

Making an Impact Together

Sharing the learning on dementia activism
from and across the DEEP network



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Introduction

This booklet is written by and with several groups which are members of the DEEP network, with the aim of helping other dementia influencing and activism groups. It is authored, on DEEP's behalf, by Philly Hare of Innovations in Dementia.

DEEP (the Dementia Engagement & Empowerment Project)¹ is the UK network which brings together groups of people with dementia, supporting them to influence and change services, attitudes and policies that affect their lives.

DEEP is supported by Innovations in Dementia, and funded by three charities: Joseph Rowntree Foundation, Life Changes Trust and Comic Relief.

The booklet draws together learning from a number of groups, three of whom came together at a residential event on 'impact' in London in Spring 2016. It offers hints, tips and suggestions based on their experience of trying to make change happen.

The booklet aims to be a helpful resource for other groups in DEEP (or indeed other dementia activism groups), in the UK and possibly beyond. It is written **by and with** people with dementia, **for** people with dementia... and should also be useful for group facilitators/supporters.

It does not presume to tell anyone what to do or not do. DEEP is purely a network: each group is completely independent, and there are many different ways to do things. In some cases, the groups have shared **how** to do something. In others, it's more about sharing examples of **what** they have been doing – which they hope may inspire you.

You don't have to read it all at once – just dip into the sections that seem most relevant to you at this point.

There is also a Glossary on Page 3 which explains any acronyms that have been used.

And a summary of the key messages can be found in Section 8.

Acknowledgments

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- East Kent Forget Me Nots: Chris Norris, Carolina and Michael Young, Keith Oliver, Reinhard Guss, Lewis Slade
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- Agnes Houston

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Glossary

Acronym	What it stands for	Details
DAA	Dementia Action Alliance	A network of organisations in England that have a role in providing dementia support. There is one national DAA and many local ones.
DEEP	The Dementia Engagement & Empowerment Project	The national network which brings together groups of people with dementia from across the UK, supporting them to change services, attitudes and policies that affect the lives of people with dementia. http://dementiavoices.org.uk/ 01392 420076.
EDUCATE	Early Dementia Users Co-operative Aiming To Educate	A DEEP member group in Stockport http://www.educatestockport.org.uk/ Contact: markperry@nhs.net
EFID	European Foundations Initiative in Dementia dementia http://www.efid.info	A group of European Foundations working on common issues around
ESRC	The Economic and Social Research Council	A major academic funding body
FIT	Face it Together	A DEEP member group in Bradford. Contact: cathy.henwood@alzheimers.org.uk
IDA	The Impact of Dementia Activism project	A joint project between The University of Edinburgh and Innovations in Dementia

Glossary

Acronym	What it stands for	Details
Kent FMNs	Kent Forget me Nots	A DEEP member group in East Kent Contact: reinhard.guss@kmpt.nhs.uk
SURF	Service User Reference Forum	A DEEP member group in Liverpool https://surfdementia.org/ Contact: sarah.butchard@merseycare.nhs.uk
TIDE	Together in Dementia	The new national TIDE network for carers Everyday of people with dementia Contact: enquiries@lifestorynetwork.org.uk http://www.lifestorynetwork.org.uk/tide/
VERDe	Values, Equality, Rights and Dementia	A network that aims to embed different thinking and a rights-based approach in policy and practice for people living with dementia.

Section 1: Getting going

If you are reading this, you are probably already part of a group or thinking about starting one with others. In this section we look at some of the early questions you might ask and the decisions you will need to make when you start up as a group. Why have a group at all? What are your aims? Who will 'host' the group? How structured will you be? How will you attract members? Will carers be involved and if so, how? What help might you need – and how will you get it?

Why have a group?

People with dementia often say that they feel really isolated when they have been given a diagnosis, and don't know anyone else with dementia in their area. They say that meeting up with others 'in the same boat' can be a powerful and very helpful experience, and that it helps them realise that it is still possible to live life, albeit with adaptations. Meeting others also means they can get first hand information about local services or entitlements – and tips on ways of coping with new issues as they arise. The peer support that groups provide is vital and should not be underestimated.

As Alice from EDUCATE Stockport puts it:

“ The project completely changed my outlook on dementia. I realised that what seemed like the end of my life was actually just a new beginning.² ”

As people talk about their experiences of services and support (or lack of it), they often find common issues. Some decide they want to try to change things, usually locally at first. As more people join in, they start to think about structures – and a group is formed. Often the group also joins the DEEP network (see section 4), though this may happen a bit later.

People who are members of groups say that they grow in confidence as they start to work together – and that gives them a greater chance of making change. They learn skills from each other (such as public speaking or using technology) and can share their successes and frustrations.

Being clear about your aims

It is important to decide on the main aims of the group early on, so that expectations are realistic and shared. If this does not happen, there may be discord further down the line – or the group may simply be less focused and successful than it could be:

- Kent Forget Me Nots agreed Terms of Reference together, that they review as a group on a regular basis. The Terms set out aims and objectives, to help guide the group in their long term priorities such as writing a book and starting a film club, complemented by more reactive activity, such as accepting invitations to speak.
- SURF Liverpool is very clear that it is an action group. It regularly reviews what it is doing and keeps a flowchart of progress. Everyone has the chance to put forward new issues they would like to address, and these are voted on to establish the priorities.



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Sometimes groups realise that have reached a stage when they are not quite clear about what they are aiming for. They need to find a way of re-establishing priorities:

- The Scottish Dementia Working Group (SDWG) underwent an external review of the group in 2010. After taking time for discussion and debate, the group agreed to focus on: early diagnosis; good post-diagnostic support; and a well-trained workforce. They concentrated on these three priority areas over the next three years.

Models and structures

Groups that are members of DEEP have all come about in different ways – there is no one model.

Some are linked to a post-diagnostic service (such as Liverpool SURF and Kent Forget me Nots), or exist within service settings such as day centres (such as Swindon Forget Me Nots). They can be supported and ‘housed’ by a variety of organisations, including the NHS, local authorities and local charities such as the Alzheimer’s Society.

A small number of groups have set themselves up independently.

