A scope of peer support interventions for people with long term conditions living in Leeds



CONTENTS

1.0	Introduction		1
2.0	Evidence base for peer support		2
3.0	Learning from other programmes		
4.0	Methodology		6
5.0	Limitations of the data Key findings 6.1 Valuntary and Charity Sector Led/Affiliated Boor Support		7
6.0	Key findings		7
	6.1	Voluntary and Charity Sector Led/Affiliated Peer Support	8
	6.2	Carers	9
	6.3	Marginalised and vulnerable communities	10
	6.4	Local branches of national programmes	12
	6.5	Statutory led organisations	12
7.0	Final conclusions and recommendations References		12
8.0			14
Appendix 1	Mapping of peer support groups		
Appendix 2	List of peer support groups		17

1.0 Introduction

Leeds City Council's Public Health Team identified there was a gap in knowledge around what Long Term Condition (LTC) peer support interventions existed in Leeds; formal and informal. With a timescale of 8 weeks, the focus of this exercise was to provide an in-depth scope into different peer support groups offered, to help inform future public health commissioning and service design planning.

The objectives of the scoping exercise were to:

- Scope current provision of peer support for people living with LTC's in Leeds.
- Clearly map out the current provision and gaps in provision of peer support for people living with LTC's.
- 3. Review the evidence base and learning from other areas.
- Identify the need and requirements of peer support across Leeds to ensure sustainability.

Our charity, Health for All, has worked across Leeds for over 25 years to support the health and wellbeing needs of vulnerable and marginalised communities, and has successfully developed strong connections and effective methods for engaging with these communities, who are often 'hard to reach' by health professionals. Our community development skills and experience placed us in an apt position to take this work forward and to shed light on groups at a local level that may otherwise remain undetected through traditional enquiry routes.

Peer support is receiving significant attention through policy movements as a way forward to reduce the burden on the public purse, and help people in society to better self-manage their chronic conditions. It is distinct from other forms of social support, in that a peer has similarities around lived experience with the recipient of the support, thus the relationship is built on equality. Mead and MacNeil explain that peer

support has been defined by the fact that people who have like experiences can better relate, and can consequently offer more authentic empathy and validation. It is also not uncommon for people with similar lived experiences to offer each other practical advice and suggestions for strategies that professionals may not offer or even know about (p.4. Mead and MacNeil, 2006). The World Health Organisation further stipulates that peer support can be provided on a formal basis with paid 'specialist' trained peer group facilitators or on a more informal basis with volunteer peer specialists (Funk and Drew, 2017).

Yet peer support is a not a new concept. Various forms of peer support have been in operation since the 1970s; its roots can be found in the mental health social movement, where mental health service users empowered began to help each other and advocate for themselves and their peers. From these roots, peer support movements gained momentum and we saw applications in chronic disease management very quickly (Tang, 2013). Today in the UK, across the whole system there is recognition of the value and contribution peer support brings to the health and social care agenda. Our review of the existing evidence into the impact of peer support interventions for people with LTCs has shown that more needs to be done to highlight the benefits being realised.

As you will see from this report, the term peer support is not always used in a group's name or its written description. For the purpose of this scoping exercise, we shed light on all forms of peer support, to include those that are peer/user-led, staff-led (without a peer identity), or the focus is on another activity such as social or art based activity but peer support and/or self-help – where there is a shared need in relation to better management of a LTC – is an important feature. Due to the timescale of this project it was not always possible to enquire/seek clarity on which groups were exclusively peer led or staff led. Where the information was easily available, we have captured it in the detail in Appendix 1.

2.0 Evidence base for peer support

There is a substantial body of research and evidence which demonstrates the benefit and value of peer support for managing long term conditions; not only for individuals but for the whole system. Think Tank Nesta and National Voices offer the most up to date systematic review of studies that report on the outcomes of peer support and effects on people's experiences, behaviour, health outcomes and health service use. The top three most useful types of peer support interventions for improving emotional and physical wellbeing were considered to be:

- Face to face groups run by trained peers which focus on emotional support, sharing experiences, education and specific social and exercise orientated activities. Running groups regularly, such as weekly for at least three months has been found to work well.
- One to one support offered face to face or by telephone, with a range of provision including but not exclusive to information provision, emotional support, befriending and discussions. This type of support is likely to be reciprocal if it involves volunteers rather than paid peer support facilitators.
- Online platforms such as discussion forums.
 These have been found to be particularly useful for improving knowledge, reducing anxiety, though their use may be for a limited time only rather than a long term strategy for support.

National Voices and Nesta (2015)

However, the review concluded that research around cost-effectiveness is limited but crucial if we are to make sound decisions for future commissioning of peer support interventions (National Voices and Nesta, 2015).

Another report by Nesta brings together learning and evidence and proposes four models for the delivery of effective peer support:

- Activity-based peer support where people learn new skills or share practical experiences in ways that create a context for mutual support between people with similar problems.
- One-to-one support that is dedicated help offered on the phone and/or face to face by someone who has experienced similar circumstances, often sharing the same longterm condition.
- Befriending through an informal but intentional relationship that may or may not centre around similar experiences, often to support a transition from one stage of recovery to another.
- Locality-based peer support organised around a community hub or neighbourhood and focused on building strong, supportive and sustainable social connections.

Temperley et al. (2013)

Nesta's evaluation of the British Lung Foundation's volunteer-led Integrated Breathe Easy groups has shown that people with COPD who attend groups obtain knowledge, skills and confidence that help them to stay well. Being involved in Breathe Easy programme appears to increase wellbeing and reduces the likelihood of medical emergencies and crises (Nesta, 2016).

These outcomes are consistent with other academic work that looks at what constitutes best practice in terms of how to support people to better manage their LTCs. A review of the evidence carried out by the Kings Fund concludes that access to information and education about self-management is vital, and peer support in the community and voluntary sector was an opportunity for this. The third sector was considered to play quite a large role in terms of early intervention and support. It was suggested that psychosocial and psychological interventions at an early stage, can decrease admissions to hospital (Goodwin et.al, 2010).



A study conducted by the Institute for Public Policy Research, with people living with LTCs explores what type of control and support patients want to better self manage their condition. Peer support emerged as one of the key recommendations, as a significant proportion of study participants stated that peer support and coaching would be useful (61% and 58% respectively). Around half of these respondents thought that peer support (33%) and coaching (29%) would be likely to reduce their use of clinical services. It is interesting to note that all study participants were recruited via an online social networking site 'Health Unlocked,' - an online platform for discussion for people UK wide - however when questioned about their attitudes around apps and devices for condition specific advice and information, there was very limited interest (McDonald, 2014).

Looking at the role of online technologies and their potential to connect virtual communities, we looked at studies seeking to determine effectiveness of such approaches. A longitudinal study assessing a chronic-disease self-management programme offering online support, considered a range of health status, behaviour and service utilisation measures and reports statistically significant improvements (to varying degrees) around health distress, selfrated health, illness intrusiveness, fatigue, pain and shortness of breath, aerobic exercise, stretching exercise, stress management and communications with physician, GP visits, pharmacy visits and PT/ OT visits. Self-efficacy and satisfaction with the health care system also improved. The peer-led online programme appeared to decrease symptoms, improve health behaviours, self-efficacy and satisfaction with the health care system and reduce health care utilisation up to 1 year (Lorig et al. 2008).

These findings challenge earlier research and demonstrate how health seeking behaviours have evolved over the last decade with technological advances; a systematic review of the effects of online peer to peer interactions for health related virtual communities and electronic support groups concluded that no robust evidence was available

to support the effectiveness of online peer to peer communities in 2004 (Eysenbach et al, 2004).

A randomized controlled trial looking at the impact of peer support for first-time male cardiac surgery patients concluded that dyadic approaches can bring about positive outcomes. The study reported a reduction in anxiety and higher levels of self efficacy and uptake of physical activities post-surgery. Peer support was considered to be a valuable tool for people recovering from and better managing their conditions (Parent and Fortin, 2000). The work of Fisher (2014), although America based, similarly asserts that there is merit in a peer support approach for post-operation patients, such as those recovering or managing cardiac or cancer events etc. Fisher (2014) suggests patients are more likely to respond to recommendations from peers or coaches, and also share their information with a peer. For example, where an individual has grown tired of taking a particular medication, something they may be reluctant to tell a doctor or a nurse, may be shared with a peer who could encourage compliances in an empathic non-judgemental manner.

Funded by the Department of Health, the University of Worcester, and Association for Dementia Studies reports on a pilot with 22 schools, delivering information to teachers and pupils with a focus on 1. Understanding dementia; 2. Caring for someone with dementia; 3. Assistive and digital technology and 4. Meeting someone with dementia. The evaluation for the pilot is very promising and highlights the potential benefits that can be achieved with an investment of this nature. School children are the people of our future and have a pivotal role to play in developing sustainable and inclusive dementia-friendly communities; hence the need for settings based approachs that engage schools (Atkinson and Bray, 2013).

Peer support and opportunities to gain accessible information and break down myths and misinterpretations of dementia is considered paramount for some BME communities. Moriarty et al (2011) report on an example in a Chinese

community, where negative perceptions of dementia resulted from poorly-translated terms which give dementia the meaning of 'lost intelligence disease'. Engagement with health and social care services is often resisted or delayed by some BME communities because it is considered shameful to use an external source of support outside of the family network. Rauf (2011) highlights that Islamic, Hindu and Sikh cultures consider the duty of care as a 'test from God'. Some communities also regard it as a punishment for past misdemeanours. There is an urgent need to address these unique issues and barriers some BME communities face; engaging community and faith leaders may be a way forward.

