

Peer Support in Long Term Conditions: The Basics

This document has been produced by the Mental Health Foundation (MHF) and partners¹ to support the implementation of peer support services for people with long term conditions throughout Scotland. This work is part of a larger project funded by the Long Term Conditions Alliance Scotland (LTCAS) to build capacity in peer support services for long term conditions.

This guidance builds on a two-stage research project undertaken by MHF from 2010-2011. The research found evidence of peer support activity for people with long term conditions across Scotland with positive impact on emotional and physical health, but that access to such services was patchy. Furthermore peer support services (all voluntary sector based) reported difficulties integrating with statutory services and felt they often lacked credibility in the eyes of potential referrers, especially clinicians and beneficiaries.

There is an increasing body of research and anecdotal evidence which demonstrates the benefit of peer support for managing long term conditions. There is a need not only to support increased access to this valuable and unique form of support but also to enhance the quality and impact of existing peer support throughout Scotland. It is hoped that this document will contribute to supporting NHS and voluntary sectors to work in partnership to develop services to address these needs.

This guidance is designed to support organisations currently delivering peer support or planning to develop peer support for people with long term conditions. It brings together good practice and guidance, based on research evidence as well as the experiences of experts in delivering peer support and those who have received peer support. This guidance is intended to provide a brief and concise starting point, to be accessible to a wide audience and is applicable across all long term conditions. Throughout this document links to further detailed guidance and sources of support are provided.

The guidance covers the following topics, the basic building blocks to developing and improving the quality of peer support services, which are:

- Background (what is a peer in long term conditions, the benefits of peer support, different models of peer support)
- Who benefits most from peer support
- The matching process
- Formalising peer support
- Roles and functions
- Confidentiality
- Clarifying boundaries
- Support and supervision
- Training
- Partnership working
- Sustaining peer support services
- Evaluation and monitoring

¹ Angus Cardiac Group, The British Heart Foundation Scotland, Chest, Heart and Stroke Scotland, Diabetes UK Scotland, NHS Lanarkshire, NHS Lothian, The Royal College of General Practitioners (Scotland), Waverley Care

What is a peer in long term conditions?

“If you have a long term condition you have so much in common with another person with a long term condition in terms of the emotional impact and challenges involved that you can identify as peers on that level.” (Interviewee Feasibility Study)

“Someone who has been through similar situations and problems as another person.” (Interviewee Feasibility Study)

There are two key elements within the peer relationship in long term conditions; the connections between those in the relationship and the quality of the relationship. Peer connections can be found on a number of levels; for example it might be a similar health condition, similar leisure interests, professional backgrounds, religious beliefs, social values, or age. One crucial area of peer connection is the capacity of peers to understand the impact having a long term condition can have on your life; for example what is like to live on benefits or to lose your job or have to give up working because of the limitations that a long term condition has imposed.

What is deemed to constitute a peer relationship will vary according to the individual requiring support and the care providers delivering the peer service. Key to the peer relationship however, is the development of empathy and trust. Identifying peer connections can increase the chances of facilitating a good relationship with empathy and trust as central components.

Further information about peer relationships in long term conditions: www.mentalhealth.org.uk/publications/exploring-peer-support/

The benefits of peer support

Research indicates that peer support can have multiple benefits, not only for the recipient and the giver of support, but also for organisations and systems within which the peer support is delivered. Individual benefits may include improved physical and mental health, increased life expectancy, improved knowledge about one's condition and better self-management skills. Providers of peer support may experience less depression, heightened self-esteem and self-efficacy, and improved quality of life. Organisations and systems may benefit from reduced health care use, increased uptake by hard to reach groups, greater service choice and improved cost-effectiveness.

Peers for Progress summarises some of the current research evidence for peer support: peersforprogress.org/scientific-evidence

Different models of peer support

Peer support can exist in many forms from informal friendships to more formal peer support worker services. Recent research scoping out peer support activity for people with long term conditions across Scotland categorised existing provision under the four broad models described on the next page.

