But we need to identify, share & get our hands on them!!

Living Well with Long-Term Conditions

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Introduction
by Dr Harry Burns and Susan Douglas-Scott

Long-term conditions pose many challenges to Scotland’s population and to Scotland’s health and social services. It is estimated that around 2 million people in Scotland are living with long-term conditions.

A key strand of Scotland’s health policy, Delivering for Health, focuses on long-term conditions. Central to taking this work forward is a partnership between The Scottish Executive Health Department and the Long Term Conditions Alliance Scotland (LTCAS).

Traditionally in health care, progress is made by getting together a group of high-ranking health and social care experts who offer their opinions to inform strategic thinking. We quickly realised that in the field of long-term conditions, such an approach would not be right.

What is most important in this area is not just the undoubted expertise of professionals, but of the real experts – people living with long-term conditions, their unpaid carers and the voluntary groups who support them.

The events in Glasgow and Aberdeen therefore turned the traditional model of seeking consensus on its head. The format of the events was equally unconventional. They were designed to ensure that the voices of people living with long-term conditions and their carers predominated. Rather than these people being ‘talked at’ by expert presenters, it was their contributions in small group work that provided the value from the day.

It is the ideas, views, experiences and needs shared in those groups, that reflect the real issues that impact on the quality of life of people with long-term conditions and their carers and it is these that form the basis for the messages in this report. I believe this gives the report genuine authenticity as a record of the events. More importantly, it provides service planners with vital information and ideas for action that are based not on theoretical ideas, but on people’s lived experience.
The success of the two events is down to the 400 participants who came from diverse walks of life to share their thoughts, experiences and dreams. Their ideas and observations will make a major contribution as we embark on this journey to improve services for people with long-term conditions and their carers. It is only a beginning, but an important beginning, and we are totally committed to doing everything we can to put these ideas into action.

This report takes all the aspirations for improving services for people and their carers with long-term conditions and pulls them into key themes and messages for people who plan and manage services. Whilst some individual messages will not be included what is important is that we do not lose these.

All the outputs from the day are captured on the Long Term Conditions Alliance Scotland website www.ltcas.org.uk and will be built upon as we move forward in partnership on making these visions and aspirations a reality.

Harry Burns
Chief Medical Officer
Scottish Executive Health Department
The Long Term Conditions Alliance Scotland (LTCAS) was established in 2006. Our aim is to bring together hundreds of voluntary and community organisations across Scotland. Our major objective is to give a national voice to ensure the interests and needs of people living with long-term conditions are heard and addressed.

LTCAS were very pleased to be invited to participate in the design, delivery and as participants at these key consultation events. For LTCAS this meant we could begin to address some of our key aims.

LTCAS’ four overarching aims featured strongly in these events:

1. Influencing and campaigning
2. Supporting and improving practice
3. Supporting the voluntary and community long-term conditions sector
4. Tackling health inequalities

By working in partnership with NHSScotland and by the involvement of all the participants who live on a day-to-day basis with long-term conditions, LTCAS believes real change can and will happen.

Our vision is for a Scotland where people with long-term conditions and carers enjoy full and positive lives. This includes being free from discrimination and supported by access to high quality services, information and support. We believe these events, this report and the Scottish Executive’s Health Department’s backing is a strong foundation to build better services fit for today and for the future.

Those of us involved with LTCAS believe this is important as we are people with lives and families, not just patients. In order to live well as people with long-term conditions we need quality support and services. We believe this means quality for life as
life is for living not enduring. If our lives are improved then there will be a reduction of the burden that long-term conditions place on individuals, families and society. The changes committed to by Harry Burns and his team should mean that this will happen. It is an exciting time for us all to be involved and LTCAS will continue to speak to everyone necessary to ensure change as suggested in this report becomes reality for us all.

Susan Douglas-Scott
Chief Executive, Epilepsy Scotland and non-Executive Director, Long Term Conditions Alliance Scotland
1. How did the events work?

The events were held in Glasgow on 13 February 2007 and in Aberdeen a little over a month later on 15 March. They were designed to be interactive and to encourage people to answer the question:

“How can NHSScotland support people who have long-term conditions and their carers?”

Those involved were people living with long-term conditions, unpaid carers, professionals from health, social care and voluntary organisations and policy makers.

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 asked whether they were there because of a personal or professional interest in long-term conditions. Those with a personal interest either lived with a long-term condition or were unpaid carers. People with a professional interest worked for the NHS, local authority or voluntary sector.