A tool published by NHS England brings together components that lead to effective peer support. They ask you to consider, does the peer support:

- Ensure services are co-produced; take an asset-based approach; listen to what participants
 want and need; ensure that people with lived
 experience are driving the service; establish
 a culture of reciprocity; target the service
 towards wellbeing and recovery (if applicable);
 incorporate learning around behavioural insights,
 e.g. EAST framework?
- Functional elements assist people in daily management of their condition; provide social and emotional support to encourage management behaviours and coping with negative emotions; provide ongoing support because chronic disease/disability is for the rest of a person's life; facilitate linkage to clinical care and community resources.
- Good peer support and positive outcomes

 improve quality of life; improve patient
 experience; lead to fewer crises and unplanned
 hospital and institutional care.

(NHS England, 2017)

Furthermore, Peers for Progress, working internationally to build the evidence base for peer support in terms of feasibility, reach and engagement, effectiveness, sustainability and spread and adoption, highlights four key functions for effective peer support – but requires flexibility and adaptability to group and local context:

1. Assistance in daily management:

- a) particular skills e.g. cooking skills
- b) overcoming barriers
- c) regular encouragement/reminders e.g. text prompts.

2. Social or emotional support, opportunities for encouragement:

- a) space to talk about wellbeing or issues
- b) concerns that people feel uncomfortable raising with professionals
- c) offer variety of settings e.g. one to one and group.

3. Facilitate linkage to clinical and community resources:

- a) signposting to resources
- b) locating interventions in other settings
- c) drawing on professionals as appropriate e.g. sessions on disease management.

4. Ongoing support:

- a) flexibility around meeting times
- b) encouraging informal support e.g. Facebook group, WhatsApp
- c) allowing a group to evolve according to patients wishes.

Peers for Progress (2018)

3.0 Learning from other programmes

The Q Improvement Lab, drawing together professionals from a range of disciplines, is working to consolidate ideas and experience on a national level to highlight what it takes to develop effective peer support to help people in their management of long term health and wellbeing needs. Still in the final stages of completion (available Summer 2018) the findings from this research will be a valuable resource for stakeholders wanting to learn about tried and tested ideas and experience, and can be adopted by organisations and commissioners across the health and care system (The Health Foundation & NHS Improvement, 2018). The Health Foundation (2012) shares an example of how a hospital based self-management programme following a cardiac health issue led to a successful community-based peer led self-management programme, offering physical activity opportunities and advice for older BME men and women in an informal and accessible way.

The Dementia Engagement and Empowerment Programme (DEEP) is a movement with national reach, connecting, involving and influencing groups of people with dementia – groups where people with dementia are working together to raise awareness about dementia. DEEP is also seeking to reach policy-makers and decision makers, to influence at both a delivery and strategy level and advocate for change in the way people think about dementia. The evaluation of this network offers commissioners a unique insight into the benefits that can be achieved by engaging and empowering people living with dementia to join with other groups and start to influence and shape political agendas (Litherland, 2015).

South London's Health Innovation Network offers a comprehensive resource pack, consolidating examples of good practice and evidence based guidance on peer support, to help groups and organisations better support people with dementia in their communities. The key principles they consider

to be important when setting up peer support groups are:

- Written materials: accessible, simple language that is easy to understand and sensitive in the choice of words.
- Venue and Environment: consider the physical environment in which a group will be held.
- Activities: provide mental stimulation; encourage social connections; help people remain active and learn new skills.
- Staff/Volunteers: Good facilitation (paid or unpaid) is crucial to the success of any type of group.
- Evaluation/Feedback: Organisations with a social purpose increasingly have to evidence the added value of their work to funders and commissioners.
 Gathering feedback around effective ways of working, impact and outcome data can help develop the business case for funding.
- Funding: grants for community groups are widely available.

Further guidance for commissioners on developing effective peer support states that the information that should be considered when setting up peer support is how people get referred; aims and expected outcomes; requirement for peer support organisation to signpost /refer to relevant services; how many sessions are provided in a course of peer support, and over what time period; exit strategy – how people are supported at the end of their peer support course; how to meet the needs of people from Black, Asian and minority ethnic groups; how to monitor quality (feedback forms); reporting requirements – such as activity data and reporting on protected equalities characteristics (Health Innovation Network, 2015).

Health Improvement Scotland shares an insightful case study, showcasing the journey of a client diagnosed with COPD and the need for localised programmes of support once formal structured peer support groups end. Enlisting support from local councillors, GP practices staff and charities, an

individual successfully set up training for leisure staff in respiratory disorders and helped set up appropriate physical activity classes for people with respiratory difficulties. Recognising that patients have differing needs, the individual went on to work with GP staff, negotiated the use of meeting space and successfully set up peer support groups in GP practice settings. People had an accessible and supportive environment for learning breathing exercises and how to control exacerbations, discussion and socialising. Sending out newsletter articles to practice patients proved to be a successful strategy for raising awareness. The individual concludes 'Being diagnosed with COPD can make you feel so isolated, but people have told me that our groups have allowed them to really get their lives back. They're a source of support, reassurance and empathy. A place where you can share issues and help one another. Above all it's a chance to have a cup of tea, chat and make friends', (Health Improvement Scotland, 2011).

4.0 Methodology

To be eligible for the current scoping review, the data collection phase looked at adults across Leeds (>18 years of age) with a focus on the following long term conditions: cancer, heart disease, hypertension, stroke, chronic respiratory diseases (asthma, sleep apnoea etc.), diabetes, inflammatory bowel diseases, multiple sclerosis, neurological disease, arthritis and osteoporosis. The area of mental health was excluded on the basis that a review of peer support has already been conducted by expert agency Mind. The ground work was carried out by a team of experienced and dedicated community outreach workers employed by Health for All who are well versed in data collection techniques and also possess a range of community languages; they also helped inform the development of the data collection template.

The workers initially approached service users affiliated with the 50+ groups facilitated, delivered and co-delivered by Health for All, to start building a profile of what people rely on for support and enquiring about other services being accessed by friends and family who are experiencing a LTC. They utilised databases held by Voluntary Action Leeds and Leeds Community Foundation to identify voluntary sector agencies and carried out telephone, email and face to face enquiry to follow up people who had experience of facilitating or attending a peer support group in Leeds. Through Health for All's work with marginalised communities, we know that peer support can often happen on a small scale, with a shared culture and background becoming a more prominent feature of the group and the LTC becoming a secondary focus. We ensured that groups were not excluded from this study based on the term 'peer' not featuring in their title or description.

Four focus groups have been carried out and the data has been presented as case studies in the report, to highlight what is working well in different areas and settings in Leeds, and where there is need that will ensure sustainability in the future. (Case Study 2 is an anomaly; the data has been extracted from published material available on the Alzheimer's Society website).

The scoping review also undertook a literature review of the evidence and best-practice guidance across the UK.



5.0 Limitations of the data

This report is not a complete picture of the coverage of LTC peer support in Leeds, but rather it seeks to demonstrate the types of support available for residents. There will be gaps due to groups closing and opening; funding coming to an end; change in providers/timings/venue etc. Other gaps may include informal small peer support groups that have not been captured, as they are primarily described as a provision for the social and holistic health needs of individuals and the LTCs may be hidden.

Completing the work in 8 weeks was also a challenge. Additionally, as this period fell over two public holidays and school holidays, the field workers found that some groups were closed, therefore face to face enquiry was compromised.

GP staff did not have time to talk through what was being offered; a questionnaire/survey approach may have enabled better engagement in this case. Additionally, staff who answered the phone were not always knowledgeable about what face to face support was available for patients in their practice or were too busy to talk. Some groups running once a month were missed because they fell outside of the field work period.



6.0 Key Findings

The data was organised under a number of categories based on the different forms of peer support we discovered. We have tried to identify the nature of peer support groups that exist and their key characteristics, and this will help inform commissioners of key functions, gaps, and areas that require more attention.

The most common form of support was a face to face approach, which is consistent with the evidence base around effective forms of peer support (Nesta, 2015). Most of the groups that we found during this scoping exercise appeared to offer regular ongoing support - especially those delivered or affiliated with a VCF organisation, as opposed to a one off structured course/support as found in clinical settings. This is encouraging as the evidence base suggests groups that convene frequently appear to offer better outcomes (Nesta 2015). The use and value of other approaches such as telephone, email, and online chat were less clear. Most of the groups we visited talked about hope, encouragement, mutuality, respect and improved wellbeing as some of the key benefits of being part of a group.

Gentle exercise is now recommended by the government as part of a plan for managing chronic pain. We know there are both mental and physical benefits of exercise as it can be a distraction from pain. It was really encouraging to find that many of the groups we came across were offering a range of physical activity interventions, at varying levels of intensity from yoga to aerobic groups. In the focus group with a peer support group based in a GP practice, people talked about being frightened about exercise and there was a lack of consistency around guidance for 'bed rest' especially in the case of back pain and joint pains in the legs. There is need for better guidance from health professionals around rest and when to start gentle exercise, as we know that muscle wasting and subsequent stiffening of joints after prolonged periods of rest can exacerbate pain in the long term.