Within some organisations multiple methods of peer support delivery may be offered to meet different needs.

The Australian Chronic Illness Alliance outlines some of the pros and cons to different peer support models here: www.chronicillness.org.au/peersupport/framework2.html

Who benefits most from peer support

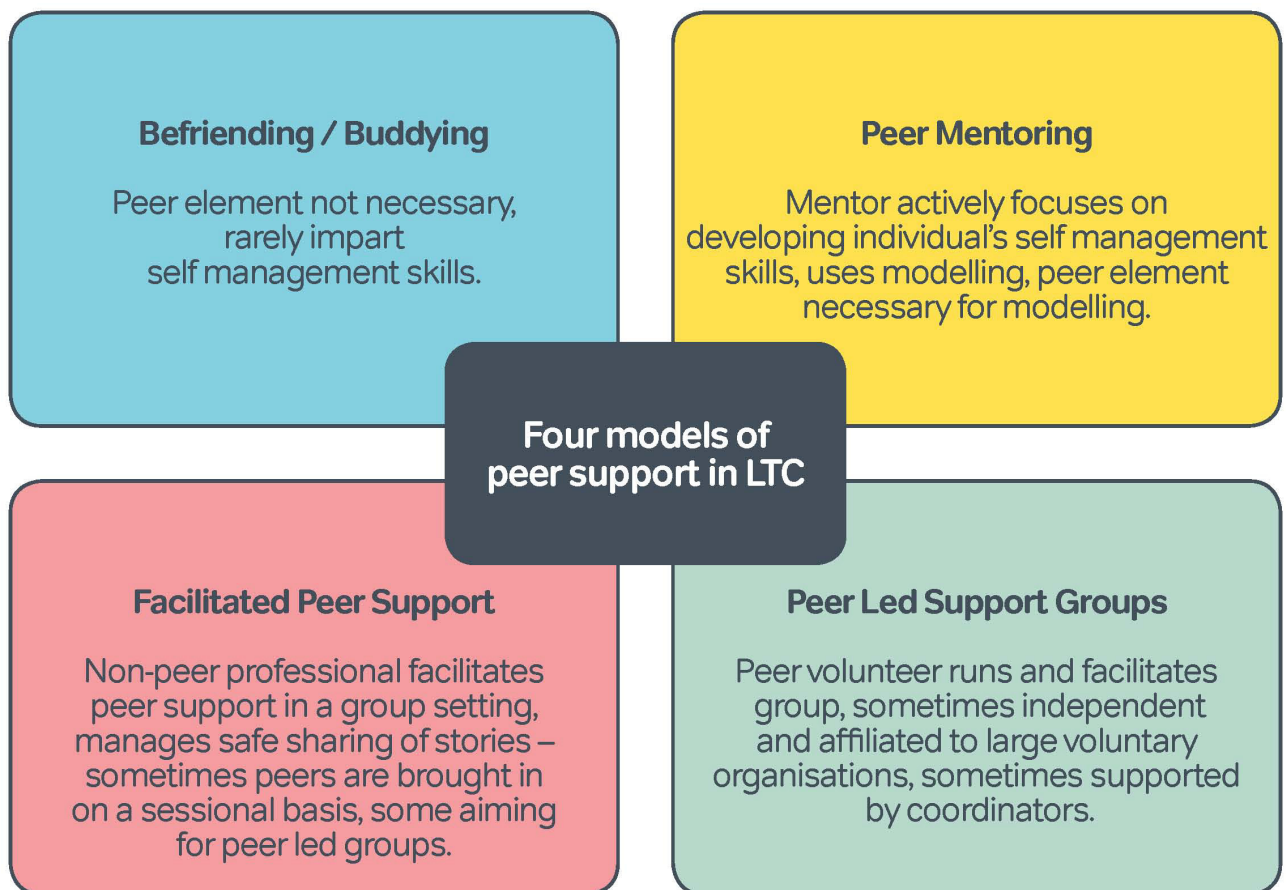
“There is something within each long term condition that will impact on an individual's mental wellbeing and merits support for self management and peer support.” (Interviewee, Feasibility Study)