> People worked in small groups. Each group was asked to select a ‘table host’ and a scribe.

> The day was divided into three discussion sessions:

> Session One – During the first part of the morning people sat in groups of either professionals or those with a personal interest.

> Session Two – People moved into mixed groups. This meant each group included people with long-term conditions and unpaid carers and professionals.

> Session Three – People went back to the groups they were in for session one. They looked at what should be priorities for action and presented their top three ‘How To’s’.

At lunchtime and coffee breaks there were a range of stands giving information about long-term conditions. Many different organisations had stands and people at the event could get information in person or by taking away leaflets, booklets or DVDs.

A reporter took notes of discussions and a conference graphic artist captured key points in cartoons. People could also record their thoughts and ideas in writing at a variety of locations throughout the events. All of these were used to help write this report.
2. What do people want?

In their groups people talked about the issues that really matter to them as people living with long-term conditions, as unpaid carers, as professionals and as policy makers.

We’ve summarised the discussions under five main headings. These start by seeing people living with long-term conditions and unpaid carers as being at the centre of services. They go on to talk about how services can be delivered in a way that keeps the focus on the person.

> Involving people and supporting self-management
> Communication and information
> Services working together
> Professional practice and development
> Providing services

As well as making recommendations about how services should be designed and delivered, people also stressed that they need to be involved at local and national level in making sure change actually happens.

“Why does every hospital not carry out user surveys as part of a service review... and actually believe what people say?”
3. Involving people and supporting self-management

3.1 PEOPLE AS EXPERTS
Involvement in services was one of the issues people felt most strongly about, in particular people with long-term conditions and unpaid carers.

“We need] to be heard without scepticism.

The ‘bottom line’ was that people with long-term conditions, unpaid carers and communities need to be included by professionals at all stages of their journey. This involvement must be central to providing services for people with long-term conditions and their carers. For this to happen services must understand the rights of the person to make decisions about his or her own needs.

NHS [needs to] listen better. Hear what patients and carers are saying, act immediately if the issue is urgent.
3.2 SUPPORTING UNPAID CARERS

As well as recognising the expertise of people with long-term conditions, services must also understand the role of unpaid carers. People pointed out that supporting unpaid carers leads to better outcomes for people with long-term conditions. It could also mean large cost savings for services.

A key part of supporting people with long-term conditions is supporting unpaid carers.

Unpaid carers have a right under law to have their emotional, practical and financial needs assessed. Assessments should be done to help decide how much support an unpaid carer can provide. Assessments should also identify what kind of support the unpaid carer needs.

Help people to recognise they are carers and give the right support.

The events highlighted some of the difficulties for unpaid carers:

> There is a dilemma when carers are not allowed to be involved in consultations with professionals. The reason is to protect a person’s confidentiality. However, if a person needs constant support from an unpaid carer, for example to make choices or remember things, then they need to be included.

> There is not enough support for times when unpaid carers have to leave the person they care for.

> Unpaid carers do not always know their way around services, for example what is available or who to contact.

> The system is not responsive enough when there is a crisis or a change in someone’s condition. Unpaid carers and people with long-term conditions need organised crisis support.

> Professionals tend to treat unpaid carers’ descriptions of the situations they face on a daily basis ‘with a pinch of salt’.
Carers’ testimonies must be taken seriously and at face value. If this does not happen there is a risk that carers lose faith and confidence in services. This could be damaging for the person and the unpaid carer.

3.3 SELF-MANAGEMENT

“Even if you spend 15 hours a week going to physio, GP, OT, etc. there are heaps of hours left in the week when you’re on your own.”

People were aware that Scottish Executive policy is to promote supported self-management. This was largely seen as positive but there were some fears about services ‘abandoning’ people and unpaid carers. During discussion the professionals at the event tried to reassure people that this is not how services view self-management. Professionals talked about approaches that harness people’s abilities to reach the best possible outcomes. This should not mean people with long-term conditions and unpaid carers ‘going it alone’.

Some people still had concerns about self-management and stressed that the right education and support must be in place.

Participants pointed out that the degree to which people want to self-manage will vary from person to person. Not everyone will want to self-manage and those who do not must have the support they need.

“It [self-management] is not to replace service provision, but in addition to your care.”