- SURF Liverpool was born out of Mersey Care Trust’s post diagnostic courses and Memory Group. It was set up for those more interested in activism and being consulted. After about a year, it was realised that there were benefits to becoming independent. The group would be more free to comment on Trust services, and it could also help to streamline the growing number of invitations that were coming in. SURF is now an (independent) unincorporated society with its own constitution and bank account. Becoming

Section 1: Getting going

independent did involve quite a lot of paperwork and decision making at the time. SURF feels that this independence allows them greater freedom and avoids bureaucracy. On the downside there is less protection e.g. no official contact address, and no policies about research ethics etc. Overall though it gives a different feel to the group: “We’re all in it together”.



Groups vary a lot in terms of the level of formality that they adopt. Some have very few rules, while others have a clear committee structure supported by agendas, minutes and voting:

- The Scottish Dementia Working Group (SDWG) comprises over 100 members, and both its Chair and Vice Chair have dementia. The group is coordinated by a committee of 18 members, elected annually, and four co-opted members, all professionals with an extensive working knowledge of dementia and related services. All members have a diagnosis of some type of dementia and voting rights are reserved for members only. Open meetings are held every two months in Glasgow and in Dundee. Committee meetings also take place every two months, with an Annual General Meeting each November.

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- EDUCATE Stockport has become gradually less structured than when it started, and it prefers to keep its administration very light. At meetings there are only one or two items on the agenda, as well as a quick catch-up of what has been happening. This allows more space and time for people with dementia to talk. Members have given Mark and Ruth, the facilitators, a mandate to sort other business arrangements outside the meeting. This relationship is based on trust and is very pragmatic.

Chairing is an important but potentially challenging role which needs some thought:

- In SURF Liverpool, there is an annual election and the Chair (a person with dementia) rotates every two years.
- Kent Forget Me Nots have used a model of co-chairing, in which one member with dementia co-chairs alongside one of the psychologists who support the group. This worked well for a while, but became unrealistic due to the increasing burden of correspondence. A new system is being trialled where members who would like to share chairing responsibilities divide up the roles to make it more manageable.

Finding more members

Groups often start with just a few people getting together. But very soon they begin to wonder how they can find others. The Scottish Dementia Working Group (SDWG) has found that the motivation for newer members tends to be finding out more about their illness and diagnosis, sharing experience, emotional support and a little curiosity around what the group is about. Few people come in as ready-made activists.

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If there are post diagnostic support groups or courses in your area, one effective way is to make sure that those attending know about your group and are invited to join:

- EDUCATE Stockport is now fully involved in the planning, review and delivery of the local post diagnostic course 'In Two Minds', which runs for five 2-hour sessions. Those who attend are always invited to join EDUCATE.
- In York, projects such as Getting Along - which supports couples living with dementia - and My Dementia - a course for people with a new diagnosis - have helped to reach out to people in the early stages, who may then go on to join the York Minds & Voices group.

There may be some drawbacks to making your group open to everyone:

- Kent Forget Me Nots have found they need to be quite firm about the route via which members join – they must come through contact with the psychology service and have a diagnosis. When this route has been bypassed, it has not worked well. People who turned up without knowing what to expect have sometimes found the business meetings daunting and not the kind of group that they are looking for. However, non-members can come to events, projects such as the film club and the social club.

Some groups have made major efforts to engage with people with dementia from minority groups, such as Black and Minority Ethnic (BME) communities.

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- Memorybilia in West Kent and Medway arranged for leaflets to be sent to identified clients of the local Community Health Services for Older People. After following up the leaflets with a phone call, people were invited to the Memorybilia meeting and were offered transportation to and from the venue, if required. Though this did not prove very fruitful, they then used the Dartford Action Alliance Event in February 2015 to run further discussions on how to engage people who have a diagnosis of dementia from BME communities³.

How will carers be involved?

Some groups involve carers/partners and some don't. Some members need or prefer their carers with them, while others prefer to come alone (though many of course do not have a carer anyway). And of course some people with dementia are also carers.

However, a common principle is that carers do not speak on behalf of those with dementia, but on their own behalf. They must allow the people with dementia to speak for themselves.

- SURF Liverpool is made up of people with dementia and carers on an equal footing: "The carer and the person with dementia are as one". They have found that this approach leads to an "environment of mutual support", in which everyone mixes and looks after each other. The carers have also set up their own social group, and some of them give talks to organisations such as the tax office on care-related issues.

- In contrast, carers do not attend Kent Forget Me Nots meetings, even as supporters. Members are clear that “some people only come out of the shadow” when their carer is not next to them, as they feel the latter can sometimes dominate the conversation and speak for them. The acknowledged risk is that carers will feel excluded – but they can come to the social group, the six monthly event and specific projects such as the film club.
- In EDUCATE Stockport, some couples prefer to stick together and so the carers come along with the member to meetings. Other couples prefer to split up. However, the carers never dominate discussions. They can be more actively involved in outside events, such as Dementia Awareness Week.

Though entirely separate from DEEP, the new national TIDE (Together in Dementia Everyday) network⁴ for carers of people with dementia presents opportunities for continuing alliances, where both perspectives need to be heard.

How to find support for your group

One of the main challenges of this kind of group is that everything takes more work and time than you think – you can't just do it on your own. The nature of dementia means that many members will need help with getting to and from meetings or events, or with contributing their views. Some one will need to respond to invitations, to organise venues, refreshments etc, and to oversee communication. Members may also feel that they also lack certain skills – maybe around IT and social media.

But the truth is that these tasks are often - perhaps usually - carried out for the groups by people who do not have dementia. Indeed most of the groups have paid staff members who provide practical support to the running of the group, as well as volunteer support. In some groups, the partners/carers of members help a lot with practicalities. In some, people who have formerly been carers contribute their time and give practical help to the group.

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The common factor is however is that the people with dementia have control over the agenda and the activities of the group – they are running the group, albeit with support.

Many groups have paid supporters who support the group as part of – or often on top of – their day job.

- EDUCATE is supported by Mark (a Development Worker employed by Pennine Care NHS Foundation Trust and Stockport Council) and Ruth (Occupational Therapist with the Trust).
- In SURF Liverpool, supporters have divided up specific roles. Sarah, the Clinical Psychologist at Mersey Care NHS Trust, links in with DEEP and coordinates the influencing opportunities in research, while Jill, Dementia Lead for Liverpool Clinical Commissioning Group (CCG), coordinates speaking events and ongoing activities of the group, and keeps it running smoothly. Hilary, a former carer, is Treasurer and organises the transport.

