Long Term Conditions Collaborative
Improving Self Management Support
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Ten approaches to help you to deliver better outcomes and an enhanced experience of care for people living with long term conditions

A collaborative resource to support partnerships
Sharing Solutions for a Shared Challenge

The increasing number of people living with long term conditions presents a major challenge for health, social care, community and voluntary sector partners. Better awareness of their long term conditions helps people understand their symptoms and experiences and improves their long term health and wellbeing. The role of the care professional is to encourage self confidence and the capacity for self management and to support people to have more control of their conditions and their lives.

The national Long Term Conditions Collaborative (LTCC) improvement programme, the Scottish Government’s Long Term Conditions Unit (LTCU), the voluntary sector represented by the Long Term Conditions Alliance Scotland (LTCAS) and others are working together to promote self management approaches across Scotland.

A Self Management Fund, launched in March 2009, will be a catalyst for testing, implementing and learning about self management. It will do so through a combination of grant aid and support for networking and learning. The fund is specifically targeted at voluntary and community health organisations and groups, for projects that support sustainable and innovative approaches to self management. These projects will be complemented by other work that will help us to change the culture within NHSScotland to one which is mutual and informed by service users. More information on LTCAS and on the Self Management Fund can be found at www.ltcas.org.uk, or by calling their offices on 0141 404 0231.

The Long Term Conditions Collaborative’s focus is to support shared learning and to provide tools, techniques and a range of practical supports to enable partnerships to deliver timely, safe, effective, efficient and equitable services that achieve better outcomes and an enhanced experience of care. Approaches include Plan Do Study Act (PDSA) cycles, lean-thinking, targeting steps and activities that don’t add value and addressing capacity and flow to improve pathways, reduce delays and to increase reliability and productivity across the whole system.

High Impact Changes and Improvement Actions

The Long Term Conditions Collaborative developed a set of clear and tangible improvements that we expect to make a big impact on the way people with long term conditions manage their own care and experience care provided by others.

These High Impact Changes are generic and apply across the long term conditions pathway from diagnosis through self management, living for today, change in condition and transitions of care to palliative and end of life care.

Each High Impact Change has a bundle of Improvement Actions, all of which have to be implemented to successfully deliver the change. These improvement actions are based on changes that have been tried and tested in the UK and beyond. They reflect what people living with a long term condition have said should be done to improve their experience of living with a long term condition.
Supporting Delivery

We have identified examples of improvement actions that will help you to support self management. The list isn’t exhaustive, or intended to be a comprehensive evidence base. It reflects the experience in Scotland and builds on examples outlined in Scotland’s approach to self management set out in the strategy document Gaun Yersel\(^1\), developed by people with long term conditions in partnership with the Long Term Conditions Alliance Scotland (LTCAS).

We hope that the background information, ideas, examples and contacts in this resource provide you with practical ways to improve care for people living with long term conditions.

Defining self management support and the Principles of Self Management

LTCAS defines self management as ‘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’.

Support for self management is what services provide to encourage people to take decisions and make choices that improve their health, wellbeing and health-related behaviours. It can be viewed in two ways: as a portfolio of techniques and tools, and as a fundamental transformation of the relationship between the person living with long term conditions and their caregiver into a collaborative partnership.

Support for self management requires a focus on improving health and wellbeing and reducing health inequalities and involves:

- Providing individualised assessments of self management support needs
- Tailoring self management support to an individual’s preferences, culture, level of comprehension, skill, educational need and learning style
- Systematic assessment of individual self management goals
- Supporting self management goals follow up (including the way in which confidence in achieving goals is monitored and recorded)
- Developing ways to ensure that people are actively involved in planning their self management support

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• A shared and explicit multidisciplinary team understanding of what self management support means and an ability to explain this clearly
• Sharing information on self management needs, goals and plans
• Considering ways in which people living with long term conditions can become involved in the provision of self management support
• Developing systems of referral and monitoring for self management support provided by non NHS services
• Training for generalist and specialist staff across professions and agencies to listen, inform, empower and enable people to self manage
• Attention to the role of unpaid carers
• Easy to access information, educational materials and multi-media interactive programmes

Principles of Self Management

The principles set out in Gaun Yersel propose a more holistic approach, less emphasis on a model of medical interventions and specific outcomes and a shift towards care environments that are both clinical and therapeutic. These principles are a valuable contribution to the discussion about taking forward a mutual NHS in Scotland which affirms people as partners rather than recipients of care. They will help us create a cultural change that balances our emphasis on evidence-based technical interventions with the humanisation of care.
This resource will help you and your team to implement these principles as you make local improvements in care for people with long term conditions by:

- Raising awareness of the principles and make them available to staff
- Referring to them in appraisals, job descriptions and project proposals
- Reflecting on how your Long Term Conditions Action Plan will help make them a reality
- Using the principles as a basis for tests of changes that will enable people to manage their condition
- Taking steps now to systematically test and spread the ten approaches outlined in this document
Improvement Actions

Ten things you can do now that make a difference
Where it’s happening … and who can help

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1. **EMPOWER PEOPLE TO HAVE MORE CONTROL AND CHOICE**

**Background**

Eighty-five per cent of clinicians believe that they share decisions about treatment with patients but only fifty per cent of patients believe this to be the case (Hibbard et al, 2008).

Why not send people their test results in advance of an appointment so they can prepare to discuss them, ask questions and raise important issues?

Cancer services developed a supported self management pathway with people who live with cancer, their relatives and healthcare professionals in cancer services. It is really a generic model. It represents key stages along a person’s journey with clear signposting at points of referral, diagnosis, tests, planning and treatment, follow up and ongoing supportive care and management. ‘Thinking about Yourself’ bubbles highlight relevant questions, information and opportunities for thinking about an individual’s specific needs. The model aims to empower the person to be a more active participant in their own care. Promoting positive health and wellbeing and maintaining normal everyday life and activities as much as possible are overarching themes throughout the pathway.

“Self-care will require a change of culture; partnership with patients, carers, families and NHS staff; training for staff and patients … to be an ‘active participant’, not a ‘passive pyjama’ patient.”

