

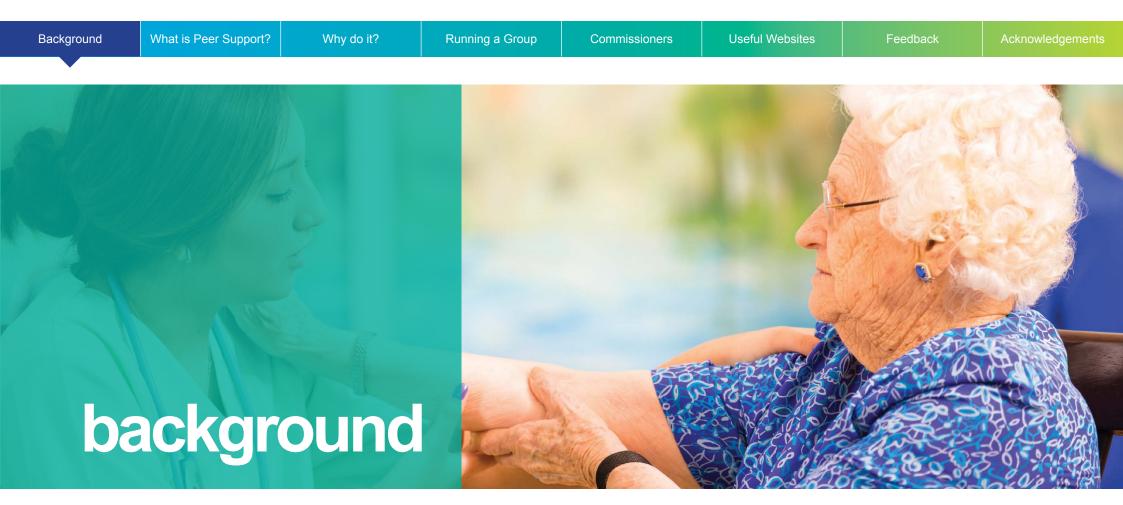
Peer Support for People with Dementia Resource Pack

Promoting peer support opportunities for people with dementia Get started >



Health Innovation Network South London





The purpose of this resource pack is to bring together examples of good practice and evidenced based guidance on peer support, to help groups and organisations better support people with dementia in their communities.



This guide includes:

Why do it?

- Information about what peer support is and how different types of groups can support people with dementia.
- Why peer support can help people with dementia stay connected with their communities.
- Guidance and resources to help people who want to run groups for or including people with dementia.
- Some ideas for how you can tell if the group is doing well.

Lots of people develop dementia as they get older.

Peer support services get people with dementia together and enable them to talk about their lives and how to live with dementia.

Most people want to continue taking part in social groups and activities within their communities, but for many people dementia can lead to social isolation. "It is really important to form friendships and that's just what the café does. Everyone is so nice and it is really helpful to hear other people's stories"

Person with dementia, The Jasmine Club.

"I love your group – it is so lovely, we have a real laugh." Person with dementia, Healthy Living Club.

"

"

"When you have dementia, you're fighting with yourself all the time – it is hard work! You're struggling all the time to be what you'd call 'normal' but coming here is safe and relaxing. I can be myself here because I'm not worried about saying the wrong thing."

Person with dementia, Hope & Doodle Group.



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Feedback

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Who is this guide for?

People working in the statutory, voluntary and community sectors who want to offer people with dementia the opportunity to meet with other people in a similar situation.

People setting up, running or involved in peer support groups or community groups which include people with dementia.

People who are commissioning or funding services for people with dementia.



Why Peer Support Matters

Why this resource guide was developed

- The value of peer support is recognised as key to living well with dementia.
- Peer support is routinely advocated in policy and strategies for dementia care across the UK.
- Access to peer support opportunities varies from one place to another and the waiting lists can be long.
- Opportunities are limited for people from specific communities or backgrounds, for example, ethnic minority groups (especially those where English is not, or is no longer the first language), lesbian and gay people, or younger people with dementia (under 65).
- Not all people with dementia want or need a structured approach to peer support. But many people might benefit from the wider informal peer support opportunities available in the community, such as social clubs for people with dementia, dementia cafes and community activities and groups for older people. It is important that these groups are able to support people with dementia well.