Group members often comment that the group facilitator is an essential part of making the group work and holding the group together. The presence of a professional with experience of working with people living with dementia, to facilitate the meetings and coordinate the activities, is seen to be critical for many groups. This is not about leading the group but enabling the group to function and meet its goals. From booking venues and refreshments, to the brokering of meetings with commissioners or service providers, having this input is perceived by groups as helping to keep a focus and provide the continuity of memory needed to help groups contribute to projects and activities.

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A few groups employ people who have a diagnosis of dementia:

- Open Doors at Oldham employs Kevin, who has dementia, as facilitator.
- Kensington & Chelsea and Westminster Memory Service employs people with a diagnosis of dementia in their peer support mentoring scheme.

Having a team of buddies, students or other supporters can make a huge difference to what a group can achieve:

- EDUCATE is supported by several volunteer 'buddies' who come from, and are managed by, Age UK. They are usually retired and from the health and social care sector. The members find that having buddies reduces the stress associated with booking tickets, travelling and understanding documents. The buddies say they get a lot back and often have a good laugh too.
- Kent Forget Me Nots are linked into the Psychology services of Kent and Medway NHS Trust, and usually have half a dozen psychology students on placement with them at any one time. The students learn about the lived experience of dementia, while providing the members with access to individual support e.g. in booking transport, travelling to speaking events, taking notes, fixing meetings etc. This arrangement is very helpful, though there are disadvantages - for example, when the students move on, people have to build new relationships from scratch and may feel unsupported, at least for a while. But there have been many successful placements, which has built up a strong relationship with the University.

Section 2: Making allies and getting noticed

In this section we look at how you can link up with those who have the power to make change happen, whether locally or nationally. Groups also stress the need to be clear about how you want to be engaged – many groups find it helpful to let people know what works well for them and what doesn't.

How to make local allies

Some DEEP member groups start as service user groups and so have always been a group that commissioners and service providers would go to for feedback or advice. However other groups need to develop awareness of the group and build their reputation over time.

Many areas in England now have a Dementia Action Alliance (DAA), which is a network of local organisations that have a role in providing dementia support. Some Dementia Action Alliances have a specific remit for helping to create a dementia friendly community, while others focus more on formal services. You can find out if there is a local Dementia Action Alliance in your area on the national Dementia Action Alliance website⁵.

Some groups have found their local Dementia Action Alliance is a really useful route to influencing.

- York Minds & Voices recently took over the whole agenda at one York Dementia Action Alliance meeting, reinforcing for those present the importance of working with them.
- SURF Liverpool SURF has representatives on each of the local Dementia Action Alliance's sub committees.

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If groups want to make changes in their local health and care services and the wider community, they need to develop strong relationships and alliances as soon as possible:

- SURF was formed in 2014 at the end of a year of dementia action in Liverpool, with a remit to change policy. From the start they had the strong support of the Mossley Hill Hospital and the Clinical Commissioning Group (CCG). The CCG provides some funding and provides the room and catering. SURF invites people from local organisations who can support its work to the meetings, including Mersey Care Trust, Alzheimer's Society, community organisations, theatres, and Liverpool Council. SURF also found the support of the former Lord Mayor particularly helpful. This all helps SURF to work directly with these organisations - they say: "It is useful to have the right people in the right place to do something" and they don't have to "go out and ask". Some SURF members get involved in other influential local groups. For example, Hilary, a former carer and member of SURF, is a governor at Mersey Care Mental Health Trust, a member of TIDE (the carers' group) and on various other committees. This all helps to keep SURF's profile high in Liverpool: "People are aware they have to go through us".
- Kent Forget Me Nots have targeted individuals by inviting them to come to a meeting. One example was the local Member of Parliament (MP) – though this did not prove very fruitful and caused frustration among members as the MP did not listen to the views and concerns of members. Kent Forget Me Nots also have a strong relationship with Alzheimer's Society, from whom they have received grants. The proceeds from the book they wrote goes back to Alzheimer's Society.

Section 2: Making allies and getting noticed

Gaining a national profile

Some groups also get involved with the national Dementia Action Alliance (DAA), which brings together all the local ones as well as bodies which have a more national focus. There are two service user representatives on the Board (both of whom are active in DEEP member groups), and the Dementia Action Alliance will fund a number of other people from DEEP member groups to speak at, or come to, events. This is important because it ensures that the voice of people with dementia is heard loud and clear.

Some groups have worked hard to get a more national profile, with the end aim of achieving national change. More and more groups are also moving into public speaking, often on a national or even an international stage:

- The first plenary presentation at the UK Dementia Congress 2015 was led by people living with dementia from DEEP (with family carers from TIDE), and followed by a presentation on Women and Dementia, which included Wendy from York Minds & Voices.
- Gina and other SURF members presented at the national British Psychological Society Faculty for the Psychology of Older People (FPOP) conference in 2015.
- DEEP had pride of place on the agenda at the UNISON Greater London Region Health Training Conference in October 2015. Keith and Chris from East Kent Forget Me Nots, and Dianne from Westminster Memory Services, shared their stories and explained how health and social care staff can really make a difference. The organisers of the event went out of their way to make sure that DEEP was welcomed at the event and that the talks went smoothly.
- SURF Liverpool's European networks have led to them speaking at events in Belgium (via the Transport Network) and Holland (via the research project Innovate Dementia).

Section 2: Making allies and getting noticed

Others find it really useful and re-energising to attend events, even if they are not presenting. Of course this can be expensive, but it is sometimes possible to get reduced places for people with dementia and their supporter/carer (always ask) or even bursaries. The Life Changes Trust (a major Scottish funder) have been very proactive in this area. Their recent evaluation sets out the benefits of attending and also gives a lot of useful feedback on what makes an event either successful or stressful for people with dementia.

Networking at launch events can be a good way to meet influential people.

- SURF Liverpool was invited to the House of Commons for a tea party launch of House of Memories – this gave them the opportunity to meet and talk with MPs and Ministers.



Social media can also be very important in building a national profile (see Section 5).

Section 2: Making allies and getting noticed

Being involved in research

Many people who are involved with DEEP groups are actively involved in research.

- EDUCATE Stockport are involved as a group on a contractual basis in Manchester University's major 'Neighbourhoods and Dementia Study'.
- SURF Liverpool was an active participant in the 'Innovate Dementia' European technology project⁷. The group are also involved in a study on human rights (the Co-Chairs are on the Project Board) and with other research work at The University of Edinburgh.
- Keith from Kent Forget me Nots is in the Alzheimer's Society Research Network, though he has some concern that this is still dominated by (former) carers and would like to see more direct representation from people with dementia themselves.
- Wendy and Gina have signed up with Join Dementia Research⁸ to be subjects of dementia research.

