about the range of different services available into NHS practitioners systems to make sure this is passed on to people with long term conditions and their families. | - Scottish Government Directorate for Healthcare Policy and Strategy  
- NHS Inform | • Build on existing programmes such as clinical portal to enable this. | A strong third sector is able to provide people with a level of person centred, in-depth support that statutory agencies often cannot offer. |

Health, social service and education services need to work as planning partners and identify ways of pooling resources to support services that enhance emotional and psychological wellbeing. They also need to be explicit about this.
This report sits alongside a range of other work being done by LTCAS, the Scottish Government and others. We have highlighted a few activities that are of particular relevance.

**Self Management Fund for Scotland**

The Self Management Fund has been available to voluntary organisations and community groups throughout Scotland since March 2009. The aim has been to improve work to expand the capacity of people living with long term conditions to learn more about the management of their conditions and to be become active partners in their own care.

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

The Fund was a key recommendation of ‘Gaun Yersel’ The Self Management Strategy for Long Term Conditions in Scotland. The Strategy recognises the significant psychological impact that living with a long term condition can have and calls for increased access to emotional and psychological support.

26% of the projects specifically deal with mental health conditions and many provide emotional and psychological support for people with physical long term conditions.

For full details, including case studies, please see the Self Management Fund Interim Evaluation Report and series of ‘Special Reports’ at www.ltcas.org.uk

**Quality Strategy**

The Healthcare Quality Strategy for NHSScotland was published by the Scottish Government in May 2010. The Quality Strategy aims to deliver the highest quality of healthcare services to people in Scotland through pursuing three ambitions:

- Person-centred – Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making.
- Safe – There will be no avoidable injury or harm to people from healthcare they receive, and an appropriate, clean and safe environment will be provided for the delivery of healthcare services at all times.
- Effective – The most appropriate treatments, interventions, support and services will be provided at the right time to everyone who will benefit, and wasteful or harmful variation will be eradicated.

The Strategy is based on what people using and delivering services have said are their priorities:

- Caring and compassionate staff and services
- Clear communication and explanation about conditions and treatment
- Effective collaboration between clinicians, patients and others
- A clean and safe care environment
- Continuity of care
- Clinical excellence
- Implementation of the Quality Strategy will be overseen by the Quality Alliance Board on which LTCAS is represented.
**Better Together – Long Term Conditions Module**

Better Together – Scotland’s Patient Experience Programme – aims to improve the care experience of people using NHS services. The commitment to improve the care experience has recently been reinforced through the publication of the Healthcare Quality Strategy for NHS Scotland.

The Programme began by focussing on improving experiences in two specific service areas – adult hospital inpatient and GP services. A third work stream now seeks to improve the experiences of people living with long term conditions and is being taken forward in partnership with the Long Term Conditions Collaborative and LTCAS.

While the programme is focusing on the aspects of experience that the NHS can influence and is accountable for, it is recognised that the experience of living with long term conditions is of course much broader than this.

For more information please visit www.bettertogetherscotland.com

**ALISS**

ALISS is a community-driven initiative which makes it easy to find and point to local online information about keeping well. The focus is about helping people to live better with long term health conditions by providing tools and frameworks and working with communities. The overall aim is that we build a support infrastructure together.

ALISS is an opportunity to encourage a culture of mutuality and contribution by harnessing our most valuable asset: the ideas and diversity of our population. People and organisations offering support to self manage have many ways to publicise their information (web sites, posters, leaflets). At the same time people seeking that information can miss it, because there are so many places to look. ALISS aims to help more people find the information they need.

For more information please visit www.aliss.scot.nhs.uk

**Seen and not Heard? Exploring issues facing children and young people living with long term conditions**

LTCAS has worked with its members, children’s sector organisations and the Scottish Government to ensure the needs of children and young people with long term conditions are addressed.

Mental health and wellbeing is one of three key themes explored in the ‘Seen and not Heard’ report available at www.ltcas.org.uk

**Multiple Conditions**

Many people live with more than one condition and this is becoming increasingly common. People’s risk of mental health problems increases along with the number of conditions they live with. This is further exacerbated by deprivation. LTCAS is working with its members, the NHS and Scottish Government to identify ways to improve the experience of people living with multiple conditions. The report of LTCAS’ recent multiple conditions conference, held in partnership with NHS Quality Improvement Scotland, will be available shortly.
Background

Living Better aims to improve the mental health and wellbeing of people with diabetes, coronary heart disease (CHD) and Chronic obstructive pulmonary disease (COPD). The project is funded by the Scottish Government until March 2011.