Self-management is particularly scary and challenging at the start after diagnosis and there should be more support made available from health professionals. Even just to contact them to ask questions without feeling like it’s a hassle.”
There were a number of suggestions about how self-management could be developed in Scotland:

> Self-management courses should be available to people on an ongoing basis.

> Courses should be developed using the experience and expertise in the statutory and voluntary sectors.

> Support groups are valuable in developing people’s capacity to self-manage. There were mixed views about whether these should be condition specific or generic. Some suggested generic groups with ‘bolt-on’ sub-groups catering for condition specific needs.

> Reducing hospital stays is one of the aims of developing people’s self-management skills. The savings made through this should be ploughed back into self-management education courses. This would ensure ongoing savings in the future.

Diabetes management would be easier if we all had access to structured education programmes to teach/maximise self care skills (same info from every centre!).

It was clear that self-management relies on more than just traditional health services. In particular people stressed how important complementary therapies and psychological support can be. Suggestions included:

> Access to treatment choices outside of the conventional NHS services, for example complementary therapies.

> Personal development in schools.

> Access to personal development tools.

> Techniques to raise self-esteem levels.

> Availability of life-coaching to raise and maintain self-esteem.

> Support with motivation.

> Counselling.
Whatever self-management support is developed it must respond to the range of people’s needs.

Recognise self-management programmes are life long educational processes that must include the person and/or carers as well as professionals, including from the voluntary sector.

Unpaid carers or lay mentors can support people to self-manage. There was strong agreement that this has many benefits as long as professional support is there when people need it. It was suggested that people and unpaid carers should be able to access professional support by contacting a key worker/co-ordinator. This should be through a variety of means including telephone, text messaging and email.

People have the right to make choices

(This is what I want to happen to me)

Err... ok, but...

... what if it’s the WRONG choice?)
4. Communication and information

4.1 COMMUNICATION

People saw good communication as being at the heart of good care. It was suggested that accurate, up-to-date information is the basis of successful self-management.

Don’t just whip out the prescription pad – listen! Ask…

Needs culture change, e.g. friendly professionals.

Services have to recognise that communication is a two-way process. First and foremost people said that services have to be ‘listening services’. Only then can they understand what people and unpaid carers need and provide the right information. It was suggested that the NHS has not always worked in this way.

4.2 INFORMATION

Diagnosis was identified as a time of particular need for good information. Agreed and shared communication systems have to be in place across and within services. This would mean professionals are able to access the information they need and
in turn provide the right information to people and unpaid carers. It would also help professionals to discuss issues with people in a clear, consistent and jargon-free way.

People with long-term conditions don’t know what is available, don’t know who to ask, don’t know their rights!!

People discussed the type of information they need:

- Dedicated co-ordinator to signpost to information.
- Information about specialist services.
- Information about local and national voluntary organisations that might be relevant to them.
- Information in a variety of formats and media.
- Virtual information network to link people, unpaid carers and professionals across the whole of Scotland. This would signpost people to specialist knowledge and sources of information. It would make use of technology including telephone, television and mobile phones as well as written materials and face-to-face support groups. NHS 24 was identified as a possible base for the network.
The events also looked at personal information and found support for the idea of a ‘patient passport’. This would be a single record that all professionals could see. People were positive about this as it would remove the need to repeat the same information to each professional they met.

People recommended that the Scottish Executive develop a strategy to describe best practice in providing information.

### 4.3 ACCESSIBILITY AND CLEAR COMMUNICATION

> Consultants need more people skills.

The events made it clear that the best information systems in the world are useless if the information itself is not clear and effective. This was viewed as particularly important for people whose first language is not English or for those with communication difficulties.

> Don’t forget about getting info to people who may not read e.g. people with learning difficulties, people from black and minority ethnic groups…

There was a strong message that professionals need to stop using jargon and ‘codes’. Instead they must communicate in a way people understand. People with long-term conditions and unpaid carers described finding it difficult to build a relationship with professionals who spoke in a way they did not understand. They talked about having little respect for professionals who made little or no effort to communicate with them meaningfully.

More than anything people said they want professionals to deal with them as a person and not as a condition.

> Communication needs to be improved by recognising the importance of the person not just the condition.
4.4 COMMUNICATION WITH THE GENERAL PUBLIC

The community must recognise that a person with a disability is no different than anyone else

I have hopes and dreams

I laugh and I cry

I love and I can fall out of love

A key issue raised at the events was the way in which people with long-term conditions are seen in society. People talked about problems of stigma and discrimination caused by a lack of understanding about long-term conditions.