Others have played a role as Panel Members or Co-chairs for a research project.

- Keith and Daphne took these respective roles in the Mental Health Foundation's Enquiry⁹ into the challenging and distressing symptoms which people with more advanced dementia quite often experience.

Groups find that being involved in research has many benefits. It makes them feel useful and respected; it can generate income for the group; and it is also a social outlet.

⁷ <http://www.innovatedementia.eu/en> ⁸ <https://www.joindementiaresearch.nihr.ac.uk/>

⁹ <http://bit.ly/2ajlPXF>

Section 2: Making allies and getting noticed

Setting expectations and the ‘terms of engagement’

Many groups have learnt from bitter experience that it is worth setting out clearly how they want to be treated. As they grow in confidence and experience, they are much more selective about which consultations, awareness raising and influencing opportunities they get involved with.

- The Cornwall Dementia Leadership Group is regularly approached by local health and social care professionals for its perspective on various initiatives, leaflets, policies, and service specifications. It now asks visiting professionals to provide them with some background information before the visit, in an accessible format using a template that the group has designed. Professionals are encouraged to present their ideas with visual information at the meetings to back up the discussion, and are explicitly asked to keep the group informed about what happened following their involvement.

Groups in the DEEP network which have been involved in national conferences have fed back on their experiences and given advice as to how things could be improved.

There has been particular impact on the UK Dementia Congress, which year on year has involved more people with dementia. They have worked hard to make the venues dementia friendly, with groups auditing them in advance and producing a guide¹⁰. In response, the Congress organisers produced their own policy¹¹. DEEP has also been given a position on the editorial board of the Journal of Dementia Care. There has been considerable change in culture at national events, e.g. at the dementia conferences run by Hawker Publications and Alzheimer Europe. People with dementia have been much more visible as delegates and presenters, with many adjustments being made to improve the experience. This includes guidance to other presenters and delegates on the appropriate use of language, signage, quiet spaces, reserved seating and easy access to refreshments and food.

Section 2: Making allies and getting noticed

Some groups have also produced their own commentaries on how they have been involved in research, for example in the Dementia Without Walls programme.

Groups can give out copies of the DEEP guides (see section 4) to help others understand the best methods of involvement (they are downloadable from the DEEP website).

Section 3: Working together effectively

In this section, we look at the ‘nuts and bolts’ of an effective and happy group. This covers money; group communication; how to keep it fun; what to do when the group keeps growing; knowing your rights; keeping members involved; and keeping well.

Money matters

Every group will find that it needs some funds to keep going – although this may not be a lot. The costs of running a group are variable and a lot of staff members help to keep costs down by absorbing the support they give into their day jobs (or indeed into their own time). But there are always some financial costs to involvement e.g. venue hire, transport costs, supporter costs and refreshments. Organisations working with groups in the DEEP network may not recognise these as important, so it will need to be spelt out.

Groups have found many ways of raising funds or avoiding expense:

Core funding:

- Some groups are funded directly as a recognised service user group.
- Some are funded indirectly as part of the contract of a third sector organisations such as the Alzheimer’s Society.

Help in kind:

- You can ask for a free venue for your meetings or events. Many organisations such as hospitals will donate these ‘in kind’.
- You can ask train or bus companies for free tickets. SURF has had success with Virgin Trains.

Raising money from members and supporters:

- You can run a raffle. SURF Liverpool has raised £750 this way in one year. Remember there are rules that should be followed¹³.
- You can ask for donations for things you produce, such as cakes, cards, DVDs, joke books and calendars.

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Getting grants:

- You can apply for national grants such as the Big Lottery's 'Awards for All', or for small local grants.
- You can apply to DEEP for a grant for a specific project (see Section 4)
- You can apply to the Alzheimer's Society for an Innovation Grant.

Keeping costs down:

- You can ask members to bring their own food to meetings to save on catering.

Generating income:

- You can ask for a fee for some of the work you do for other organisations e.g. training their staff or teaching students (and always for your expenses to be covered). Many research projects also pay fees or 'thank-you's'.

It is probably sensible not to rely on any one source of funding, in case it runs out and leaves you high and dry.

Section 3: Working together effectively

- SURF Liverpool has a range of funding sources such as the Dementia Action Alliance, a DEEP grant, the Clinical Commissioning Group (CCG), fees for teaching University students, raffles and specific funded research projects.

Keeping accounts can be time consuming, so it is helpful to find a trusted host organisation who can take this on.

- Kent Forget Me Nots are supported in this way by The Friends of Mental Health in East Kent. They feel that a small voluntary sector organization like this is likely to be less bureaucratic and more flexible than a large statutory one.

Communicating well

As groups develop, they often find they need to set up systems to coordinate invitations to speak or take part in consultations.

- SURF has a single email address run by the Clinical Commissioning Group (CCG). These emails are discussed at the next meeting, and work is then shared out.

Some groups use technology such as iPads and free internet calling methods such as Skype or Zoom to make communication easier for those who would find it hard or expensive to travel.

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- The Scottish Dementia Working Group has used its DEEP involvement grant to buy iPads to connect individuals and help communication. Nancy, a group member who does not live near any other group members, has been able to use the iPad to connect with group members meeting in Glasgow. During the meeting, the iPads are passed around the room so that Nancy can see people as they are speaking. Nancy describes the experience as “fantastic... just wonderful”. Using the FaceTime app, members of the group can now ‘attend’ meetings without travelling great distances.



- Agnes (member and former chair of Scottish Dementia Working Group) also used her iPad to connect with a meeting in Luxembourg through Zoom while sitting at her kitchen table (she is now vice chair of the European Dementia Working Group). The meeting in Luxembourg raised ideas about how people with dementia from across Europe can connect and take part in conferences and events using technology.

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Some groups also now have their own websites.

- EDUCATE Stockport recruited a Buddy to set up this website www.educatestockport.org.uk for the group, with help from DEEP.
- SURF Liverpool's website www.surfdementia.org was set up by a friendly local technology company. SURF did have to address some new issues in doing this e.g. around data protection and safety – for example, what address should they use as their contact address (they decided to use only email).

But groups also warn that we shouldn't rely on the Internet, as many won't or can't use it and they will feel excluded. Some people prefer or need hard copies of invitations or documents.