Whilst anyone with a long term condition may benefit from participating in peer support, research indicates that peer support may be of particular benefit to the following individuals:

- Individuals with mental health needs, such as low mood, anxiety, stress or social isolation
- People who are socially excluded through poverty, unemployment or discrimination
- Individual who have been newly diagnosed with a long term condition and may be coming to terms with what impact this will have on their lives
- Individuals with low motivation to self-manage
- People who want or are ready to start rebuilding their lives
- People who want to continue their rehab
- People who need one-to-one support from someone who has had similar experiences

It is useful to recognise that some people are at the stage where they can be helped with peer support and some are not. It is also possible

² McLean J et al, 2012: www.mentalhealth.org.uk/publications/exploring-peer-support/



however that some people who may not feel at first that they are ready for peer support, buy into the idea once they have experienced it first-hand.

The matching process

The process by which individuals seeking peer support are matched with peer supporters is often described as an art rather than a science. There are arguments for and against matching individuals with peers based on a shared long term condition. Condition specific charities are often the route through which individuals find peer support, and through which volunteers are recruited. There are also some common experiences which can be shared by people who are living with the same physical condition.

However, in reality matching peers depending on their long term condition can be difficult, as many people have multiple long-term conditions, for example. One thing that people with long term conditions do often have in common is their mental wellbeing and there may be wider potential for creating positive matches based on that level.

It is clearly for individual peer support services to decide how best to match individuals to peers, but that said, there may be an argument for condition specific peer support in a number of situations, where the experience of a condition may be unique or raise particular issues and concerns. This could include:

- Mental illness
- Degenerative illnesses
- Gender specific illnesses that have gender specific impacts such as prostate cancer

It is also important that the worker responsible for matching gets to know the client a little as well as knowing the volunteer/peer before matching them.

Formalising peer support

Within the mental health field in Scotland considerable work has been undertaken by the Scottish Recovery Network, Scottish Development Centre for Mental Health (SDC) / Mental Health Foundation (MHF) and others to

formalise the peer support worker role, through producing guidance, standardised training and piloting paid peer supporter roles within a range of voluntary and statutory services.

Formalising peer support has been shown to enhance the credibility of the service with referral agencies, funders and beneficiaries. However, the extent to which peer support can and should be formalised will vary from service to service. What is important for credibility is that systems of training and support and supervision are agreed within services and are implemented on a consistent basis.

Further information about peer support pilots: www.scotland.gov.uk/Resource/Doc/291864/0089933.pdf

Roles and functions of peer supporters and coordinators

“A peer support worker helps coach people to cope better and move on to something more sustainable. Peer support workers do not tell people what to do but empower them to do it for themselves.” (Interviewee, Feasibility Study)

“Having spoken to many people over the years, if you can't speak to family or friends, a peer is someone you can relax with.” (Interviewee, Feasibility Study)

“There's something about working with someone who understands the impact of physical impairments (e.g. tiredness, difficulty going to the loo, living on benefits) on an individual's lifestyle and mental wellbeing.” (Interviewee, Feasibility Study)

“Users of our service find that the peers ‘get it, this is a huge advantage over non-peer professionals in providing emotional support.” (Interviewee, Feasibility Study)

Peers are often involved in a range of roles including:

- Providing one-to-one peer mentoring support
- Facilitating self-help groups
- Facilitating/delivering self-management courses
- Feeding in to the development of self management courses
- Training professionals about self-management
- Befriending

- Leading self help groups
- Acting as self-management champions
- Signposting to services and resources that can assist self-management and encouraging their use

The functions of peer supporters will inevitably vary from situation to situation, but will incorporate at least some of these dimensions:

- Providing an outlet for individuals to safely share their thoughts and feelings
- Helping individuals overcome their loneliness and reducing isolation
- Motivating and supporting people with their own self-management aims
- Providing a type of support that professionals cannot
- Helping people to accept their condition
- Inspiring people
- Preventing mental ill health and promoting positive mental health and wellbeing

Whilst promoting positive mental health and providing emotional support are two core functions of peer support for people with long term conditions, peer support workers have told us that supporting people to be mentally well is often one their key challenges, particularly where individuals develop or already have depression. In such situations specific experience and training in mental health may be necessary.