We were unable to identify any peer support groups for LTC management amongst vulnerable groups such as Gypsies and Travellers and LGBT communities. There is clearly a gap in service provision here that requires attention.

Within the hospital and GP environment, groups were being offered a safe place to meet others with shared experiences, and the main focus was on the delivery of topic specific information and skills for better self-management of conditions.

A small number of independent groups were found, with most of them situated in North Leeds and the rural suburbs.

6.1 Voluntary sector and community based support

Whilst many manifestations of peer support exist, we found that to a large degree, whether they were formally or informally recognised as a peer support group for people with LTCs, the majority of groups we came across were embedded within VCF sector organisations; around 80% of groups we captured can be identified under this category. Some were physically based in the building/premises affiliated to the organisations, others were based in community venues, but the facilitator/ worker was paid for by the organisation. We were not able to make distinctions around how many groups were exclusively user-led and organic in nature, as opposed to groups being led by organisations, due to issues around gaining face to face contact.

Of the vast number of support groups being delivered at a community level, many had been set up on the premise that they offered social activities; service users identified with a range of LTCs, but it was not the primary reason for why they attended a group. A majority of these groups did not have access to formal training or information around their LTCs or onward

referral to any external services, but peers did appear to gain health benefit from the activities they engaged in. Take for example the following group:

CASE STUDY 1

Middleton Minstrels: The evolution of a peer support group for women living in and around Middleton, South Leeds (affiliated with charity, Health for All)

What have been the benefits for group members?

It's a safe space for shared experiences and feels very welcoming.

Informal support outside of structured support sessions

Crèche facilities have enabled me to come as they are free so I don't need to struggle with childcare.

It's helped build my confidence, self-esteem and all my stress disappears when I'm here. The singing helps me to relax and I'm able to focus and really immerse myself in the activity and forget about my condition.

The singing helps me forget my pain. I live with cerebral palsy and it makes me feel hetter

Coming to the group reduces my blood pressure.

Nobody is any more powerful than anybody else we all treat each other with respect and that's what keeps me coming to this group.

What is really significant about this group?

Thoracic breathing really helps with my respiratory condition as it helps exercise my lungs. My nurse told me it was good for me and I enjoy singing so I was chuffed to find this group on my doorstep.

Peer support groups in Leeds affiliated with a VCF organisation appear to be successful in part due to the non-hierarchical, reciprocal relationship that is borne when there is similarity in shared life experiences. People's accounts – as described in the case studies - of what it means to be part of a group highlight the range of benefits being achieved; psychosocial outcomes and increased confidence and self-esteem are surfacing as the intrinsic measures of success. The offer or delivery of training around LTCs was scarce amongst groups organised under this category. Some groups were being led by paid staff and others were being led by peers/volunteers with their own grant funding. The organisation was often seen as providing venue space or worker support on an ad hoc basis to the group.

6.2 Carers

We know that there are a large number of people acting as primary and unpaid carers for people experiencing a long term condition. As part of our enquiry work, we spoke with the Development Manager at Carer's Leeds; the details are captured in Case Study 2. The experience of care giving can be overwhelming and have a bearing on relationships, social isolation and people's lives; therefore peer support is crucial and is having a positive impact on the health and wellbeing of group beneficiaries. Peer support groups for carers in Leeds offer ways of coping, opportunities for information exchange, social support, activities to increase physical and mental vitality and a safe environment to share stories/experiences.

CASE STUDY 2

Carer's Leeds: Worker's account of what their peer support groups offer for carers of people with dementia.

What are the key benefits of the groups?

The 3 key things people can expect when they come to our group are a short break, peer support and being looked after. Being looked after is really important because carers don't always get this in their day to day lives. We offer them a really nice venue, there are always nice refreshments – not just the cheapest you can get, and it's always served to them. If people want to help we don't say no, but the whole idea is that people come and they get cared for and looked after by a member of staff. The groups don't usually have an agenda, people come to chat and socialise, but sometimes we have external people booked in to deliver things like therapy, relaxation

etc. Socialisation is particularly important for our older carers who are isolated. The really important thing to note about our groups is that they do what it says on the tin. We always deliver, people trust us to run the group every month. We are reliable, and there is attention to detail; we contact everybody in advance to remind them that the group is happening. This is really important as people's day to day lives can be unstable due to the nature of the issues they are dealing with.

Are there any limitations?

The only limitation could be timings. Groups run on the same day at the same time every month. We don't really offer many groups during the evening; we find that day time works for people as they are able to book respite care for the people they care for.

6.3 Marginalised and vulnerable communities

Peer groups where there is a shared background, culture and language appear to be really important and valuable for BME communities in some of the groups we discovered. The following case study is an example of how peer support is being delivered successfully for a group of mixed South Asian men and women:

CASE STUDY 3

Hamari Yaadain (which means 'our memories' in some South Asian languages), a monthly dementia café for people in Harehills, run by charity Touchstone. The group brings a mix of men and women from South Asian backgrounds with dementia, carers and relatives together.

Listening and talking: "I like being invited to groups where I can talk about my experiences"; "listening is as important as talking". The worker is of a South Asian background herself and described as a 'key person' and "concerned with everybody's needs".

Mood lift: One member accompanies his wife, who has Alzheimer's, to the group. 'When we come in, she's a bit on the low side. But we spend two hours here and her mood changes,' he says. 'We used to feel lonely back home – loneliness is a big disease. The group is like a family. I find it very helpful coming here. The staffs speak our language, they understand."

Nobody knows: Members talk about there being a lack of understanding about dementia among South Asian communities. One person comments 'Nobody knows about dementia – we hadn't heard of it. Being at the group helps the family to better understand what his father is experiencing. It also allows his father to meet people who have life histories that he can relate to. 'Dad realised that there are friends here who can relate to him – to his days in Africa,' he says. 'He made a connection straightaway with people who could understand what he was saying.'

Mother tongue the worker says it's crucial that the group's activities are planned around the specific needs of its members: 'Groups like this one are really important for people from black, Asian and minority ethnic backgrounds,' she says. 'It's run in their mother tongue so people feel comfortable'. "It's the only group that most of them go to, because of the language and the culture. It's about bringing people together and making them feel more comfortable talking about the issues they are facing" (extract taken from Alzheimer's Society Living with Dementia magazine)

We were not able to identify many groups in primary care settings; reasons for this have been outlined in section 5.0 of this report. The groups we were able to identify were all being held during normal working hours and delivered within the GP practice environment, with a focus on topic specific courses for patients. A number of practices have key information around a number of long term conditions available for their patients on their website. Below is an example of one group that is being delivered at an East Leeds practice:



CASE STUDY 4

Humzoli (meaning Together Friends) is an independent group based at Conway Medical Centre, for Pakistani women who are pre-diabetes and some members identify with early signs of dementia. Below is feedback from the group facilitator.

How did the group come together?

Need for the group was identified by the practice manager. She noticed that there was a lack of accessible information for South Asian women patients who had limited English language skills. She asked women if they wanted to access a support group and the group was born. It started with a few women attending but through word of mouth group membership has grown.

What have been the benefits for group members?

Patients enjoy coming to the group. I understand how difficult it can be when you don't really know the language because I was in the same position 25 years ago. Because of cultural and family restrictions, women will not always feel comfortable going out to somewhere new to access support. Delivering support in a GP practice is acceptable to women, the family and it is local. It is a safe place to talk, learn new information and share ideas. We teach them about healthy eating and women enjoy sharing new recipes with one another and techniques for different ways of cooking. We have also started an exercise session in the group which is going down well. We share memories from back home and what life used to be like compared to now, that's really enjoyable. Women understand how their lives have become sedentary since moving to the UK and why it is important to keep active and healthy.

Everybody respects each other, there is trust; that's really important and it's why women come back every week.

Are there any limitations?

The group is for women only; it would not work if it was a mixed group, but we need something for men too. They are also at risk of diabetes and dementia.

6.4 Local branches of national programmes

We found a number of local branches of national programmes that appear to be accessed well. Support for people with respiratory conditions, funded by LCC is being delivered through 'Breathe Easy' clinics across the city, located in local community venues such as churches which increases accessibility. VCFS organisations such as Space 2 have also been successful in supporting local people to manage COPD through community based peer support with post pulmonary rehabilitation exercise and creative social activities.

A number of other organisations were found covering a range of conditions; details can be found on Appendix 2.

6.5 Statutory led organisations

The majority of groups identified under this category are being delivered in a clinical setting. Being facilitated by health workers, attendees have access to information and advice, opportunity to make new connections, emotional support, space to share their stories and learn from each other – and relaxation sessions in some groups.

The M&S Memory Cafe runs in the City Centre and is an open space for people to go to for relaxed chat, crafts, reminiscence and tea and cake – all free of charge

7.0 Final conclusions & recommendations

Peer support in Leeds for people living with LTCs is varied and diverse in nature, with the VCF sector currently making the largest contribution to this agenda. It is encouraging to find that most of the groups we came across in this scoping exercise were being delivered in local community venues which maximises accessibility. There appear to be a number of interventions addressing the support needs of vulnerable groups such as South Asian communities, but LTC specific support for groups such as Gypsy and Travellers and LGBT communities appeared to be non-existent which identifies a gap in provision. We intended to shed light on groups in outer rural areas of Leeds, to test the assumption that people living in more affluent areas with relatively greater levels of education would be more likely to engage with peers via virtual means. It was difficult to connect with leaders of the groups we identified as nobody responded to messages left by workers. We did try to gain insight into people's use and acceptability of social media as a form of engagement but people were limited in their response to this, owing to the lack of knowledge and competence around digital literacy.