Better Cancer Care Consultation Respondent
Sharing resources and experiences

- Diabetes services in Bolton, Greater Manchester use a series of cards which convey feelings, concerns and priorities and help ensure consultations and conversations are focused on the areas that are most important to the person living with a long term condition. http://www.communityhealthcarebolton.co.uk/bond/web_index.aspx

- In Australia, the Flinders Model developed a generic set of tools and processes. These are designed to allow clinicians and people with long term conditions to collaboratively assess self-management behaviours, identify problems, set goals and develop individualised care plans. http://som.flinders.edu.au/FUSA/CCTU/self_management.htm#Flinders_Model

- The Health Foundation site has useful resources on self management such as Coulter A and Ellins J (2006) *Patient focused interventions – A Review of the Evidence*. http://www.health.org.uk

- Go to http://www.selfcareconnect.co.uk/ for information on Stepping Stones to Quality (Ss2Q) a quality framework and self assessment tool for organisations delivering lay led self management courses.

- NHS Education for Scotland has developed a Self Management and Rehabilitation Managed Knowledge Network for staff, individuals using health services, carers and the public. http://www.enablinghealth.scot.nhs.uk

- Two support groups in Angus represent a partnership between those living with COPD, the voluntary sector, local community and the NHS. Their initial purpose was to enable people who had completed pulmonary rehabilitation to continue to meet for peer support and unsupervised exercise. The groups recently affiliated to Chest, Heart and Stroke Scotland http://www.chss.org.uk and employ a yoga teacher. A people’s story based DVD is being produced for staff training and to inspire others. Feedback from health staff involved is “be prepared to roll up your sleeves and work with the group for as long as it takes for them to be comfortable to go it alone. It’s hard work but definitely worthwhile”. Contact: rhona.guild@nhs.net

- More information on voluntary organisation support for empowerment can be found at http://www.ltcas.org.uk, or by calling their offices on 0141 404 0231.
2. PROMOTE BETTER MENTAL HEALTH AND WELLBEING

Background

Positive mental health is a crucial component of health and wellbeing, associated with the positive ability to enjoy life and cope with difficulties. It also enables us to grow, learn and experience life as enjoyable and fulfilling.

Depression is the most common mental health problem in Scotland. In later life physical ill health and disability are the most consistent factors contributing to depression. For example, one in three people with heart failure and one in five people with coronary heart disease (CHD) experience depression. Depression is also found in 30% of people with diabetes.

The diagnosis of a long term condition can challenge a person’s view of life as orderly and having continuity. Such challenges may have significant psychological consequences. Some people feel unsupported emotionally and psychologically and people with more negative views of their condition are more likely to be depressed. Those who view their conditions as more serious, chronic, and uncontrollable tend to be more passive, report more disability, have poorer social functioning and more mental health problems.

Perceptions of control over symptoms and/or the course of disease often relate to mood and are associated with the process of recovery from disability. The presence of psychological symptoms will often make it more difficult to cope with physical symptoms. Some people face significant challenges in regulating and expressing the emotions and feelings associated with life with a long term condition. Enabling people to express their feelings will often have positive benefits on how they cope with physical symptoms and can have positive benefits on mental health (e.g. less unwanted intrusive thoughts) and physical health (e.g. influence health status and quality of life). Many psychological disorders are long term conditions too.

It is important to ensure that emotional and psychological needs are considered on an ongoing basis and that links are made between staff and services with interest, expertise and involvement in meeting psychological, mental health and wellbeing needs. Clinical health psychologists, liaison psychiatrists, counsellors and psychotherapists can provide advice on how non specialist staff can screen for the presence of more serious psychological responses. They can also advise on training and supporting health and social care staff to provide psychological care focused on common emotional reactions to living with a long term condition.
Sharing resources and experiences

- Health Psychologists in Training – is a NHS Education for Scotland (NES) project to train health psychologists build health psychology capability through training other NHS staff, and establish an evidence base for the contribution of health psychology to meeting health improvement targets.
  Contact: Simon Williams, Educational Projects Manager simon.williams@nes.scot.nhs.uk
  Tel: 0131 313 8079

- Living Better: Improving Mental Health & Wellbeing of People with Long Term Conditions is a three year programme to improve detection and diagnosis of mental health problems in primary care among people with long term conditions. It currently operates within six CHP areas and focuses on improving interventions and treatment for people with CHD and Diabetes. Partners are Scottish Development Centre for Mental Health (SDCMH), Royal College of General Practitioners and University of Stirling.
  Contact: Linda McGlynn, Project Officer, SDCMH linda@sdcmh.org.uk
  Tel: 0131 555 5959

- NHS Education for Scotland (NES) has funded a mindfulness-based cognitive therapy post to build capacity and infrastructure to support future delivery of mindfulness based cognitive therapy.
  Contact: geraldine.bienkowski@nhs.net

- The Forth Valley Dementia Project provides education and information, enhanced skills and capabilities and shares good practice on improving detection rates of depression and anxiety. It aims to improve joint working, and optimise the overall experience and outcomes of care for people with dementia. http://www.dementia.stir.ac.uk
  Contact: Tel: 01786 467740

- Nine Steps to Improving Scotland’s Mental Health in Primary Care: Practical Examples is a useful practice supplement. This was developed to accompany a guide to work led by Scottish Development Centre for Mental Health and the University of Edinburgh Primary Care Mental Health R&D Programme.
  Contact: sdc@sdcmh.org.uk Tel: 0131 555 5959

- Helping people to find their way to emotional support based within their own communities and the context of their daily lives is important. Voluntary organisations offer a wide range of provision including peer support groups, befriending, counselling and advice lines, complementary therapies and support with lifestyle, such as cooking or exercise.
  http://www.ltcas.org.uk Tel: 0141 404 0231
3. ENABLE BETTER ACCESS TO INFORMATION, ADVICE AND SUPPORT

Background

Support for people to self manage may be available from local resources and services, community and voluntary groups, schools and national organisations. However, people may need help to access this support. Self management support should be tailored to the needs of local communities, particularly the needs of individuals and communities who traditionally find it harder to engage with services.