- SURF Liverpool produces a paper calendar of regular events, with details of who can come, the cost, parking etc. This is given to everyone who comes to the post diagnostic course.

Keeping it fun

Groups find that simple enjoyment and the chance to laugh together is massively important.

- SURF Liverpool even has FUN written into its constitution! Members say the group has become a real 'friendship community'.

Some groups have developed a range of activities around the group, such as dance and art.

Section 3: Working together effectively

- EDUCATE Stockport has a reading group which, although serious in its intent to create inclusion in literature, often reads humorous authors such as Roald Dahl and Pam Ayres.

Some groups have introduced 'transition' groups, through which members continue to meet and have a role but don't have to take part in the business meetings.

- EDUCATE has a pop-up café for more social interaction: this can be a "route back in" for those who haven't been able to keep up with the business.
- The Kent Forget Me Nots have also recognised that some members would like to see more time for relaxed informal socialising (not just business), and have supported the start-up of a separate social group that meets on a monthly basis. The social group is open to all members and their families, friends etc, and provides the opportunity to get together over a coffee and biscuits to chat about anything and everything. They have also arranged a regular fortnightly film screening: members voted on seven modern films out of a list of 16, and discuss them after the screening in a very social atmosphere.



Section 3: Working together effectively

Some groups have enjoyed making contact with overseas groups.

- EDUCATE Stockport recently had a European award that has enabled some of them to visit Italy and Belgium.
- People with dementia in York have met with people from Bruges and Japan.
- SURF Liverpool welcomed a delegation from Rotterdam, Gina from SURF has worked with Australia on Dementia Friends, and Tommy is on the board of Dementia Alliance International.

These visits and exchanges can be really enjoyable and good for morale. It is also true that the best ideas often come out of relaxed fun moments.

What to do when the group keeps on growing

It's great when groups grow – but it also presents some challenges in terms of keeping everyone on board (or even just finding a large enough space to meet in). So you might need to make some adjustments in the way you work.

- SURF Liverpool have found they needed to cope with larger numbers by buying a sound system, asking members to bring their own lunch, and breaking into smaller groups for discussions. They also limit all visiting speakers to a maximum of 15 minutes. They plan in the future to start up more geographically based groups.
- EDUCATE Stockport have helped to start drop-ins in nearby neighbourhoods such as Offerton and Marple, to prevent social isolation. Marple drop-in was runner up in Alzheimer's Society national awards for dementia friendly community initiatives.

Section 3: Working together effectively

- The Kent Forget Me Nots have also tried to accommodate the increasing size of the group by having more of the agenda items discussed in small groups. Whilst this is popular with some members, others have fed back that they like to know what each small group has discussed. They therefore ensure that each small group summarises their discussion to the rest of the group as a whole, so that no-one feels they are missing out on information or on others' views.

Know your rights

People with dementia are starting to talk more about their rights and how they can use the law to gain the support they need. Dementia Alliance International (DAI), which is run by people with dementia, has a mission to promote Human Rights based approaches that are applied to the pre and post-diagnostic experiences of people with a dementia, in every way. DAI has produced a useful guide¹⁴.

- In Liverpool, members of the SURF groups are on the Steering Committee of a research project which is testing out a Human Rights Based Approach in care homes and hospitals. The project is running public engagement events to help people with dementia and families recognise that they have rights, plus a resource to heighten awareness. SURF also worked with Liverpool Council to send information about the access needs of people with dementia to all local polling stations at the last General Election.

Some DEEP member groups are taking part in the new VERDe network¹⁵ - this stands for Values, Equality, Rights and Dementia. The aim of the project is to embed different thinking and a rights-based approach in policy and practice for people living with dementia.

Section 3: Working together effectively

- Keith from Kent Forget Me Nots has given a presentation about 'men and dementia' at one VERDe event.

Keeping members involved

Meeting in a calm, comfortable, quiet space with good lighting and acoustics also helps everyone to participate. The environment needs to feel safe and inclusive for everyone.

All group members should be enabled to contribute to the work and discussions of the group. This will often be built into ground rules and may include turn taking, a limit on how long you can talk, confidentiality rules, or a person with dementia acting as chair.

Many groups break from business discussions during meetings to share news, have comfort breaks, get a breath of fresh air or take part in a different kind of activity such as poetry reading. This can give people who find it difficult to contribute to the business part of the meeting a chance to join in.

- Kent Forget Me Nots spend time with a potential new member before their first meeting to tell them about the group and try and make sure they feel comfortable speaking out in meetings. It can be difficult, though, to encourage all members to speak and feel involved at meetings. Kent Forget Me Nots recently carried out a review of members' experiences and asked what could be done to support the 'quiet majority' in speaking out, if speaking out was something they wanted to do.

Section 3: Working together effectively

Some people are not comfortable speaking out in larger groups to contribute their views. Small group discussions, sticky notes to write down ideas, props such as a red card to indicate when a person wants to speak, and individual support from a volunteer can all help.



- The Scottish Dementia Working Group have found that experienced members tend to become role models for newer members, ensuring succession or what they call 'handing on the baton'. Most people who come to the group have not had any experience of public speaking or campaigning and so they learn as they go along, observing others and being supported in the activities they choose to be involved in. Through this work they regain their self-esteem and confidence¹⁶.

One of the constant challenges for the group is the support and retention of valued members, particularly when they become less able to participate.

Section 3: Working together effectively

- In the Scottish Dementia Working Group, many members offer peer support and visit members when they are no longer able to attend meetings, but still want to contribute to the work of the group. One member still participates from their residential care home.
- EDUCATE Stockport find that involving people in audits enables a range of abilities to contribute and is also a way of reconnecting socially. It can “provide a bit of a boost” to those who may no longer be up for something more exposing such as public speaking.

Another way to maintain a contribution is to invite the more experienced members to talk about what they have learnt and share their ways of coping.

- In EDUCATE one member has recently had major surgery: his experience of, and reflections on, his post-operative delirium will be really useful for the group as a whole.

Many groups become very aware of the need to continue supporting members as their dementia advances. It is important to plan how to support each other in groups, how to stay ‘held’ and connected. If a group has a variety of activities it is easier to accommodate members as their condition progresses – or even if they just have good and bad days.

- Many SURF members join in with the monthly ‘Making Memories’ trips arranged by Mersey Care Trust. After each one, participants are given a photo album to remind them of the day. In SURF, there are both carers and people with dementia. If one of the couple dies, then the other person can still take part in the group.