"I think I've come on quite a bit since I was first told [that I have dementia] and it's coming here and having support from people like you [dementia advisors] that makes a difference. Being here has given me my confidence back. At first I didn't want to know about dementia but when you see all different people have got it, it makes me feel better to know that."

Person with dementia, Hope & Doodle Group.



Why do it?

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what is peer (support?

We've made a short film of people with dementia and their relatives talking about why peer support is so important

> People with dementia and their carers say that peer support groups are important as they provide opportunities to speak to other people in a similar situation and provide social interaction, which often is much needed.



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Formal Support Mormal Support Suppor Online Peer Support **Opportunities** Community Groups and Activities Opportunities for Specific Groups dealer

A vision for peer support

Peer support groups are a good opportunity to meet other people and share experiences with others who are in a similar situation, but peer support is not available everywhere and in many areas, peer support is oversubscribed or difficult to access. People with dementia also say how important it is to stay connected to their communities and to be able to continue seeing their friends and doing the activities they enjoy, but some community groups find it difficult to accommodate people with dementia. Community organisations and specialist peer support groups both have an important role to play in supporting people with dementia to live well. We hope this guide will encourage both community organisations and more specialised dementia services to think about what they can do to better support people with dementia.

We are proposing a whole system approach to peer support which is affordable and flexible, so that it meets the needs of the whole population of people with dementia. The components of our proposed 'system of peer support' include:

- · Specialist and structured peer support, usually for a time-limited period
- Dementia cafes where people can 'drop in' to meet others who are in a similar situation on a more informal basis
- Community groups, clubs and societies which are able to accommodate people with dementia
- Up-to-date information for people with dementia and their carers about local services and support and how to access them
- Dementia advisers or navigators who are able to support people through 'the system', signposting them to services and support and connecting them to their communities.



Formal support group

Hope and Doodle case study

A group facilitated by a person trained to support people with dementia, to explore shared experiences and coping mechanisms.



Watch a film made by Alzheimer's Society on Peer Support Groups

Informal support group

A group which people can join at any time: these usually meet at regular times and place and are useful sources of information and social interaction.

Dulwich Helpline Case Study

Online support

Web based discussion forum for anyone affected by dementia: a safe place to ask questions, share experiences and receive advice and support from others.



Opportunities for specific groups of people

These can be formal or informal, and are for people who share a certain background or beliefs (age, religion, ethnicity, sexuality, nationality, culture etc.)

- (I) The Jasmine Club (BAME Group)
- Dire Straits not the Rockband Young Onset Dementia Group
- **Younger People with Dementia Support Group**

Community groups and activities

Support for people with dementia to attend community groups made up of people with and without dementia which gives people the chance to meet informally, often supported by volunteers.

Healthy Living Club case study



Watch the Healthy Living Club's dementia-centred, multi-talented community on film



Watch a variety of short film clips from the Healthy Living Club



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why do it?

We've made a short film of volunteers and group facilitators talking about why having opportunities to meet others in a social group setting is so important for people with dementia



Policy Recommendations for Peer Support for People with Dementia

• The National Dementia Strategy *'Living well with dementia'* promotes the establishment and maintenance of local peer support networks for people with dementia and their carers.

Visit Link

• The Care Act 2015 stipulates that care and support systems intervene early to support individuals to help people retain or regain their skills and confidence, and to prevent or delay deterioration wherever possible.



Measuring the social value (published in Summer 2015)

The Health Innovation Network South London is carrying out an economic analysis of peer support groups, using the Social Return on Investment (SROI) methodology developed by The <u>New Economics Foundation</u>. Findings will demonstrate the social and individual value gained from each £1 invested in peer support services. Prime Minister's Dementia Challenge to support the national strategy.

Visit Link

"To date old friendships have been renewed, interests and hobbies restarted, new activities begun and friendships developed, both via peer support groups and through accessing other groups and activities. In addition, support is given to access local services, from shops to banks and the local pub and to ensure access to wider support services." Age UK Lancashire.

"With my diagnosis I can feel worried about seeing old friends who don't understand. Coming here is different, it's good not to feel like an outsider."

Person with dementia, Hope & Doodle Group.