The Living Better project is a partnership initiative between the Royal College of General Practitioners (Scotland), the University of Stirling, the Scottish Development Centre for Mental Health, Chest Heart and Stroke (Scotland), Depression Alliance Scotland, the British Heart Foundation (Scotland) and Diabetes UK (Scotland).

The project is working with five Community Health Partnerships (CHPs) and ten GP practices across Scotland to address mental health and wellbeing in people with long term conditions. In four CHP sites the project is focusing on diabetes and/or CHD and in one CHP site Chronic Obstructive Pulmonary Disease (COPD). The pilot site CHPs involved in the project are: Angus, South East Glasgow, East Dunbartonshire, North Lanarkshire and The Western Isles.

Key Findings

Living with COPD or Diabetes and/or CHD causes both acute and chronic stress and impacts people in the following ways:

- Shock of being diagnosed
- Feeling that family and friends do not understand the strains of living with a long term condition
- Frustration over lifestyle change
- Loss of confidence
- Strains on family and wider personal relationships
- Frustration, anger, guilt, fear, embarrassment

Key issues raised by health professionals include:

- The Quality Outcomes Framework (QOF) mental health questions feel like a ‘tick box’ exercise
- There is a feeling of ‘what do we do next’? after identifying a mental health issue
- Practice and Specialist Nurses would like more time with people to tease out mental health issues
- The stigma of mental illness remains a problem in addressing mental health and wellbeing in people with long term conditions
- Need for greater knowledge of, and how to access, existing support services
- Greater integration of appropriate community health, voluntary and social care services, especially between CHPs, GP practices and social services
- Practice and Specialist Nurses expressed a desire for more mental health and wellbeing awareness training
- Greater need to raise awareness in primary care staff of the importance of mental health and wellbeing in the care of people with long term conditions
- Need more information about long term conditions relevant NHS and non-NHS services at CHP level
- Stronger partnership working with local authorities to utilise and also develop social support services for people with long term conditions

For more information see www.livingbetter-scotland.org.uk
What kind of support do people want?

- Broad social support services to share experiences and exchange information with peers
- Easier and more rapid access to health worker or peer to confide in on a one-to-one basis
- General talking support, either face to face or on the telephone
- Access to condition specific exercise classes to help their physical condition
- Financial/benefits advice to address financial consequences of living with long term conditions
- Greater support with, and access to, public transport
- More information about locally appropriate support services provided by health, social care and voluntary sector services
- More ‘talking time’ with nursing or other health/social care staff
- Counselling
- Greater advice and information about medication

Key recommendations for CHPs

- Greater mental health and mental wellbeing awareness training should be provided to nurses, AHP and health support staff working with people with COPD, diabetes and/or CHD
- Each Living Better CHP reference group should discuss how to develop partnership working with relevant local authority and voluntary sector services to address access/transport issues, financial/benefits advice, exercise/leisure facility issues and other social support needs
- Greater recognition of the benefits in developing appropriate social support services should be discussed by each Living Better CHP reference group
- Identify the key players in each of the five Living Better CHPs who will facilitate the coming together of appropriate staff to develop the collaborative working required to meet the mental health needs of people living with CHP, diabetes and/or COPD
- Social support services are non-complex and low cost interventions and have the potential to bring significant benefits to people
- Nurses, AHP and health support workers, in collaboration with social and voluntary sector colleagues, have a vital role to play in addressing the mental health and wellbeing needs of people living with long term conditions

References

A comprehensive literature review was not in the remit of this report. The research which supports this work is vast and the following represents only a few key texts.

i ‘Characteristics of adults in Scotland with long term health conditions’, University of Edinburgh, Scottish Executive Social Research 2007

ii ‘Epilepsy (Fast Facts)’, M Brodie, S Schachter and P Kwan 2005

iii ‘Identification and treatment of depression in people with diabetes’, Marie Clark in Diabetes and Primary Care Vol 5 2003


v ‘Identification and treatment of depression in people with diabetes’, Marie Clark in Diabetes and Primary Care Vol 5 2003

vi Overview of Mental Health Services, Audit Scotland, 2009

vii Integrative care has been described as care that reduces fragmentation and increases coherence or wholeness in the person and/or their care experience. Reilly D. Enhancing human healing. BMJ 2001;322(7279):120-1.