Sharing of Good Practice

More needs to be done to share good practice and help others who are considering setting up peer support, to help them identify what a quality intervention should look like.

Frequency of meetings

Many groups delivered by organisations, whether run fully by local VCF or national, appeared to run monthly or fortnightly whereas many self-run groups appeared to run weekly. The frequency of the latter appears to offer the possibility of more sustained, regular peer support and the building of friendships outside the group meetings.

Networking peer support groups

In the same way that groups bring individuals with similar needs or conditions out of their isolation, networking the groups could provide opportunities to share ideas, experiences, resources and information and the chance to organise joint events or publicity/recruitment campaigns.

Training for peer support volunteers

There certainly appears to be a need for training for individuals willing to start and run peer support groups. A precedent is the training offered through the BME Seniors Network, run by Health for All as part of the Leeds Older People's Forum Lottery funded Time to Shine programme. Older BME volunteers running their own groups receive training in health issues and conditions, First Aid, Safeguarding, Grant applications, Programme Planning so enabling the sustainability of their group and ensuring quality of governance.

Resourcing/capacity building peer support groups

The majority of groups run as part of local or national organisations were fully funded by those organisations, which provided workers, venues and running costs such as refreshments and transport where needed. This dependence may impose limitations on the number of groups established and on the ability of members to fully 'own' their group. Independent groups, in particular those given capacity building support and training in leadership and fundraising skills, were able to secure their own small grants to cover these costs. Every group requires seed funding for start-up costs but promoting the independence of peer support groups where possible appears to offer an attractive way forward particularly given current pressure on public budgets.

Cost effectiveness

More focus on research around cost-effectiveness of groups is necessary if we are to make sound decisions for future commissioning of peer support interventions.

Measurement of Impact

It would be useful to carry out more in depth consultation with current beneficiaries of peer support groups. Several contributors to this scoping exercise gave heartfelt praise for such groups in helping them to cope with their condition, with comments including: 'It is a lifeline for me'. 'If it were not for this group, I would definitely visit the GP more often'.

'I don't know how I coped before'.

Virtual Groups

A number of virtual peer support groups were identified, but appeared to be 'closed access' for the groups to which they were attached (Appendix 2 provides an indication of virtual support available group by group). This mode of support will require users to have access to relevant IT equipment and be IT literate and confident. The current digital exclusion experienced by many people with LTCs in the more deprived areas of the city appears to create a barrier to their use.

Definition of an LTC Peer Support Group

While a number of groups were clearly defined as being a peer support group for those with a specific long term condition, especially those fully run by national or local organisations, many groups did not identify themselves as such. The latter frequently had as their focus a specific activity, for example, community choir, arts and crafts or Friendship group, or a specific community of interest or geographical community, for example, BME elders. Despite the variance in titles, all of the groups engaged and provided peer support to those with a long term condition. The conclusion to draw therefore is that the name or title of a peer support group is of less importance than what happens within the group and the positive impact on each of the beneficiaries.



8.0 References

- Atkinson, T. and Bray, J. (2013) Dementia
 Awareness & Intergenerational Exchange in
 Schools: A Pioneer Project supporting Dementia
 Friendly Communities [Internet] available from:
 www.worc.ac.uk/documents/Schools_Evaluation_
 Final_Report.pdf>
- Eysenbach. G., Powell, J., Englesakis M., Rizo
 C. and Stern, A. (2004) Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. The British Medical Journal [Internet] Available from: www.bmj.com/content/328/7449/1166?ct
- Fisher, E. (2014) Peers for Progress, AAFP
 Foundation [Internet] Available from:
 www.aafp.org/news/health-of-the-public/201403
 19peersupportwebinar.html
- Funk, M. and Drew, N. (2017) Creating peer support groups in mental health and related areas. World Health Organisation [Internet]
 Available from: apps.who.int/iris/bitstream/handle/10665/254813/WHO-MSD-MHP-17.13-eng.pdf;jsessionid=8D307555BB3200BCE5C90F6DC28B50E1?sequence=1
- Goodwin, N., Curry, N., Naylor, C., Ross, S. and Duldig, W. (2010) Managing people with long term conditions. The King's Fund [Internet] Available from: https://www.kingsfund.org.uk/sites/default/files/field/field_document/managing-people-long-term-conditions-gp-inquiry-research-paper-mar11.pdf>
- Health Improvement Scotland (2011)
 www.healthcareimprovementscotland.org/
 our_work/long_term_conditions/copd_resources/
 peer_support_case_study.aspx

- Health Innovation Network (2015) Peer Support for People with Dementia Resource Pack [Internet] Available from www.housinglin.org.uk/_assets/Resources/ Dementia/OtherOrganisation/Peer_support_ resource_pack_HIN.pdf>
- Institute for Public Policy Research (2014)
 Patients in control: why people with longterm conditions must be empowered
 [Internet] Available from: www.ippr.org/files/ publications/pdf/patients-in-control_Sept2014.
 pdf?noredirect=1
- Jolley, D., Moreland, N., Read, K., Kaur, H., Jutlla, K. and Clark, M. The 'Twice a Child' projects: learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services Emerald Group Publishing Limited
- Litherland, R. (2015) Developing a national user movement of people with dementia – learning from the dementia engagement and empowerment project (DEEP) Joseph Rowntree Foundation [Internet] Available from: www.jrf.org.uk/report/developing-national-usermovement-people-dementia
- Lorig, K., Ritter, P.L., Dost, A., Plant, K., Laurent, D.D. and McNeil, I. (2008) The expert patients programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions [Internet]
 Available from: http://journals.sagepub.com/doi/abs/10.1177/1742395308098886
- Mead, S., Hilton, D. and Curtis, L. (2001) Peer support: a theoretical perspective. *Psychiatric Rehabilitation Journal*, 25 (2), pp.134-41 [Internet] Available from: www.ncbi.nlm.nih.gov/pubmed/11769979
- Mead, S. and MacNeil, C. (2006) Peer Support:
 What makes it unique? [Internet] Available from:
 http://citeseerx.ist.psu.edu



- McDonald, C. (2014) Patients in control: why people with long term conditions must be empowered [Internet] Available from: www.ippr.org/files/publications/pdf/patients-incontrol_Sept2014.pdf?noredirect=1
- Moriarty, J, Sharif N and Robinson J (2011) Black and Minority Ethnic People with Dementia and their Access to Support and Services, SCIE
- National Voices and Nesta (2015) Peers Support: What Is It and Does It Work? A summary of the evidence
- Nesta (2016) At the heart of health: Realising the value of people and communities [Internet]
 Available from: www.nesta.org.uk/report/at-the-heart-of-health-realising-the-value-of-people-and-communities
- Nesta (2016) Breathing Easy: The power of peer support [Internet] Available from: www.nesta.org.uk/blog/breathing-easy-powerpeer-support
- NHS England (2017) Community Capacity and Peer Support [Internet] Available from: www.england.nhs.uk/wp-content/ uploads/2017/06/516_Community-capacity-andpeer-support_S7.pdf
- Parent, N. and Fortin, F. (2000) A randomized, controlled trial of vicarious experience through peer support for male first-time cardiac surgery patients: Impact on anxiety, self-efficacy

- expectation, and self-reported activity. Heart and Lung, *The Journal of Acute and Critical Care*[Internet] Available from: http://heartandlung.org
- Peers for Progress (2018) What Is Peer Support?
 [Internet] Available from:
 http://peersforprogress.org/learn-about-peer-support/what-is-peer-support
- Rauf, A (2011) Caring for Dementia: Exploring good practice on supporting South Asian carers, Bradford Metropolitan District Council
- Tang, P. (2013) A brief History of Peer Support:
 Origins [Internet] Available from:
 http://peersforprogress.org
- Temperley, J., Baeck, P., Hampson, M. and Langford, K. (2013) People Helping People: Peer support that changes lives, NESTA [Internet] Available from: www.nesta.org.uk/publications/people-helpingpeople-peer-support-changes-lives
- The Health Foundation (2012) www.health.org.uk/newsletter/power-peersupport#comment-41096
- The Health Foundation & NHS Improvement (2018) What would it take for effective peer support to be available to everyone who wants it, to help manage their long-term health and wellbeing needs? [Internet] Available from: http://q.health.org.uk/q-improvement-lab

APPENDIX 1

Map of groups providing peer support for people experiencing long term conditions in Leeds GROUPS LINKED TO NATIONAL ORGANISATIONS GROUPS LINKED TO HOSPITALS GROUPS LINKED TO GP PRACTICES COMMUNITY BASED GROUPS **VOLUNTARY SECTOR AND**

APPENDIX 2

List of groups providing peer support for people experiencing long term conditions in Leeds



VOLUNTARY SECTOR AND COMMUNITY BASED GROUPS

Memory Lane Café

Group for people with Dementia, Alzheimer's and memory problems, couples who care for those living with Dementia. Third day of the month from 1.30pm

Strawberry Lane Community Centre, Leeds LS12 1SF Contact: Karen, Tel: 0113 279 9292/more information on Armley Helping Hands

Lychee Red Chinese Seniors Project

Group for people with one or more long term conditions such as depression, cancer, arthritis, dementia and heart problems. Improving physical and emotional well-being of members by organising culturally appropriate activities within the Chinese culture e.g. Chinese chess, singing Chinese folk songs.