What we know: peer support for people with dementia:



- improves wellbeing through improved social and emotional support as a result of shared experiences and building of new social networks
- reduces loneliness (people with dementia frequently report feeling excluded and isolated)
- improves physical health through practical support, such as medication reminders and general information about staying healthy

- increases ability to manage and deal with symptoms
- increases confidence to engage with and venture into their local community
- benefits the wider community by challenging stigma through combatting discriminatory attitudes towards dementia
- leads to direct healthcare savings as individuals, their carers and family feel able and confident to manage their health better, for example
 - fewer GP appointments
 - fewer calls to social services
 - > fewer calls to NHS 111 or 999
 - fewer admissions e.g. to A&E or care homes.

References

- Department of Health 'Healthbridge Report ' evaluating peer support networks and role of dementia advisers (https://www. gov.uk/government/publications/peer-support-networks-anddementia-advisers-evaluation)
- Mental Health Foundation evaluation of the Dementia Self Help project, featuring three peer support groups for people in the early stages of dementia living in extra care housing (http://www.mentalhealth.org.uk/content/assets/PDF/ publications/dementia-self-help-report.pdf?view=Standard)
- Mental Health Foundation Fact Sheet on Peer Support in Mental Health (http://www.mentalhealth.org.uk/content/ assets/PDF/publications/need_2_know_peer_support1. pdf?view=Standard)
- Dementia Action Alliance and Faculty of Psychologists Report into Post-diagnostic support for people living with dementia (http://www.dementiaaction.org.uk/assets/0000/3825/Faculty_ of_Psychologists.pdf)
- Joseph Rowntree Foundation 'A stronger collective voice for people with dementia' (http://www.jrf.org.uk/publications/ stronger-collective-voice)
- Banerjee, S. and R. Wittenberg (2009). "Clinical and cost effectiveness of services for early diagnosis and intervention in dementia." Int J Geriatr Psychiatry 24(7): 748-754.
- Keyes, S. E., et al. (2014). "We're all thrown in the same boat ..." A qualitative analysis of peer support in dementia care. Dementia
- Knapp, M., et al. (2013). "Dementia care costs and outcomes: a systematic review." Int J Geriatr Psychiatry 28(6): 551-561.



40,000

There are 40,000 younger people with dementia in the UK, but this group is poorly supported in terms of age appropriate peer support.



Two thirds of people with dementia live in the community. It is likely these people are accessing existing community groups, which may not have the skills or knowledge for how best to support people with dementia.

25,000

25,000 people from black and minority ethnic groups have dementia in the UK but there is little culturally appropriate support available for these people.

One third of people with dementia live in care homes. Evidence suggests that peer support tailored for this group is beneficial.

£26bn

The financial cost of dementia to the UK is £26 billion per annum. Evidence suggests good peer support can reduce this.





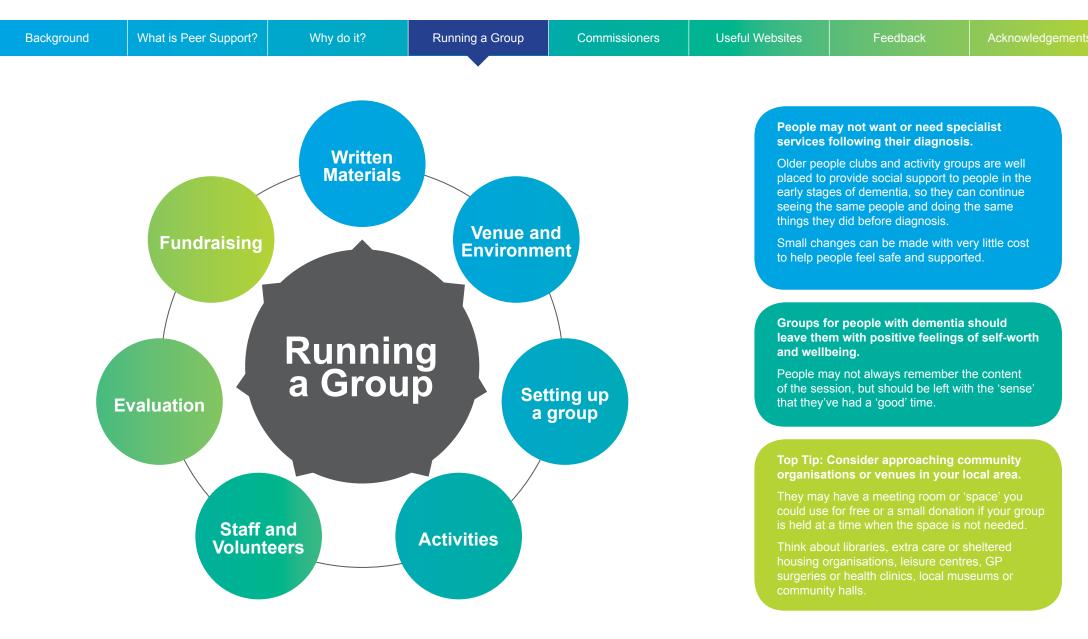
Click here to access the Department of Health Dementia Prevalence Map. You can search by postcode or town to look at diagnosis rates, dementia support, care and research activities near you.