Section 3: Working together effectively

Keeping well

To be effective activists, individuals need to be well. That means eating well, keeping fit, feeling welcome and included, and not overdoing it.

- In Kent Forget Me Nots, a trainee clinical psychologist gave information on mindfulness as part of her research project. A member also gave a talk to his fellow members about food which he found helpful – this proved a good way of sharing the expertise which exists within the group.
- In Liverpool, SURF members have access to a number of exercise programmes.

Some groups recognise the importance of fresh air and exercise:

- York Minds & Voices often go outside together for a short walk around lunchtime.
- EDUCATE Stockport has recently started an allotment group which is accessible to all members, and especially helpful perhaps to those who have reduced language skills.



Section 3: Working together effectively

Finally, groups also emphasise the importance of simply getting together in reducing their stress and improving their quality of life.

- EDUCATE Stockport very consciously ensure there is enough time for the mutual support that they see as a key element of their group. They see sharing the experience of living day to day with dementia, and supporting each other through the adjustments they have to make, as vitally important for health and well-being – and truly therapeutic.

As Carolina says: “There is no better psychiatrist for us than us”.

Section 4: Changing public understanding of dementia

Many groups see changing the attitudes and understanding of society to dementia as their core mission. Groups have been very creative in how they have portrayed a more positive view of dementia. In this section we give many examples that might get you thinking.

Films

A number of groups have produced short films which show members living well and looking beyond their dementia.

- SURF Liverpool has its own YouTube channel with 14 videos¹⁷, the main aim being educational. One of its members, Gina, was poster girl for the acclaimed Alzheimer's Society film promoting Dementia Friends.

One tip from SURF is to request permission for filming in a community location such as a bus station.

- The film Make a Point About Dementia¹⁸ was launched by DEEP member groups at the UK Dementia Congress in November 2014, relaying viewpoints from people with dementia and carers about their priorities around dementia. Following this, a meeting was held with Norman Lamb, Minister of State for Care and Support, where he committed to ongoing engagement with the DEEP network.
- Five Kent Forget Me Nots members had their stories recorded for the Live It Library project¹⁹, an online resource of stories from people who have experienced or are experiencing mental health issues (a collaborative project between Kent County Council and Kent and Medway NHS and Social Care Partnership Trust). These were the first entries from people living with dementia. They have since been used with post diagnostic groups.

Section 4: Changing public understanding of dementia

Theatre

Drama can be a great way of changing attitudes and increasing understanding. It's also a lot of fun!

- In partnership with the Everyman Theatre, SURF Liverpool members have written a play about dementia which will be performed by people with dementia on World Mental Health Day 2016. This new partnership has had spin-offs for all members, such as finding out about accessible tickets and dementia friendly performances at the Everyman and at the Playhouse.
- EDUCATE Stockport has partnered with HAYLO Theatre to raise awareness about dementia through drama. Their first performance at the Plaza had an audience of 500, and there have since been performances at two UK Dementia Congresses. They are now working on a play which brings together group members' life stories and pictures 'A Seagull on my Head' – this will be shown at the UK Congress in 2016.

Arts and music

Arts and music provide other opportunities, either to build on past skills and talents, or to discover new ones. They are also a great way to reach different audiences.

- SURF Liverpool is planning a major festival in 2018 which will be held in FACT Picturehouse's event space. New artworks will be commissioned and a link has been forged with New South Wales in Australia.

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- John from SURF Liverpool is an artist: one of his paintings will illustrate the new accessible version of the British Psychological Society's guide on psychosocial interventions.
- Some of the members of York Minds & Voices have been involved in a new choir 'Vocal Flourish' which includes people with and without dementia. It has a professional conductor and its performances have demonstrated the skills and resilience of people with dementia.
- Paul from SURF Liverpool is a song writer - see his songs such as 'The Same Man'²⁰. Paul launched his new songs with an event at FACT Picturehouse in Dementia Awareness Week in May 2016. SURF has now part funded Paul's next studio recording, and all proceeds will come back to SURF.
- Gina from SURF played a starring role in Public Health England's awareness campaign, singing the Beatles song 'I get by with a little help from my friends'.



The media and social media

DEEP member groups are getting more and more involved with both local and national media, including news papers, radio and TV.

- SURF Liverpool members have appeared on the Victoria Derbyshire programme, on Panorama, on Red Nose Day and on BBC Breakfast news.

Section 4: Changing public understanding of dementia

Media exposure can reach huge numbers of people. However, it is worth preparing thoroughly and also ensuring that the reporters and editors understand how you want your dementia to be presented and what language to use – or not to use.

Social media such as Twitter or Facebook enables people to connect with each other, find out what is going on – and maybe to comment. It also helps DEEP groups to reach and influence others. It can be very effective, enjoyable and sociable. But it is not for everyone, as it can feel quite complicated and occasionally also leads to confrontation or even highly personal attacks which can be stressful.

Some DEEP member groups, such as SURF (@SURFLiverpool), Kent Forget Me Nots (@EKForgetMeNots) and Scottish Dementia Working Group (@S_D_W_G) have set up their own Twitter or Facebook accounts. It is important that someone in the group – or a facilitator or supporter - who is confident with social media takes responsibility for managing these.

- In Kent, the student who manages the Twitter account feeds back key tweets to the group, and also tweets about issues which group members select. Other groups have individual members who tweet or use Facebook.

In March 2015, people with dementia, with the support of the Red Nose team at Comic Relief, took over Twitter for a day, posting viewpoints via the hashtag #dementiadiaries, which trended (i.e. became very popular for a short time). There were simultaneous broadcasts on national TV and radio by people with dementia, raising awareness about living with dementia.

A number of people who are in DEEP member groups, including Tommy, Agnes, Wendy and Carolina, are regular or even prolific bloggers. They don't blog on behalf of their groups, but they often talk about them in their blogs.

Section 4: Changing public understanding of dementia

- Wendy writes her blog ‘Which me am I today?’ nearly every day and she finds it also helps her remember what she has done. It has led to her being interviewed on BBC 2’s Victoria Derbyshire programme. Wendy has also blogged her reflections on writing her blog.^{21 22}

It’s not hard to set up a blog. Just go to a website such as Wordpress²³ and follow the instructions. Or ask a young person to help!

Writing and audio diaries

Writing and audio diaries provide another way of influencing attitudes, and may particularly suit those who are less confident as public speakers.

