



# Peer Support and Dementia

A resource for  
creating better lives

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*The help and support that people with lived experience of dementia, or caring for a person with dementia, are able to give to one another.*

## Introduction

People with dementia and unpaid carers say that the support of their peers is something they value the most. It helps to keep people more socially connected, giving them confidence and motivation to participate in their communities and friendship circles. It helps them feel valued by being listened to and being able to help others with similar experiences; it fosters a sense of belonging.

The Life Changes Trust funds many different types of peer support in Scotland and we are told regularly of the different ways in which peer support has transformed the lives of people with dementia and unpaid carers. We are using this information to contribute to a growing body of evidence which demonstrates the positive impact of peer support on the quality of life of people affected by dementia. This includes identifying ways of establishing long term peer support initiatives that are innovative and sustainable and which can operate alongside existing services as part of a continuum of approaches to supporting and empowering people affected by dementia.

Being listened to by peers, and knowing that their voice is valued, has boosted the confidence of many people with dementia and unpaid carers to take their experience to a wider platform in order to be influential. It is far easier to influence when a person feels they have the support of their peers.

Peer support should take place quite naturally in dementia friendly communities and evidence shows that it does. There are also some key networks in Scotland that work on the principles of peer support and empowerment:

- ▶ the DEEP network includes more than twenty independent groups of people with dementia across Scotland, including the Scottish Dementia Working Group (SDWG)  
[www.dementivoices.org.uk](http://www.dementivoices.org.uk)
- ▶ the Scottish Dementia Working Group is a national campaigning and awareness-raising group whose members all have a diagnosis of dementia. They are the independent voice of people with dementia within Alzheimer Scotland  
[www.sdwg.org.uk](http://www.sdwg.org.uk)
- ▶ Together in Dementia Everyday – **tide** – is a network that empowers carers of people with dementia, helping them recognise that they are experts by experience  
[www.tide.uk.net](http://www.tide.uk.net)
- ▶ the National Dementia Carers Action Network (NDCAN) is Alzheimer Scotland’s national campaigning network for members who have personal experience of caring for a person with dementia  
[www.alzscot.org/ndcan](http://www.alzscot.org/ndcan)



The Life Changes Trust has run a conference bursary scheme since 2014 to help people living with dementia or unpaid carers share their experiences at conferences and hear from others about their experiences.

Peer support can be an important source of practical support, information and advice. This is why the Trust has funded a number of excellent and useful peer-to-peer resources, and is continuing to do so. These resources are important because they are written from the perspective of someone living with dementia or of the carer. We know that some of these resources are being used to change the way that services are being delivered. You can read more about them from page 38.

If you would like to read more about the evidence base for peer support for people with dementia and for carers, some further resources are listed on pages 6 and 7. Further resources will be added to the Life Changes Trust's website as they are published. Pages 8 to 54 give examples of peer support work that has been taking place in Scotland since 2015.



# Summary of the benefits of peer support\*

## Emotional Support

- ▶ Sharing experiences, at difficult points of the journey
- ▶ 'Doing something with the person I care for, rather than for them'
- ▶ Carers feel listened to and not judged
- ▶ Maintaining relationships and identity and not just being seen as a 'person with dementia' or 'a carer'
- ▶ Carers feel valued, respected, listened to and in control
- ▶ Forging friendships
- ▶ Reminiscing
- ▶ Reduced isolation
- ▶ Carers have a sense of purpose, confidence and empowerment
- ▶ Improved physical and mental well-being

## Practical Support

- ▶ Access to practical information, advice and support
- ▶ Participating in activities
- ▶ Being able to connect with other people living with dementia

## Passing on Learning

- ▶ Carers feel better informed and supported in their caring role
- ▶ Development of new resources by people with dementia and unpaid carers
- ▶ Informing the next generation
- ▶ Contributing to research

## Influencing Change

- ▶ Influencing and improving service delivery by having their voice heard
- ▶ Informing and influencing local businesses
- ▶ Involvement with wider dementia friendly initiatives



## Reading and resources available to all

- ▶ Peer Support for Carers: A Qualitative Investigation of the Experiences of Carers and Peer Volunteers (2013)

<https://bit.ly/30MWwYL>

- ▶ Peer support groups to facilitate self-help coping strategies for people with dementia in extra care housing (2014)

<https://bit.ly/3eb85No>

- ▶ *'We're all thrown in the same boat...'* A qualitative analysis of peer support in dementia care (2014)

<https://bit.ly/2UONtml>

- ▶ Peer support for people with dementia resource pack: promoting peer support opportunities for people with dementia (2015)

(You will need to sign up for a FREE Social Care Institute for Excellence account to access this resource)

<https://bit.ly/2Y6EkYv>

- ▶ The value of peer support on cognitive improvement amongst older people living with dementia

<https://bit.ly/2B9GU6S>

- ▶ Quantifying the benefits of peer support for people with dementia: A Social Return on Investment (SROI) study (2016)

<https://bit.ly/3e7eVn5>

- ▶ The Life Changes Trust Peer Support Projects, Report 1 October 2015 – October 2016 (2017)

<https://bit.ly/3frojCb>

- ▶ The Life Changes Trust Peer Support Projects, Report 2 October 2016– October 2017 (2018)

<https://bit.ly/2YCsmVm>

- ▶ The Zubairi Report: the lived experience of loneliness and social isolation in Scotland (2018)

<https://bit.ly/2N5sHK0>

### **Evaluation currently taking place:**

- ▶ Independent evaluation of Life Changes Trust funded peer support projects, University of Stirling, reporting in spring 2021
- ▶ Independent evaluation of the **tide** network in Scotland, University of the West of Scotland, reporting in summer 2021

# Life Changes Trust Funded Peer Support Projects

2015–2020



# Ceartas: De Café



## *East Dunbartonshire*

Ceartas is a small dynamic charity rooted in East Dunbartonshire. Our services are open to all adult care groups. We provide independent advocacy and information services, and actively promote user involvement within the organisation.

Our main focus is ensuring that people, regardless of their circumstances or diagnosis, are informed and have access to independent advocacy in order to be included at the heart of decision-making. Ceartas was established in 2004 and has consistently worked closely with people living with dementia and unpaid carers in a variety of innovative peer support and group activities that have ensured that people are educated about dementia, know where to go for support, and have their views represented.

## **What we do**

Accessing practical and peer support can have a positive effect on those affected by dementia. It can foster feelings of being included in your community rather than excluded. Ceartas currently runs five De Cafés in East Dunbartonshire where this practical and peer support is offered as well as referral and signposting to wider support networks.

Ceartas pioneered the first Alzheimer café in Kirkintilloch in 2005 and has since facilitated this and witnessed the growth and development of this initiative. The people we work with came up with the name De Café, which is short for Dementia Café. As a result, we now have strong foundations across East Dunbartonshire.

Around 80 people attend each month and they continue to be lively hubs of information, peer support and advocacy. De Café meets the needs of people, wherever they are on their dementia journey. Many carers still attend the cafés when the person they care/cared for has moved into long term care or has passed away. Meeting with other carers provides invaluable support.



In addition to De Cafés, a number of specialist peer support projects have been developed that enable people with dementia to engage with each other. These provide an initial platform for individuals to meet, share and learn. Specialist peer support projects currently include:

- ▶ Faces of Dementia self portraits (see <https://bit.ly/2lXzOuM> for a video)
- ▶ I AM creative writing group
- ▶ Dementia Walking Football
- ▶ Sporting Memories
- ▶ Golfing Memories

Our 'Making Sure' group gives people with dementia a voice within our organisation. They help us decide our priorities and shape our services. This shows the value we place on people with lived experience being at the heart of everything Ceartas does.

As an independent advocacy organisation, we know the importance of working in partnership to benefit people with dementia and unpaid carers. We link in with post-diagnostic link workers and other relevant staff so we can identify individuals who have been recently diagnosed with dementia and support them through their whole dementia journey, even to the end of life. We are able to offer independent advocacy alongside the peer support that people with dementia and unpaid carers get from each other.

## Training

As well as offering independent advocacy services in East Dunbartonshire, we offer bespoke dementia awareness and dementia informed training on a number of dementia-related topics, in addition to dementia awareness and dementia informed training in line with the Promoting Excellence Framework.<sup>1</sup>

<sup>1</sup> Promoting Excellence – a framework for all health and social services staff working with people with dementia, their families and carers <https://www2.gov.scot/resource/doc/350174/0117211.pdf>

Ceartas staff are not legally trained, but we can cover the practical implications of things like:

- ▶ adults with incapacity legislation
- ▶ power of attorney and guardianship
- ▶ Mental Health Act
- ▶ adult Support and protection

Please see page 19 in the Information, Awareness, Training and Education Book for more information. Also see [www.lifechangestrust.org.uk/project/ceartas-advocacy-peer-support-Café](http://www.lifechangestrust.org.uk/project/ceartas-advocacy-peer-support-Café).

## How our peer support work benefits people with dementia and unpaid carers

- ▶ people with dementia and unpaid carers experience a reduction in the levels of isolation they experience, by making new friends and having a sense of belonging
- ▶ they have greater access to advice, information and signposting for information on dementia and dementia-related issues
- ▶ they are more likely to access additional support
- ▶ they are more likely to speak positively about their lives
- ▶ unpaid carers are given some respite from their role: ***“When my husband is at the football I feel I can relax with a cuppa, knowing that he is being entertained and looked after.”***



*I feel I have made friends with the other carers, and you end up looking forward to seeing one another. It is great...being able to have a relaxed chat.*

*My husband enjoys coming and he will speak to family and friends about the group.*

*Finding out from Ceartas about the help that is out there has been a big help. I don't feel I need any help at present but knowing help is there gets you through.*

*My husband was ready for the golf at 10am this morning, although it doesn't start 'till 1pm. I wish it was on more often.*

*My husband really looks forward to coming, he will ask ‘when are we going to the putting?’ He doesn’t ask about any of his other activities.*

*He remembers the golf after he has been. This is unusual as he doesn’t often remember where he has been.*

**If you want to know more, please contact:**

**Gordon Thomson**

Ceartas  
Suites 5–7,  
McGregor House  
10 Donaldson Crescent  
Kirkintilloch  
Glasgow  
G66 1XF

**Tel:** 0141 775 0433

**Email:** [gthomson@ceartas.org.uk](mailto:gthomson@ceartas.org.uk)

**Website:** [www.ceartas.org.uk](http://www.ceartas.org.uk)

**Twitter:** @CeartasAdvocacy



# North West Carers Centre: Side by Side Project



## *North West Edinburgh*

North West Carers Centre (NWCC) is a carer-led organisation supporting unpaid carers from the age of five to 90+ years. Side by Side is a befriending and peer support project for unpaid carers of people affected by dementia or a cognitive impairment.

The main aim of the Side by Side Project is to help unpaid carers and people living with dementia or a cognitive impairment live to their maximum potential.



## What we do

The Side by Side Project provides support to unpaid carers through face-to-face or telephone contact. We organise and facilitate courses that offer information, education, recreation and practical support. We also run courses and events where unpaid carers and the person they care for can attend together.

The project provides opportunities for unpaid carers and the person they care for to meet others, share experiences and benefit from peer support.

The Side by Side Project's main objective is to provide a service that puts **carers first** and offers each carer the **right service at the right time** to meet their needs and their wishes.

This approach gives unpaid carers the flexibility of dipping in and out of the project, putting them in control of the support they want to receive, and aims to provide unpaid carers with **the right level of support**.

A quarterly programme with a variety of courses is distributed to unpaid carers and also to professionals. The programme incorporates visits to places of interest, barge trips, information talks, afternoon shindigs and reminiscence, as well as intergenerational groups with our Young Carers Project and many more. We facilitate regular groups that include walking, exercise, singing and support.



## Our strengths

Where possible the Side by Side Project enables the person with dementia to attend courses and events with the carer. This supports carer attendance and reduces carer isolation.

*I would like to say that without North West Carers Centre I don't think I could have coped. I feel that having meetings helped a great deal and various activities with my husband being present are truly a godsend as we do not go out much and speaking with people in a similar position to us helps a great deal.*

*– Side by Side carer*

The NWCC staff team benefits from good in-house joint working, sharing skills, knowledge and good practice. The team promotes in-house referrals resulting in a holistic service that benefits unpaid carers from aged five to 90+ years. This means that someone who comes to the Centre receives as much support as we are able to provide, rather than just one element of it.