Quality of life can be improved and mutuality developed at both individual and community levels. At an individual level, living with a long term condition can be particularly challenging for children. Young people have to cope with the physical and emotional changes of adolescence as well as issues of managing their own condition. This can include dealing with medicines, interruption to classes to attend appointments and coping with challenging symptoms and social barriers. Action for Sick Children (Scotland) (http://www.ascscotland.org.uk) plays an important role in supporting children and their families and carers. It informs, promotes and campaigns on behalf of the needs of all sick children in Scotland.

The Gorbals Healthy Living Initiative project focused on a small number of groups, agencies and services to understand the health information needs of hard-to-reach groups. It provides training and facilitates access to quality-assured health information designed for the public (http://www.healthinfoplus.scot.nhs.uk). It demonstrated that raising awareness and providing tailored training to well-designed sites of health information improves access to good quality health information for some hard-to-reach groups. For other groups, additional barriers need to be addressed (e.g. language or additional needs due to disability). Building on existing community resources and using key ‘knowledge workers’ or champions in the community maximised uptake and sustainability.

The internet is now a major source of health information. 80% of people who look at consumer created web content change their behaviour after doing so. 37% of people look at such a resource to discuss their condition, 39% to discuss their medication and 41% to see how others are coping. (http://www.kingsfund.org.uk)

The National Health Information Support Service aims to provide a single shared health information online resource (http://www.nhs24.com) to bring together quality assured national and local information from across the NHS and other sectors; a national health information helpline (0800 22 44 88 – 8am to 10pm, 7 days) and a coordinated, networked approach to the delivery of health information via direct access information points embedded in local communities.

Contact: Tel: 0141 435 3901
Sharing resources and experience

- The Access to Local Information to Support Self Management (ALISS) project is using new and emergent mobile technologies to empower people with long term conditions to support each other by easily accessing, co-creating and sharing information.
  Contact: christine.hoy@scotland.gsi.gov.uk

- Disability Information for Greater Glasgow (http://www.digg.org.uk) is a voluntary sector organisation funded by Greater Glasgow and Clyde NHS Board and the Big Lottery Fund. It provides an information and support facility for patients, users and carers – particularly those with neurological and neuromuscular conditions, including acquired brain injury.

- Stay Well Lanarkshire is a 3-year community project to empower young people aged 11 to 18 years to manage their lives so that their long term condition is not the main factor in their life. This generic programme aims to promote resilience, encourage coping resources, life skills and skills in communication, decision making and problem solving.
  Contact: Karen Martin asc@btconnect.com Tel: 07935 305930

- Borders Health in Hand (http://www.bordershealthinhand.scot.nhs.uk/your-health.aspx), in partnership with Council Library services, provides web-based health information, advice and support, a directory of local services and contacts and training on searching for good quality health information. Information is available in English and in six other languages to support local migrant workers.

- Aberdeenshire are testing Staywell for COPD. The computer based package helps to identify gaps in patient’s knowledge so customised information and resources can be prepared to help them manage their condition. (http://www.intouchwithhealth.co.uk/self_care_COPD.htm)

- Grampian Care Data (http://www.grampiancaredata.gov.uk) is a website service which hosts information on local health, social and community services, groups and organisations. It is a joint venture between Aberdeenshire and Aberdeen City Councils and NHS Grampian with support from Aberdeenshire Library and Information Service.

- NHS Greater Glasgow and Clyde and Arthritis Care (http://www.arthritiscare.org.uk/InyourArea/Scotland) run Challenging your Condition courses that target hard to reach individuals and communities. The course handbook and CD are also available in Punjabi and Arabic.
  Contact: 0141 954 7776
4. CARE PLAN TO SUPPORT PEOPLE TO SELF MANAGE

Background

The role of the care professional is to encourage self-confidence and capacity for self management and to support people to have more control of their conditions and their lives. This means sharing with the person with the long term condition and their family in developing a care plan, identifying a person’s goals and problem solving and signposting people to the type of support and information they need. It also means having a more systematic and outcome focused approach to planning, monitoring and reviewing the care plan.

Planning should be tailored to individuals – a ‘one size fits all’ approach will not work. People tell us that they want us to help them to consider personally meaningful and important actions that will help them live well with their condition. As part of this you should make sure that there are opportunities for follow-on conversations and support. Discussing potential risks and benefits associated with different treatment options will help people make choices and have confidence in agreed treatment and care plans. Try using prompt sheets that include questions and issues raised by others living with similar concerns, symptoms or conditions. Decision aids can help people facing important choices, particularly if used by staff who are confident in coaching and supportive approaches to managing consultations. Communication and consultation skills training can assist staff in adopting a more person centred partnership approach to planning and delivery of care. Small changes can make a big difference.

Planning should include consideration of whether local self management support groups and community resources might be helpful. Seek out leaflets, web material and computer packages which support people in making decisions about self management. The individual’s self management support needs should be included in their care plan and health records.

It is important to take an anticipatory approach that creates opportunities for conversations to explore wishes and choices for managing future flare-ups, deteriorations or crises. People are particularly vulnerable at times of transitions of care, e.g. child to adult services, adult to old age services, hospital to home, home to hospice. Careful planning and communication across staff and with patients and their families can, when needed, reduce stress, build confidence and help people retain control at times of transitions. The care plan should be accessible to all members of the care team to improve communication and promote continuity of care.

Guidance on the National Minimum Information Standards for Assessment, Care Planning and Review sets out standards for assessment, shared care and support plans and reviews for adults and carers in Scotland.