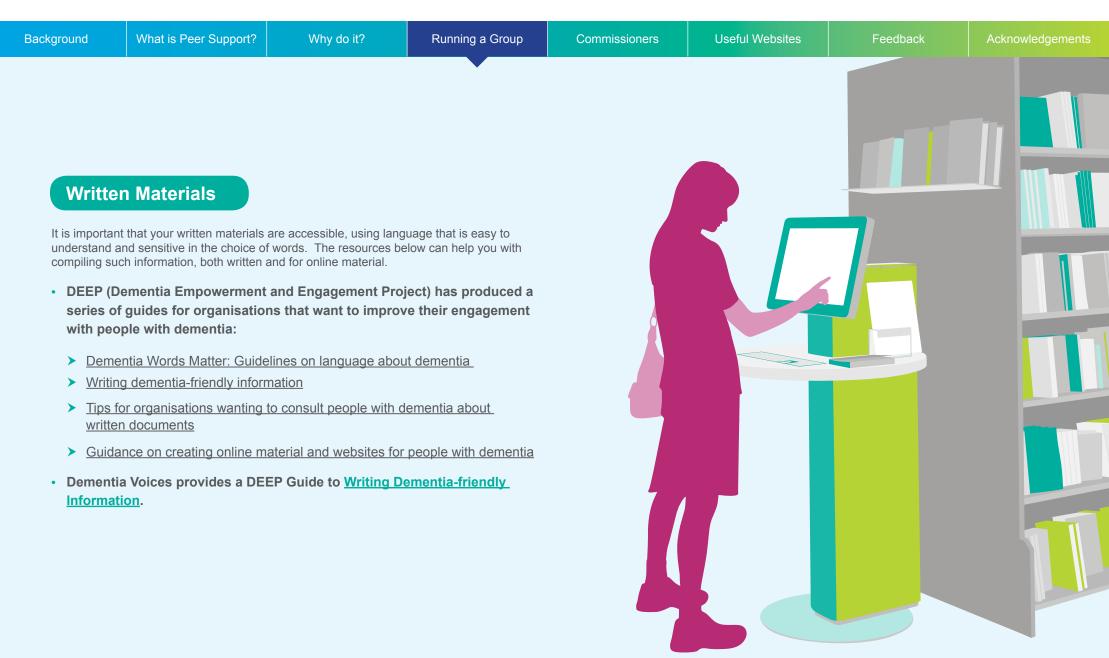


Running a Group Background What is Peer Support? Why do it? Commissioners **Useful** Websites Feedback running a group Listen to the Mental Health Foundation about how they set up self-help groups for people with dementia