The Project is supported by a wonderful and highly skilled team of volunteers. Services offered are not time-limited, even when an unpaid carer's caring situation changes.

## How our peer support work benefits people with dementia and unpaid carers

- ▶ unpaid carers and people with dementia have an increased social network of support and feel less lonely
- ▶ unpaid carers, including former carers, have a sense of purpose, confidence and empowerment
- ▶ unpaid carers are more informed about their support options and entitlements

### **If you want to know more, please contact:**

#### **North West Carers Centre**

The Prentice Centre  
1 Granton Mains Avenue  
Edinburgh  
EH4 4GA

**Phone:** 0131 315 3130

**Email:** [joan@nwcarers.org.uk](mailto:joan@nwcarers.org.uk) or [moira@nwcarers.org.uk](mailto:moira@nwcarers.org.uk)

**Website:** <https://nwcarers.org.uk/>

**Facebook:** [facebook.com/northwestcarerscentre](https://www.facebook.com/northwestcarerscentre)



# Outside the Box: Food Buddies



## *Scottish Borders*



Outside the Box provides independent development support to groups and people across Scotland who want to make a difference in their communities.

We work on a broad range of projects, under the four key themes below, offering support, information, training, evaluation and advice.

- ▶ having different conversations
- ▶ creating inclusive communities
- ▶ people having more choice in their lives
- ▶ building strong sustainable organisations

## What we do

The unique features of this project are the focus on food, finding practical approaches to solve a problem that many people and families experience, and the strong focus on people living well with dementia and being part of their community.

Food Buddies Peer Support Project undertakes work in the following ways:

- ▶ we help to raise awareness about the challenges people living with dementia and their carers can face around aspects of food – planning for meals, shopping, cooking, eating and eating out
- ▶ we deliver practical sessions that let people try food that works well for people living with dementia who have a weaker or changed sense of taste, and for people who find cooking difficult for other reasons
- ▶ we share people's experiences with others and produce resources that are based around peer support
- ▶ we use our resources to encourage people to identify their own 'everyday solutions' and share these within their own networks
- ▶ we use our resources to raise awareness and skills for people in the wider community who could adapt their activities to make them more accessible for their peers living with dementia – for example, community groups, lunch clubs, coffee shops, etc.

## Training

We provide training for Cafés to support them in becoming dementia friendly.

We also provide training for community groups and care providers around aspects of supporting people living with dementia and other older people to have more choices and good experiences around food.



All of our resources, including the training materials, can be found here: <https://bit.ly/2kqtE5W>. These include resources such as:

- ▶ food Buddies – Tips for Days Out
- ▶ food Buddies Café Checklist
- ▶ tips for Older Vegetarians and Vegans
- ▶ getting the Motivation to Cook
- ▶ sensory Changes and Dementia

Please see page 24 in the Information, Awareness, Training and Education Book for more information. Also see [www.lifechangestrust.org.uk/project/outside-box-food-buddies](http://www.lifechangestrust.org.uk/project/outside-box-food-buddies).

## **How our peer support work benefits people with dementia and unpaid carers**

- ▶ we raise awareness and understanding of the sensory aspects of dementia. Dementia can be ‘more than memory’
- ▶ people with dementia and unpaid carers have confidence to discuss any changes in their condition or eating patterns and can be supported if required
- ▶ we are providing a greater number of opportunities for a wider range of people living with dementia and carers to discuss issues related to food and dementia
- ▶ people living with dementia and unpaid carers have the support, knowledge and everyday solutions to enable them to live well throughout changes in their dementia
- ▶ we support and promote the human rights of people living with dementia and enable them to be part of their communities for as long as possible
- ▶ we help reduce social isolation for people living with dementia and unpaid carers and help them create new friendships

**If you want to know more, please contact:**

Christine Ryder  
Outside the Box  
3.10 The Whisky Bond  
2 Dawson Road  
Glasgow  
G4 9SS

**Tel:** 0141 419 0451

**Email:** [Christine@otbds.org](mailto:Christine@otbds.org)

**Website:** [www.otbds.org](http://www.otbds.org)

**Twitter:** @OTBCommunities



# VOCAL: Peer Mentoring for Carers



## Edinburgh

VOCAL's peer support project has two complementary elements:

- ▶ small group support providing structured mutual support
- ▶ peer mentoring providing one-to-one, time-limited, highly personalised peer support – to meet the individual carer's peer support needs

Both activities have been developed in response to carer feedback, allowing carers to select peer support which best responds to their needs, their confidence and their day to day commitments.

## What we do

### Small group peer support

VOCAL provides up to five peer support groups for unpaid carers every year. These groups are time limited and bring together up to ten unpaid carers over several sessions to explore key themes. Carers share experiences and concerns and learn from each other. Groups are held in accessible local locations across Edinburgh including community centres, libraries, GP practices and voluntary sector agency premises.

Each group is facilitated by VOCAL staff and a peer volunteer for six to ten sessions during which ground rules are established. Guest speakers (usually local dementia practitioners) are invited to share their expertise on key themes such as understanding diagnosis, local services and support, advocating for someone with dementia, looking after yourself whilst caring and changing relationships.

## One to one peer support

VOCAL has recruited and trained a small group of peer mentors who have personal experience of caring for someone with dementia.

The peer mentoring process brings together an unpaid carer, who is feeling isolated and is interested in meeting someone who has had a similar role, with a volunteer who has been trained to share their experiences of caring.

Our peer mentoring is a structured but informal relationship with mentoring sessions taking place approximately every fortnight in informal settings of the carer's choice, e.g. chats over coffee and cake.

Mentoring usually takes place over three to five sessions and can be themed around specific topics such as managing behaviour that challenges, using respite care or, more generally, living with someone who has dementia.

Prospective volunteer peer mentors participate in a six-session induction course which covers:

- ▶ VOCAL services and referring clients for further support
- ▶ the role of mentors/client outcomes
- ▶ confidentiality
- ▶ boundaries
- ▶ telling your story
- ▶ keeping safe
- ▶ record keeping

Both elements of the peer support project are embedded in VOCAL's well established carers support team. The team support carers of people with dementia in a variety of ways including information, support to access services and welfare benefits, creation of power of attorney documents, counselling and more.



## How our peer support work benefits people with dementia and unpaid carers

Carers participating report an improvement in one or more of the following areas:

- ▶ being better informed about issues linked to their caring role
- ▶ improved confidence in their ability to shape services and support
- ▶ improved confidence in managing their caring role
- ▶ improved physical and mental wellbeing
- ▶ improved confidence in their ability to deal with the changing relationships resulting from the caring role
- ▶ improved social wellbeing
- ▶ improved economic wellbeing
- ▶ improved personal safety in relation to their caring role

### If you want to know more, please contact:

#### **VOCAL**

Edinburgh Carers' Hub  
60 Leith Walk  
Edinburgh  
EH6 5HB

**Tel:** 0131 622 6666

**Email:** [centre@vocal.org.uk](mailto:centre@vocal.org.uk)

**Website:** [www.vocal.org.uk](http://www.vocal.org.uk)

**Facebook:** [www.facebook.com/VOCALCarers](http://www.facebook.com/VOCALCarers)

**Twitter:** @EdinburghCarers

# Peer Support Networks

## Deep: Dementia Engagement and Empowerment Project



### *Scotland*

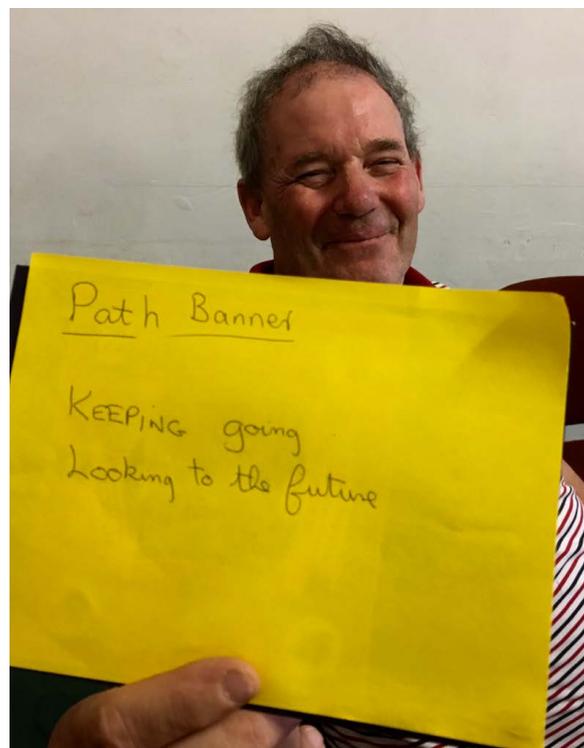
DEEP is a UK wide network of groups of people with dementia – groups that want to change things. The network engages and empowers people who live with dementia to collectively and locally influence attitudes, services and policies that affect their lives. Each group is independent and the network is made up of groups of many kinds, working in all contexts. The network is independent, diverse and rights based. Scottish groups are listed on DEEP's website: [www.dementivoices.org.uk](http://www.dementivoices.org.uk).





The work of groups is broad. Some are campaigning groups or awareness-raising and training groups, whilst others work to influence local changes in practice and policy e.g. creating local dementia friendly communities. For other groups, influencing social change is not their primary purpose – be they arts groups, education groups or even groups in care homes. But what connects them to the DEEP network is the desire to amplify and connect the voices, wishes and intentions of people with dementia.

DEEP's experience-led culture and its UK wide dimension are some of its unique elements. DEEP supports groups through networking, mentoring, gathering together, and by awarding small grants to initiate and develop pieces of work led by people with dementia in Scotland and across the UK. At all stages, decision-making and control is devolved to people living with dementia, and our small staff team facilitates these processes on the network's behalf.



**PRIORITIES IDENTIFIED BY PEOPLE LIVING WITH DEMENTIA IN SCOTLAND  
AT THE DEEP GATHERINGS OF 2017**

Find the full reports and much more at - [www.dementiavoices.org.uk](http://www.dementiavoices.org.uk)  
For more information contact Paul Thomas, DEEP Co-ordinator North UK  
on 07510284760 [paul@myid.org.uk](mailto:paul@myid.org.uk)

**We have  
the right to  
get out and  
about.**

**We want  
to work  
to reduce  
stigma.**

**We want to  
improve the  
experience of being  
given a diagnosis  
and understanding  
medication.**

**We want  
to address  
issues of  
bullying and  
intimidation.**

**We want to help  
develop support  
right through  
the dementia  
journey.**

**We want to use  
Technology,  
Creativity,  
Community, and  
Gatherings to  
reduce isolation  
and loneliness.**

**We have the  
right to be  
supported to live  
independently in  
our community.**

**We have the right  
to do normal  
things, the things  
that we want to  
do.**

**We support the use of  
cultural and creative  
opportunities to help  
people with dementia  
to speak, whatever  
their circumstances.**

**We want support  
to keep our key  
relationships  
healthy, we are all  
care partners.**

**We want to receive  
and develop clear,  
accessible, and  
understandable  
information about  
all aspects of the  
dementias.**

**People with  
dementia can lead  
research, we are  
not just research  
subjects**



The independence and gathering together culture of the DEEP network in Scotland is one of our unique elements. People from all parts of Scotland meet together, share experience and develop pieces of work and research aimed at influencing positive changes. Groups and individuals who are part of the DEEP network in Scotland reflect a rich diversity of cultural and geographic initiatives and experiences. Being able to share those Scottish experiences and initiatives with the whole of the UK (and internationally) helps to ensure that the voice of experience leads and influences development.