(http://www.scotland.gov.uk/Publications/2007/12/13130738/0)
Sharing resources and experience

- Dunfermline and West Fife and Ayrshire and Arran CHPs use individualised COPD action plans to support self-management. The Ayrshire plans have four steps: what to do when well and to keep well, what to do if more breathless, when to contact a health professional and when is it an emergency. Plans contain key contact numbers, an oxygen saturation recorded when stable, details of treatment and social circumstances and are shared with Out of Hours services to enhance clinical decision making.
  Contact: Janet.McCarlie2@aapct.scot.nhs.uk

- NHS Quality Improvement Scotland collaborated with Asthma UK Scotland to develop Personal Asthma Actions Plans (PAAPs) to improve the health and wellbeing of adults and children with asthma in Scotland. Asthma UK’s ‘Be in Control’ materials contain other useful information. http://www.asthma.org.uk/

- NHS Lothian’s Heart Manual helps people with coronary heart disease to self-manage their conditions. A specially trained health professional takes people through the relevant aspects of the manual so that they can co-develop a plan. This considers goal setting in terms of diet, exercise, cardiovascular risk factor and use of relaxation techniques to manage the stress often associated with health concerns. People continue to receive support from a specialist healthcare professional in the community.
  Contact: Louise.taylor@nhslothian.scot.nhs.uk, Astley Ainslie Hospital

- The Young Stroke Support Worker post in Lanarkshire focuses on self management and care planning for vocational rehabilitation following stroke at a young age.
  Contact: katrina.brennan@lanarkshire.scot.nhs.uk

- The Diabetes UK ‘Year of Care’ approach supports self-management by making routine consultations truly collaborative through care planning and systematically linking people’s needs and goals into population level commissioning. It is being piloted in three sites: NHS North of Tyne, Tower Hamlets PCT and Calderdale and Kirklees PCTs.
  Contact: yearofcare@diabetes.org.uk

- The Health Passport is a personalised health record ‘plus’ developed by people with arthritis/rheumatism for people with arthritis/rheumatism in consultation with clinicians. It has space to log medications, therapies and any other treatments against a monthly record of changes in health and ability to carry out daily activities. The passport has suggested pre-consultation prompts and questions and a consultation record sheet.
5. SUPPORT PEOPLE TO UNDERSTAND THEIR MEDICATION

Background

Up to 50% of medicines are not taken as prescribed and adverse reactions to medicines are implicated in 5-17% of hospital admissions. Problems with medicines can be prevented by monitoring the effects of long-term medication, by identifying people at risk, and by modifying their medication where necessary. This is an important issue because we know that people’s experiences are improved by effective use of medicines. We also know that there are complex reasons why many people with long term conditions do not use them effectively, such as dislike of taking medicines, as a personal life choice and dislike of adverse effects.

The average pharmacy provides services to around 450 people with asthma, 80 people with COPD, 80 with heart failure, 160 with diabetes and 35 with rheumatoid arthritis.

Pharmacists can help people develop an action plan for self management by assessing their readiness to change their health behaviour, reviewing medication, providing education about conditions and medication, helping identify trigger factors and key issues and developing an action plan for self management. They can offer encouragement and support for the person to participate in decisions and monitor their own therapy.

Community pharmacists are well placed to encourage use of self management plans and provide reassurance, advice and early interventions at times of flare up. This is particularly important, as pharmacists have an opportunity to build close relationships with people who traditionally have less contact with health services. For instance, people who are housebound, who live in areas of deprivation or who find engagement difficult because of diversity in language or cultures.

The new Pharmacy Contract offers a range of opportunities to support self management. The Chronic Medication Service (CMS) when introduced will allow people with long-term conditions to register with the community pharmacy of their choice. A shared agreement between the individual, pharmacist and GP will improve understanding and support a person to better manage their condition and medicines and reduce visits to the GP practice.

The Public Health Service and Minor Ailments Service also provide a means of supporting self care and self management of long term conditions. This includes providing helpful advice about immunisations, diet, exercise, support for smoking cessation and adoption of health improving behaviours and lifestyles.
Sharing resources and experience

• In Forth Valley an enhanced COPD Pulmonary Rehabilitation programme is in place giving people improved access to antibiotics and steroid medication through community pharmacy. Contact: Katrina.kilpatrick@fvpc.scot.nhs.uk

• A sustainable model for pharmacy involvement in a falls prevention programme has been developed in Glasgow. The focus is on reducing falls inducing medication, introducing bone strengthening treatment and supporting adherence, particularly in relation to anti-osteoporotic therapy. This involves case finding from community pharmacy, pharmacist led medication review and follow up support for people who fall. People who fall and who are prescribed two or more medicines are referred by Community Older Peoples Teams. Contact: Richard.lowrie@ggc.scot.nhs.uk

• Grampian’s Carers’ Medicines Management Project provide guidelines, training packages and support for home care workers and others assisting people to manage their medicines. Contact: wendyrobertson@nhs.net

• Pharmacy Health Information Bus promoted the work of local pharmacies and the Minor Ailments Service together with self management advice across NHS Dumfries and Galloway. Contact: Gordon.loughran@nhs.net

• In Lanarkshire a specialist clinical pharmacist provides pharmaceutical care for people discharged home following stroke. Close working with stroke support nurses and local community pharmacies helps people to understand their medication, increases concordance with secondary prevention and minimises drug related adverse events in a group of patients with significant cognitive, communication and swallowing difficulties. Contact: billy.lang@lanarkshire.scot.nhs.uk

• The Pain Association run pain education classes that include sessions from pharmacists with a special interest in chronic pain. There are one to one sessions with the pharmacist and follow up to talk about concordance with medicines. (http://www.painassociation.com)
6. PROVIDE TELEHEALTH SUPPORT FOR SELF MANAGEMENT

Background

Telecare and telemedicine are the two components of telehealth.

Telemedicine is the provision of healthcare with clinical professional involvement at a distance, using a range of digital technologies, including videoconferencing.

Telecare is the use of a range of technologies to support those at home, or in a community environment who would otherwise be at increased risk of coming to harm from a range of causes. Professional clinical involvement is not necessarily part of their package.

However, there is increasing convergence between telemedicine and telecare – the term ‘telehealthcare’ describes a range of care options remotely via phones, mobiles, broadband and videoconferencing.

A ‘telehealthcare’ package, available in a person’s home, can improve a person’s experience of care by reducing the need for travel to major cities and hospitals to receive care and treatment. It has been used successfully to provide treatment for dermatological, cardiac and neurological conditions. It enables care to be delivered in remote communities. It also allows GPs to consult specialists remotely to avoid unnecessary referrals and enables networks of learning for clinicians and maximisation of skill mix for teams.