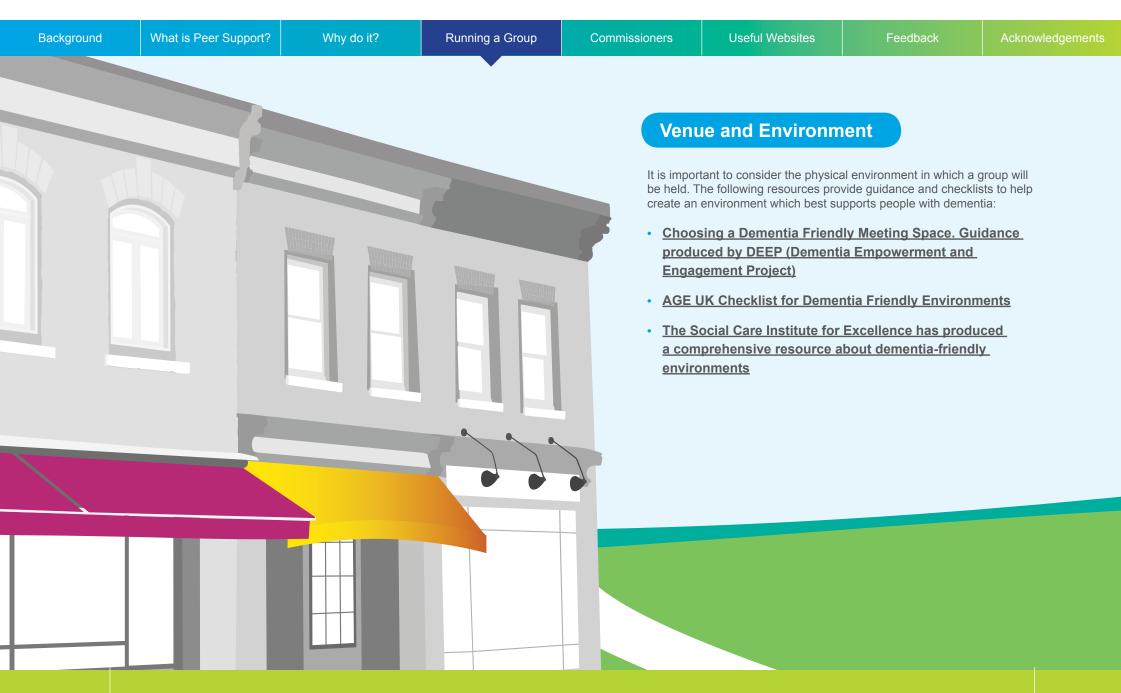














Why do it?

Activities

The Mental Health Foundation has produced a useful 'Activity Guide' containing activities to use in a group setting. The activities aim to:

- provide mental stimulation
- help members make social connections
- reduce loneliness, which often occurs as a result of dementia
- help people remain active in their community
- emphasise healthy living, independence and learning new skills.

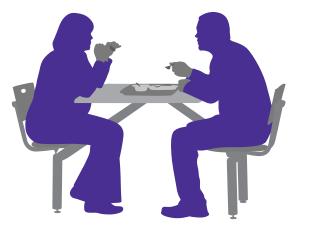


Setting up a group

The below evidenced based guides will help you set up and manage your group, whether it is a peer support group, a general group for older people or a specific activity group for people with dementia.

- Alzheimer's Disease International produced an <u>online booklet</u> which helps to start self-help groups for people with dementia. It presents useful ideas and on how start and maintain such groups.
- <u>'Running self-help groups for people with dementia'</u> A detailed guide developed and evaluated by The Mental Health Foundation. Primarily aimed at those working with people living in sheltered or extra care housing but equally relevant to the community setting. Includes information on
 - Recruitment
 - Environment
 - Structure
 - Activities to aid memory and health
 - Sustaining the group
 - Evaluation
 - > Challenges
 - Exit strategy.

- AGE UK in partnership with <u>Dementia Adventure</u> has developed a <u>training package and</u> <u>downloadable toolkit</u> for organisations wishing to encourage people living with dementia to access and enjoy the outdoors and green spaces.
- Arts 4 Dementia's <u>'Reawakening the Mind'</u> as part of this programme Arts 4 Dementia developed a workshop model for arts venues to re-energise and inspire people in the early stages of dementia and their carers and work with Dementia Pathfinders to deliver training for arts facilitators.



"Mum hasn't stopped talking about the group since she got home."

Relative, Dulwich Helpline Group.

"It has been a joy to watch how the group and its members have developed and grown in confidence. It is truly validating to see the face of members when someone in the group is being open about an experience they are also going through. It means a lot for people to have the space to share how their dementia affects them and to realise they are not alone. Organising the sessions is definitely a lot of hard work but moments like that make it all worthwhile."

Facilitator, Hope & Doodle Group.



