



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 Trust¹ 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 you², 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

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East Lothian Carers Event Steering Group

Moyra Birnie
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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

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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 pack³. 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 area⁴, 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.

⁴ 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 pack⁵. 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 carers⁶.

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.

⁶ 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 NDCAN⁷ 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 pack⁸. **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 pack⁹.

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.

⁹ '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 it¹⁰.
- ▶ 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).

¹⁰ 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.

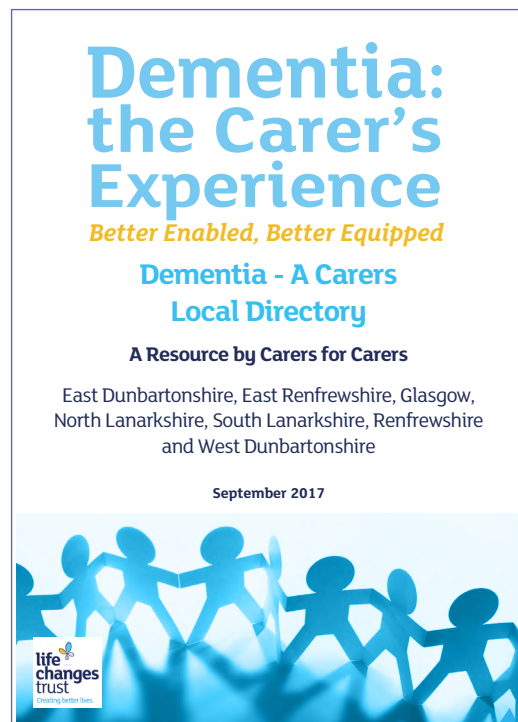
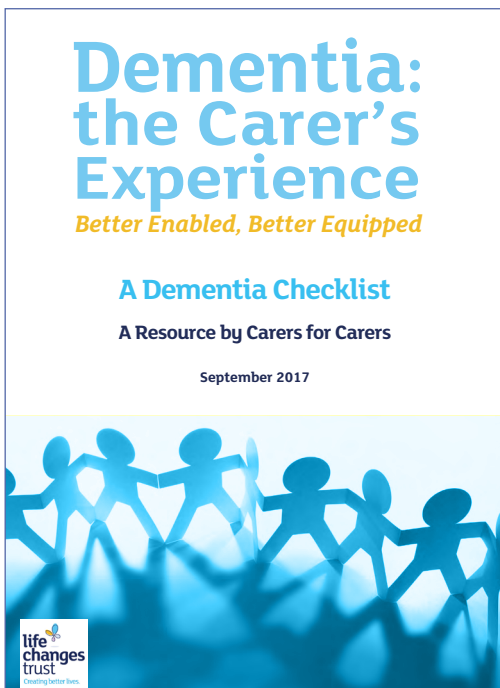
Find all four resources (as distributed at the Glasgow and East Lothian events) here: <https://www.lifechangestrust.org.uk/project/conferences-and-carers>

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 Respitality¹¹ 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.

¹¹ 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 pack¹². 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 pack¹²
- ▶ 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 pack¹²

¹² '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 pack¹³. 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.

¹³ '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**¹⁴ may be able to offer your steering group and other carers support.



¹⁴ **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



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
- ▶ 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/>