Mondays from 11am-1pm.

Parochial Hall, North Lingwell Road, Middleton, Leeds LS10 3SP.

Contact: Liu Huazha, Tel: 07930 250508.

Kushy Nanna's

Weekly Group for elderly Bangladeshi Women with multiple long term conditions, cancer remission, high blood pressure, diabetes. Meet to support one another and talk about different topics.

Mondays from 10am–12pm.

Building Blocks Maude Avenue, Leeds LS11 7DD. Contact: Thahmina Begum, Tel: 07984 101394.

Rags to Riches

Group for young mums with multiple long term conditions, gaining sewing skills to boost self-confidence and self-esteem. Providing an environment for young mums to engage with each other to battle post-natal depression and pressure of being a young mum.

Wednesdays from 10am-12pm.

Tenants Hall Enterprise Centre, Acre Close, Leeds LS10 4HX.

Tel: 0113 270 6903.

Sew it Seams

Learning how to use a sewing machine, to gain confidence through being creative, users include cancer patients, women with disabilities, experiencing anxiety and isolation. Wednesdays from 10am–12pm.

Tenants Hall Enterprise Centre, Acre Close, Leeds LS10 4HX.

Contact Tereza Mazurkiewychz, Tel: 0113 270 6903.

Care n' Hounds Cafe

Dementia awareness for people living with or caring for people suffering with dementia.

Mondays from 2-4pm.

Commercial Street, Rothwell, Leeds LS26 OUE.

Contact: Peter Smith, Tel: 0113 288 9068/07845 935233.

Sunflower Memory Café

Group open to everyone especially people with Dementia, offering training around the condition, skills for self-management, access to social activities, informal support outside of meetings via WhatsApp, FB etc.

Third Thursday of the month from 10am–12pm.

St Johns the Evangelist Church Hall, New Street, Pudsey, LS28 5DJ.

Contact: Lorna, Tel: 0113 229 8066.

Kushy Dil

Weekly support group for young Bangladeshi women above 16+ offering support to tackle isolation, depression, coping with diabetes and arthritis. Health and wellbeing activities of great interest to the group.

Mondays from 1-3pm.

Building Blocks Maude Avenue, Leeds LS11 7DD. Contact: Thahmina Begum, Tel: 07984 101394.

Open Door Café

Safe place for people with Dementia to socialise in a cafe setting with activities, group users are dropped off and picked up by their carers.

Last Monday of the month except Bank Holidays from 1.30–3pm.

The New Headingly Club St Michaels Road, Headingly, Leeds LS6 3BG.

Contact: Fiona Pourteous, Tel: 0113 246 8338.

Cosy Corner Memory Café

Cafe opens to all who need support especially those affected by Dementia.

Third Thursday of the month from 2–3.30pm.

Woodlesford Methodist Hall, Church Hall, Leeds LS26 8RD. Contact: Facebook: Cosy Corner Memory Cafe.

Rothwell Dementia Carers Support Group

Place to socialise for people suffering with Dementia, regular Dementia awareness talks

Last Wednesday of the month 10.30–12pm

The Black Bull, 15 Commercial Street, Rothwell LS26 0AX.

Contact: Peter Smith,

Tel: 0113 288 9068/07845 935233.

Hidden Memories Café

Provides support for carers and people struggling with memory.

First day of the month from 1–3pm.

Hawthorn Mill Cobden Road, Leeds LS12 5HQ.

Contact: Sandra Clibbens, Tel: 0113 231 1561.

Buddies at the Bull

Support for those living with or affected by Dementia. Tuesdays from 2–4pm.

rucsdays from 2-4pm.

Black Bull Commercial Street, Rothwell, LS26 0AX.

Contact: Peter Smith,

Tel: 0113 288 9068/07845 935233.

Cop Shop Memory Café

Cafe open to all, support available to those affected by Dementia and memory problems.

Last Wednesday of the month from 1-3pm.

Elland Road Police Station m, Elland Road Beeston, Leeds LS11 8BU.

Contact: Peter Smith,

Tel: 0113 288 9068/07845 935233/0113 271 6201.

Tea Cosy Memory Café

Cafe offering cost effective meal and support to those affected by Dementia and memory problems.

First Saturday of the month from 9.30am–12.30pm.

Rothwell Parish, Church Street, Rothwell LS26 OQL.

Rothwell Parish, Church Street, Rothwell E320 OQL.

Contact: Peter Smith, Tel: 0113 288 9068/07845 935233.

MENSPACE

This Group aims to address the unmet needs of men living in inner South Leeds, engaging local men, mainly aged between 40 and 60 years, at risk of poor physical and mental health and socially isolated. The group provides personal-centred user led activities ranging from woodwork, Horticulture, Confidence Building.

Monday–Friday from 8.30am–4.30pm.

Rear of Cockburn High School Gipsy Lane, Leeds LS11 5TT.

Contact: Martin Brennan 07432 702911.

Sanskar

Enables BME women to meet together to pursue social, education and leisure interests as well as supporting each other, offering social activities, exercise, to help older people to improve their health and mobility.

Wednesdays from 12–2.30pm.

Cardigan Centre, 145–149 Cardigan Road, Leeds LS6 1LJ.

Tel: 0113 245 1968.

Namaste

Group provides opportunity to socialise, with overall aim of reducing social isolation and improving health and wellbeing. The group provides yoga sessions, gentle chair based exercises, arts and crafts. Most men and women attending have one or more long term condition.

Mondays from 11-2pm.

Contact: Usha Bhardwai, Tel: 0113 239 5844.

Parnaby Pals

Support group for people affected by Dementia.

Wednesdays from 2-4pm.

Parnaby Tavern, 1 Middleton Road, Hunslet,

Leeds LS10 2 AB.

Facebook: Parnaby Pals

Underneath the Arches Memory Café

Safe space to overcome social isolation for people struggling with memory.

Second Monday of the month from 12.30–2.30pm. 17 Ingram Gardens, Holbeck, Leeds LS11 9SA. Tel: 0113 245 5553.

Reflections Dementia Café

Support and companionship for those affected by memory problems.

Second Saturday of the month from 10.30am–12.30pm.

Trinity Network, Nesfield Road, Belle Isle, Leeds LS10 3LG.

Tel: 0113 270 3935.

Headingley Friday Support Group

Support for adults affected by mental health conditions. Mental health does not need to be diagnosed. Organised talks, social activities & information.

Fridays from 1.30-2.30pm.

HEART Centre, Bennett Road, Leeds LS6 3HN. Contact: Carol Branham, Tel: 0113 230 6043.

Grandparents Support Group

Open to grandparents who have full responsibility of grandchild/grandchildren. The support group is a shared safe place, including activities, relaxation, facilitators for seniors to help alleviate the stress and mental anxiety of being a parent to their grandchild/children.

Wednesdays from 12.30-2.30pm.

Tenants Hall Enterprise Centre, Acre Close, Middleton, Leeds LS10 4HX.

Contact: Gayle, Tel: 07852 945286. www.healthforall.org.uk

Krok Po Kroku (Step by Step)

Group of mainly Polish women meet to part take in varied exercise activities Salsa, Pilates, informal support outside of sessions, day trips for the whole family. The range of activities improves mobility and helps manage pain, improves wellbeing, alleviates stress, social interaction reduces isolation, alleviates depression and helps with confidence building.

Fridays from 12.30-2.30pm.

Tenants Hall Enterprise Centre, Leeds LS10 4HX. Contact: Joanna Calder, Tel: 07941 376496.

Middleton Minstrels Community Choir

Choir attended by women, aiming to combat depression and isolation. Physical benefits improve breathing for people suffering with long term lung conditions, improves confidence, as the group takes part in public performances. The activity gives members sense of belonging.

Fridays from 10.30–12.30pm.

Tenants Hall Enterprise Centre, Acre Close, Middleton, Leeds LS10 4HX.

Contact: Claire Westhgarth, Tel: 07792 424290.

Birds of a Feather Cafe

Support for people living with Dementia and memory problems, and support for the carers, refreshments and meal provided.

Third Tuesday of the month from 1.30–3.30pm. Station Road, Crossgates, Leeds LS15 7JY. Contact: Maria, Tel: 0113 260 6565.

Sumangal Group

Group aims to tackle isolation in older people and long term health problems, offering social activities, exercise, activities to help older people to improve their health. The older people improve their breathing by singing traditional songs in mother tongue.

Wednesdays 11.30-2.30pm.

Burton Resource Centre. Banstead Street,

Leeds LS8 5RU.

Contact: 0113 3459870.

Sweet Memories Café

A safe space for dementia suffers and carers, peer support and place to share experiences and coping strategies. Second Tuesday of the month from 10.30–12.30pm Shadwell Independent Library, 99 Main Street, Shadwell, Leeds LS17 8HL.