## Training

There is a range of guidance published by DEEP for people with dementia and for organisations/professionals. These include:

- ▶ our dementia, our rights
- ▶ making an impact together
- ▶ setting up an influencing group
- ▶ involving people with dementia in advisory groups
- ▶ writing dementia friendly information
- ▶ creating websites for people with dementia

See [www.dementivoices.org.uk/deep-guides/](http://www.dementivoices.org.uk/deep-guides/)

## What DEEP is achieving for people with dementia

- ▶ people with dementia participating in DEEP groups feel less lonely and more positive about life
- ▶ people with dementia participating in DEEP groups feel valued, respected and influential
- ▶ people with dementia participating in DEEP groups have more confidence to do and influence the things that matter to them
- ▶ people with dementia are able to give tangible examples of how being a member of a DEEP group/network has made a difference to their life

We have recently secured a grant from the National Lottery Community Fund to involve DEEP groups in developing their own research – Dementia Enquirers. Part of this grant is to ‘Capture the Story of DEEP’ using creative methods and led by groups.

The Life Changes Trust funded a project to capture the story of dementia activism in Scotland.

Two publications by Philly Hare were published in June 2020. *Loud and Clear!* Exploring two decades of involvement voice and activism by people with dementia in Scotland tells the story of how people living with dementia in Scotland have become activists and influencers in their own right over the last twenty years.

An appendix ‘Loud and Clear! Practical tips for newer dementia activists and their advocates and allies’, is available here: <https://bit.ly/3k99PMN>

### **If you want to know more, please contact:**

Rachael Litherland  
Innovations in Dementia  
PO Box 616, Exeter, EX1 9JB

**Phone:** 07510284760

**Email:** [rachael@myid.org.uk](mailto:rachael@myid.org.uk)

**Website:** [www.dementivoices.org.uk](http://www.dementivoices.org.uk)

**Twitter:** @DementiaVoices



## tide (Together in Dementia Everyday)



### Scotland

**tide** – Together in Dementia Everyday – is a UK wide involvement network for carers and former carers of people living with dementia, hosted by the Life Story Network. Life Changes Trust currently funds the network in Scotland.

## What we do

**tide** brings together and connects current and former carers of people with dementia. Through our bespoke development programme, we give carers the tools and confidence to get involved and influence policy, practice and research.



At **tide** carers' network, we also recognise that not all former carers may want to stay actively involved in campaigning and influencing. Through our work with them, we facilitate former carers in moving on with their lives once their caring role has reduced or come to an end.

The overall aim of the **tide** carers' network is to improve our members' experiences as unpaid carers, as well as improve the services available to them and those they care for.

**tide** brings members together and connects them, which empowers them to build the capacity of carers and former carers to:

- ▶ **challenge** the perceptions of carers of people with dementia in society
- ▶ **campaign** for better support for carers of people with dementia
- ▶ **influence** government, legislation, policy and practice – at local, regional, national levels – starting at the local level
- ▶ **speak on behalf of people** who can't speak out for themselves
- ▶ **provide carers** of people with dementia **with the tools and confidence** to help themselves and others
- ▶ **educate** people, organisations and the public on the important role that carers of people with dementia perform
- ▶ **connect carers of people with dementia with each other**, creating a peer support and involvement network
- ▶ **retain support structures** after their relative/friend with dementia has passed away

## Who can join?

**tide** is a free network open to any carer, or former carer, of someone living with dementia. Each individual's experience is valuable and welcomed. There are several ways in which you can be part of **tide**.

Here are some examples:

- ▶ **keeping informed:** our newsletters, website and social media will keep you up to date with the network's activities and opportunities to take action, as well as developments in dementia policy and practice
- ▶ **development programme:** our bespoke development programme will give you the skills to use your caring experience constructively to influence change, empowering yourself and other carers



- ▶ **research:** you can be involved in research in several ways, such as helping to shape proposals, giving feedback and advice during the research and as participants in the research itself
- ▶ **campaigning:** use your voice locally, regionally or nationally to raise awareness, campaign on specific issues and influence policy, practice and research
- ▶ **learning:** join our work streams on particular topics that interest you and that you want to find out more about
- ▶ **networking:** meet and keep in touch with new people who understand your experiences, adding your voice to theirs to create a powerful social movement

## Training

We offer a unique, bespoke carer development programme which is co-designed, co-produced and co-delivered by our Learning and Development team alongside our carer members. It is a commitment from **tide** to invest in the personal development of our carer members as individuals in their own right.

To find out more about our development programme and how to access it, please visit our website:

[www.tide.uk.net/get-involved/carers-development-programme/](http://www.tide.uk.net/get-involved/carers-development-programme/)

Please see page 39 in the Information, Awareness, Training and Education Book for more information. See also [www.lifechangestrust.org.uk/project/tide-together-dementia-everyday](http://www.lifechangestrust.org.uk/project/tide-together-dementia-everyday).

## How unpaid carers are benefiting from our work

- ▶ current and former carers of people with dementia report feeling less isolated and their health and wellbeing has improved as a result of being a member of the network and accessing peer support connection. We often hear that there is no-one else who can understand what carers are going through apart from another carer. There is this instant connection based in the shared experience
- ▶ current and former carers of people with dementia gain confidence and new skills – for example, being able to speak at a cross-party group or a conference where they previously lacked the confidence to do so
- ▶ current and former carers of people with dementia increase their ability to influence positive changes in policy, commissioning and service – for example, because they have attended a session that teaches them more about how local or national government operates
- ▶ policy, research, education and commissioning has changed as a result of the voice of carers and their lived experience through the **tide** network at local, regional and national level – for example, we know that speech and language therapists have committed to changing their practice because of learning they gained from talks by **tide** members

## Evaluation

The University of the West of Scotland is carrying out an independent evaluation of the **tide** network in Scotland. The final report will be available in summer 2021.



**If you want to know more, please contact:**

**tide (Scotland Office)**

Robertson House  
152 Bath Street  
Glasgow  
G2 4TB

**Telephone:** 0141 353 4310

**Website:** [www.tide.uk.net](http://www.tide.uk.net)

**Twitter:** @tide\_carers



# Conference Bursaries

*Nothing about us  
without us.*





*If we are not here, it's as if a football match has been arranged with all the officials being present, but no footballers invited to participate.*

## Life Changes Trust Conference Bursary Scheme

It is important that people with dementia and unpaid carers can participate in conferences on an equal basis to other delegates. The Life Changes Trust conference bursary scheme has been running since 2014 and is a small project which enables people with dementia and unpaid carers to contribute to, and influence, meetings, seminars and conferences that affect them.

It has not always been the case that people with dementia were involved at dementia conferences. One person with dementia recalls a time when he gained access to a dementia conference only by wearing a camera and pretending he was a newspaper reporter!

The Trust has provided bursaries for people to contribute to a variety of dementia conferences, including:

- ▶ 2014 Alzheimer Europe Conference, Glasgow, Scotland
- ▶ 2015 Alzheimer Europe Conference, Ljubljana, Slovenia
- ▶ 2015 Alzheimer Scotland Conference
- ▶ 2016 Alzheimer Europe Conference, Copenhagen, Denmark
- ▶ 2016 Alzheimer Scotland Conference
- ▶ 2017 Alzheimer Disease International Conference, Kyoto, Japan

- ▶ 2018 Alzheimer Disease International Conference, Chicago, USA
- ▶ 2018 Alzheimer Scotland Conference
- ▶ 2018 UK Dementia Congress, Brighton, England
- ▶ 2019 Alzheimer Scotland Conference

Based on feedback (see below) and significant interest in this type of funding, the Trust will continue funding bursaries so people can contribute and influence.

*It matters to me that my words are said by me, not someone who takes my words to run up the career ladder on the back of me...if people continue to think they can take our knowledge and speak on our behalf they will de-skill us. Too many people are running away with our words.*

*The conference was brilliant. It was good to share knowledge and understanding. Having different people speak and finding out what they think about dementia was really useful.*



*No matter how much we tell people, no-one knows what it is like to be in our heads. (It is) important for the newly diagnosed to know we can still do so much.*

*During breaks I did have lots of conversations with other attendees where we swapped ideas and thoughts and as I benefited from these, I hope others benefited from my input.*

*As a result of attending I feel my network is stronger and much more varied and I am thinking wider than Scotland for future improvements and ways for countries to work together. Thank you once again. It really is most appreciated and I very much hope to be able to attend again next year.*

*My financial circumstances would make it impossible to have paid for attendance.*

*Money is tight so the award allowed me financially to be able to attend.*

*Without the help and support of the Life Changes Trust, attending the conference would have remained a distant dream.*

*Due to giving up work to care for my wife, our only income at present is benefits and without this award I would not have been able to afford either the travel or tickets to the conference...Even if I did have income from full time employment I believe ticket prices for the event would have stopped me attending.*



*If I go, I need to pay out of my (rather empty) pockets. If a professional person goes, their company pays for it and also for their wages. Maybe their ticket prices should be a bit higher so people with dementia can go for free.*

## **What conference bursaries are achieving for people with dementia and unpaid carers**

- ▶ people with dementia and unpaid carers meet their peers, which can provide opportunities for short and longer term peer support and influencing activities
- ▶ people living with dementia and unpaid carers are empowered to have a voice at a wider variety of conferences and other events relevant to dementia – for example, through presentations about work they have been involved in or through telling their story
- ▶ people living with dementia and unpaid carers are involved in policy discussion and, potentially, decisions
- ▶ conference organisers are encouraged to think more carefully about whether venues are dementia friendly to support attendance of those with dementia
- ▶ since funding bursaries we have seen other organisations provide some free places at conferences for people living with dementia and unpaid carers (but this needs to increase)

**If you want to know more, please contact:**

Colm McBriarty  
Funding Manager  
Life Changes Trust  
199 Sauchiehall Street  
Glasgow  
G2 3EX

**Tel:** 0141 212 9600

**Email:** [colm.mcbriarty@lifechangestrust.org.uk](mailto:colm.mcbriarty@lifechangestrust.org.uk)

**Website:** <https://www.lifechangestrust.org.uk/>

**Twitter:** @LCTcolm





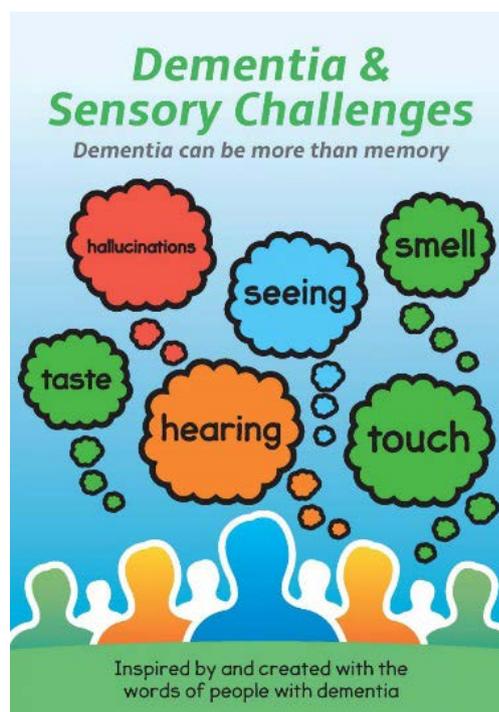
# Peer-to-Peer Resources

## Life Changes Trust Peer-to-Peer Resource Awards

The Trust's peer-to-peer resources programme offers small awards of £500 to £4,000 to people with dementia and unpaid carers to create practical peer-to-peer resources, such as leaflets, DVDs, videos etc. The main aim of this project is to allow people with dementia and unpaid carers to equip and encourage each other. These resources are also valuable sources of education and information for people who want to know more about dementia, e.g. hospital or care home staff, relatives or friends.

## Dementia and Sensory Challenges booklet

The peer-to-peer resources project started in 2015 when the Trust decided to fund a booklet produced by a person with dementia called Agnes Houston, in collaboration with other people with dementia, on sensory challenges. Due to the success of the Sensory Challenges booklet (more than 60,000 copies distributed to date and translated into more than four languages), the Trust went on to fund further peer-to-peer resources.



Agnes was frustrated when professionals did not recognise that dementia is more than memory loss and that misconnections in the brain can also lead to misinterpretation of data going into the brain – for example, some people with dementia find their sense of taste completely changes and so reject certain types of food.

This is often interpreted as a refusal to eat or 'being awkward' whereas, in reality, they no longer like that meal. If not recognised, this can lead to significant weight loss or illness.