Telecare usually refers to equipment and detectors that provide continuous, automatic and remote monitoring of care needs using information and communication technology to trigger human responses or shutdown equipment to prevent hazards. Telecare can be used in a variety of ways, for example to inform an assessment of need, as a direct service provision to manage individual or environmental risks more effectively, to inform a review as part of a wider package of care and support. It is also increasingly used to support access, information and consultations via an interpreter for deaf people or those using other community languages.

For more information about how telehealth is supporting people with long term conditions to self manage you can use the Scottish Centre for Telehealth (http://www.sct.scot.nhs.uk/contact.html), or go to the website of the Telecare Programme in Scotland (http://www.jitscotland.org.uk/action-areas/telecare-in-scotland/telecare-publications/).
Sharing Resources and Experience

- In a Lothian telehealth project, touch screen technology is being installed in the homes of around 200 people with COPD to enable vital sign collection, prompts and video conferencing connecting patients online to specialist nurses who will monitor their care remotely. The nurses assess and coach people, monitor trends, refer when appropriate and encourage self-management. Older people have found the equipment easy to use. The service will extend in future to a further 200 patients with heart failure and diabetes.
  Contact: Brian.McKinstry@ed.ac.uk

- Arthritis Care in Scotland is delivering their Challenging Your Condition course to remote communities by video conference link, ensuring that distance does not stop people accessing self management support. The North Sea can make travel around the Orkney islands difficult and time consuming. NHS Orkney provided equipment to enable course leaders to see and talk with participants from the outer isles by video conference link between Orkney mainland and equipment in Stronsay School.

- In the Moray CHSCP – Dufftown BP Home Monitoring Project, baseline blood pressure measurements are taken in the GP surgery, before patients are trained in the self use of Omron M10-IT electronic device for use at home. When monitors are returned, information is downloaded, analysed and patients advised of any changes to drug treatment and time for review.
  Contact: christine.mcclusky@nhs.net

- East Lothian, Moray and West Glasgow CHPs are using the Met Office to provide automated telephone weather alert service and an information leaflet for patients with COPD to promote self management, reduce exacerbations and hospital admissions.
  Contact: Carol.lumsden@nhslothian.scot.nhs.uk

- Remote access to specialist support for people with motor neurone disease (MND) living in remote areas is provided via home broadband/local surgery connection to an internet bridge in Aberdeen.
  Contact: cathy.dorrian@nhs.net

- Remote access to specialist epilepsy services for people with complex epilepsy and learning disability saves vulnerable people a 350 mile round trip and builds confidence in both patients and their carers. Collaboration of The Scottish Centre for Telehealth, Quarriers & NHS Highland.
  Contact: cathy.dorrian@nhs.net
7. SUPPORT CARERS IN THEIR ROLE

Background

Unpaid carers are a vital part of the care workforce. However, long term caring can have an adverse impact on the mental, emotional and physical health of carers. Unpaid carers have their own needs, lives and relationships and deserve a care plan in their own right. They need information, advice, practical support, education and training to enable them to continue in their caring role.

Talking Points are tools that support the Community Care Outcomes Framework. They describe outcomes that are important to unpaid carers.

<table>
<thead>
<tr>
<th>Quality of life for the cared for person</th>
<th>Quality of life for the carer</th>
<th>Managing the caring role</th>
<th>Process</th>
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<tbody>
<tr>
<td>Quality of life for the cared for person</td>
<td>Maintaining health and well-being</td>
<td>Choices in caring, including the limits of caring</td>
<td>Valued/respected and expertise recognised</td>
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<td>A life of their own</td>
<td>Feeling informed/skilled/equipped</td>
<td>Having a say in services</td>
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<td>Positive relationship with the person cared for</td>
<td>Satisfaction in caring</td>
<td>Flexible and responsive to changing needs</td>
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<td>Freedom from financial hardship</td>
<td>Partnership with services</td>
<td>Positive relationship with practitioners</td>
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A National Carers Strategy for Scotland will be developed in 2009.

Resources are essential to enable unpaid carers to continue to contribute their expertise and quality of care. The Scottish Government has invested more than £13 million in a package of measures to improve support for carers:

- £9 million for all NHS boards to develop Carer Information Strategies and roll out initiatives in their local area, including training events for NHS staff and carer information sessions.

- An additional £4 million – on top of funding already provided to local authorities – to help councils deliver an additional 10,000 weeks per year of personalised short breaks for carers by 2010-11. New national guidance has been issued to ensure these short breaks meet the individual needs of carers.

- £300,000 for two further national festivals exclusively for young carers. Young carers will receive annual VIP access, offering them a break from their caring role and an opportunity to tell decision makers what support will make a difference to their lives.
Sharing Resources and Experience

- **Western Isles** – Carers attending pre-discharge case conferences are included, with consent, on the Carer Register. This triggers relevant information and also post-discharge support from Community Nurses.
  Contact: Pat.Welsh@wihb.scot.nhs.uk

- **Dumfries and Galloway** – The Patient Information Centre at Dumfries and Galloway Royal Infirmary provides one-to-one advice, benefits maximisation and specific information for carers.
  Contact: Agnes Somerville, Patient Information Officer. Tel: 01398272711, or http://www.hris.org.uk/index.aspx?o=1250#dumfries_and_galloway

- **Lothian** – The LTC Action Group commissioned a Rapid Response Carer Support service with VOCAL (Voice of Carers Across Lothian) http://www.vocal.org.uk/. A project with Community Pharmacy has carers as a ‘named person’ on a patient’s prescription so they can collect and discuss changes to medication on behalf of the person being cared for.