Contact: Pam, Tel: 07761 288133.

Beetey Din Group

BME women's group for elders suffering from a range of long term conditions including dementia, arthritis, heart conditions and depression, providing access to social activities; exercise sessions mainly chair based and relaxation to aid long term conditions.

Fridays from 10–12pm.

78 Lady Pit Lane, Beeston, Leeds LS11 6DP. Contact: Sarbjit Rayat, Tel: 07983 111730.

Caring Sharing Café

Support for people living with Dementia and carers. Budget friendly café, a safe place to share experiences and coping strategies for Dementia.

Fourth Tuesday of the month from 2-4pm.

Pudsey Congs Cricket Club, Intake Road, Pudsey LS28 9AP. Contact: Ann or Pat at Pudsey Live at Home Scheme on 0113 256 2717.

Penny Lane Café

A safe environment for members to come together and address social isolation.

Second Tuesday of the month 2-4pm

Pudsey Cricket Club, Intake Road, LS28 9BZ.

Contact: Farsley Live at Home 0113 290 9340.

Pudsey Live at Home 0113 256 2717.

Forget Me Not Café

Group offers support and signposting for people with dementia. refreshments at the café.

First Wednesday of the month 1.30–3.30pm.

Yeadon Cricket Club, High Street, Yeadon, Leeds LS19 7TA.

Contact: Margarete Goodyear, Tel: 0113 855 9350.

Al-Khidmat Dementia Café

Support for dementia sufferers, peer support and a place to share experiences. Primarily for Pakistani and Kashmiri Origin.

Wednesdays 10.30am–2.30pm. 48 Spencer Place, Leeds LS7 4BR. Contact: Asghar Ali, Tel: 07851 259392.

Friendship Group

Group offers social activities, providing informal support outside of meeting. Majority of attendees are seniors with illnesses relating to age, diabetes, arthritis & heart conditions.

Mondays from 10-12 pm.

Parochial Hall, North Lingwell Road, Leeds LS10 3SP. Contact Gayle, Tel: 07852 945286.

Walk and Talk

Walking Group helps improve physical mobility and improving physical health and emotional wellbeing. The social activity reduces stress and improves breathing. Wednesday from 2–3pm.

Tenants Hall, Acre Close, Leeds LS10 4HX. Contact: Gayle, Tel: 07852 945286.

Inside Out

Wellbeing group offering exercise sessions to improve mobility and mental health users develop greater confidence through social interaction.

Tuesdays from 6–8pm.

Middleton Conservative Club, 4 Ring Road, Leeds LS10 4AX.

Contact: Gayle, Tel: 07852 945286.

Wildlife Walks

Meet people and get some fresh air. Guided walk exploring plants and animals in the Kirkstall area. Group supports people with low self-esteem & mental health.

Mondays from 1-3pm.

Hollybush Outdoors Active and Well

Contact: 0113 2742335.

Peer Support Groups. Delivered by Leeds Mind at Hollybush. Users spend time in a supportive environment, explore relaxation and mindfulness, share experiences and develop skills to manage wellbeing in a safe place.

Tuesdays from 10am-12pm.

Contact: The Roundhouse, Hollybush Conservation Centre, Broad Lane, Kirkstall, Leeds LS5 3BP.

Tel: 0113 305 5803.

Women's Wellbeing Group

Safe space to share lived experiences. Access to social activities and guest speakers of subject of interest. Group members suffer various health conditions e.g. mobility issues, memory, emotional low mood, arthritis, onset dementia. Reduces isolation, improves emotional wellbeing by improving confidence and flexibility through various activities.

Mondays from 1-3pm.

256–266 Middleton Family Centre, Sissons Road, Leeds LS10 4JG.

Contact: Gayle, Tel: 07852 945286.

Remember When Café and Carers Drop In

Peer support and cognitive stimulation therapy, activities and carers support for people with memory dementia and Alzheimer's.

Second and Fourth Tuesday of the month 1.30–3pm. Quaker Meeting House, New Adel Lane, Leeds LS16 6AZ.

Contact: Sally Anne, Tel: 0113 278 2475.

St Chads Memory Café

Offering people with dementia and their carers a warm welcome. Providing support, companionship and reassurance. Wide range of activities for people with memory problems and gaining support from one another.

Second Monday of the month 1.30-3pm.

St Chads Church, Otley Road, Far Headingley, Leeds LS16 5JT.

Contact: Tim Ward 0113 278 5734.

Peaceful Minds

Beat stress, meet new people & relax. Enjoy refreshments and a chat. People suffering from depression attend the group.

Wednesdays from 1.30-3.30pm.

Armley One Stop, 2 Stocks Hill, Leeds LS12 1UQ.

Contact: Kay, Tel: 0113 245 9610. E: kay@oblongleeds.org.uk

LTC Café and Peer Support

Group supports people living with Long Term Conditions by offering a safe place where people can socialise, helping reduce isolation and depression. It also focuses on dementia once a month.

Wednesdays, 11–1.30PM at Oasis Café, Trinity United Church, Roundhay Road, Leeds LS8 5PU, and Thursdays, 11–1.30, at Roscoe Café, Francis Street, Leeds LS7 5P.

Contact: Heisha at Feel Good Factor,

Tel: 0113 350 4200.

E: hiesha@fgfleeds.org

Leeds Skyline

Offering training and peer support groups to people living with or affected by HIV.

Contact: BHA Skyline, 4th Floor, Gallery House, 131, The Headrow, Leeds LS1 5RD.

Tel: 0113 244 9767.

E: leedsskyline@theBHA.org.uk

Hamari Yaadain

Group supports people from the South Asian Community diagnosed and living with memory complications. It offers a safe space to socialise and runs various activities, including art sessions to empower and build confidence of the attendees

First & Third Thursday of the month from 1–3pm.

Touchstone, 53-55, Harehills Avenue,

Leeds LS8 4EX.

Contact: Ripaljeet or Vanysha, Tel: 0113 219 2727.

Women Only Chair Based Exercise

Group offers chair-based exercise at the Sikh Centre on a weekly basis to support women living with long term conditions, including dementia, Alzheimer's, depression and mobility impairment. It helps improve emotional and physical well-being.

Wednesdays from 9.30am.

Feel Good Factor, 53, Louis Street, Chapeltown, Leeds LS7 4BP.

Contact: Heisha, Tel: 0113 350 4200.

www.fgfleeds.org

Yorkshire Dance:

Yorkshire Dance is a charity which champions the value of dance and its development in Yorkshire. Group offers social activity for users with Parkinson disease and dementia, improvement for health with dance and music.

Wednesdays from 11am-12.30pm.

Middleton Community Centre, Acre Road, Leeds LS10 4JQ.

Grab & Games

Support group for individuals with mental health conditions. Individuals get to meet new people, access food vouchers and enjoy arts and crafts or play games.

Support and information also available.

Fridays from 11 am - 1 pm.

47 Cromwell Mount, Leeds LS9 7ST.

Tel: 0113 248 4880.

The Moonlight Café

Group for people suffering depression, isolation and hunger. Nutritious food is served along with good conversation. Oher support information and advice is available.

Mondays from 5-8pm.

47 Cromwell Mount, Leeds, LS9 7ST.

Contact: Wendy Bartlett, Tel: 0113 248 4880.

Breakfast Club

Group offers social support to people suffering depression and isolation. The group also provides socialising activities.

Wednesdays from 10am-12pm.

47 Cromwell Mount, Leeds, LS9 7ST.

Tel: 0113 248 4880.

Plan to Change

Support group for people alcohol and drug dependent. Advocacy support is provided.

Advocacy support is provided

Tuesdays 10.30am-12.30pm.

41–47 Cromwell Mount, Lincoln Green,

Leeds LS9.

Tel: 0113 248 4880.

IBS Support group in Leeds

Group for people suffering from IBS (irritable bowel syndrome). Safe place to share their experiences and gain skills for self-management.

Second Monday of each month from 7pm.

Contact: The Heart Centre, Bennett Road, Headingly,

Leeds LS6 3HW.

Tel: 0113 275 4548.

www.theibsnetwork.org/self-help

Peer Led Support Group for HEP C

Support group for people who have HEP C, providing peer support and advice around treatment.

Last Thursday of the month.

Kirkgate Hub, 74 Kirkgate Leeds LS2 7DJ.

Contact: Karen Towning (BBV Nurse),

Tel: 0113 887 2477.

Men's Health Walking group

Group for visually impaired men, offering peer support & walking in the park.

Second Thursday of every month.

53-55 Harehills Avenue Leeds LS8 4EX,

Contact: Fawad Lak, Tel: 0113 219 2727.

AVSED

Group for elderly people who are socially isolated, supporting them to live happy, healthy and independent lives. Users have multiple LTCs.

Monday-Friday from 10am-4pm.

Contact: Nunroyd Pavillion, Nunroyd Park, New Road, Leeds LS19 7HR.

Tel: 0113 250 1702.

The Monthly Group Chapel Allerton

Group for elderly people to reduce isolation and keep them physically and socially active. Meet other people and make friends as most service users are over 80 and have one or more multiple LTC.

First Tuesday of the month 2-4pm.

Methodist Centre, Town Centre, Leeds LS7 3NB.

Contact: Andrew Parvan.

Easy Exercise Group

Group for people with mobility and long term health conditions, providing chair based exercise.