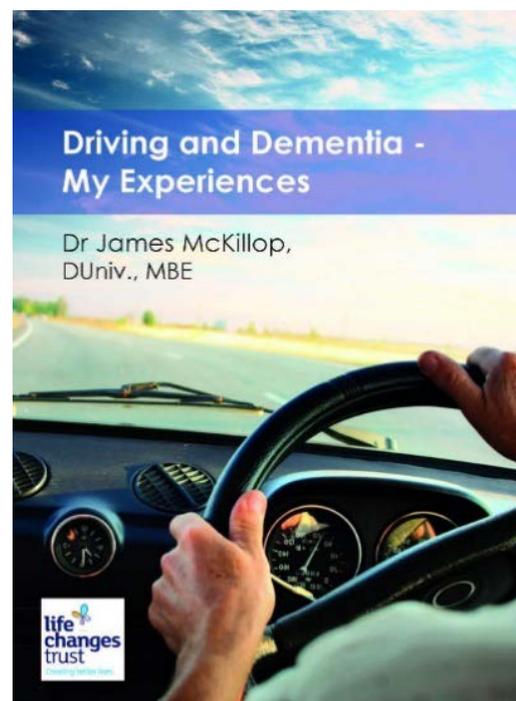
The Sensory Challenges booklet has made carers, professionals and others sit up and take note of what people with dementia are saying. It has influenced the re-writing of training and guidance for professionals in a number of organisations.

A very conservative estimate would say that the booklet has been read by at least 45,000 people in Scotland alone. It has also been distributed in the Czech Republic, Slovakia, Wales, France, Japan, Australia, Canada, Jersey, Guernsey, Hungary, Belgium, Spain and Slovenia. This is a concrete example of empowerment.

This simple booklet struck a chord with many other people with dementia and with carers.

## Driving and Dementia booklet

This very useful resource was written by James, who lives with dementia and wanted to share his experience of giving up driving because he thought it might help other people with dementia who have to do the same.





James talks us through what it was like when he started to notice difficulties with his driving, his dementia diagnosis, how he coped with eventually having to give up driving altogether and the impact it had on his life.

He offers tips and advice on how to move forward with a dementia diagnosis and how it affects driving and mobility, and also provides information on useful resources for drivers who have medical conditions.

James is still a very active member of his community and an advisor for the Life Changes Trust. Just because he now gets the bus, does not mean that he is no longer in the driving seat of his own life.

James has travelled the length and breadth of Scotland talking to people about this resource and sharing copies. He has done this in health clinics, GP surgeries and hospitals in the Highlands and Islands and along the west coast of Scotland. He even manages to have a stock packed when on family holidays!

***I want to help others  
in my position as it's  
devastating to lose your  
license, and its difficult  
to come to terms with.  
The pain still exists for  
me to this day.  
James***

## Travelling Safely with Dementia

This project came about when a group of people with dementia from the Scottish Dementia Working Group (SDWG) devised and put together a leaflet called 'Travelling Safely with Dementia'. The group wanted to find ways to travel with confidence and to share these with others across Scotland.

The group started with two objectives:

1. to produce a booklet on tips and strategies when travelling on public transport; and
2. to use the booklet to raise awareness amongst the public.

Feedback from the original booklet was very positive and there was a lot of interest from the transport sector. This spurred SDWG on to produce a short film, with funding from the Life Changes Trust.



## Travelling Safely with Dementia





The booklet and film are full of useful information for people who are travelling with dementia and those who provide transport services. They cover travelling by car, bus, train, taxi, underground, ferry and air.

Both were produced by members of the Scottish Dementia Working Group.

You can watch the video here: <https://bit.ly/2mlQnAF>

## Come on In

'Come On In' was a project that involved residents and relatives at Campbell Snowdon care home in Inverclyde. The booklet aims to help friends and family of people living in care homes make the most of their visit to the care home and their time spent together.

Moving into a care home is a big step and, along with the changes that living with dementia or other long term conditions can bring, it can be a difficult time.

Some of the family members involved with writing the guide said that it can take some time to come to a good understanding of what makes a good visit with their relative. They hope that the guide shortens that process and helps relatives make the most of their visit to see loved ones who are living in residential care.



*I leave mum's bedroom door open, so that when I visit mum, the staff will walk past and have a chat with us both about different things. It's nice to have that friendly relationship with staff and mum and I get to hear about what's happening amongst the staff, such as weddings, big birthdays.*

*I'm not able to make my family tea any more. At home, the kettle was on as soon as someone visited. I like it when my visitor is offered tea with me, or we can go to the conservatory and my visitor can make me one. They have fresh milk there, which means my visitor doesn't have to go looking for someone to get milk, they can stay and blether with me while they make the tea.*



## Living and Learning with Dementia

The Scottish Dementia Working Group was given funding from the Life Changes Trust to produce a short film which aims to inspire others living with dementia to learn new skills and make friends.

The film features three men – Henry, Pat and Geordie – who all have different types of dementia and a great sense of humour. They share learning from an IT course in which they participated.

The film demonstrates iPad/tablet skills that viewers can try. The chaps discuss the importance of friendships and socialising for people living with dementia. There is also discussion about different types of dementia and how to challenge stereotypes about dementia.

Henry, Pat and Geordie were all involved in the production planning, filming, sound recording and editing of the film, supported by a small video production team from the Untold Motion Picture Company.

You can watch the video here:

<https://bit.ly/2mmFPkV>



## MILAN Senior Welfare Organisation Urdu/Punjabi dementia awareness resource video

MILAN (Senior Welfare Organisation) Ltd was awarded funding from the Life Changes Trust to produce an Urdu/Punjabi dementia awareness resource video.

Dementia is increasing within the South Asian communities and it is vital to have information to cope with the changes and issues that come with dementia. Through this film we learn more about dementia, including the importance of seeking medical help straight away, so that a proper diagnosis can be made and the correct treatment plan can be given.

People with dementia and unpaid carers/families were supported to create this film, which highlights major concerns, myths and the difficulties faced by unpaid carers.

The film also provides people with valuable advice and an insight into living with dementia.

MILAN (Senior Welfare Organisation) Ltd published the film on the South Asian TV channel C44, MILAN website and MILAN Facebook page. 100 USB copies of the film have also been distributed.

You can watch the video here:

<https://bit.ly/2kgUSM2>





## Come and Sing Café video

The Come and Sing Café group at Ruchazie Parish Church was awarded funds to film a 'How to' video which advises other people with dementia, carers and organisations on how to set up a dementia friendly Come and Sing Café (or similar).

The 'Come and Sing' sessions allow people to participate in singing and some light dancing if they choose, while helping people with dementia to get out of the house, have fun, and hear some memorable tunes.

The film also features information about how to get involved with the group and useful information for people affected by dementia. The Come and Sing Café group runs every first and third Monday of the month at Ruchazie Parish Church.

You can watch the video here:

<https://bit.ly/2klHVAN>



## **NDCAN resilience booklets**

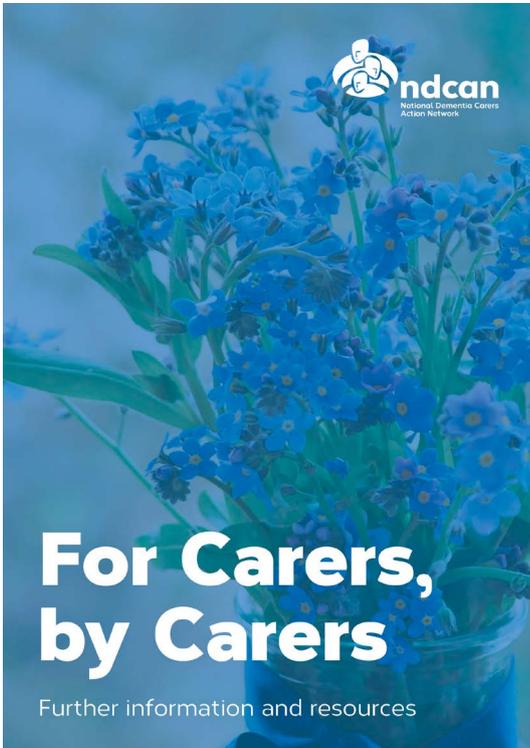
The National Dementia Carers Action Network (NDCAN) is a network of unpaid carers and former carers from across Scotland who all have experience of caring for someone with dementia. NDCAN exists to strengthen the voice of carers of people with dementia and to raise awareness of the issues that impact on them. It is funded by the Scottish Government and hosted by Alzheimer Scotland.

In 2016, members of NDCAN took part in a conference on building resilience amongst family carers. They became interested in helping other carers of people with dementia to be more resilient by sharing their knowledge and experiences of what has helped and worked for them.

The group applied to the Life Changes Trust for funding to develop a series of eight booklets explaining what has helped carers of people with dementia to succeed in their caring role. These booklets offer words of encouragement, tools and tips. They are not professional advice guides, rather they are the things that have worked for NDCAN's carers and other carers in Scotland.

To put these booklets together, NDCAN not only drew upon the expertise of their entire membership, they also worked closely with groups of carers all across Scotland. NDCAN would particularly like to thank those members who worked on its resilience project team: Janette Kean, Myra Lamont, Maggie Muir, Bernard O'Hagan and Lorna Walker.

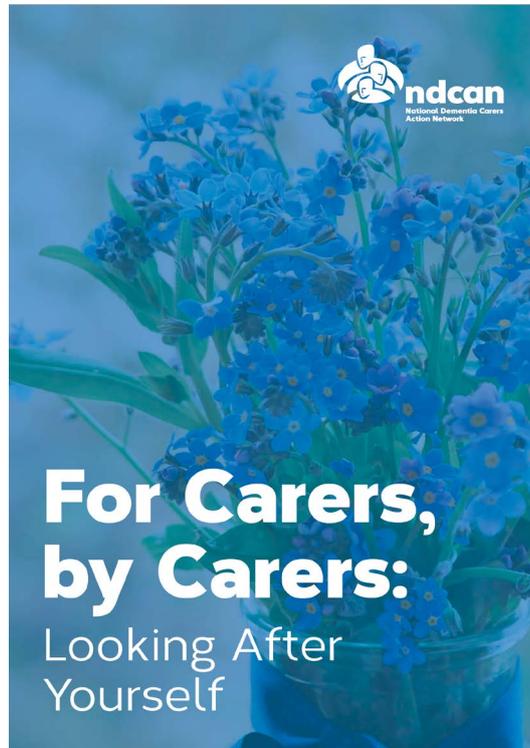
<https://www.lifechangestrust.org.uk/project/easy-read-self-management-and-resilience-resources-dementia-carers>



 **ndcan**  
National Dementia Carers  
Action Network

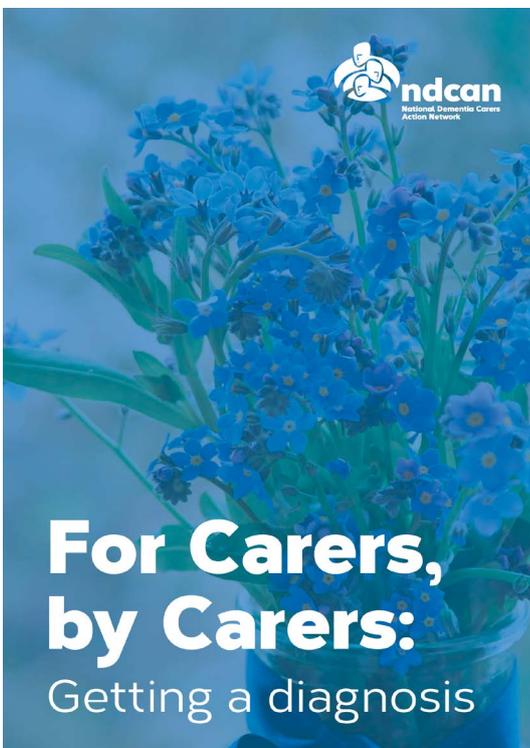
**For Carers,  
by Carers**

Further information and resources



 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
Looking After  
Yourself



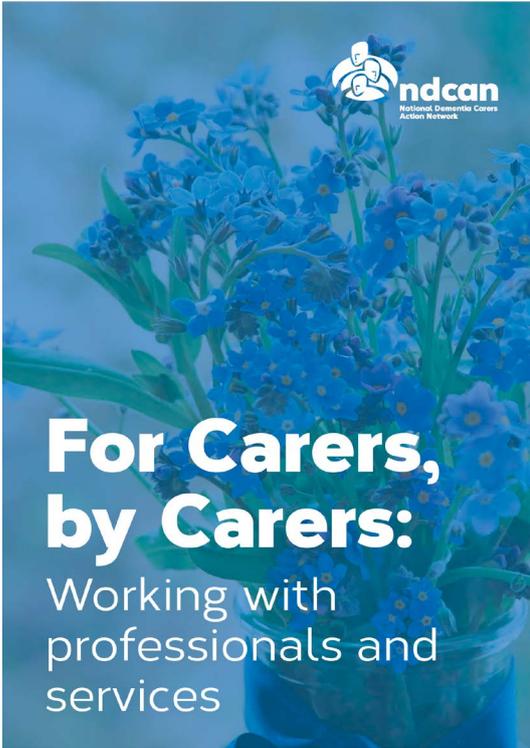
 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
Getting a diagnosis



