



LIVING WITH A LONG-TERM
CONDITION PROGRAMME

Improving health & enhancing quality of life

Impact Report

*Living with a Long Term Condition
Programme*

2016 – 2018



South
Derbyshire & City

Welcome to the Impact Report into the *Living with a Long Term Condition Programme*, delivered by Citizens Advice South Derbyshire and City (CASDAC) in Derbyshire since September 2016.

Here, we outline the positive impact this programme has had on the people who attended during the period September 2016 to November 2018, and the benefits this has brought to those close to them, their employers and their wider communities. We also highlight the benefits to health and social care services.

We describe the *Living with a Long Term Condition Programme*, what it does for those who attend and why it works.

We also outline the additional value that the volunteer tutors bring to their interactions with volunteers, each of whom have been through the programme and manage long term conditions.

You will find quotes throughout this document – from both participants and tutors – which bring to life the impact of the programme for those engaged with it.

In short, this is a programme that works. There is no doubt that people are living longer and with more complex and multiple health conditions. This means that pressures on statutory services can only increase.

Because we know that this programme works, and because we understand the very real need for non-medical interventions to support people with long term health conditions to live more positive lives, we want to expand this

offer and are seeking to increase referrals into the programme.

The benefits of this approach have been delivered to over 500 people at 54 courses held throughout Derbyshire since September 2016.

We want to bring these benefits to more people in Derbyshire, to increase the quality of life for this growing sector of the population, and to continue to alleviate pressure on carers, families and communities, as well as the health and social care professions.

We hope you enjoy reading about the impact of the *Living with a Long Term Condition Programme*, and can see the potential of broadening this service to others.

David Symcox
Chief Executive, Citizens Advice
South Derbyshire and City

Living with Long Term Health Conditions Programme –

Summary

In Derbyshire there are an estimated 180,000 people that have at least one long term health condition.

Caring for people with long-term health conditions accounts for:

- 50% of all GP appointments, with 33% being for people with multiple long term conditions
- 64% of all outpatient appointments
- 70% of all hospital bed days
- 50% of emergency bed days for over 75s

Of the total health and social care expenditure in England, treatment for people with long-term health conditions is estimated to take up around £7 in every £10 spent.

At the same time the impact for the individuals themselves and their families is huge; aside from the challenges associated with problems such as pain, discomfort and distress, managing one, or often multiple, long term health conditions can have a significant impact on a person's ability to work and their quality of life. This can also lead to social isolation and poor physical and mental wellbeing.

Since 2016 CASDAC's "Living with Long Term Health Conditions Programme" has delivered **54 courses in all eight districts of Derbyshire to 506 participants.**

The programme was successfully delivered by 24 trained and accredited

volunteer Tutors who provided over 2,700 volunteering hours.

Feedback from participants of the courses has shown:

- 87% enjoyed the course and would recommend it to others,
- Nine out of ten of the participants said they still used techniques learned on the course six months on.
- 75% felt more positive about themselves as a result of attending.
- One in six believed that, since the course, they had made fewer NHS visits and that medical appointments were now more meaningful,
- One in two of the participants reported that the course had helped to reduce or have a better understanding of the medication they were taking.

The map below highlights the locations where courses have been delivered:



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LONG TERM HEALTH CONDITIONS – THE CONTEXT

Although more people are living for longer, many are doing so whilst managing chronic or long term health conditions.

Long term conditions are defined as health problems *“that can’t be cured but can be controlled by medication or other therapies”*¹; they include conditions such as high blood pressure, arthritis depression and dementia. Around 15 million people in England are thought to be affected, with around two thirds of these having two or more long term conditions¹.

Translating this into the local context, an estimated 180,000 people in Derbyshire have at least one long term condition².

The number of people with long term conditions in our county will increase in future as the population ages.

Also increasing is the proportion of people that manage three or more conditions simultaneously.

The impact for the individuals themselves and their families is huge; aside from the challenges associated with problems such as pain, discomfort and distress, managing one, or often multiple, long term health conditions can have a significant impact on a person’s ability to work and their quality of life. This can also lead to social isolation and poor physical and mental wellbeing.

Although more prevalent in older people, long term health related problems are not solely a condition of later life; 15% of young adults ages 11-15 are estimated to have a long term condition¹.

Long term conditions are more prevalent in deprived groups, with people in the poorest social class having a 60% higher prevalence than those in the richest social class, together with 30% increase in disease severity¹.