Every Tuesdays from 10-11am.

Contact: St Stephen's Church, Moortown,

Leeds LS17 5DX.

Contact: Suzy, Tel: 0113 240 6677.

Chair Based Exercise Group

Group for people with long term health conditions and have mobility issues, delivering chair based exercise.

Mondays from 10.30–11.30am.

BAME Wellbeing Hub, Reginald Terrace,

Leeds LS7 3EZ.

Tel: 0113 378 4892.

Hamara Ladies Group

Group for south Asian women aged 50+, who are isolated and living with Diabetes. Shopping, sauna, yoga, and do various other exercises.

Wednesdays, Thursdays and Fridays from 11am-1pm. Hamara Centre, Tempest Road, Leeds LS11 6RD.

Contact: Aziza Din, Tel: 0113 277 3330.

De-Caf Central-Dementia

Dementia Groups, Mental Health. Share experiences, peer support, emotional support.

Second Wednesday of the month from 1.30—3pm.

6-8 The Headrow, Leeds LS1 6PT.

E: info@carersleeds.org.uk.

Horsforth Dementia Information Group

Group meets and gives support sessions for carers of people with memory problems and dementia, giving advice, refreshments & coping strategies.

First Tuesday of each month from 11am-12pm.

Horsforth Library, Town Street, Leeds LS18 5BL.

Contact: Alison Smith, Tel: 0113 380 4300.

PACES

Group supports parent carers of children with LTC, offering emotional support and arranging activities arranging guest speakers to give them information.

Second day of each month from 12.30-2.30pm.

BITMO, Aberfield Gate, Belle Isle,

Leeds LS10 3QH.

Tel: 0113 380 4300.

www.carersleeds.org.uk

Young Adult Carers Support Group

Group for people between the ages of 16-25 for carers of people with LTC. Members go for lunch and have a chat. They arrange trips and other activities.

First Thursday of each Month from 5-7pm.

Tel: 0113 380 4300.

www.carerleeds.org.uk

Carers Support Group at the Autism Hub

Group is one of many specialist care groups within the city, offering support and shared experiences, providing emotional support from other people in similar situations.

11th Day of each month from 5-6pm.

Contact: Lovell Park Hub, Wintoun Street

Leeds LS7 1DA.

Tel: 0113 378 2275.

Horsforth Carers Support

Group meets and shares experiences – get emotional support & advice. Some sessions feature speakers attending to give information.

First day of each month from 1–2.30pm.

Grove Methodist Centre, Horsforth, Leeds LS18 4BH.

Tel: 0113 380 4300.

www.carersleeds.org.uk

Alzheimer's Carers Support Group

Group for carers of people with dementia, Alzheimer's and memory problems to join in for support and activities.

Last day of each month from 10.30-12pm.

Pudsey Wellbeing Centre, Robin Lane, LS28 7BR.

www.carersleeds.org.uk.

Mehfil Group

Group offers shared experiences, get a break from caring. For South Asian women who support someone with Mental Health issues. Activities and speakers, talks and information.

Last day of every month from 1.30–3.30pm.

Touchstone 53-55 Harehills Avenue,

Leeds LS8 4EX.

Tel: 0113 219 2727.

www.carersleeds.org.uk

Morley Dementia Carers Group

Group meets to support people living with/caring for a loved one with dementia. The group gives advice, arranges activities and has guest speakers.

Second day of the month from 1.30–3pm.

The Church of Nazarene, Albion Street, Morley, Leeds LS27 8DT.

www.carersleeds.org.uk

Bat & Chat

Group offers support for carers living with LTCs. Informal way to get support over a game of table tennis.

Fridays from 11am-1pm.

6-8 The Headrow, Leeds LS1 6PT.

Tel: 0113 380 4300.

Khushi (happiness)

Healthy wellbeing group for Asian women to combat isolation and mental health. Provide peer support. Wednesdays from 10am–1pm.

Fredrick Hurdle Day Centre, Reginald Terrace, Leeds LS7 3EZ.

Contact: Dosti Project Leeds, Tel: 0113 378 4892. www.touchstonesupport.org.uk

Activity Group by Leeds Black Elders

Provides information for older people of the black community about health. Informing users about what is happening locally, peer support and chair based exercise. Tuesdays from 11–3pm.

Church of God Prophecy, 116 Chapeltown Road, Leeds LS7 4HL.

Contact: Leeds Black Elders Association, Tel: 0113 2374287.

Modern Living

Mens group tackling their skills of using modern technology. Group members are senior and have a range of long term conditions such as isolation, arthritis and joint pain.

Tuesdays from 10am–12pm. Feel Good Factor, 53 Louis Street, Leeds LS7 4BP. www.fgfleeds.org.uk

Walking Group

Womens group meeting at Asha, leaving together for the park. Group provides motivation and regular encouragement, improving self-confidence and self-esteem. The attendees have various long term health conditions diabetes, mobility and emotional low mood. Wednesdays from 10.30am–1.30pm.

43–45 Stratford Street, Leeds, LS11 6JG.

Contact: 0113 270 4600.

www.ashaneighbourhood.wordpress.com

Walking Group - To walk a daily mile

Group meets daily at 1pm at Farnley Park.

Joining the group you can walk, run, push a buggy, walk a dog or join in your wheelchair.

Part of the Expert Patients programme.

Asha Group

Group for women with various long term health conditions such as diabetes, heart conditions and depression. Provides opportunity for creative arts and craft making activities in association with SKIPPKO ARTS. A safe place to share lived experiences and feelings, reduce stress, improve confidence, social interaction, therapeutic activities, and relaxation, reduce high blood pressure and improve your emotional and physical wellbeing.

Signposting to other activities.

Tuesdays from 12.30–3pm.

43-45 Stratford Street Leeds LS11 6JG.

Contact: Asha, Tel: 0113 270 4600.

www.ashaneighbourhood.wordpress.com

Men's Social Group

Support group for men aged 50+ most of the attendees suffer from diabetes. The group provides peer support, health information and exercise in the way of walking. Thursdays.

Hamara Healthy Living Centre, Tempest Road, Leeds LS11 6RD.

Contact: Arshad@Hamara org.uk

Carpet Bowls

Group for members of Alwoodley Community Association living with long term conditions, including isolation and loneliness. It offers a safe space to socialise and chat as well as improve mobility in the bowling activity.

Fridays from 7.30-9.30pm.

Alwoodley Community Association, The Avenue, Leeds LS17 7NZ.

Contact: Brian Binks, Tel: 0113 225 6132.

Memory Lane Café Yeadon

Group supports people living with, and carers of people living with dementia by providing a safe space to socialise. Last Friday of the month from 1–3.30pm.

The group will be moving to new premises in June. Yeadon Charities Association, Yeadon Town Hall, High Street, LS19 7PP.

Contact: Amanda Botterill, Yeadon Charities Association, Tel: 07989 356923.

M&S Memory Café

Group offers support to anyone living with or is affected by dementia.

Third Friday of the month from 1–3pm. M&S Company Archive, Michael Marks Building, (off Clarendon Road), Leeds LS2 9LP.

Contact: Katie Entwistle, Tel: 0208 718 2800.

Eating Out Group

Group supports individuals who suffer with eating difficulties by increasing their confidence in managing their eating in social settings, challenging their eating habits and supporting clients in developing skills like mindfulness to help manage their condition.

67, Hilton Road, Leeds LS8 4HA. Contact: Tel: 0800 6906838. www.insighteating.co.uk



GROUPS LINKED TO GP PRACTICES

Hawthorn Surgery

Singing for Health Group. Aims to promote good health through singing in a relaxed & stress free environment. Wednesdays from 2–3pm.

Ring Road, Lower Wortley, Leeds LS12 5SG. Tel: 0113 2954770.

www.Oakwoodlanephc@gmail.com

The Roost Oakwood Lane Medical Practice

Group offering lots of activities including coffee and chat, exercises for long term conditions, loss & bereavement information. Also support in accessing social activities. First Tuesday of the month from 10am–12pm. 2 Amberton terrace, Leeds LS8 3BZ. Contact: Shelley, Health Champion, 07835 990967.

Tuesday Club Oakwood Lane Medical Practice

Group is a Dementia support group supported and run by a psychiatrist, offering socialising, help with isolation and a safe space. Tuesdays from 10am–1pm.

2 Amberton Terrace, Leeds LS8 3BZ.

Contact: Shelley, Health Champion, 07835 990967.

www.Oakwoodlanephc@gmail.com

Caring Hands North Leeds Medical Practice

Group meets and offers befriending, support, offering support with mental health.

Wednesdays from 1–3pm.

North Leeds Medical Practice, Leeds LS17 6PZ.

Contact: Beverley Kite 07808 736339.

COPD Clinic Manston Surgery

Clinic for people living with COPD. They are invited to the clinic for check-ups & specialised services & training.
Annual group.

Manston Surgery, Station Road, Leeds LS15 8BZ. Contact: Ruth, Locality Lead Nurse, Tel: 0113 264 5455.

Leigh View Wellbeing Club Diabetes Support Group

An evening meeting organised by patient volunteers and for patients. Informal session open to patients and carers. Professional speakers are invited each time with topics ranging from consultant advice about how to manage Diabetes, manageable exercise, eye health and cooking tips. Third Thursday of the month from 6–7pm.