Lack of education and awareness of illness – public’s attitude to some illnesses [is] pure ignorance.

The media was highlighted as particularly important in communicating with the public about long-term conditions. There were concerns that the media often causes confusion by providing biased or misleading information. As a result people suggested more publicly funded campaigns like ‘see me’ to raise awareness and challenge inaccurate information.

Impairment/condition is the thing wrong with me, diabetes, etc. Disability is the social exclusion/experience, e.g. stigma, lack of support etc.

Fight isolation and exclusion!
It was clear from discussions that participants saw services for people with long-term conditions and unpaid carers as a responsibility that extended beyond the NHS. This means that close partnership working and collaboration across the sectors – NHS, local authority, independent and voluntary – is essential.

People spoke about a vision in which people could select from a ‘menu’ of options for support. This would allow people to mix and match services from different sectors to meet their own needs. The barriers that prevent this from happening included:

- ‘Professional territorialism’.
- Lack of awareness of services provided by different sectors.
- Inequalities in budgets that particularly disadvantage voluntary sector service providers.

GPs should be able to signpost patients to support groups and social workers.

NHS needs to work beyond its traditional boundaries.
People felt strongly that these cultural, professional and structural issues need to be tackled head-on. This would mean that services could be joined-up and offer people and unpaid carers real choices that truly reflect their needs. In relation to health and social services people talked about delivering on the Scottish Executive’s ‘Joint Future’ agenda.

A number of specific suggestions were made on how services could work together better:

> NHS should promote working across disciplines and sectors.

> Money available from a single source to support joint services for people with long-term conditions.

> Money to support voluntary organisations to provide self-management education for people and unpaid carers. It was suggested this could come from NHS Education for Scotland.

> Identify specialist within Heath Board Area who has links with local and national services.

> NHS should know where to signpost people to in the voluntary sector.

> Have people who co-ordinate services across sectors around particular conditions.

> Train staff to manage change.
6.1 PEOPLE AS PARTNERS

There was overwhelming agreement that service professionals should work with people living with long-term conditions as partners. However, people suggested that for this to happen professionals need to give up some control and be willing to empower people and unpaid carers.

To help people to have more control over their own care it was suggested that a key worker or co-ordinator should be appointed at diagnosis.

Provide access to ‘navigators’ to guide [people] through the system.

This person would:

- Help to interpret the diagnosis.
- Offer up-to-date information.
- Provide support, advice and education.
> Help deal with wider issues, for example family or finances.
> Signpost people and unpaid carers to support, services or resources.
> Act as a ‘lead’ person for people with complex conditions.

6.2 PROFESSIONAL EDUCATION

The events suggested that training programmes for service professionals currently do not cover long-term conditions adequately. It was suggested that effective, quality assured, evidence-based education on long-term conditions should be built into undergraduate and pre-registration education. This should recognise the expertise of people who live with long-term conditions.

At postgraduate/post-registration level, there was a call for the NHS, further and higher education sectors and NHS Education for Scotland to work together to ensure practitioners continue to learn about long-term conditions throughout their working lives. One suggestion for achieving this was to use a tool-kit approach as well as ‘professional portfolio building’. This should be supported by sharing good practice through existing means such as conferences and journal articles.

It was also suggested that GPs in particular required training in the range of support available locally and nationally to which they can signpost people with long-term conditions.

“GPs also need training in the use of the support network, e.g. pharmacists, voluntary sector, specialist services and what is available locally and nationally.”
7. Providing services

At the events people reported that existing services for people with long-term conditions and unpaid carers are inadequate and under-resourced. There were concerns that decisions about funding are made according to what service providers think is needed and not according to the real needs of people using the services.

7.1 CONSISTENCY

People said they wanted services to be consistent throughout the country. This would mean equal quality and access across rural and urban areas of Scotland. Some suggested this would mean redesigning the NHS as one single health board covering the whole country. This would have the benefit of allowing there to be one approach to managing long-term conditions across all geographic areas. There was some support for this as a way to remove the risk of ‘post code lotteries’ of care.

It was suggested that the first step towards consistent services would be through strengthening managed clinical networks. These should be properly resourced so they can promote high quality care and share best practice in long-term conditions.
7.2 PERSON-FOCUSED
The care that services deliver must be centred around the person and be proactive rather than reactive. It must focus on the person’s care pathway designed around individual need, and not the needs of the service. It must strike a balance between physical, social and psychological care and take account of the needs of unpaid carers. It must also be designed to meet the needs of people with all kinds of long-term conditions, not just those that are current political priorities.