- **Tayside** – Carer support workers linked to GP practices identify carers, raise awareness of carer issues and promote links to local carer centres
  Contact: rosie.cameron@nhs.net

- **Grampian** – Pharmacy prescription bags carry details of carer support service.
  Contact: wendyrobertson@nhs.net

- **Lanarkshire** – has a freephone helpline, a ‘Home from Hospital’ pack for local carers and a carer support team in partnership with local carer organisations.
  Contact: Marjorie.McGinty@lanarkshire.scot.nhs.uk

- **Borders** operates a Scottish Enhanced Services programme (SES) to train staff, raise awareness of carers’ issues and encourage signposting to local carer support agencies.
  Contact: sandra.pratt@borders.scot.nhs.uk

- **Highland Carer Services**, run by Alzheimer Scotland, provides information, advice and support to people with dementia and their carers either by telephone, letter, in person and through leaflets, books, tapes, videos, reminiscence materials, carers aids and a quarterly newsletter. There are a number of Carer Support groups and a drop in dementia cafe in Nairn.
  Contact: HighlandCarerServices@alzscot.org

- **Carer organisations**
  http://www.sharedcarescotland.com
  http://www.carerscotland.org/Home
  http://www.carers.org
8. COMMISSION RESOURCES TO SUPPORT PEOPLE TO MANAGE THEIR CONDITIONS

Background

Self management interventions vary considerably in their objectives, content, method of delivery, duration and target population. Educational programmes teaching practical self-management skills are more effective than the provision of information alone. Self-management education has been associated with improved knowledge, coping behaviour, adherence, self-efficacy, symptom management, enhanced quality of life and some evidence of a reduction in healthcare utilisation.

Evaluation of the Expert Patient Programme (EPP), a UK lay led self management course based on the Chronic Disease Self-Management Program developed by Kate Lorig at Stanford University produced mixed findings. (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080680) Participants valued the generic course for poorly recognised conditions that are not well supported, but many felt that they would have benefited more from a condition specific course. Most studies of condition-specific education programmes have involved people with asthma, diabetes or arthritis. Success factors include longer interventions (twelve weeks or more); higher intensity programmes; regular review by health professionals; focus on specific rather than general educational topics; participative rather than didactic teaching methods; multi-component approaches, and involvement of family or carers.

EPP participants also valued the social support generated through sharing of information and experiences, practical exchange of ideas and solutions and a reduction in social isolation. Community and voluntary groups provide emotional, psychological and peer support for people living with specific conditions or in similar circumstances. Peer-led interventions are effective in promoting confidence, engagement and participation in local communities and are a useful source of information, advocacy, education and support for carers and family. They are well rated by people living with long term conditions, but professional support appears to be critical for sustaining effect.

NHS, community and voluntary organisations are working together to deliver a range of educational, support, rehabilitation and enablement programmes. The Self Management Fund will enhance our capacity to tailor these supports to an individual’s preference, culture, level of comprehension, skill, educational needs and learning style and to ensure that people with long term conditions are actively involved in planning and delivery of self management support.
Sharing resources and experience

- The Patient Activation Measure can be used to help gauge readiness to join a self management support programme.
  Contact: Professor Craig White, National Clinical Lead for Self Management at craig.white@scotland.gsi.gov.uk

- The Scottish Diabetes Group has directed funding for centres to provide Dose Adjustment For Normal Eating (DAFNE) structured education courses for Type 1 diabetes. The Scottish Diabetes Education Network (http://www.diabetes-education.net/index.php?link=about), with Diabetes UK Scotland, supports diabetes educators to develop appropriate resources and national standards for delivery of diabetes education.

- Lothian – Community Physiotherapy services with Chest, Heart and Stroke Scotland are delivering a 6 weeks exercise programme to help people cope with breathlessness, improve their muscle strength and fitness and stop smoking.
  Contact: carol.lumsden@nhslothian.scot.nhs.uk

- The Pain Association developed a programme in collaboration with the Chronic Pain and Low Back Pain services in Forth Valley. The annual uptake for the intensive seven week programme is around 400 people. The programme is complemented by local self-management groups in Stirling and Falkirk. This model, now extended to Tayside and Lanarkshire, addresses many of the recommendations in NHS Quality Improvement Scotland’s GRIPS report.
  Contact: http://www.painassociation.com, Tel: 0800 783 6059

- Grampian cooking courses offer practical support for people with diabetes to learn how to cook healthily.
  Contact: fphilip@nhs.net (MCN Administrator)

- The Thistle Foundation’s Lifestyle Management courses build on participants’ own recovery strategies. The 10 week courses are designed around a framework of planned discussions, safe and appropriate exercise and therapeutic relaxation. They are about building confidence, boosting self esteem through experiencing small successes and benefiting from the supportive environment in the Thistle Foundation facilities. http://www.thistle.org.uk/
9. USE INFORMATION SYSTEMS TO CREATE PERSON HELD RECORDS

Background

To support people to manage their conditions, patient information systems need to be able to link the person’s identifiable data across conditions, teams and care settings. This will enable co-production of a personalised care plan.

An effective information system for long term conditions supports:

- Registration
- Risk-stratification of the population, ensuring that everyone with a long-term condition is ‘on the radar’
- Recall – information to co-ordinate and manage the care of each individual
- Review – information for monitoring, performance management and quality improvement

NHSScotland is progressing an incremental and pragmatic eHealth Strategy based on access to an integration platform through a single clinical portal. Access will be supported by SCI Gateway using tools to deliver integration and help us all to work together more effectively. An integral part of this Strategy will be to design, develop, and implement a system which supports a personal health record or electronic care plan and the sharing of information to support people with long term conditions and practitioners working across sectors and agencies.

SCI-DC (Scottish Care Information – Diabetes Collaboration) is an example of this approach in practice. It is an integrated national IM&T programme to support clinical communication across the entire patient journey for diabetes. The system is directly accessed by a variety of different professional groups and is now an integral part of diabetes care in Scotland.

SCI-DC is developing a single electronic portal for people with diabetes and their carers. This project will allow them to access their personal record and diabetes related data. Enabling access of this kind has been shown to enhance people’s ability to manage their own condition.
Sharing resources and experience

- NHS Ayrshire and Arran are developing an ehealth/web based demonstrator system that will support people to manage their personal health information. This will include recording personal health information, accessing clinical information and managing relationships and interactions with NHS staff.