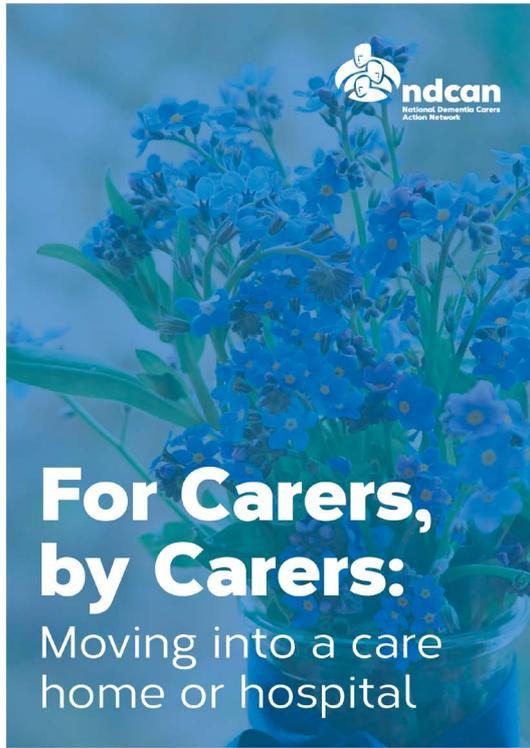
 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
Friends, family and  
community

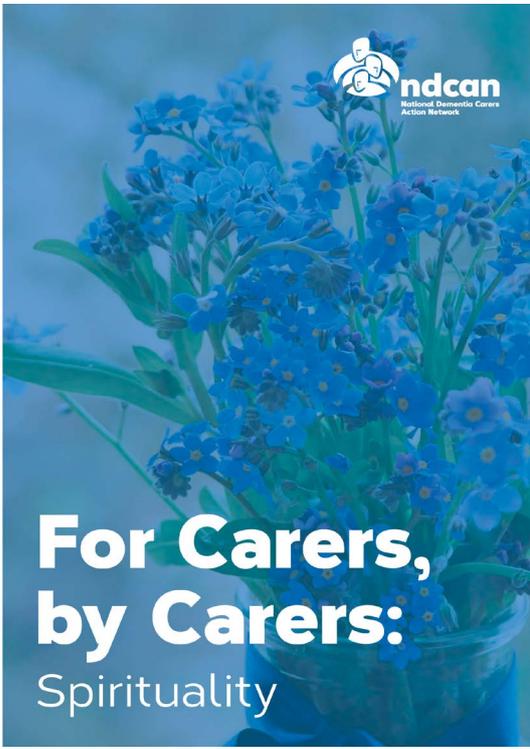
 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
Working with  
professionals and  
services



 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
Moving into a care  
home or hospital



 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
Spirituality



 **ndcan**  
National Dementia Carers  
Action Network

**For Carers,  
by Carers:**  
When Problems  
Arise



## Video installations – ‘Things I Like About Dementia’ and ‘The Fog’

This peer-to-peer resource consists of two video installations to capture the voices of people with dementia – ‘Things I Like About Dementia’ and ‘The Fog’ – and have been made by Christeen Winford and Jennifer Souter (Cormorant Productions & Film Ltd) and Edward McLaughlin, a wonderful artist who is living with dementia.

### ‘Things I Like About Dementia’

Edward McLaughlin is an artist with dementia whose work inspires the confidence and imagination of his peers and the empathy and understanding of the wider community. Several exhibitions of his art work have been held in local libraries, the Festival Theatre in Edinburgh and the Iris Murdoch Centre at the University of Stirling.

The Life Changes Trust gave Edward McLaughlin an award to convert his short film ‘Things I Like About Dementia’ – in which he talks about his life, ideas and works – into a video installation.

The video installation can be displayed at exhibitions and provides an effective and non-traditional way of capturing the voices of people with dementia. The first showing of this exhibition took place in June 2017 at the Festival Theatre Studio in Edinburgh and visitors were able to listen to the video installation through headphones.



## ‘The Fog’

The funding was also used to create another video installation capturing reactions to a series of pictures Edward calls ‘The Fog’, which has sparked lots of discussion. The video features testimonies of other people diagnosed with dementia, and offers shared experiences, stories of hope and coping strategies. The film is intended to be shown alongside Edward’s artwork to help create a deeper understanding of the condition and those who live with it.

You can watch these videos here: <https://www.lifechangestrust.org.uk/project/things-i-about-dementia-fog-video-installations>

There are more peer-to-peer resources underway funded by the Trust, keep a track of them via our website or by following us on Twitter @lifechangestrst.

### **If you want to know more, please contact:**

Colm McBriarty  
Funding Manager  
Life Changes Trust  
199 Sauchiehall Street  
Glasgow  
G2 3EX

**Tel:** 0141 212 9600

**Email:** [colm.mcbriarty@lifechangestrust.org.uk](mailto:colm.mcbriarty@lifechangestrust.org.uk)

**Website:** <https://www.lifechangestrust.org.uk>

**Twitter:** @LCTcolm



# ‘By Carers For Carers’ – events by and for carers of people with dementia

In 2017, the Life Changes Trust invited some carers to design and organise their own conference. For the Trust, the key priority was that this would be something that works for people caring for someone with dementia: an event for carers by other carers.



## Dementia: the Carers Experience

**Better Enabled, Better Equipped**

“Time out and a chance to think about  
how we care for ourselves, as well as our  
loved ones.”

East Lothian, 22 May 2018

Two events, badged by carers as '***Dementia – The Carer's Experience (Better Enabled, Better Equipped)***', were held in Glasgow in Sept 2017 and in North Berwick in May 2018. The first was for carers from Glasgow and six neighbouring local authority areas. The second focused on carers in East Lothian.

A report from the East Lothian event can be found here:  
<https://bit.ly/3d6tFBD>.

We have also produced a guide to support carers in running their own 'For Carers' events – the 'How To Guide', which is in the annexe to this publication.

Each event was planned, organised and delivered on the day by its own local carers steering group. The Trust provided funding and support to help make it happen. Carers chaired and presented at their event too, sharing their insights about what has helped them deal with the challenges of caring for someone with dementia. The **tide** carers involvement network provided support and training to carers.

The phrase 'By Carers For Carers' is a 'litmus test' used when steering groups take decisions about every aspect of their event, working out together what they want to do and how best to do it:

- ▶ What is the purpose of their event and who it is for?
- ▶ What goes in the programme and who should be invited to speak (i.e. any professionals alongside carers)?
- ▶ Which organisations will be asked to host an exhibition stand?
- ▶ What information goes into the delegate pack?
- ▶ What are the costs and how much should be spent on what?
- ▶ What practical help – for example, covering expenses or care costs, will enable carers to come along?



These events were free and for unpaid carers only. Some professionals attended as delegates in a personal capacity but only if they are unpaid carers themselves or were making a presentation.

After each event, feedback from those attending, as well as feedback from steering group members on the process and the event, was reviewed by the group to identify learning, impact and potential follow up issues or activity. If they did want to do any follow up to their event, **tide** provided carers with ongoing support.

## Quotes from carer delegates attending events

*When do we have the chance to feel safe enough to share our personal experiences – and cry if the tears come – knowing that everyone there would understand? That was a very special experience for me.*

*The fact that it was carers that were involved in organising the event, and spoke with honesty about their own situation, made the event so special. But also, the fact that there were so many bodies present to advise on all the things you need help for with dementia...*

*Very useful and hope these will be run on a regular basis as can see others benefitting from this experience.*

## **Quotes from carer steering group members**

*I soon realised how much of me I had lost, at the start I had very little confidence...I had been solely focused on caring for [person with dementia]...now I know I can still do those things but work in the time for me as well.*



*Although this can be difficult and sometimes hard for others to hear I fundamentally believe that, by giving carers a voice in their own right and giving them a platform to talk about their real life and how caring has affected them, is not only upholding their human rights but it is an excellent opportunity for them to influence change, help others and most importantly help them make a change in them.*

*I came to the group with a lot of past experience, but this was completely different as it was something new, peer-to-peer. I could put my previous skills to use, but learned more about peer-to-peer contributions in developing services.*

## Quote from a professional\*

\*professionals attended as speakers, exhibitors and discussion group facilitators:

*It certainly gave me personally and professionally a different perspective towards carers which I hope to develop and roll out to our staff here.*

## How the conferences benefited unpaid carers

- ▶ carers who attended the events or who planned them have a better understanding that they are individuals in their own right, with their own identity, and not just an adjunct to the person living with dementia
- ▶ the peer-to-peer approach throughout, with carers in the lead, meant the events were most relevant to carers rather than professionals
- ▶ carers of people with dementia felt this was specifically for their situation and not a more generic one where they have to try and glean what they can for themselves
- ▶ a programme based on carers' lived experience resonated deeply with other carers – it recognised carers' need for practical information and acknowledgment of the emotional impact of caring for someone with dementia
- ▶ the event provided a programme and resources which allowed carers to go home feeling better equipped in both their caring role and in maintaining their own individual identity



Carers provided an example to other carers:

*If we can do it, so can you and here's how you can do it.*

The Glasgow steering group produced two peer-to-peer resources – a checklist of things to help people caring for someone with dementia and a directory of support and services available locally.

## Short films

Some of the carers who organised the Glasgow event made two films in which they talk about what the steering group experience meant to them and the publications they produced. You can watch the videos here:

Maureen, Myra and Annette – Being Part of the Steering Group

<https://bit.ly/2mhxP4o>

Maureen, Myra and Annette – Resources

<https://bit.ly/2khjYue>

## 'How to Guide' Annexe

Based on the learning to date, we have developed *'Events by Carers for Carers: A Practical How to Guide'*. It can be found on the following pages.



# Dementia: the Carers Experience

**Better Enabled, Better Equipped**  
*Events and Resources by Carers for Carers*

## A How To Guide for Carers

Annexe

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# Introduction

*When do we have the chance to feel safe enough to share our personal experiences – and cry if the tears come – knowing that everyone there would understand? That was a very special experience for me.*

This is a practical resource for people caring for someone with dementia, unpaid. It is for carers wanting to come together in their local community and organise their own event – an event By Carers For Carers.

The Life Changes Trust<sup>1</sup> funds work which will improve the lives of people with dementia and unpaid carers. People living with dementia and carers have a huge amount of knowledge to share with each other, and both groups tell the Trust that they value peer-to-peer support.

The Guide grew out of the Life Changes Trust's carer-led conferences initiative which is about empowering carers. The focus is on enabling you<sup>2</sup>, as carers, to create events for your peers, on carers taking the lead and being seen to be in the lead. It started in 2017 when the Trust invited carers to design and organise their own event for fellow carers of people with dementia. The Trust's priority was that the event should be meaningful for people caring for someone with dementia.

Two events have taken place, badged as 'Dementia – The Carer's Experience (Better Enabled, Better Equipped)'. The first was in Glasgow in September 2017 and the second took place in North Berwick in East Lothian in May 2018.

1 To find out more about the Life Changes Trust, go to – <https://www.lifechangestrust.org.uk/>

2 Language – as this Guide is written for people caring for someone with dementia who may want to use it to help them do something similar, throughout, the text is addressed to 'you' – carers who care for someone with dementia, unpaid.