7.3 IMPROVING SERVICES
Participants called for a change in culture among services so that they become ‘listening’ services. Listening to individuals and carers and genuinely trying to shape services around their needs. This was recognised as a shift that would demand changes in the way managers, clinicians, practitioners, individuals and unpaid carers thought and acted.

The events also highlighted the need for people to be informed about what they should expect of services.

“People should know what care is good quality care.”

The events found strong views about how services should be set up and delivered. The main suggestions were:

- A ‘one-stop diagnostic shop’ so that people can get their diagnosis quickly and effectively.
- Professionals to take more care in the way they break bad news. In particular people’s dignity and confidentiality must be protected.
- Psychological support for people with long-term conditions and unpaid carers. This should be available from the start of living with a condition.
- Urgent need for local co-ordination of care for long-term conditions through key workers or co-ordinators to ‘navigate’ people through services.
People with long-term conditions and unpaid carers as the leaders of services, not just recipients of care. People, unpaid carers and professionals should discuss and agree on their care.

Well prepared, well supported consultant-led services for all long-term conditions.

Opportunities to meet with professionals in a range of settings including hospitals, community and ‘non-traditional’ settings (for example leisure centres and libraries) and people’s own homes.

Services that are able to change over time in response to changes in people’s needs.

7.4 MULTIPLE CONDITIONS
There were particular concerns about people who live with more than one long-term condition. It was suggested that lack of co-ordination of services often means the needs of people with multiple conditions are not met. People recommended that streamlined service provision was especially important for these people. This would include co-ordinated medicine prescribing and liaison between different hospital departments to avoid people having to attend as outpatients for multiple appointments.

7.5 OUTPATIENT SERVICES
In outpatient settings people wanted to be seen, diagnosed and treated quickly. It was viewed as reasonable to expect the same timescales as for inpatient treatment. People reported waiting several months for appointments and weeks for results. These delays meant people having to wait longer before being able to start treatment and this was seen as unacceptable. One option for overcoming these issues was the use of self-referral clinics. People highlighted these as a way of offering multi-disciplinary, holistic approaches and talked about the role they can play in reviewing medicines and monitoring side effects.
Access to services was consistently identified as an area of concern. Issues included access for people in rural areas and availability of transport to travel to appointments.

People described the advantages of ‘single points of access’ through which they could access a number of different services. It was suggested that single points of access should enable people to reach all of the benefits they are entitled to. People also felt that this should include free medicines.

People emphasised the fact that the needs of people with long-term conditions and unpaid carers change over time. Some suggested that NHSScotland set up a system of ongoing assessment for people with long-term conditions and their carers. This would mean that services could respond to changes in people’s needs over time. As well as helping make sure people’s individual needs are met this would also be a way of monitoring overall needs in terms of long-term conditions (for example as the population gets older).

As well as discussing general barriers to services, the events also highlighted a number of specific gaps:

> The need for social, emotional and psychological support for people living with long-term conditions and unpaid carers came across very strongly. People described the effect that coping with long-term conditions has on their mental health and well-being. Many people talked about not having access to support and said there should be more help available including: community psychiatric nurses; counsellors; cognitive behavioural therapy; and ‘talking therapies’. In particular people highlighted the links between long-term conditions and depression.
People identified the need for more allied health professionals with expertise in supporting people with long-term conditions.

The events raised the question of how to tackle areas where there are service shortages, for example speech and language therapy.

Good social support can avoid the need for crisis intervention and in many cases admission to long-term care.
8. Learning the lessons, and moving forward...

The meetings in Glasgow and Aberdeen were very powerful events which sent fundamental messages to the NHS and partnership organisations on the key question – ‘How can NHSScotland support people who live with long-term conditions and their carers?’

As well as answering that key question, the events were also designed to encourage participation, be enjoyable and let people have fun. It is to the credit all those who were involved and attended that both were achieved.

Everyone who attended the events will have taken their own key messages away with them. It may have been a profound or moving statement from a participant. It may have been an example of good practice which shows the way for further improvements in services. It may have been an amusing anecdote that was recounted or the expression of someone’s anger about a difficult experience. It may have been one of the cartoons produced by the conference illustrator or a comment from someone that was attached to the drawing.