A web based system will allow people to access a wide variety of clinical information, to record some measurements at home and make these available to the Practice and to selected third parties, and to access information to support and enable their self management.

People will be able to send messages in advance of consultations and to record details on important personal goals and follow-up arrangements. This will be supported through access to secure communication, e-generated prompts, guidance and data capture facilities in a way that patients and staff can access/input to in order to maximise self management support.

An automated reminder service such as an online ‘care calendar’ of upcoming appointments at the practice or hospital clinics could help reduce DNA rates. This reminder service could be email, SMS or by flagging when the patient logs in and could be integrated with the communication interface elements. This facility could include alerts, e.g. Flu vaccination or repeat blood test due.

Automated reminders or prompts could also be generated to support people as they work on goals agreed as part of self management support.
Contact: morag.stevenson@aapct.scot.nhs.uk

- The Managed Clinical Network for Epilepsy (West of Scotland and Tayside) is working to develop a web based generic clinical system using Axsys software and this will be piloted in paediatric services in NHS Tayside.
Contact: Gillian.Alexander@ggc.scot.nhs.uk
10. TRAIN STAFF TO ENABLE PEOPLE TO MANAGE THEIR CONDITIONS

Background

The World Health Organisation (WHO, 2005) identified the competencies required to deliver effective care to those with, or at risk of, developing long term conditions. These competencies include patient-centred care, partnering with the patient and other healthcare providers, adopting a public health perspective and, where appropriate, empowering people to adopt self management strategies. This requires a workforce that can build on traditional health education skills to incorporate problem solving, consultation and motivational approaches.

Good communication skills are fundamental to assessing and raising levels of health literacy, encouraging people to share decisions, identify preferences, set goals, and access appropriate health information.

“...there has been a failure to tackle the most important issue, namely the quality of interaction between patients and clinicians.”

Hibbard and Collins, 2008

We need to prepare staff, people living with long term conditions and their unpaid carers for new roles and approaches by identifying everyone’s learning needs, addressing gaps through locally delivered practice development initiatives and, where appropriate, through access to tailored educational solutions. Many health care professionals have not received adequate training in communication skills. Effective training can enhance and sustain improved communication style and ability across assessment, establishing trusting relationships and exploring emotional and psychological wellbeing.

The voluntary sector has an important role in educating staff. Staff benefit from collaborative learning opportunities with people who use their services to explore their needs, expectations and values through open-ended inquiry and assessment of individual expectations and priorities. Attention to past experiences and successes can help conversations to be focused on skill and confidence building and shared problem solving.

Goal-setting and motivational interviewing approaches create highly-rated patient experiences and have shown positive effects on health behaviours. The evidence base for their impact on clinical outcomes, or on quality of life is at an early stage. People’s self-management skills can and often do evolve over the course that their condition takes. Self-management support strategies that are tailored to the person’s specific stage of self-management are more likely to help people engage with self-management skills.
Sharing resources and experience

- Approaches to Communication and Human Relationship education is being considered by a group which includes LTCAS, NES, Scottish Government, NHS QIS and LTC Collaborative.

- A Higher Education Certificate in Person Centred Approaches is run by the Thistle Foundation and Queen Margaret University, Edinburgh and recognised by Scottish Social Services Council for workforce registration. It is designed to support staff working with people at risk of exclusion – people with learning difficulties or physical impairments, homeless, living in areas of high deprivation, older people and people released from prison.

- Thistle Foundation (http://www.thistle.org.uk/) are spreading effective, sustainable, professionally led and fully governed Thistle brand self management services through franchise agreements with workers trained in relevant competencies. Thistle will also deliver a two day Solution Focused Brief Therapy training course, a mindfulness training course and a one day self management course (with follow on supervision) for Edinburgh CHP.

- The Scottish Diabetes Group has funded and launched a national training programme for all professionals caring for people with diabetes to develop skills in communication and negotiation and delivery of behavioural change interventions. It is also planned that psychologists will design and deliver training to staff involved in the provision of care to people with diabetes. This includes design and implementation of screening, care pathways and innovative group interventions for anxiety and depression for people within primary and secondary care.
  Contacts: AnnGold@nhs.net or Andrew.Keen@arh.grampian.scot.nhs.uk

- NHS Education for Scotland (NES) in collaboration with NHS Fife, Borders and Lothian have developed an essential guide to support multi-agency managers, teams, and individuals to identify appropriate self management skills and knowledge for different levels of staff within their organisations. It is anticipated that this will assist recruitment, workforce planning and development, role redesign, and career progression.
  Contact: cherylharvey@nhs.net or 07776 473076.

A NES website hosts a unique fully searchable database consisting of individual modules that practitioners and workers can take to complement and increase their self management knowledge and skills. Courses cover a broad spectrum of topics related to long term conditions from different organisations, spanning different levels and modes of learning. The database is within the Self Management and Rehabilitation portal of the elibrary and can be accessed at www.LTCtraining.scot.nhs.uk.
Ayrshire and Arran are a demonstrator site for Co-Creating Health

This Health Foundation programme, delivered across eight UK sites, aims to enable clinicians and patients to make their interactions as productive as possible. It provides training on how to establish collaborative partnerships between patients and staff and clinicians and builds the required processes into the delivery of clinical care. Three processes or ‘enablers’ are at the heart of Co-creating Health: joint agenda-setting, goal-setting and goal follow-up.

**Agenda setting** – supports patients and clinicians to jointly agree the aims of each meeting they have. The evidence shows that when this does not happen effectively, patients feel dissatisfied with their experience and are less likely to adhere to treatment advice, act on the lifestyle change advice or even attend their next appointment. Establishing the patient’s perspective at the start helps clinicians to work with the patient’s own motivations and interests and improves both patient experience and outcome.

**Goal setting** – the most effective way for someone with a long-term condition to begin to make health-improving changes is by choosing their own small and achievable goals. These do not need to be clinical in nature – but achieving them must be important to the patient and something they will be proud of. Achieving these goals builds confidence and momentum and is the first step towards the all-important belief that they can make a difference to their health (known by health psychologists as ‘self-efficacy’).