The Trust wants to enable more carers to do the same. The Guide is intended to offer you, the carers, a template for planning and organising an event for carers. It draws on the learning and experience of carers of people with dementia who have done just that, alongside feedback from carers who attended their events.

The Guide provides guiding principles, practical tips and links to sample materials. It suggests ways for you to do something similar by taking the lead in organising your own event, without feeling that you need an organisation and professionals with a sizeable budget taking the lead.

Equally, this does not stop you collaborating with others – you can collaborate and still take the lead. In fact, working with local organisations who are working with carers, such as your local carers centre and dementia care providers, will add to your local knowledge and help you work out what kind of event will work well in your area. In addition, you might be able to request practical support and funds to help run your event.

Carers involved so far are clear this empowerment process is not a one-off. In organising their event, they often rediscovered their self-confidence, realising they are an example to other carers – ‘we can do this and, if we can do it, so can you – and here’s how you can do it’.

Overall, the hope is that other carers are encouraged to run their own event and, from the experience, they gain new and expanded learning, renewed confidence and empowerment.

***I feel I have a voice now and I hope I can support others in finding their voice. I surprised myself [with] what can be achieved.***



## How to use the Guide

This guide outlines the full process and you might opt to read it from start to end or, as you need to, go straight to a particular heading to click on a template.

Our recommendation is that you look at the 'Think About' checklists throughout, put together to hopefully save you time, effort and stress.

You will see links to all the practical materials in context throughout the text. There is also a full list of templates and other resources at the end of the Guide.



# Acknowledgements

Huge thanks to all the carers who took a leap of faith and came on this journey with the Life Changes Trust, responding with enthusiasm to the idea of putting on an event of their own making for others also caring for someone with dementia:

## **Glasgow Carers Conference Steering Group**

Katharyn Barnett  
Myra Lamont  
Maureen McKillop  
Bernard O'Hagan  
Anne Rankin  
Annette Tait

## **East Lothian Carers Event Steering Group**

Moyra Birnie  
Anne Bissett  
Alison Reynolds

This How To Guide, and the approach it outlines, is testament to their insight and experience, creativity and resourcefulness, commitment and sheer hard work. It is part of their legacy.

The Life Changes Trust would also like to thank Anna Gaughan and Amanda McCarren, in particular, but also other staff from **tide** (together in dementia everyday) for their support of the Glasgow and East Lothian Carers Steering Groups.

## **Author**

Elizabeth Morrison, Evidence and Influencing Coordinator (formerly Funding and Carers Programme Manager), Dementia Programme, Life Changes Trust.



# The 'by carers for carers' approach – guiding principles

The phrase, By Carers For Carers, emerged as the first carers steering group planned its event. Use the following key principles to guide you.

## Think about:

- ▶ You are an individual in your own right – ‘when was I last me?’
- ▶ An independent event, informed by the perspectives and lived experience of carers (not policy makers or other professionals working in dementia, or even people with dementia) – it is a carers-only space, your space.
- ▶ A peer-to-peer approach, with carers in the lead – ‘seeing them in control, front, back and centre’.
- ▶ Catering for carers specifically caring for someone with dementia, not a focus on general issues for carers irrespective of the condition the person has.
- ▶ A programme about carers’ lived experience, recognising a need for information and the emotional impact of caring for someone with dementia, with you as carers presenting and sharing tips about what you would recommend and what you would do differently.
- ▶ A carers event where professionals attend by invitation only for the purpose of giving carers relevant, wide-ranging information e.g. as a stall-holder.

- ▶ The programme, information and resources provided allow carers to go home feeling better enabled and better equipped, both in your carer role and in maintaining your own individual identity.
- ▶ A legacy created by example – ‘courage breeds courage’ – carers motivating other carers by example and by sharing the approach they have developed.

***It gives a strong message to local professionals about carers’ capacity and value.***





# Where to start – forming a steering group

*I enjoyed being part of a team working towards a goal of offering an event, which could potentially reach out to other carers and open up some of the difficult issues which face carers of people with dementia.*

The first step is carers wanting to form a group to organise a carer-led event. You might want to watch the two films by carers who put on earlier events, where they describe what they did and what they got out of the experience.

<https://www.lifechangestrust.org.uk/project/conferences-and-carers>

## Think about:

- ▶ What do you want to do – what is the purpose of your event?
- ▶ What do you want carers attending your event to get from the experience?
- ▶ What will the steering group do? Define broadly the what and the how (you will work out the details as the group starts work).
- ▶ Who do you need for your steering group?
- ▶ How many people do you need?
- ▶ How will you contact other carers to invite them to volunteer?

- ▶ How will you contact carers who belong to communities which are marginalised or excluded, as well as carers who have very little contact with services or groups?
- ▶ How will you become a strong supportive team?
- ▶ How will you settle any differences amicably?
- ▶ How will each of you use your difficult life experiences?
- ▶ What are your individual strengths and how can you use them?
- ▶ Who is good at handling money so the group will manage costs versus any funds you obtain?
- ▶ Who will keep the team on track?
- ▶ What will carers involved in the steering group gain from the experience? Keep in mind too that you might not really know this until after the event.
- ▶ How many meetings will you need and where will you hold them? You might decide to meet in someone's home or prefer a free external venue such as a community centre.





- ▶ What are you asking of carers in terms of their time? And for how long?
- ▶ What, if any, is the cost of meetings and of carers getting to meetings? And, if needed, how might costs be met? To an individual, the cost of taking part might be travel, but also replacement care so they can leave the person with dementia.

***...it would be great if we could...build in some time to just get to know each other and develop our relationship before actually getting down to work.***

Reading this Guide can help you answer these questions. Also, see a sample carers briefing prepared for an open meeting with carers potentially interested in getting involved. You will find this, along with other sample templates and resources in our planning and information pack<sup>3</sup>. Also included in this pack is a sample invitation flyer to help publicise this meeting, as it will be important to spread the word widely, so you have a good turnout. Some carers might be very keen to be involved but cannot commit to joining the steering group and attending meetings.

### **Think about:**

- ▶ How can you include carers with different levels of interest, confidence and availability?
- ▶ How can a buddy system work? How can steering group members team up with other carers so they can contribute ideas and feedback via their buddy? Can steering group members themselves also 'buddy up' to share roles or tasks, so they might not need to attend every meeting?

3 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>

- ▶ How can a core steering group and a wider involvement group share the work – how can others take on smaller tasks, so they too feel they are involved and are playing their part?
- ▶ What are the smaller, shorter tasks and/or tasks done easily at home, in liaison with a steering group member?
- ▶ Will the likes of a closed Facebook group help you communicate in between meetings? This might be something you decide to continue after your event.

***The success of the day was due to the fact we worked so well as a team, open to suggestions and all did our share.***

Think about using By Carers For Carers guiding principles as shorthand to keep you on course as you work out together what you want to do exactly, and how best to do it.

Allow enough time to plan and organise your event in a way that allows you to work as a team, without being too rushed, and that is enjoyable. Six to eight months is a reasonable timeframe, depending on how many people are involved, how often you plan to meet and the nature of your event.



# What do you want to do – designing your event

*It offers time out and a chance to think about how we care for ourselves, as well as our loved ones.*

## Overall focus and purpose

Carers involved so far saw the key issue as *'living well in the caring role'*, so took a twin focus and centred their events on both:

- ▶ What helps?
- ▶ How do you hold onto your sense of identity when you're focused on the needs and wellbeing of your loved one?

Their aim was for carers to leave feeling better enabled, and better equipped, both in their carer role and in maintaining their own sense of self.

### Think about:

- ▶ Content which delivers on the practicalities around caring for someone with dementia.
- ▶ Content which addresses the emotional impact of caring for someone with dementia.

## Your audience – who is your event for?

The By Carers For Carers approach advocates a carers-only event.

### Think about:

- ▶ Is your event for people currently caring for someone with dementia or also those who cared for someone in the past?
- ▶ How to reach and encourage new carers to attend?
- ▶ What is your geographical area (e.g. is it your local authority area, your town, your neighbourhood)?
- ▶ How will you make your event inclusive and of interest to local carers in communities which are more marginalised?
- ▶ Some professionals working in dementia and living in your community might also be unpaid carers themselves and want to attend in a personal capacity.

How you answer these questions will also inform what you put into your programme. Once you have a clear idea of who lives in your area<sup>4</sup>, for example carers from a minority ethnic community, you might want to invite others to join your steering group. Equally, you might identify a topic relevant for local carers.

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<sup>4</sup> Go to Census Scotland for a breakdown of the population living in your community – <https://www.nrscotland.gov.uk/statistics-and-data/census>).



## Scale and format – what size of event do you want to hold?

Size matters – for a host of reasons. Experience so far indicates that ‘small is beautiful’.

### Think about:

- ▶ A bigger event means you will have more to do and it will cost more.
- ▶ A small, local event might be the thing to persuade those less confident to come.
- ▶ A small event might encourage more participation and easier networking, in turn resulting in ongoing contact and mutual support (earlier steering groups observed carers exchanging contact details).
- ▶ A half day event will be more accessible at a practical level, and it may be easier to arrange (and possibly pay for) cover care, if needed.
- ▶ Estimate your numbers – how many carers and how many information stalls.
- ▶ A small-scale, low cost event will be easier to repeat or adapt as a follow-up.

# What do you need to do next – planning and organising your event

## Think about these key questions:

- ▶ What to do yourselves or rather what, if anything, can you not do together?
- ▶ Who to approach to ask for advice, support and/or money?

## Think about other important decisions for your steering group including:

- ▶ What to include in, and alongside, the programme to enable carers to share and learn from each other, and also provide information of real practical benefit?
- ▶ Who to invite to speak (do you want professionals speaking alongside carers)?
- ▶ What organisations to invite to host an information stall?
- ▶ What information to include in your carers bag? A generous delegate pack including plenty of localised content is worth the effort. Only so much can be covered in a day and this makes it a gift that keeps on giving.
- ▶ Who amongst you will chair your event? This really helps make your event truly carer led. Or, if more reassuring, you might want to share the task and co-chair.
- ▶ What are the type of costs involved in your event, how much do you want to spend on what, and how will you meet essential costs?
- ▶ What practical or financial support might help carers to attend?
- ▶ How to get feedback from carers and others to find out the impact of your event?



Your enthusiasm will build, and the ideas will flow. It is okay to recognise you probably cannot do all you want ‘in one go’ in a single event. Be wary of ‘information overload’ for carers attending. Equally, you might want to think big in another sense – keep in mind that you could repeat your event or run several short, themed events as a series. Carers at the first events were very clear they wanted more.

***Please can we have another one before too long – or even on a regular basis?!!***

You will find general checklists for event-planning and venue-booking online to assist you with all the general tasks involved at each stage of putting on an event. You can also find a helpful checklist of the things the steering groups have identified to date in our planning and information pack<sup>5</sup>. You will make the list your own as you make decisions and work towards your event.



5 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>

# Programme

## *What are you going to do for you?*

### **Carers telling their own stories**

Feedback from carers putting on events, carers attending them and professionals also present (as a speaker, exhibitor or facilitator), indicated that hearing carers speak – the carers’ voice – was the highlight. Consider how your event will acknowledge the emotional impact of caring for someone with dementia and how it will allow carers attending to feel valued and connected.

#### **Think about:**

- ▶ Who on your carers steering group wants to speak? Don't think you must decide this at your first meeting. Take time to get to know each other, to get used to the idea and to become more comfortable with what you're working towards as a team. The first steering group found 'courage breeds courage'. Equally, be realistic and acknowledge not everyone will want to stand up in public and tell their story, and that's okay.
- ▶ What are your 'top tips' – personal insights you want to share about what has helped you deal with the challenges of caring for someone with dementia and about what has helped you hold onto your own identity (outwith being a carer)?
- ▶ If you have cared for someone for a long time and/or the person has passed away, what would you tell your younger self?



- ▶ Contrasting experiences of caring (for example caring for a partner or a parent, caring in various situations e.g. at a distance, whilst also working, or bringing up children, caring for someone at different stages in their dementia journey or diagnosed at an early age).
- ▶ Recognise each story will chime with individuals in your audience – ‘that is me’ – and ‘it’s so comforting to know that you are not alone’.