For us, the key message has to be that people’s experiences of living with or caring for someone with long-term conditions must be central to how services are designed and delivered. The events revealed to us that there are inadequacies and deficiencies in services in some areas. However, it also highlighted the many, many examples of good practice that can be found throughout Scotland. These give us a very strong foundation from which to build the kind of services we now know people want and need.

We wanted to make this document come alive through case studies that explore the realities and the aspirations of real people. 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 NHSScotland, these have been developed by the Long Term Conditions Alliance and are included in the appendix to this report.
You have our assurance that the messages set out in this report will be our focus as we move through a programme of service improvement with partners across the NHS, Social Care and Voluntary Sector.

Harry Burns
Chief Medical Officer
Scottish Executive Health Department

Susan Douglas-Scott
Chief Executive, Epilepsy Scotland, and non-Executive Director, Long Term Conditions Alliance Scotland

What we have in abundance to help make things HAPPEN
Appendix

These case studies have been developed by the Long Term Conditions Alliance Scotland to explore the realities and aspirations of real people living with long-term conditions.

LONG-TERM CONDITION CASE STUDY 1:
Fiona, a young person with complex needs

Fiona is 19 and six months ago left the residential school she has gone to for the past eight years. She is back living with her mum and dad and is feeling a bit frustrated. Her folks are great but they fuss a lot. Fiona would like to develop skills to work and live more independently so she goes to a resource centre for disabled people three times a week.

Although she is learning some new things, she finds the centre very different from school. The staff are not as supportive as her teachers and they don’t always take time to understand what she is saying. She remembers her communication methods being talked about at a review meeting before she left school. At this stage it was agreed that the staff at the resource centre would have training. They also agreed to spend time with her at school to make sure that her voice would be heard. None of this seems to have happened and often Fiona thinks staff are pretending to understand her rather than taking time to get to know her. However, she is trying to persevere as she knows how important it is to keep talking so people around her tune into her.

Other support in terms of personal care is fine except when she has a bad seizure. The minor ones are ok, no one seems to panic about them. Sometimes they don’t even notice. Fiona thinks they don’t realise that her jerks are all part of epilepsy. The panic happens when Fiona needs to get her emergency medicine. This doesn’t happen often but when it does staff don’t follow her care plan and phone her mum instead. If they can’t get a hold of her mum they phone an ambulance. This is worse as Fiona hates going into hospital. She especially hates it if there is no need to be there in the first place. She has spoken to her consultant at the hospital and he says he has done everything he can by making sure she has an emergency care plan and an up-to-date prescription.

All of this is making her mum worried which Fiona also hates as she fusses even more. No one seems to treat Fiona as a young adult. She thinks this is because she is disabled and that she will always be treated like a child. She thinks there is no point in telling anyone what her dreams for her future are as no one seems to
Another thing that is happening for Fiona is that she needs to change her hospital care from the children’s hospital to adult services. She’s been waiting for months for an appointment. At this appointment she is due to meet the adult epilepsy specialist nurse (ESN) who will introduce her to the consultant. The ESN from the children’s hospital has agreed to go to this appointment with her. Fiona thinks they have forgotten about her.

Fiona’s life could be better than this. Read on to see how the implementation of a strategy for long-term conditions could help make things better for Fiona.

When Fiona was planning to leave school and go to a resource centre, staff from the resource centre began working with her during her last six months in school. They came to visit her, spent time with her and her teachers learning about how Fiona communicates. They also learned about the best ways to approach Fiona’s personal care. Part of this included training on administration of her emergency medication. The support staff at school showed the new staff Fiona’s emergency care plan. They talked about Fiona’s seizures and described what a serious seizure needing emergency medication looked like for her. The resource centre staff then understood the nature of Fiona’s seizures and how to deal with them.

Back at the resource centre, staff still felt anxious about dealing with Fiona’s seizures. To help with this the manager organised for the voluntary sector to offer epilepsy awareness training to the whole team. Everyone on the team learned a lot about the complex and diverse nature of seizures. Staff who were to be working directly with Fiona got extra training on the administration of emergency medication. At this training session the nurse trainer looked at the specifics of Fiona’s emergency care plan and based this part of the course around Fiona’s needs.

The speech therapist Fiona works with at the hospital also came with Fiona and trained staff on the best way to communicate with her. She knows Fiona well as she liaises with the school and also sees Fiona when she goes to the outpatients clinic.