**Goal follow-up** – For all of us, the ability to keep up health-improving changes diminishes without regular reinforcement. Our existing health system is poorly designed to do this. Proactive ‘follow-up’ by the health service fairly soon after a goal has been collaboratively agreed is needed to provide encouragement, advice and support. This marks a radical departure from our current system of reactive contact between healthcare professionals and patients.
## Patient-clinician interactions

<table>
<thead>
<tr>
<th>Traditional Interactions</th>
<th>Collaborative Interactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and skills are taught, based on the clinician’s agenda</td>
<td>Patient and clinician share their agendas and collaboratively decide what information and skills are taught</td>
</tr>
<tr>
<td>There is belief that knowledge creates behaviour change</td>
<td>There is belief that one’s confidence in the ability to change (‘self-efficacy’), together with knowledge, creates behaviour change</td>
</tr>
<tr>
<td>The patient believes it is the clinician’s role to improve health</td>
<td>The patient believes that they have an active role to play in changing their own behaviours to improve their own health</td>
</tr>
<tr>
<td>Goals are set by the clinician and success is measured by compliance with them</td>
<td>The patient is supported by the clinician in defining their own goals. Success is measured by an ability to attain those goals</td>
</tr>
<tr>
<td>Decisions are made by the clinician</td>
<td>Decisions are made as a patient-clinician partnership</td>
</tr>
</tbody>
</table>

Based on Bodenheimer, California Health Care Foundation 2005:7
Further References

Models of Self Management

- Five A’s: Assess, Advise, Agree, Assist, Arrange
  http://www.who.int/diabetesactiononline/about/fiveAs/en/index.html

Health Coaching

- http://www.communityhealthcarebolton.co.uk/bond/web_index.aspx
  DH_063081
- http://www.talkingmats.com/
- http://www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Children_and_Young_People/Home_Care_Service_-Southport_and_Formby/
  DH_4134006
  DH_4130725

Shared Space – Long Term Conditions

- The Long Term Conditions Collaborative has a work area on Shared Space within the e-library. The Shared Space is a ‘secure’ area to enable the sharing of documents, case studies, conference abstracts and posters; links and signposting to good practice and other resources available; on-line discussions and networking; up-to-date information on events and news.

In order to use Shared Space, you will need to obtain an ‘Athens’ password by following the link below:
 http://www.elib.scot.nhs.uk/SharedSpace/ist/Pages/Index.aspx?ContainerID=143
 then access the shared space
 http://www.elib.scot.nhs.uk/SharedSpace/ist/Pages/login.aspx?ContainerID=207650&ret=http%3a%2f%2fwww.elib.scot.nhs.uk%2fSharedSpace%2fIST%2fPages%2fIndex.aspx%3fcontainerID%3d207650 to log on.

Improvement resources

- Improvement & Support Team Toolkit:
  http://member.goodpractice.net/ContinuousImprovementToolkit/Welcome.gp
- Improvement & Support Team Website:
  http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/Delivery-Improvement
- NHS Institute for Innovation & Improvement, 2007, High Impact Changes for Practice Teams
Department of Health

- May 2004, Chronic disease management: A compendium of information
- 2005, Supporting People with Long Term Conditions: An NHS and Social Care Model to support local innovation and integration
- 2008, Raising the Profile of Long Term Conditions Care: A Compendium of Information

Empower people to have more control and choice


Promote better mental health and wellbeing

- Sainsbury Centre for Mental Health (http://www.scmh.org.uk): This site contains a briefing on Mental Health promotion for implementing standard one of the national service framework for mental health and work produced by the Mentality mental health promotion team (responsible for producing Making it happen: a guide to delivering mental health promotion (2001) Department of Health).
- NIMHE programme for Primary Care Mental Health and Education (http://www.primhe.org): Details of their resource packs Mental Health promotion in primary care (2005) and Promoting mental health, cultivating social inclusion and managing mental health problems in primary care: a guide to developing integrated services in line with the national service frameworks for mental health (2003) and Improving Primary Care Mental Health Services (2007) can be found on this website.
- National Library for Health (http://www.library.nhs.uk) is a key deliverable of the NHS ‘Information for Health’ strategy. It is designed to bring together a wide range of public health activity into a simple, easy-to-use resource
- Health Development Agency http://www.nice.org.uk/page.aspx?o=hda.publications: This agency worked to develop the evidence base for improving health and reducing inequalities in health. In 2005 the HAD remit was transferred to NICE (National Institute for Health and Clinical Excellence).
• Health Rights Information Scotland produces clear, accurate, and up to date information about health rights, and provides assistance to produce patient information.
  http://www.hris.org.uk/

• Patient UK – site for patients with health information and advice http://www.patient.co.uk/

• Alzheimer Scotland runs a freephone (0808 808 3000) 24hr dementia helpline, staffed by trained volunteers supported by a staff team, to provide information and emotional support to people with the illness, their families, friends and professionals.
  http://www.alzscot.org/pages/helpline.htm

• The Scottish Recovery Network is a group of agencies collaborating to act as a vehicle for learning and sharing ideas around recovery from long-term mental health problems working with people who have experience of mental health problems, their friends, families and carers, and service providers.
  http://www.scottishrecovery.net/content

Commission resources to support people to manage their conditions


• MS condition management programme
  www.mssocietyscotland.org.uk/life_with_ms/learning_more/self_management.htm

Train staff to enable people to manage their conditions


• Department of Health (2006) *Supporting People with Long-term Conditions to Self Care: A guide to developing local strategies and good practice.* Gateway ref: 5411

• Department of Health (July 2007) *Self Care Support: The evidence pack – summary of work in progress 2005-07.* (Gateway ref; 8534).

• Hibbard J H, Tusler M. *Assessing Activation Stage and Employing a ‘Next Steps’ Approach to Supporting Patient Self-Management.*


  http://www.diabetes.org.uk/Professionals/Year-of-Care/The-Year-of-Care-programme/
Long Term Conditions Collaborative
Improving Self Management Support