What competencies do peer supporters need?

The skills described below do not necessarily represent the skills that all peers currently have, rather they are a list of skills and competencies that would be optimum for a peer supporter to possess:

- Ability to self-manage their own condition
- The ability to demonstrate strategies for maintaining good emotional/wellbeing that can be shared
- Communication skills both in terms of using one's own experience productively and encouraging others to share their experiences
- Role modelling - using one's own experience of what has worked in terms of self-management
- Ability to empathise and show understanding
- Relationship management skills to establish

boundaries

- Motivational skills
- Needs assessment and goal setting skills, including recognising when it is not appropriate to undertake peer support
- Knowledge of the care system
- Peer matching

For further information about peer supporter roles, functions and competencies see: mypeer.org.au/design-implementation/human-resources/recruitment/peer-supporter-role-descriptions/

Co-ordination

Many peer support services recruit paid, non-peer coordinators or facilitators. The coordinators can be directly involved with the peer support service (e.g. facilitating a group) or have a more peripheral role (providing materials and telephone support). Coordinators may provide support to peer support workers in the following ways:

- Facilitating group discussions
- Providing support to peer volunteers by telephone/email
- Training peer support volunteers
- Making sure safeguards are in place to ensure that peer workers and individuals using the service are safe
- Attending and supporting peer group events
- Producing and updating materials to support the running of the peer group/service
- Management issues/resolving problems between peers within groups
- Coordination of services

Confidentiality

Although peer supporters may share information about their lived experience of long term conditions as part of their role, this should be done in a way that is appropriate to the context of helping others and controlled completely by the peer supporter. The disclosure of personal information about a peer supporter to colleagues should be fully controlled by the peer supporter.

It is important to develop clear policies and procedures and provide appropriate training for the peer supporters on protecting the confidentiality of recipients of peer support. In

some communities, people may come across the person they receive peer support from in a social setting; it is crucial that this is recognised and both peer and individual feel safe. It is also important to recognise that there may be certain circumstances, such as where there is a suicide risk, to break confidentiality.

My Peer Toolkit guide to confidentiality: mypeer.org.au/design-implementation/ethical-practice/confidentiality/

Clarifying boundaries and avoiding dependency

One potential pit-fall of non-trained peer support is the danger of a dependency relationship developing. This can occur where the peer adopts a 'saviour' role or where individuals want their peer to do things for them and to continue with them indefinitely.

Managing the potential for dependency, either from the individual or the peer is a key challenge for organisations offering peer support. To mitigate this, some peer services offer individuals the option to meet with a variety of peers. A balance needs to be struck between providing long term peer support that helps individuals to maintain their self management and providing people with the confidence to move on from and not become dependent on the peer support.

My Peer Toolkit guide to boundary management: mypeer.org.au/design-implementation/ethical-practice/boundary-management/

Support and supervision

The level of support and supervision required will depend on the model of peer support implemented. One-to-one peer support workers will need regular access to good quality support and supervision. Some common support needs for all types of peer supporters include:

- Support to help peers deal with mental health and emotional issues that come up during their support sessions and also the effects of offering peer support on their own mental health and wellbeing. For peers hearing things that trigger memories of their own difficult times can be very challenging. It can also be challenging for peers to use their own stories and to be asked to share these with professional staff.
- Support to enable peers to keep managing their own conditions