- Carolina spends a lot of time writing about the stigma of living with dementia - including articles for the British Psychological Society. She says: *“It’s my moral duty to tell the world”*.
- The Kent Forget Me Nots have written a book ‘Welcome to Our World’²⁴ which has raised thousands of pounds for the Alzheimer’s Society. The book is unique in that it is written by a group of people who each have a diagnosis of dementia, and who want to share some stories from their lives alongside expressing some thoughts surrounding inhabiting the world of dementia from the inside.

Around 50 people in DEEP member groups are part of Dementia Diaries²⁵, a UK-wide project that brings together people’s diverse experiences of living with dementia as a series of audio diaries. Specially customised mobile handsets allow the diarists to capture and record their thoughts and experiences as they occur. So far, the Dementia Diaries participants have submitted more than 450 diary entries. The project has been featured on BBC radio and television, and in national and local newspapers. More than 3.8 million people have seen it on Twitter.

²¹ <http://bit.ly/29HPyYd> ²² <http://bit.ly/2a5IPK9> ²³ <http://bit.ly/2a1SkoC>

²⁴ <http://bit.ly/2azRaXj> ²⁵ <http://www.dementiadiaries.org/>

Section 4: Changing public understanding of dementia

DEEP member groups are also involved in the evaluation of Dementia Diaries.

A relatively new phenomenon is that people with dementia are writing their own books or booklets on specific topics, based on their lived experience.

- Agnes co-authored a book about the development of the Scottish Dementia Working Group²⁶, discussing the ways in which the group has worked to increase awareness and the significant policy changes achieved. She also highlighted the importance of the group for support, friendship and a sense of camaraderie.
- Agnes and 20 other people with dementia from around Europe have also produced a booklet on Dementia and Sensory Challenges²⁷.



- James has recently written a booklet about Driving and Dementia²⁸.

Section 4: Changing public understanding of dementia

Public events

Groups are using events such as World Mental Health Day and Dementia Awareness Week to raise awareness.

- SURF Liverpool held a Business event at the town hall during Dementia Awareness Week 2015.
- SURF has also been involved in local Memory Walks which help to publicise their group.

Service providers

Many groups see their core business as raising awareness among local service providers.

- SURF Liverpool has worked hard with doctors' receptionists, advising them on how to make it easier for people with dementia to see a doctor. Mystery shopper visits back to the surgeries have shown that – at least in some cases – this work has made a difference to receptionists' attitudes.
- The Kent Forget Me Nots have also given training to doctors and receptionists about the importance of diagnosis. A simple voting process before and after the session showed improved awareness of the positives (63% up to 72%).

Section 4: Changing public understanding of dementia

- EDUCATE Stockport regards its core work as educating service providers. They have trained over 500 professionals alongside Mark through Person Centred Care courses. In 2013 the group delivered training to 250 Hungarian health and care managers at an EU-funded event hosted by Manchester University. They also presented on 'visual processing in Alzheimer's Disease' at an event for optometrists in the North-West. Jo gives regular talks for speech therapy students and other professional groups.

Many groups have found it very rewarding to go into schools to talk about dementia to the pupils, and perhaps to help them become Dementia Friends.

- Kent Forget Me Nots work with both primary and secondary schools, educating not only the children but also the staff.

Making complaints

Individuals often feel reluctant to stand up and complain, but it is much easier to do this with the backing of a group.

- A well-known drug company placed an advert in a prestigious magazine portraying dementia in a very negative light. The Scottish Dementia Working Group wrote to complain about this and the advert was withdrawn. The company then consulted the group prior to publishing their next advert. Success!



Section 4: Changing public understanding of dementia

Being involved in decision-making

Being involved in decision making demonstrates very positively and clearly that people with dementia have contributions to make to society, and many skills to offer.

- In York, people with dementia advised Joseph Rowntree Foundation's York Committee on its community grant-giving to dementia focused projects. Between 2012 and 2015, this Committee awarded over 30 small grants, worth in total around £130,000, to seed-fund projects ranging from music, art, gardening, cycling and croquet, to a café, a film archive and a youth programme. All the applications went through the advisory group of people with dementia.
- Following this model, EDUCATE Stockport and Swindon Forget Me Nots have advised EFID (a European Dementia programme) on their grant giving.

Some groups have been involved in interviewing for key dementia posts.

- Bradford FIT group have interviewed for Bradford Community Trust and for Dementia Action Alliance posts.
- Kent Forget Me Nots are involved in most interviews of a dementia related post for the local NHS Trust.

Section 5: Improving the environment

Many DEEP groups have noticed that the physical environment is often quite disabling, and can prevent them from continuing to be part of society and their local community. Some have decided to do something about this. Here are some of the things they have done.

Auditing buildings

'Auditing' means commenting constructively on a building, part of a building or an outside space. It can be a lot of fun and it really uses members' expertise. Everyone can be involved, and even if some members have difficulty making verbal comments, their observed responses to the environment can be very useful.



- The Bradford Face it Together group (FIT) has advised on St. Luke's Hospital refurbishment. The redesign of its public areas has included clearer signage, better use of colour and light, and two dementia gardens. The hospital also now uses the forget-me-not symbol in patients' case notes and above their beds (with the permission of the patients and relatives) to enable staff to plan their care accordingly. The group has also been involved in a range of activities including a trip to St Ives (near Bingley) to consider the area and its visitor's centre, café and toilets from the perspective of someone with dementia. The group sent initial feedback (mainly around poor signage) to The Friends of St Ives and the council has expressed an interest in the feedback to see if any suggestions made by the group could be implemented. FIT has also advised on the planning of the huge Westfield Shopping Centre.

Section 5: Improving the environment

- EDUCATE Stockport audited five wards at Stepping Hill hospital and have also advised on general signage. Unfortunately, they have had no feedback and feel they don't have the capacity to chase it up. In contrast, their audit of The Meadows, an NHS community hospital, resulted in major improvements. EDUCATE are also involved with Innovations in Dementia in Manchester University's 'Neighbourhoods and Dementia Study'²⁹ to evaluate audit tools for dementia friendly environmental adaptation.

Another success for EDUCATE Stockport has been their audits for West Yorkshire Playhouse's dementia friendly performances, which saw full implementation of all the many changes recommended. This work has resulted in a new national guide³⁰.