There are also significant inequalities in relation to employment for people with long terms conditions, only 59% of whom are in work compared to 72% of the general population¹.

The cost of long term conditions to health and social care services is sizeable; the Department of Health and Social Care¹ estimates that care for those with long term health conditions accounts for 70% of the total money spent in these sectors in England and that caring for people with long term conditions accounts for:

- 50% of all GP appointments, with 33% being for people with multiple long term conditions
- 64% of all outpatient appointments
- 70% of all hospital bed days
- 50% of emergency bed days for over 75s

Of the total health and social care expenditure in England, treatment for people with long term conditions is estimated to take up around £7 in every £10 spent.

“The course content was great and helpful to a range of attendees - great fun too - thank you so much. What worked? Everything!! The suggestions were brilliant.”

Course participant

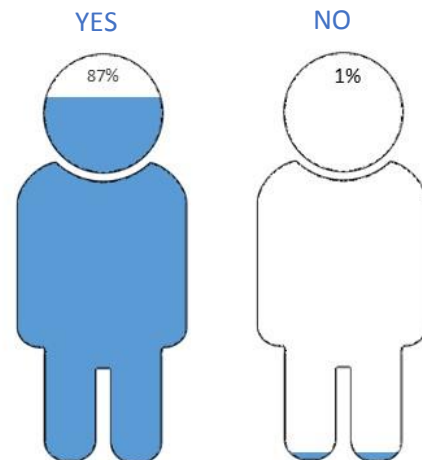
HOW DOES THE PROGRAMME HELP?

Known as a chronic disease self-management course' (CDSMC), Derbyshire's *Living with a Long Term Condition Programme* provides high quality self-management education to adults affected by a long term health condition. Over six weekly sessions, participants learn a variety of skills and strategies to help them manage their condition and enhance their quality of life.

Through understanding strategies to help with problem solving and goal setting, participants find that they have more control over their physical and emotional well-being. Complementing existing health care programmes and treatments, the aim of this course is to empower participants by enabling them to be more informed and thus better able to develop partnerships with their medical practitioners; it achieves this by:

- Providing self-care skills, enabling participants to understand better how to look after themselves and create more positive health outcomes
- Empowering participants to have greater control over their lives by generating increased confidence and understanding to better manage their conditions
- Equipping individuals with the knowledge to take their medication responsibly and appropriately.

Did you enjoy the course?



* 12% of participants did not respond

"I came through the doors week one as a disabled person. I am leaving on week six as a person with a disability."

Course participant

THE UNDERPINNING RATIONALE AND EVIDENCE

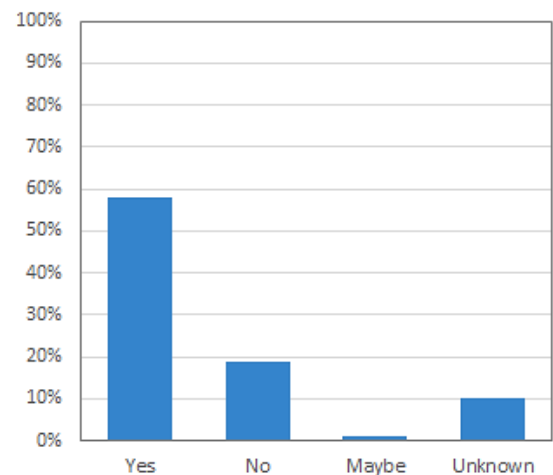
Based on the premise that the patients themselves are experts in their own health conditions, there is now an understanding that such knowledge and experience can be shared to help others improve their own quality of life and self-care.

The *Living with a Long Term Condition Programme* is founded on the Expert Patient programme developed at Stanford University, which builds on the experiences of people who have found a way to manage the impact of their long term condition(s) on their lives by managing their pain and stress, and by developing coping skills.

Uniquely, this expertise is then shared with participants through a structured programme of education delivered by teams of trained volunteers, all living with long term conditions.

Volunteer tutors delivering Derbyshire's *Living with a Long Term Condition Programme* all undertake the Stanford University accredited training and are regularly reassessed to assure continued compliance and quality standards.

Has the course information helped reduce visits to your GP or hospital, or made appointments more meaningful?



“This programme is a success not only because the participants are committed to making positive change, but because they are inspired and motivated by the volunteers who deliver the courses, and who themselves have used the programme to help manage their own long term conditions.”