Wales Council for Voluntary Action's guide to

support and supervision for volunteers: www.wcva.org.uk

Training needs

Most peers working in long term conditions have received some form of training; often volunteering training, but rarely peer support specific training and rarely mental wellbeing specific training. Our feasibility study identified a training need within organisations to support their understanding of peer support and enable the development and delivery of high quality peer support services. To address these gaps, two new training courses have been developed as part of this project:

- Peer Support in Long Term Conditions: Making it Happen – a 1 day course to provide an understanding of peer support in long term conditions for organisations, commissioners and practitioners developing or interested in developing peer support services
- The Principles and Practice of Peer Support in Long Term Conditions – a 2 day course aimed at peer support workers and co-ordinators to develop their knowledge, skills and confidence in delivering peer support

Other training courses which may be of benefit to peer supporters and service managers:

- safeTALK and ASIST – suicide awareness and intervention training: www.chooselife.net/Training/index.aspx
- Scotland's Mental Health First Aid: www.smhfa.com/
- Thistle Foundation Lifestyle Management Programme: www.thistle.org.uk/our-services/health-wellbeing/lifestyle-management
- Befriending Networks Training Programme: www.befriending.co.uk/trainingandevents.php
- SCVO Training Programme: www.scvo.org.uk/training-employability/scvo-training/

Partnership working

Good partnership working between peer support services and the wider health and social care sectors is important to the successful delivery of peer support services, particularly with regards to appropriate referrals to and from peer support. Evidence suggests, for example, that many individuals are more likely to use a service if they have been referred to it by a professional working in statutory services or

even if the professional appears to support the organisation.

Unfortunately at present peer support services for people with long term conditions tend not to be well integrated with the NHS. Often there is a credibility issue at stake here, whereby clinicians may not understand or value the role of peer support in supporting people with long term conditions. They may also have legitimate concerns about the quality of service they are referring individuals to.

It takes time to gradually build up an appreciation of the value and safety of peer support amongst clinicians and other professionals. Ensuring the service is of good quality, gathering and distributing evidence of impact, and providing (appropriate levels of) feedback to clinicians about their referrals can all help to bolster relationships and encourage clinicians to refer.

The Links Project report provides useful information about how links between primary care and voluntary and community resources can be enhanced and developed: www.scotland.gov.uk/Resource/0039/00393257.pdf

Sustaining peer support services

Recruiting volunteers with the right skills and retaining volunteers and volunteer co-ordinators can make it difficult to sustain peer support services. It is important that all peer volunteers receive adequate support and supervision in order to support their continued involvement and avoid burn-out.

It is also possible that peer services can become 'stale' and resistant to change, which may limiting their attractiveness to new members. It may be that a more formalised approach, with some central direction and links to other similar groups may help to overcome this issue.

Attaining on-going funding for services is another obvious component of sustainability. Peer support services are currently funded through a range of voluntary or statutory sources, all with their own criteria. But obtaining good quality evidence about the impact of the service will help to bolster any service's potential for obtaining further funding.

The National Council for Voluntary Organisation's Sustainable Funding Project: www.ncvo-vol.org.uk/advice-support/funding-finance/sustainable-funding/sustainable-funding-project

Evaluation and monitoring

It is important that peer support services are subject to ongoing monitoring and evaluation processes to provide evidence of the service's effectiveness, reach and impact on participants. Having robust evaluation systems in place can not only help to maintain and improve the quality of peer support services, but they can also act to enhance the credibility of services with referrers and funders.

Whilst implementing evaluations from scratch can be a daunting process, there are a number of free resources available online to help organisations plan and implement service evaluations.

Health Scotland in partnership with the Scottish Development Centre for Mental Health (SDC) produced a series of four evaluation guides to support projects with broad mental health improvement goals to evaluate themselves. The guides cover evidence based practice, developing indicators to gauge success, planning and implementing evaluations and interpreting results. There are also case studies available describing examples of evaluation methods used by mental health improvement projects across Scotland: **www.wellscotland.info/evidence/resources/index.aspx**

Further information

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