## Free training and support – from **tide** (together in dementia everyday)

**tide** offers carers training. For those involved to date, it was invaluable in preparing their talks, and also helping them cope with the emotions they knew they would feel telling their stories. Presenters did **tide’s** ‘Presenting to Influence’ workshop. Its aim is ‘for carers and former carers of people with dementia to be able to share their experiences and parts of their own story with others...[and] develop the essential attitudes, knowledge and skills to deliver effective presentations.’

Carers also had support in preparing to chair their event. **tide’s** module on ‘Chairing a Meeting’ helps ‘prepare participants to chair a meeting for the first time...[exploring] the role and key functions of the chair, how to get the best out of chairing a meeting, and hints and tips for successfully chairing a meeting.’ Contact **tide** directly to enquire about their training for carers<sup>6</sup>.

## More peer-to-peer sharing – small carer-only discussion groups

You might want to encourage carers attending your event to reflect on what they have heard and to share their own experiences. This was probably the trickiest but one of the most important parts of each event so far.

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<sup>6</sup> For more information on **tide’s** training programme, go to – <http://www.tide.uk.net/get-involved/carers-development-programme/>.

## Think about:

- ▶ How to offer carers an open and safe space? To date, discussion groups have been for carers only. Professionals were able to listen to carers telling their stories in the main session but could not join the groups and this was made clear in advance. Carer speakers did not attend the groups so that others could freely discuss their talks.
- ▶ How to facilitate discussions? Groups so far were led by either **tide** or NDCAN<sup>7</sup> staff (the only staff member in the room). **tide** prepared facilitator briefing notes and discussion group guidelines. You can find some sample guidelines for carers small discussion groups in our planning and information pack<sup>8</sup>. **tide** also prepared a report after each event for the steering group. It was explained on the day that content would be anonymised.
- ▶ How to encourage meaningful discussions that are not intrusive? Keep in mind that it is unlikely you can meet all expectations, as individuals are at different stages in their caring journey. In the advance information to carers and in the chair's opening remarks on the day, you can acknowledge this and propose everyone should feel able to speak about their own caring experience.
- ▶ How likely it is that, for some, their focus has been on the person they care for and this is the first time in years thinking about themselves in their own right?
- ▶ How much time to allocate to group discussions? This and the previous question about enabling a shift in perspective are probably the most important – pace and focus are key and discussions are best not rushed. Carers have said that the discussions need to be given more time.
- ▶ If content is emotive, what support can you offer? Have a 'quiet room' for carers to go for time out and/or a quiet word. Do a rota and have a carer from your steering group or wider involvement group there, especially after group discussions and during breaks. Tell people about this at the start of the day.

7 NDCAN – National Dementia Carers Action Network – <https://www.alzscot.org/ndcan>

8 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>



## Practical information – professional speakers

You might want to prioritise the carer's experience, with carers sharing their stories (especially if you opt for a short event), but you may also want to give practical information.

### Think about:

- ▶ What key issue do carers need to know about which would best be covered by a presentation by an expert on the subject, with a question and answer session?
- ▶ What issue is especially relevant for carers of people with dementia living locally?
- ▶ What big issue 'of the moment' is important to people caring for someone with dementia?
- ▶ Who is best placed to speak on your chosen topic(s)? Be sure to give speakers a clear brief and a deadline and follow up to confirm details. Ask for their presentations ten days in advance and no later than a week before your event, so you can read them in good time. You need time in that last (busy) week to test that presentations work on your IT equipment (laptop, projector and screen, if you are using technology). This applies to audio and video as well as slides (if any speakers want to show a film clip as part of their talk).

You can find a sample programme from one of our carers events in our planning and information pack<sup>9</sup>.

## Networking

Don't overfill your programme. Don't underestimate how challenging it will be to keep to that as you will come up with lots of ideas. Feedback confirms informal networking is important, so ensure that carers have enough time simply to talk together – to reflect on what they've heard, possibly share something of their own experiences, and to connect with others.

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<sup>9</sup> 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>

# Exhibitors

A 'marketplace' is an effective way to give carers easy access to wide-ranging information and contacts.

## Think about:

- ▶ What organisations, in particular those operating in your local area, can best give the information needed by carers of people with dementia?
- ▶ Decide if exhibitors will be involved by invitation only (so carers have access to the range of information you have identified as important), or organisations can ask to host a stall.
- ▶ How many stalls to have (this might be limited by the space you have available)?
- ▶ Do you want to have a 'general stall'? An extra, unattended stall will allow you to make more information available to carers if your space is limited, if organisations are unable to send staff and/or others ask to provide a stall but are not on your steering group's priority list.
- ▶ Ensure your invitation to organisations is clear about what you want exhibitors to provide (e.g. information relevant to someone caring for a person with dementia, information given in person, publications to take away) and follow up to confirm details.
- ▶ Give enough time in your programme for carers to browse the stalls and talk to exhibitors. Steering groups and carers attending events said more time needs to be given to this.

You can find a checklist detailing the main things to arrange and agree with exhibitors in our 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>



# Key practicalities – date, location and venue

Date, location and venue will affect how accessible your event is, encouraging or discouraging some carers from attending.

## Think about:

- ▶ Avoiding dates of events or other activities already publicised, local and national, which carers of people with dementia might want to attend.
- ▶ Avoid the dates of main religious and cultural festivals which will rule out your event for some people.
- ▶ An interesting and fun venue. You want people to come! ‘You think outside the box all the time as a carer, this is no different’.
- ▶ A central location in your geographical area to minimise travel time and cost.
- ▶ A location and a venue within reach of public transport from all across your area.
- ▶ Options for organising transport for those carers who need it<sup>10</sup>.
- ▶ Availability of parking at the venue including disabled parking.
- ▶ Finding a venue that meets your specification for the size and format of the event, is fully accessible for anyone with limited mobility (outside and inside, including toilets) or with other needs (such as catering/special diet), and fits your budget (suitability and value).

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<sup>10</sup> Contact your local authority to ask if they can assist with transport or go to Community Transport Association to find out about providers of community transport potentially operating in your local area – go to <https://ctauk.org/about-cta/what-is-community-transport/>

# Resources – produced by carers for carers

The Glasgow steering group created two complementary peer-to-peer resources giving carers practical information across a wide range of topics. The East Lothian group adapted both and produced a new version for their carers bag, given out at their event.

## **A Dementia Checklist, a Resource by Carers for Carers**

This is a resource to help people who care for someone with dementia put in place the right systems and support, and to suggest where carers can turn to for advice.

*Good care management is a bit like conducting an orchestra. You might not want all the musicians playing all the time, but you need to know where they are!*

## **Dementia – A Carers Local Directory, A Resource by Carers for Carers**

This lists local services, groups and activities helpful to people who care for people with dementia.



*I wish that I had been given information like this when I became a carer. It would have made my journey easier and less stressful.*

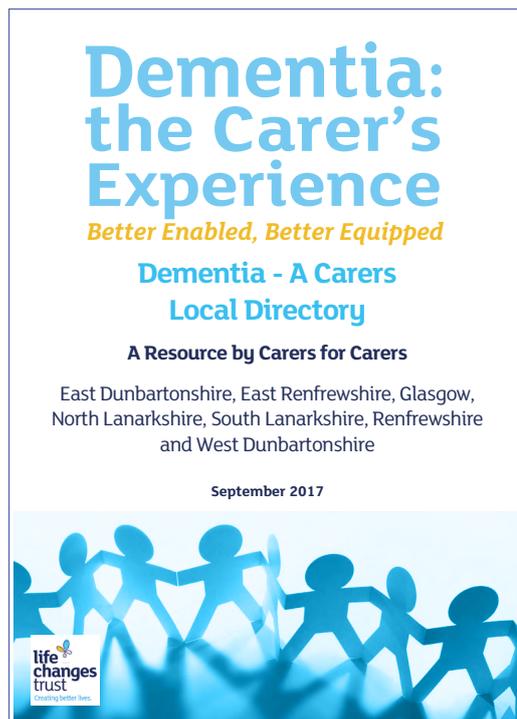
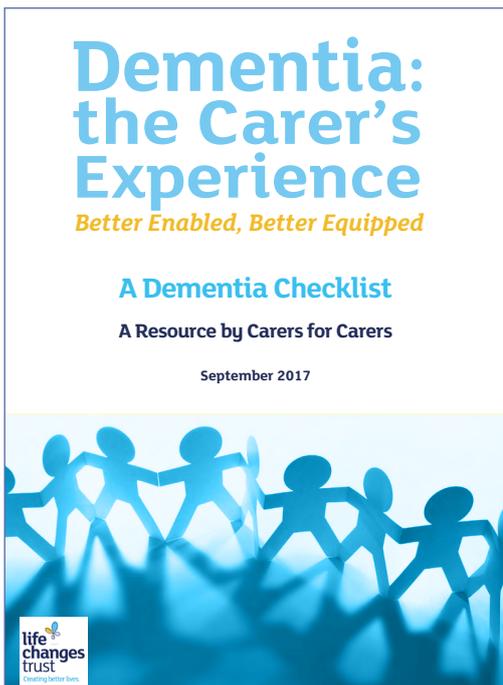
Find all four resources (as distributed at the Glasgow and East Lothian events) here: <https://www.lifechangestrust.org.uk/project/conferences-and-carers>

### **Think about:**

- ▶ Find out what exactly is available across your local community, in terms of services, information and support, and activities – both for people with dementia and carers.
- ▶ Make your own local directory for your area to give to carers coming to your event.
- ▶ Consider updating, and even adding to, the generic ‘dementia checklist’ (as you too will have knowledge and experience to share). and include this second peer-to-peer resource in your carers bag delegate pack.

*Doing the research for the two publications helped me to understand what was available in the local area.*

In addition, you may have an idea for a third carers resource, to complement the Dementia Checklist and Local Directory, which you want to produce from scratch for your carers event. Like previous steering groups, this could be a new resource for sharing with other carers following your lead in the future.





# Money and resources – working out and covering your costs

Once you have worked up your programme, plus the size and format of your event, you will be in a position to estimate your costs.

## Think about:

- ▶ How to cover all the costs to make your event free for carers to attend.
- ▶ How to minimise costs to run your event yourselves, independently ‘on a shoestring’ even, to make it more achievable (while still covering the essential aspects that keep it meaningful for carers).
- ▶ What do you need cash for – what are your ‘essential’ costs?
- ▶ Factor in a sum for paying reasonable expenses to carers, if needed, to enable them to attend (costs of travel and alternative care).
- ▶ What sources of funding are available locally? Your local carers centre will be a good source of information and advice. Check dates when you have to apply by and when you will hear the result. Apply. (You might not be able to do this in an individual capacity but need to do it supported by an organisation which will hold the money on your group’s behalf).
- ▶ How much do you need in total? What practical help could replace cash?

- ▶ What in-kind (free) support could you request from organisations, including your local council, and health and social care partnership? Find out what they might consider if you ask for in-kind contributions – such as a room for steering group meetings, a space to hold your event (possibly even catering), design and print (carer publications, producing copies for your carers bag), photocopying (steering group meeting papers and materials going into your carers bag), bags, postage (to send registration information to carers who have no email), IT support (to prepare your presentations and/or at the event), IT equipment at the event (depending on your venue and what it supplies), community transport, catering (e.g. a local deli might agree to offer a discount or even free sandwiches).
- ▶ You might have other ideas as you work out exactly what you need.
- ▶ Local businesses might have community programmes. You may need to put a request for sponsorship in writing. Allow plenty of time for a decision and be prepared to acknowledge any sponsorship given.
- ▶ Can you negotiate a carers discount?