Staff and volunteers

Good facilitation and having enough staff (paid or unpaid) is crucial to the success of any type of group but very much so for people with dementia. Making staff and volunteers aware of dementia is a big step towards supporting people well. The following organisations offer awareness sessions or training in dementia free of charge:

- <u>Dementia Friends</u>, an Alzheimer's Society initiative which aims to enlist a million people with improved awareness of dementia by 2015. Information sessions are delivered by Dementia Champions who have been trained by Alzheimer's Society.
- Social Care Institute of Excellence (SCIE) has developed an E-Learning course 'Open Dementia', which is a valuable and flexible resource as a starting point for training and awareness raising. It has seven modules, each of which can be completed in about half an hour. It is free of charge, of high quality and is values-based. The SCIE Open Dementia Programme can be found <u>here</u>.
- AGE UK has produced a guide for managers supporting learners through the SCIE course which can be <u>downloaded here</u>.
- E learning for Healthcare has produced an interactive <u>e-learning resource</u> to support the training of all health and social care staff in recognising, assessing and managing dementia and in providing high quality dementia care.
- Alzheimer's Society has produced a
 <u>How to help people with dementia: A guide for
 customer-facing staff.</u>
- Innovations in Dementia and AGE UK has produced a <u>Help pack for customer facing staff</u>.

A Dementia Adviser provides advice, information and post diagnostic support on all aspects of living well with dementia tailored to individual needs. The adviser works with people throughout all stages of dementia, pointing them to additional help and support as their needs require. Dementia Advisors provide support to local communities to help them understand more about dementia to encourage earlier diagnosis. It is usually an integrated role, working across the memory service and voluntary sector. Dementia Advisors often support or run dementia cafes and peer support groups.

Click <u>here</u> to view a job description.

"Since coming to the café I have felt good. I no longer feel so lonely and on my own with things and actually feel like I can go out and have a laugh with people again"

Person with dementia, The Jasmine Club.

"

"The Club provides respite from the experience of caring and being cared for. It provides a safe space where both people with dementia and their carers can step out of their roles as 'givers' and 'receivers' and interact with each other and everybody else as equals. It is nothing more than a weekly gathering of people and that this 'gathering of people' is them."

Facilitator, Healthy Living Club.



Evaluation

Although evaluation may seem like an unnecessary additional task if you are already short of time and resources, it is an important exercise to help you:

- · learn from your experience
- record what you have learnt, and share it with other stakeholders
- check your progress
- check whether what you are doing is still what local people want or need
- identify strengths and weaknesses in your group
- create a basis for future planning
- demonstrate whether you have used your resources
 - time and money effectively
- explain to funders and others involved in your work, what you have achieved and how successful it is.



Feedback from members of the groups will form a large part of the evaluation. The following resources from the Alzheimer's Society will help you gather feedback:

- Template for writing up the evaluation report (link to PDF)
- Guidance on writing questionnaires (link to PDF)
- · Guidance on organising focus groups (link to PDF)
- Guidance on writing case studies (link to PDF)
- Group Feedback Form Template (link to PDF)

<u>PQASSO</u>* is the leading quality standard developed for the Third Sector, by the sector.

Charities and others with a social purpose increasingly have to do more with less and prove their worth to funders and commissioners. Small community groups need evidenced based methods and tools to develop and demonstrate the value of their work. PQASSO offers a tried and tested way to do this, with a menu of options so you can tailor the tool to your specific needs. Used systematically it will help you run your organisation more effectively and efficiently. Organisations using PQASSO can gain the following benefits:

- · clearer outcome planning and delivery
- greater credibility and legitimacy with funders
- more efficient systems
- higher quality, user-centred services
- better leadership and governance
- · more creative thinking, enabling new ways of working
- a commitment to continuous improvement.

*Practical Quality Assurance System for Small Organisations

"Our project allows people with dementia to socialise and integrate within the community like everyone else. It increases confidence and enables people to continue to be as independent as possible and live life to their fullest."

Facilitator, Dulwich Helpline Group.

"Mum couldn't come for two weeks and she stopped interacting as much at home. There was no mental stimulation. Coming each week makes her more responsive. The club brings her 'self' out, she recognises people, she joins in singing and the exercise and eats her lunch."

Relative, Healthy Living Club.



Fundraising

If you are looking for funding, the below organisations offer grants to community groups or comprehensive searchable databases to see current opportunities available:

National Funding Bodies

- <u>Funding Central</u> is a free resource for charities, voluntary organisations and social enterprises based in England. It lists thousands of funding and finance opportunities, plus a wealth of tools and information supporting you to develop a sustainable income strategy.
- Governmentfunding.org.uk brings together all the regional, local and national government funding schemes in one place. It also includes independent grant administrators and European sources and keeps you updated on funding rounds coming up. Simply enter search criteria specific to your cause and location and find the relevant schemes to apply to, and most importantly how to apply.
- <u>The Big Lottery Fund</u> gives out millions of pounds from the National Lottery to community groups and projects that improve health, education and the environment. Click here to view their open funding programmes.