David Symcox, Chief Executive, Citizens Advice South Derbyshire and City

WHAT'S COVERED AND HOW THE COURSE IS DELIVERED

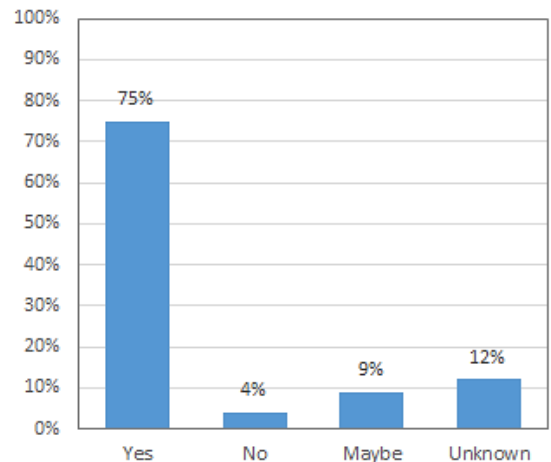
Held in community venues that provide a supportive and non-threatening environment, the course is informal, but structured. Each session is delivered to between 12 and 16 participants, with two tutors present to ensure good quality attention for all.

Those delivering the course create a careful balance between sharing information and strategies, and facilitating participation and discussion from attendees.

There's an emphasis on the practical application of skills which centre around individual action plans. These are developed by the participants themselves, and revisited every week, empowering people to take control of their long term health conditions and create lasting changes. Programme topics include:

- Problem solving
- Goal setting and action planning
- Relaxation and distraction strategies
- Fatigue and symptom management
- How to deal with emotions
- Exercise and healthy living
- Communicating with others
- Medication management
- Living wills and power of attorney

Do you feel more positive about yourself since the course?



“This is a ‘must have’ for anyone with a long term health condition. The tutors are wonderful and can empathise fully as they also have long term health condition. I feel able to use the ‘tool box’ confidently to help me with my daily living.”

Course participant

WHY DOES THE PROGRAMME WORK?

Because individuals with different conditions share many of the same problems; No matter what illness they live with, it is often the consequences of that illness that are more problematic than the condition itself. When you can't do what you used to be able to and your family and friends don't understand, anger, frustration, loss of job or mobility, depression and pain can so easily become a cycle of despair.

The *Living with a Long Term Condition Programme* moves beyond the purely medical model to look at how the illness impacts on daily life. Throughout the programme participants are able to discuss the barriers and challenges they personally face and are supported to use the tools provided to develop techniques to manage and overcome these.

There are also additional problems that people living with long-term health conditions face, such as an increased likelihood of claiming benefits leading to reduced income and problems with debts and housing. As a result of the Living with Long Term Health Conditions Programme being delivered by Citizens Advice South Derbyshire and City tutors of the courses can identify issues that participants are experiencing at an early stage and refer them into additional services the organisation offers, including advice services, which offers 1-2-1 advice and support on a wide range of issues. This ensures a fully holistic service is provided to all participants.

WHAT REFERRERS AND PARTICIPANTS SAY

Below are some of the reasons why the *Living with a Long Term Condition Programme* is believed to make such an impact on the individuals who undertake the training, from the perspective of the both the individuals themselves and the professionals who make the referral:

- A patient-centred group intervention; participants also benefit from peer support
- It has a sound evidence base and helps create 'activated' people
- Although professionals 'socially prescribe' the programme, participants choose to attend
- It develops knowledge, information, confidence and skills in people (KiCS for Life)
- The programme provides people with the skills they need to be able to manage their health budgets
- It is enabling and empowering, and helps people discover what's important
- The programme's outcomes are co-produced
- It enables people to engage in shared decision making and care planning
- It is a community centred approach that is quality assured

"I have really enjoyed my time on this course. I met some lovely people and learned a lot about self-management; I would recommend it to anyone in my situation. The tutors were all brilliant."

Course participant

LASTING AND POSITIVE IMPACT OF THE PROGRAMME

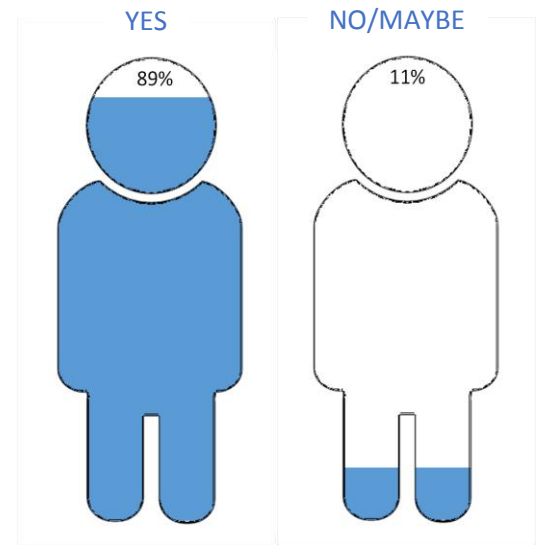
The long term benefits of attending Derbyshire's *Living with a Long Term Condition Programme* can be seen in the extract from the course the evaluation data shown below. From responses gathered from participants surveyed six months after course completion, it was found that:

- Nine out of ten of the participants said they still used techniques learned on the course six months on.
- 75% felt more positive about themselves as a result of attending.
- One in six believed that, since the course, they had made fewer NHS visits and that medical appointments were now more meaningful.
- 87% had enjoyed the course.

These findings echo those from research which show that people with a long term condition who have attended and expert patient training programme have:

- Improved energy levels
- Improved self-efficacy
- Greater confidence in dealing with their illness
- Experienced less pain, fatigue, depression and anxiety
- A greater likelihood of continuing with exercise and relaxation techniques

Do you still follow some or all of the techniques discussed in the course?



* 4% of participants did not respond

“Participants become more confident, more positive and happier as they begin taking control of their lives and conditions. They cease to be victims and move onto to be condition conquerors.”

Volunteer tutor

HIGH QUALITY TRAINING THAT GETS RESULTS

The *Living with a Long Term Condition Programme* is delivered by a team of 24 accredited volunteer tutors covering all areas of Derbyshire.

Because tutor training is delivered by lead trainers, certified by Stanford University, standards and consistency of training are assured.

Volunteer tutors undergo several assessments of their skills and abilities prior to accreditation.

MAINTAINING TUTOR SKILLS THROUGH ONGOING TRAINING AND DEVELOPMENT

Once accredited, quality of trainer skills are maintained through annual tutor assessments conducted by Stanford University assessors, and through quarterly training and supervision days where tutor skills are fine-tuned and best practice shared.

These quarterly training sessions furnish tutors with further skills designed to support practical delivery of the programme and covering issues such as problem solving, action planning, dealing with difficult emotions and safeguarding.

Tutor wellbeing is maintained by providing strategies to help them support programme attendees appropriately, and without 'taking on' individuals' problems.

ONGOING PROGRAMME IMPROVEMENT AND CONTEXTUAL RELEVANCE

Volunteer tutors are encouraged to talk about practicalities of the programme delivery and how it could be improved within allowable parameters of the Stanford University license.

Tutors are also given additional contextual training to make their training relevant to specific participants; for example, strategies to help people keep warm when delivering training to people with long term conditions as part of the Derbyshire Healthy Home Programme.



"Tutoring has been invaluable to me... It has given me confidence and a purpose in my life to reach out and support others going through similar experiences ...I continually learn from each course that I tutor."

Volunteer tutor

HOW TO SECURE A PLACE ON THIS PROGRAMME

Accessible to anyone who has a diagnosed long term health condition, and who needs help in managing the impact of this, people can refer themselves onto the programme by contacting the *Living with a Long Term Condition Programme* team.

We also receive referrals from a range of health and social care organisations, charities, businesses and community networks.

To make a referral, please complete the referral form which can be downloaded from:

www.citizensadvicesouthderbyshireandcity.org/living-with-long-term-health-conditions

Send completed forms marked 'private and confidential' to:

Living with a Long Term Condition Programme
114 Church Street
Church Gresley
Swadlincote
Derbyshire
DE11 9NR.

GET IN TOUCH

To ask about availability of places on forthcoming courses, to clarify how the programme works, or for any other queries, please contact:

Karen Ziglam, Project Co-coordinator

kziglam@citizensadvicesouthderbyshireandcity.org

01283 210107 or 07487 257187

REFERENCES

1. Long term conditions: compendium of information, 3rd edition. Department of Health, May 2012.
2. Derbyshire Health and Wellbeing Strategy 2012-2015. Derbyshire County Council, October 2012.
3. Rogers A., Kennedy A., Bower P., Gardner C., Gately C., Lee V., Reeves D., Richardson (2010) The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *Medical Journal of Australia*, 189(10):S21-23.

"We have seen first-hand the real, positive effects our work, improving the lives of those living with long term conditions."

David Symcox, Chief Executive, Citizens Advice South Derbyshire and City