- ▶ If covering costs becomes a ‘make or break’ issue, try to negotiate a free venue such as a church hall and simply propose people bring a packed lunch. Again, stay focused on what the essentials are, so the event remains meaningful for carers. At the same time, if you can’t stretch to the venue you really want, make your venue more inviting by adding small touches such as fresh flowers. Put names in a hat to see who gets to take the flowers home.
- ▶ How to make carers feel special at no cost. A free prize draw, with gifts donated by local businesses, can be a very real validation of the contribution of carers to your community and see carers go home with a surprise gift.
- ▶ Work out how you will announce the draw and distribute the gifts. However you decide to organise your draw, it will take time and will need to be considered when juggling your programme timings. To ensure impartiality, consider adding a number to each carer’s name badge and ask a few of the exhibitors to pick numbers out of a hat (for example, while carers are in discussion groups).
- ▶ Ask about Respitality<sup>11</sup> programmes at your local carers centre to find out about the possibility of including a short break donation in your prize draw. The Respitality project connects carers’ organisations with hospitality, tourism and leisure businesses willing to donate a free break to carers.

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<sup>11</sup> Respitality is a Scottish Government-supported project, currently operating in 13 local authority areas. It is delivered locally by approved delivery partners and coordinated nationally by Shared Care Scotland:

<https://www.sharedcarescotland.org.uk/respitality/about-us/>

# Promotion

An early task is contacting carers to let them know about your event, letting them know soon enough to make arrangements (e.g. for cover care), and encouraging them to book a place.

## Think about:

- ▶ Make a promotional flyer and/or a poster. Consider adding a few short, snappy quotes from carers who attended previous events.
- ▶ Use social media such as Facebook, Twitter and Instagram.
- ▶ Depending on resources, print your flyer and distribute batches across the area (for example, in libraries and GP surgeries, the local social work department and carers centre), and ask professionals to give it to carers, to tweet about it, and to include details in their newsletter and on their website and Facebook page.
- ▶ Visit local carers groups in person to explain what it is you are doing. This works really well – carers will see you as ‘ordinary folk, just like us’.
- ▶ Contact your local radio to speak on air about your event. Alternatively, they might be willing to do a free ‘shout out’ about your steering group and the event.
- ▶ Approach your local newspaper about doing an article (or negotiate a discount to place an advert).



# Registration

You will already have made decisions about the size and format of your event, and therefore the number of carers you can accommodate. You will need to know how many carers want to attend your event in advance so you can plan.

## Think about:

- ▶ Work out what you need to know about who is coming and what you need to tell carers who want to attend.
- ▶ Decide who is going to answer any queries, take bookings, deal with any specific needs such as accessibility (e.g. a hearing loop at the venue or a ramp outside) or special dietary requirements. Follow up quickly and give people the key information that they will want to have – both at the time of booking and later.
- ▶ Give clear information on your promotional materials about how carers can book a place and make the process and communication as easy as possible.
- ▶ Ask carers to fill out a simple booking form.
- ▶ Be sure you will have all the necessary information early enough to prepare your 'delegate joining instructions' to send to carers and others (e.g. exhibitors and other professionals you have asked to be involved). Send them out no later than a week before your event. You can find sample joining instructions in our 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>

- ▶ If you think you are going to reach your maximum number, start a reserve list and advise carers when they contact you to book. So carers can make arrangements to attend at short notice, decide how late you will inform someone on the reserve list that they have a place if someone else drops out.
- ▶ Likewise, when confirming someone does have a place, ask them to let you know if they find they cannot attend so someone else can have their space.
- ▶ Work out your total numbers. Remember to include absolutely everyone else in your total number of delegates attending, so you have enough seats, delegate packs, food etc. Don't forget to include the steering group in your calculations.





# D-day is here – the day of your event

You will find generic checklists for event and venue planning online to assist you with the general tasks and processes at the last stages. You can find a list of the things the steering groups have identified to date in our planning and information pack<sup>12</sup>. Prepare your final checklist and complete outstanding tasks as far as possible in the weeks and days running up to the event.

Importantly, agree in advance with your venue that you can have access the day or evening before to set up (or early morning on the day of your event if unavoidable).

## Think about:

At your last few steering group meetings

- ▶ At each meeting, go over your final event and venue checklist(s) to ensure everything is progressing as planned and/or if you must take any alternative action to solve any problems.
- ▶ Agree a 'D-day task allocation' list, assigning roles and tasks to everyone involved for both the set-up the day before and on the day. You can find a sample D-day task allocation list in our planning and information pack<sup>12</sup>
- ▶ Ensure each person has their own dedicated list of tasks and responsibilities, as well as a shared understanding of the full picture of who is doing what, when etc. You will all want to be reassured that, between you, you've got everything covered.
- ▶ Once you have agreed what your chair and co-chair(s) each need to do in their roles, prepare detailed briefing notes as a 'memory jog' on the day, and share with everyone on the steering group. You can find sample briefing notes in our planning and information pack<sup>12</sup>

<sup>12</sup> 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>

- ▶ Agree an ‘internal’ version of the programme for steering group members, with any additional details you all need to have to hand on the day to ensure the event runs smoothly.

***Really helpful to feel supported by a good team. I knew, if I floundered with anything, someone would help.***

## **In the week running up to your event**

- ▶ No later than a week beforehand, send carers ‘joining instructions’ along with the final version of the programme.
- ▶ Check in with your speakers, exhibitors and facilitators and go over all the arrangements you have already made with them. Send professionals ‘joining instructions’ too.
- ▶ Arrange to photocopy the paperwork you have identified you need e.g. copies of the programme and any other papers going into the carer delegate pack, notes for facilitators, your final steering group task allocation list etc.
- ▶ Prepare name badges if you are using them and make up the carers bags.
- ▶ Visit the venue to go over all the arrangements you have agreed and finalise any outstanding issues e.g. final total delegate numbers, special dietary or accessibility requirements, revised price (if applicable/changes made to your booking), first aid cover, fire procedure.



## Set-up the evening before

- ▶ Set up as much as possible – guided by your final checklist and your steering group task allocation list.
- ▶ Do a ‘walk through’ with the venue organiser and go over all the arrangements again in detail, checking timings and layout for each part of the programme, first aid and emergency evacuation arrangements etc, and agree who is your main point of contact on the day.
- ▶ Check hired equipment is working and compatible with yours (e.g. your laptop holding slides and presentations).
- ▶ Have a rehearsal, running through your carer presentations where you will be doing your talks for real.
- ▶ Do a second ‘walk through’ together as a group before you leave to familiarise yourselves with the whole area and layout including toilets, lifts, exits etc.

## On the day

- ▶ Do any final set-up, using your final checklist and your task allocation list.
- ▶ Liaise with exhibitors, ironing out any issues before carers arrive and making sure they are ready by the deadline you have given them.
- ▶ Greet speakers, checking their slide presentations (or films/audio etc.) are ready and working.

- ▶ Welcome carers to your event. Deep breaths all round and enjoy!
- ▶ When it's over and everyone has left, avoid a flat ending – come together and mark your collective achievements, however briefly, maybe over a cuppa or a celebratory drink (you will be tired but probably on a high too).
- ▶ Consider having a celebratory meal together in the next week or so once you've recovered, possibly after a follow-up meeting of your steering group.





# Feedback and evaluation

You will need to have made decisions about this and agreed your approach as part of your planning process. You yourselves will want to know the impact of all your hard work and how useful your event was for carers who attended. Obtaining feedback is also important to help you and others plan future carer-led events. Being able to show the benefits for carers of what you have done will help you and others make the case for financial support and in-kind contributions in the future.

## Think about:

- ▶ What do you want to find out? Keep it simple but focus on what matters to carers.
- ▶ Whose feedback is important? Ask carers who attended, but also professionals present to gain different perspectives (they may share the same views, or not).
- ▶ How will you collect feedback? You can see a sample event feedback form in our planning and information pack<sup>13</sup>. Consider building time into your programme for people to complete their form e.g. 10 to 15 minutes.
- ▶ If you want to ask if carers want a copy of presentation slides sent to them, include the question as a tear-off slip at the end of your feedback form. They can separate it, allowing them to give their feedback anonymously. Have two boxes or buckets on your registration table for carers to drop in forms and tear-off slips.
- ▶ Consider, well before the event, who can collate, or help you to collate, the feedback and identify the main points for you to discuss together.

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<sup>13</sup> 'By Carers For Carers Conference Planning And Information Pack' <https://bit.ly/2Y6Wfhs>

- ▶ Agree to record and share your own individual feedback and reflections, as this is equally important. Think about both the steering process and the event itself. You can find sample ‘Steering Group Reflection Questions’ in our ‘By Carers For Carers Conference Planning And Information Pack’ <https://bit.ly/2Y6Wfhs>
- ▶ Meet again soon as a steering group to review all the feedback and reflect on what you have learned.
- ▶ Identify how you might want to use and share the feedback and the learning to benefit carers, and who might help you do that.

***I welcomed the opportunity to do something which might make a difference, meet others in a similar situation and, most of all, learn. I know that I feel more able to cope when I feel more informed.***



## What next – After your event

You will have some tasks to follow up after your event.

### Think about:

- ▶ Thanking everyone who contributed to making your event a success such as speakers, exhibitors, facilitators, funders and in-kind contributors, business donors, venue staff, volunteer drivers and any others involved. The East Lothian steering group spent an afternoon together hand-writing a thank you card to every individual.
- ▶ Pay any carer expense claims you have and settle any outstanding bills.
- ▶ If any carers had to cancel and did not attend on the day, send them a carers bag.
- ▶ If, as a result of some people not attending, you also have prize draw gifts remaining, send a prize too if possible (a voucher can be posted) or arrange with them how to collect it.
- ▶ Send copies of speaker presentations to anyone who requested them.
- ▶ Review your expenditure and estimate the value of all your in-kind contributions to work out what the event cost in total to put on.
- ▶ Complete any formal paperwork you have to send to funders or in-kind contributors.

*I can't think we could do any more than we did this time, as long as information is shared, and the great communication continues.*

If you want to be involved in other activities to benefit carers, **tide**<sup>14</sup> may be able to offer your steering group and other carers support.



<sup>14</sup> **tide** enables and empowers carers and former carers of people with dementia to have their voice heard and become active agents of change. If you would like more information, go to their website – [www.tide.uk.net](http://www.tide.uk.net)



# Links to templates and resources

For ease, here is a full list of all the resources described in the Guide. The list includes links to websites for other sources of information, as well as the various templates cited throughout which stem from the work of the carers steering groups to date.

**1.** Films – carers talking about what they did and what they got from the steering group experience:

<https://www.lifechangestrust.org.uk/projects/conferences-and-carers>

**2.** By Carers For Carers Conference Planning And Information Pack:

<https://bit.ly/3e5veAC>

This includes:

- ▶ Sample invitation to join steering group
- ▶ Sample steering group purpose and tasks
- ▶ Sample steering group checklist
- ▶ Sample conference agenda
- ▶ Sample exhibitors checklist
- ▶ Sample last stages and D-day checklist
- ▶ Sample joining instructions
- ▶ Sample Chair’s briefing notes
- ▶ Sample carers groups discussion guidelines
- ▶ Sample feedback form
- ▶ Sample steering group reflection questions

**3.** Publications By Carers For Carers – two complementary peer-to-peer resources given to carers attending the two previous events, providing lots of practical information, both general and specific to a geographical area. The resources ‘A Dementia Checklist’ and ‘Dementia – A Carers Local Directory’ can be found here:

<https://www.lifechangestrust.org.uk/projects/conferences-and-carers>

## Websites

- ▶ Life Changes Trust:  
<https://www.lifechangestrust.org.uk/>
- ▶ **tide** (together in dementia everyday):  
[www.tide.uk.net](http://www.tide.uk.net)
- ▶ Census Scotland:  
<https://www.nrscotland.gov.uk/statistics-and-data/census>
- ▶ **tide** (together in dementia everyday) – carers training programme:  
<http://www.tide.uk.net/get-involved/carers-development-programme/>
- ▶ National Dementia Carers Action Network (NDCAN):  
<https://www.alzscot.org/ndcan>
- ▶ Community Transport Association:  
<https://ctauk.org/about-cta/what-is-community-transport/>
- ▶ Shared Care Scotland – Respitality:  
<https://www.sharedcarescotland.org.uk/respitality/about-us/>

## Getting in touch

If you have any queries or wish to share your views and ideas, you can contact the Life Changes Trust in a number of ways:

**Phone:** 0141 212 9600

**Email:** [enquiries@lifechangestrust.org.uk](mailto:enquiries@lifechangestrust.org.uk)

**Website:** [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)