- <u>UK Community Foundations</u> is the managing agent for Comic Relief's Stronger Communities theme, awarding grants to locally-based groups or organisations which have a clear understanding of local need.
- <u>GRANTNet</u> enables you to identify and select only funding schemes and awards that are appropriate for your project.
- <u>The Funding Network</u> is the friendly Dragons Den for charities and potential donors. We bring people together at live crowdfunding events to raise vital funds, transform lives and create lasting social change.



Feedback



Organisations in London and the South East

- <u>City Bridge Trust</u> supports charitable activity across Greater London and is the grant making arm of Bridge House Estates. It provides grants totalling around £15m per year towards charitable activity benefitting Greater London.
- <u>The London Community Foundation</u> specialises in funding smaller charities and community groups that do not attract mass public support. Click to see grants available by Borough.
- <u>Funding For All</u> has compiled a list of funding organisations that provide grants to organisations in the South East to develop services for older people.

Some Councils support voluntary, community and social enterprise (VCSE) sector initiatives through various funding programmes. Click to view current funding opportunities by Borough.

- Bexley
- Bromley
- <u>Croydon</u>
- <u>Greenwich</u>
- Kingston
- <u>Lambeth</u>

- Lewisham
- <u>Merton</u>
- <u>Richmond</u>Southwark
- Sutton
- Wandsworth

The NCVO* and How2Fundraise have a wealth of information and how to guides to help community groups focus their fundraising efforts:

- <u>How2fundraise</u>: Free online resource for volunteer fundraisers from the Institute of Fundraising. Has a huge amount of fundraising tips, templates, advice and 'how to' guides.
- The NCVO has produced a practical <u>'How</u> to Fundraise in Tough Times' Guide to help non-profit organisations focus their efforts on areas that are more likely to secure funding.
- Click <u>here</u> to access all NCVO's resources and videos to support your fundraising activities.

*National Council for Voluntary Organisations



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Helping you make the case as to why invest in dementia services, plus tips on what to include in a peer support service.





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Why invest in dementia peer support services?

Take a look at the Why do it? section of this resource pack for up-to-date evidence and policy related to peer support groups for people with dementia.

Structured peer support

A Service Specification for a structured peer support group should include information on:

- 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 (click <u>here</u> for an example feedback form which providers can use)
- Reporting requirements such as activity data and service-user feedback, reporting on protected equalities characteristics
- Any risks and how to mitigate

Dementia Adviser or Navigator service

Dementia Advisers or Dementia Navigators can help individuals navigate and access services and supports which are appropriate to them. These services help to ensure resources are used effectively, for example, only referring people to structured peer support services at a time when they are able to get the most out of the group. They can also help people when their peer support sessions come to end, by identifying other opportunities in their communities to continue to meet people in similar situations to themselves.

Commissioning dementia support services? Join the London Dementia Commissioners Network

The London Social Care Partnership (formerly the Joint Improvement Partnership) has been established to help shape the future of adult social care in London, providing support and capability to deliver improved quality and value. Sponsored by the London Association of Directors of Adult Social Services, the LSCP builds collaborative action across all 33 London borough councils with a wide range of partner organisations and agencies. The LSCP has established a Dementia Commissioner Network to support a strategic, co-ordinated approach to commissioning across health and social care. The Network meets quarterly to tackle key issues faced by commissioners, and share best practice and real examples of innovative dementia commissioning where services have already been redesigned.

To join or for more information about the network, contact Tristan Brice, Programme Manager, London Social Care Partnership:

Email: Tristan.Brice@londoncouncils.gov.uk Tel: 020 7934 9999



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useful websites										
Age UK			search. Has a specific der	information and advice, se nentia friendly programme		www.ageuk.org.uk				
Alzheimer's So	ciety	offers information, advic	e and support for people w	vith dementia and their fam	nilies.	www.alzheimers.org.uk	<u><u> </u></u>			
Carers Direct helpline		An online and telephone	www.nhs.uk/carersdirect							
Carers Trust		provide support, informa member or friend.	www.carers.org							
Circles of Support for People with Dementia		is a project looking at ho	www.ndti.org.uk/circles							
Dementia Action Alliance		is over 500 organisation	www.dementiaaction.org.uk							
Silver Line		is the only free confiden 24 hours a day, every da	www.thesilverline.org.uk							
Dementia Friends		is an Alzheimer's Societ things they can do that c	www.dementiafriends.org.uk							
	outhwark Older nation Directory	easy to use searches for local, regional and national older people services, including advice, information and activities for people with dementia and their carers, including Black, Asian and Ethnic minority groups.				http://directory.ageuklambeth.org.uk				