Just before Fiona left school, everyone who is involved in her care and support from the children’s hospital and school met with Fiona and her parents. They invited all the new staff who would be working with her in her adult life. Together with a facilitator from the voluntary sector, they helped Fiona develop a person-centred
plan. This process helped Fiona express her wishes and desires for her future. For the first time she was able to say that she wants her own home at some point.

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

After this meeting Fiona’s mum and dad feel reassured that there is support there for their daughter with her health and social care needs. The main thing for Fiona’s mum is the reassurance that she will get emergency medication in time. She knows how important, infrequent but vital this aspect of Fiona’s care is. This was one of her main concerns when the time came for Fiona to leave school.

As Fiona asked for help to reach her goals, further support is organised though a voluntary organisation. This support is community rather than centre-based and focuses on helping Fiona gain independence in making decisions that will chart out her life path. This type of service is flexible and allows Fiona choose the areas where she needs to develop. As she is worried about the moved to the adult hospital, the first thing she works on with her support worker is to get an appointment sorted out. At this appointment her support worker helps her ask the questions that were worrying her. Together they take away information about the service and will work together to help Fiona ask all the questions she has at her next appointment.
LONG-TERM CONDITION CASE STUDY 2:
John, a person in mid-life living with a long-term condition

John is 48 and started on new medication around six months ago, after feeling tired and run down for some time. He has been told to take tablets several times a day, to change what he eats and when, to take exercise every day and to stop drinking as much. He has also been told to lose weight. He got some leaflets at the beginning but it was a lot to take in. He isn’t sure where they are now.

At work he is finding it difficult to remember the tablets and hasn’t told anyone about his health problems because he believes that will change his opportunities in his career. He thinks it won’t make a difference whatever he does as he has eaten the same diet as his workmates all his life. He can’t imagine how to change now.

Meeting his friends after work for a drink is important to him as it is a way he deals with the stresses and strains and he is scared to lose that. His wife Elaine feels she is nagging him and keeps asking questions he can’t answer. He used to look forward to holidays but can’t see the point anymore. He has lost interest in most things, even sex. He can’t bring himself to talk to anyone about this, even and especially his wife. Things are tense between them.

He needs regular check-ups now but they are during work time and it’s difficult to get time off without telling his boss all his personal details. Sometimes at the clinic he feels he has let people down so he doesn’t always go. He likes the people there but he finds he doesn’t have the opportunity to ask the questions he would like to. He doesn’t know where else to turn for help. Sometimes he feels very stuck; he needs to keep working but finds he has little energy. At times he has thought that life isn’t worth living but is too ashamed to admit that to his family or anyone at all. He worries that his children will develop these problems too and feels guilty about this.

John’s life could be better than this. Read on to see how the implementation of a strategy for long-term conditions could help make things better for John.

When John was diagnosed and started on treatment he and his family got information on his condition and treatment. He chose leaflets that interested him and looked at a website that was recommended. He was told how to get new information throughout his life whenever things crop up and his condition and life
change. He and his family were told that this might include quality of life issues, e.g. travel, sexual health, and discrimination. They found it reassuring to know that other people had also had problems like theirs. He was also told that people can have an increased risk of depression and how to look out for this as well as where to get help.

John was offered an opportunity to attend a group that helped him set priorities for his health and believe that he can change things for the better. A self-management programme was offered along with a structured approach to education about his health problems and his treatment programme. The focus was on his priorities and how he can tackle them positively to maximise his quality of life. He also got information on the quality of care and support to expect, his test results and their implications and a key worker to contact if he has a problem.

He was offered the opportunity of flexible appointment times or drop-in services, after work or in different settings, for example close to work or in the more accessible town centre. John also received support and information to understand his rights in the workplace and where to turn for support if he needs advocacy advice or help.

John was informed of all potential services of support and information including support groups, lay mentors, help lines, web-sites and voluntary organisations and how to contact them.

When John met health professionals he was greeted and assessed as a person not as a medical condition and they also took account of emotional and social well-being. His healthcare professionals were up to date on condition-specific evidence-based care, screening and treatment for mental health problems such as depression as well as in empowerment techniques. They used active listening skills and because of this he also felt able to discuss feeling low and stuck. He was consequently referred to a counsellor who had skills in cognitive behaviour therapy as well as counselling.