Leigh View Medical Practice Bradford Road, WF3 1 RQ.

Tel: 0113 253 7629.

Lingwell Carers Support Group Lingwell Croft

Group meets each month and welcomes carers in and around South Leeds for a coffee and conversation, support & guidance for carers of LTC.

Second Wednesday of each month from 2–3.30pm. Lingwell Croft Surgery 16 Shelldrake Drive,

Leeds LS10 3NB.

Tel: 0113 270 5372.

www.carersleeds.org.uk



GROUPS LINKED TO HOSPITALS

Macmillan Cancer Support Group

Group meets to support cancer patients/carers & family members.

Second Monday of each month from 5.30–7.30pm. Sir Robert Ogden Macmillan Centre Leeds LS9 7TF. Contact: Louise Fisher 0113 206 6498.

Sleep Clinic Sleep Apnoea Trust Association

Support line for people living with sleep apnoea. Over 4000 people registered with the clinic offering a Telephone Service

St James Hospital, Leeds LS9 7TF.

Tel: 0113 206 6075.

E: leeds.sleep@nhs.net

Bipolar Group

Monthly support group offering an Informal drop in to meet & talk about the difficulties and share experiences, support each other.

Resource Centre St Mary's Hospital, Green Hill Road, Leeds LS12 3QE.

Tel: 0113 855 5000.

Yorkshire Centre for Eating Disorders

Group meets & provides an informal drop in to meet & talk about difficulties, share experiences and support each other.

First & Third Wednesday of each month from 5.30–6.30pm.

Seacroft Hospital, Newsam Centre, York Road, Leeds LS14 6UH.

Contact: Kirsty Goodall, T: 0113 855 6300.

The Leeds Programme

In Leeds the programme is offered to anyone who has been newly diagnosed with Type 2 Diabetes or has had a diagnosis in the past 12 months and is registered with a Leeds GP. The LEEDS Programme helps to improve your knowledge and skills and also help to motivate you to take control of your condition and self-mange it effectively. Monday–Friday 8.30am–4.30pm.

Leeds Community Healthcare NHS, Chapeltown Health Centre, Spencer Place, Leeds LS7 4BB.

Tel: 0113 843 4200.

Anxiety Leeds

Peer Support group for Anxiety and Panic Attacks, the group offers a friendly and supportive environment where you can talk through your difficulties, service user led discussions.

The group meet on the Second and Fourth Monday of each month 6.30–8.15pm.

B36 B Floor Clarendon Wing Leeds General Infirmary, Great George Street, Leeds LS1 3EX.

E: info@anxietyleeds.org.uk



GROUPS LINKED TO NATIONAL ORGANISATIONS

NHS National Diabetes Programme Leeds Delivered by Ingeus

A source of support for people at high risk of Type 2 Diabetes offers a 10 months course with tailored and personalised education on healthy eating and lifestyle, help to lose weight and access to bespoke physical exercise programmes.

Lines are open 8am–8pm Monday to Friday and 10am–2pm on Saturday.

Tel: 0800 321 3150 or 0121 386 6971.

Living Autism

Group offers support, advice and guidance for people living with and carers of people living with Autism.

Parkhill Business Centre, Walton Road, Wetherby, Leeds LS22 5D2.

Tel: 0800 756 2420.

E: info@livingautism.co.uk.

www.livingautism.com

More Life (Carnegie Weight Management)

Group supports people who are living with obesity and long term weight problems. It offers various activities, including physical activity sessions, healthy lifestyle sessions, and residential, day and holiday camps.

Churchwood Hall, Leeds Beckett, Leeds LS6 3QJ.

Tel: 0113 812 5233.

E: team@more-life.co.uk

www.more-life.co.uk

Yorkshire and Humber Muscle Wasting Group

Group offers Peer Support in a safe space to share lived experiences for people living with family and friends of people living with Muscular Dystrophy – muscle wasting conditions. The group runs at three different venues in the Yorkshire and Humber region, (Sheffield, York and Leeds) in the year.

Holiday Inn, Express Leeds, Cavendish Street, Kirkstall Road, Leeds LS3 1LY.

Contact: Clare Lucas, Tel: 02078 034838.

www.musculardystrophy.uk

Breathe Easy – Hunslet Support Group – affiliated with British Lung Foundation

Group run by volunteers, offering a safe space for people, their family and friends, to share support and experiences, for those living with breathing complications/a lung condition.

First Thursday of the month from 2.30–3.30pm. Hunslet Methodist Church Hall, Telford Terrace, Leeds LS10 2HR. Tel: 0300 003055.

www.blf.org.uk

Breathe Easy Exercise – Gipton Support Group – affiliated with British Lung Foundation

Group offers weekly exercise sessions and runs alongside Gipton support group for people living with breathing complications.

Wednesdays from 4.30-5.30pm.

Oakwood Lane Medical Practice, 2, Amberton Terrace, Leeds LS8 3BZ.

Tel: 0300 003055.

E: tinabettinaleslie@icloud.com

www.blf.org.uk

Breathe Easy - Seacroft Support Group - affiliated with British Lung Foundation

Group run by volunteers, it offers a safe space for people, their family and friends, to share support and experiences living with breathing complications/a lung condition.

First Tuesday of the month from 11am–1pm. St Richard's Church Hall, Ramshead Hill, Seacroft,

Leeds LS14 1BX.

Tel: 0300 0030555. www.blf.org.uk

Adult Congenital Cardiac Nurse Specialists – affiliated with Leeds Congenital Hearts

Group offers various types of support to adults and their family living with congenital heart conditions, including listening, confidential emotional support, advice regarding symptoms, and advice regarding issues preparing for surgery.

Weekdays from 8am-4pm.

Leeds Congenital Heart Unit, Jubilee Building, Leeds General Hospital, Great George's Street, Leeds LS1 3EX. Tel: 0113 392 8154.

E: info@leedscongenitalhearts.co.uk www.leedscongenitalhearts.com

Leeds Osteoporosis Support Group – affiliated with National Osteoporosis Society

Group offers various activities to support people living with osteoporosis, including social events like picnics, information and education, guest speakers and medical updates.

First Wednesday of the month from 2–4pm. Oxford Place Methodist Centre, Leeds LS1 3AU.

Contact: Rachel, Tel: 01761 473253.

www.nos.org.uk

Leeds Pulmonary Fibrosis Support Group – affiliated with British Lung Foundation

Group offers a safe space to share lived experiences for people living with pulmonary fibrosis, their family and carers. This group also offers relevant education and support as well as social activities and fundraising events.

Last Thursday of every two months from 1–3pm Stanningley Rugby Club, Leeds LS13 1PA.

Contact: Jane Slaugh. 0113 206 7120.

E: jane.slaugh@nhs.net

Pulsations affiliated with the British Heart Foundation

Cardiac rehabilitation exercise group set up for the benefit of people living in Leeds area to maintain and improve cardiac health for those with a history of heart related problems. Maintaining contact with other people and offering mutual support.

The group meet on Thursday evenings and Saturday mornings.

Pendas Way Community Centre, Pendas Way, Leeds LS15 8LE.

Contact: Richard, Tel: 0113 260 7380.

Leeds Garforth Support Group affiliated with Bi Polar UK

Group offers peer support to anyone affected by bi polar including family, friends and carers. It offers a safe space to share lived experiences and an opportunity to socialise.

First Thursday of the month from 7–9pm.

The Community Centre, Church Gardens, Garforth, Leeds LS25 1JB.

Tel: 0333 3233880.

www.bipolaruk.org

Action for Blind People affiliated with The Royal National Institute for the Blind

The Leeds RNIB group is run by Action for Blind people offering information, support and advice. Local group Tel: 0113 3862800.

www.rnib.org.uk

Stroke Clubs affiliated with Stroke Association

Stroke Association is a national charity providing advice and support on many aspects of living after a stroke. There are several stroke clubs in Leeds.

Contact: Leeds local office, Tel: 0113 2019780. www.facebook.com/TheStrokeAssociation

Spina Bifida affiliated with Shine

Shine is the national charity for spin bifida and hydrocephalus. They have lots of useful help and support for anyone with these conditions and their families and carers.

Local contact, Tel: 0113 255 6767. www.shinecharity.org.uk

The Leeds M.E Network – Affiliated with Action for M.E

Group offers Social meetings for M.E sufferers and their carers can help with all aspects of having M.E.

Third Thursday of odd numbered months from 12.30–2pm.

West Yorkshire Playhouse Café, Quarry Hill, Leeds LS2 7UP. http://leedsmenetwork.yolasite.com

Multiple Sclerosis – Affiliated with Multiple Sclerosis Society

The Community MS team helps people cope practically and emotionally with the symptoms of MS.

St Mary's Hospital, Greenhill Road, Leeds LS12 3QA.

Tel: 0113 855 5082.

There is a Leeds and district branch providing support around Leeds.Tel: 0800 111 4324.

Facebook: www.facebook.com/MSSociety

Parkinson's UK - Leeds and District Branch

Part of a national support group supporting local people and their families living with Parkinson's disease. Group offers information, friendship and support to individuals and their families and carers.

Second Wednesday of the month from 2–4pm. St Chad's Parish Centre, Otley Road, Leeds LS16 5JT. Contact: Carol Cook, Tel: 01943 513601.