Background Running a Group What is Peer Support? Why do it? Commissioners **Useful Websites** Feedback useful websites Dementia Services Development Centre is an international centre of knowledge and expertise dedicated to improving the lives of people with www.dementia.stir.ac.uk (Stirling) dementia. http://www.scie.org.uk/ The Social Care Institute for Excellence improves the lives of people who use care services by sharing knowledge about what works. The dementia publications/dementia/index.asp (SCIE) gateway is an online resource available to anybody interested in learning more about dementia. Dementia UK is a national charity committed to improving the life of all people affected by dementia. Their helpline is www.dementiauk.org staffed by Admiral nurses - specialist mental health nurses who work within the NHS and are supported by Dementia UK. Admiral nurses only work in some parts of the country. Uniting Carers is their national network of family carers who want to share their experience of caring for someone with dementia to make a difference. The Lewy Body Society is the only charity in Europe exclusively concerned with Dementia with Lewy body, a type of dementia http://lewybody.org closely associated with Parkinson's disease.

 connects you with health care services in London. Log on and you can compare health services in London,
 www.myhealth.london.nhs.uk/

 find local Dementia services that meet your needs and get information about a wide range of health
 health-communities/dementia

 matters with regular, news, features and events.
 www.myhealth.london.nhs.uk/

Dementia Connect – coming soon!

Myhealthlondon

Dementia Connect is Alzheimer's Society's dementia services directory for anyone affected by dementia in England, Wales and Northern Ireland. With over 5,000 listings of local information, support and services, it's the most comprehensive and easy-to-use online directory of its kind. Through a simple postcode search, you can find voluntary, statutory and private services nearest and most relevant to you. Each listing includes a map and clear, essential information about that service.

Alzheimer's Society

Dementia Connect will launch later this year. Please contact the Dementia Connect team to discuss adding your dementia friendly group to the directory: enquiries.dementiaconnect@alzheimers.org.uk



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Acknowledgements

feedback

Your views

Please tell us what you think of this Resource Pack. Your comments will help us update the Resource Pack to better meet your needs.

Click <u>here</u> to download the feedback form. The form can be emailed to us at <u>hin.southlondon@nhs.net</u> or printed out and posted to:

Dementia Clinical Theme Health Innovation Network South London Second Floor, Counting House Guy's Hospital, Great Maze Pond London SE1 9RT

What do you think about this resource pack?

P	ease tell us who you are:	2. W	/hich section(s) did you find useful?	3. Have we missed anything be included?
2	a. I have dementia	0	a. Information on different types of peer support	
)	b. Carer (family or friend)	0	b. Evidence promoting peer support 'Why do it'	
)	c. Dementia specific group	0	c. Resources on how to set up and run a group	
)	d. Older people's group	0	d. Videos	
)	e. Health professional	0	e. Case studies	
)	f. Social care professional	0	f. How to commission peer support	4. Has this guide influenced
)	g. Commissioning services for people with dementia	0	g. Other (Specify below)	services for older people, wi problems and dementia? If s
)	h. Other (Specify below)			problems and dementia in s
				5. Any other comments?

This guide will be updated throughout 2015 in response to feedback received and new evidence published this year related to peer support. The form can be emailed to us at hin.southlondon@nhs.net.



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Acknowledgements

The Health Innovation Network would like to thank the following organisations for their input to this resource pack:



We would like to also thank group members, volunteers and staff who contributed to our case studies and films for this Resource Pack. The Health Innovation Network is one of 15 Academic Health Science Networks (AHSN) across England. As a membership organisation, we are focused on lasting system-wide improvements in patient and population health, strengthening relationships, and capitalising on teaching and research strengths across South London.

We are driving lasting health improvements for our local communities across the following clinical priorities:

- Dementia
- Diabetes
- Musculoskeletal
- Alcohol
- Cancer

Cross-cutting themes:

- Patient experience
- · Patient safety
- Informatics
- Wealth creation
- · Education and training

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