John felt his team were working together with himself at the centre of the team, defining his own goals and priorities. He felt confident that he was able to improve his own health. He didn’t feel a failure when things weren’t so good and he knew who to talk to get support. His wife was also knowledgeable about his condition and able to support him constructively when he needed her to.
He attended regularly for follow up and negotiated time off work for this. His work colleagues were very supportive when he explained the support they could give him and the occupational health nurse was able to support his weight loss programme. He got information on health risks to his family from the voluntary organisation and enjoyed getting involved with a peer support programme; feeling that he was also benefiting whilst supporting others.

John’s health and relationships improved with the right support, information and networks.
LONG-TERM CONDITION CASE STUDY 3:

Isa, an older person with a progressive condition affecting decision-making

Isa was in her 70s and living alone when she started to have difficulties with day-to-day activities. Her daughter Joan first became aware of problems after her father died suddenly. Joan became concerned about her mother’s state of mind after her loss. She lived 80 miles away, but kept in close contact, phoning daily and visiting at weekends.

Joan was anxious that her mother seemed not to be eating properly, was forgetful and constantly losing things. She put it down to the bereavement, but when things didn’t improve she suggested Isa see the doctor.

The GP was sympathetic and arranged for Isa to see a specialist for tests. The appointment was for a day Joan had to be at work, so Isa went on her own. The specialist told her what was wrong. She told her that there was no cure, and that her condition was progressive. She said some other things as well, but Isa was in a state of shock and couldn’t remember anything beyond the bad news and that a social worker would be in touch. She went home with a prescription, but she wasn’t sure what the tablets were meant to do.

Joan heard the news from Isa. She had only a vague idea of what the diagnosis meant and didn’t know where to turn for information. The social worker did an assessment, but Isa told her she was coping fine – she didn’t like to admit to what she wasn’t managing. The social worker didn’t seem to know all that much about Isa’s diagnosis, but she arranged for meals on wheels.

Isa struggled to cope. For months Joan was on the phone to her five or six times a day, sometimes in the middle of the night, and visiting several times a week. It put a huge strain on her and her family. Isa kept forgetting to take her medication, and she didn’t think it was helping. Joan asked the social worker for more help but Isa refused it because she preferred Joan to help.

Eventually the travelling got too much and Isa moved in with Joan, who gave up work to care for her full time. It was not a success. Isa felt she’d lost her independence and got frustrated very easily. Joan found herself losing patience because Isa was slow at doing things. It was easier just to do it herself. She was often angry with her mother, and felt bad about it afterwards. Isa felt useless and
ignored and spent a lot of time sitting in her chair doing nothing. Isa’s condition got worse and new difficulties came up every week. Neither Isa nor Joan felt they had anyone they could talk to about how to cope with the symptoms or with the effect the illness was having on their lives.

Things came to a head when Isa had an accident in the kitchen and there was a fire. Luckily no-one was hurt, but Joan decided she couldn’t carry on. Isa moved into a care home. It wasn’t what she wanted, but she didn’t feel she had a choice.

Isa’s life could be better than this. Read on to see how the implementation of a strategy for long-term conditions could help make things better for Isa.

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

Isa asked for an appointment at a time when Joan could come with her, which was no problem as the clinic had evening sessions. After some tests, the specialist sat down with them both to explain the diagnosis. She said that she knew it would be a shock, and that they might not remember everything, and gave them clear information material to take away. She made a follow-up appointment for them with a link worker at the clinic, so that they could ask more questions and work out what to do next. She also prescribed some tablets for Isa and explained what they were for.

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

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

The link worker told Isa and Joan that they could contact her whenever they needed more information. A few weeks later she got in touch about a new group that was starting for people with the condition. The group would provide information about the illness and strategies for coping with the problems it could bring. It would also let Isa meet up with other people with the same condition, and she agreed to join. There was a parallel group for carers, which Joan joined.

The social worker arranged some services which helped a lot. They meant that Joan didn’t have to worry about whether Isa was eating or if she was safe. Isa’s condition did get worse but because they understood the condition, she and Joan found ways to cope with each new challenge. Sometimes they spoke to their link worker for help, and sometimes they called the helpline.

Both Isa and Joan were given the opportunity to have their say about the services in their area and how they could be improved. Joan couldn’t think of anything, but Isa said she’d like to walk to her day centre instead of going by taxi, for a wee bit of exercise. The day centre arranged for someone to accompany her twice a week, and she felt much better for it.

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