- Similarly, Kent Forget Me Nots were invited by the Odeon cinema chain to a special screening of Eddie the Eagle and to provide feedback on how to put on a dementia friendly event. They then co-wrote guidance on this topic (with DEEP involvement) which will be taken up by the chain. This work will hopefully be presented at the UK Dementia Congress and written up for the Journal of Dementia Care.
- In Liverpool, two members of SURF are on the design board at Mersey Care NHS Mental Health Trust. SURF are also working with a local architect to design a dementia friendly house to showcase in Dementia Awareness Week.
- The Torbay Dementia Leadership Group conducted a local GP surgery walkthrough to ensure it is as dementia friendly as possible and produced an Expert by Experience document on this³¹. This has now been shared with other practices locally and two more Medical Centres have asked the group to conduct a similar exercise.

Section 5: Improving the environment

Transport

Getting around is crucial to the inclusion of people with dementia, and this again is something which a group can really help with.

- In York, local taxi company Fleetways has arranged dementia awareness training for all its drivers. Ground-breaking work has been pioneered by British Transport Police at York Station to raise awareness with stations and providers on the East Coast Main Line. This is rebuilding travel confidence in some people. The work that started in York has now spread across the North East³².
- SURF Liverpool have done a lot of work on transport and have delivered training sessions to Arriva and Virgin trains to increase dementia knowledge and awareness amongst their staff. Tommy, the co-chair, is also on the Dementia Action Alliance's transport subgroup. SURF are making a film for train and bus drivers and other transport staff, and also using photos to show features such as escalators from the perspective of a person with dementia.



Section 5: Improving the environment

Mystery shopping

This is one way to check and feed back on accessibility to a specific service provider or venue.

- SURF Liverpool have produced a mystery shopping proforma to assess how dementia friendly shops are. They have found that mystery shopping works best if it is already 'owned' by the organisation in question.
- Bradford F.I.T (Face it Together) group have conducted a mystery survey of the local "Swimming Village".

This method has also been used for local health services:

- The Kent Forget Me Nots delivered numerous sessions for surgery receptionists and pharmacists – and a 'mystery shop' two months later in one surgery showed dramatic improvement in awareness. However, in another case nothing appeared to have changed.

Photography

Cameras can be useful tools in raising understanding of the perceptual issues associated with some dementias.

- In Liverpool, SURF has been working with photographer Tadhg Devlin and the NHS Trust, and also using disposable cameras to capture images of aspects of the environment which they find tricky. The output will be an exhibition at the prestigious Open Eye Gallery in late 2016, as well as a national newspaper, to help other people understand how dementia can impact on visuo-spatial abilities.

Section 6: Common pitfalls and frustrations

Every group in the world faces problems sometimes. When this happens it can be demoralising and stop the group being effective. All groups are different – but here are some common issues, and examples of how groups prevent them or deal with them when they happen.

Group dynamics

Most groups will go through periods when there are disagreements or differences in expectations. This may be inevitable in order for the group to grow, and to deliver results.

However, some of the process can be hurtful to individuals and potentially damaging to the group. People with dementia may find they react to confrontation or disagreement more emotionally than they would have before their diagnosis. At worst it can impact on members' health.

Being supportive to one another is key to the success of groups – it is much harder to have an impact on the outside world if the group is not united. It is important to watch out for the group starting to fragment and to try to nip any discord in the bud – though this is not always easy. Groups say that humour is a crucial tool in getting along with each other – being able to laugh at themselves and each other.

- The SURF Liverpool group has a rule on how to manage someone who is continually disruptive to meetings. They find it has been helpful to have clear rules about unacceptable behavior from the outset, and this has led to a very inclusive culture.
- The EDUCATE Stockport group feel they tend to be very tolerant and willing to make adjustments to changes in behaviour or loss of inhibition. The group “allows people to be as they are”. However, it is recognised that this demands a lot of skill and patience from the facilitators.

Section 6: Common pitfalls and frustrations

■ Kent Forget Me Nots recently carried out an evaluation survey of members' experiences, to make sure that the atmosphere in meetings was as supportive and safe as possible. This was in recognition of how meetings can sometimes become stressful and difficult due to the size of the group, differing opinions and how dementia can make it more difficult for people to monitor what they are saying. The results of the survey were really helpful in clarifying what members wanted.



Stony ground

Not all organisations in the community are willing to make the adjustments that make it easier for people with dementia to get involved. Or they may be so bound up in red tape that they can only change very slowly. This can be frustrating for people with dementia, who often feel they have a short window of opportunity for involvement, and therefore a sense of urgency to see change happen.

■ Kent Forget Me Nots invited the local MP to visit them. But – in spite of sending him their questions in advance – this proved a fruitless and frustrating experience.

Section 6: Common pitfalls and frustrations

In other cases, a pilot project might appear to work well, but it is never rolled out.

- SURF Liverpool's meeting with Tesco in Chester resulted in seeing many of the changes they suggested, such as a dedicated slow lane, and the offer of assistance. However, to their knowledge no other Tesco supermarkets have replicated this. A top down approach is needed.

Sometimes groups feel they have put a lot of effort in with little to show for it.

- For example, York Minds & Voices worked hard on York City Council's wayfinding project 'Legible York', advising on signage which would be more dementia friendly. However, the Council shelved the project due to budget problems. A project with York's National Railway Museum has also been put on hold because of issues beyond their control.

Progress too often seems to depend on the commitment of a particular individual ally – who may change jobs, retire or fall sick.

- In Kent, plans agreed with the Forget Me Nots to deliver training to NHS staff at Kent & Canterbury Hospital have been delayed due to long term sickness of one senior nurse.

Media

Media coverage can backfire when sub-editors use negative terms for dementia, or add in stereotypical imagery (such as wrinkled hands) that undermines a positive story. You can try to prevent this by giving them the DEEP guide on language³³, and by negotiating as much editorial control as possible.

Section 6: Common pitfalls and frustrations

- When Pat and Peter from SURF Liverpool were involved in a Panorama programme, SURF managed to get a good level of editorial input, including sign off by them and their children.

Some groups regularly challenge negative language and images they see in the media, often through Twitter or Facebook. It's helpful to use the hashtag #dementiawords, so that these challenges can be tracked and retweeted.

Tokenism

Groups can feel they are just ticking the box for user involvement and being used in a tokenistic way. An incidence of this can be found in Wendy's blog³⁴ about her experience of her speaker slot being missed at a conference.

- Keith from Kent Forget Me Nots was invited to be part of the interview panel for an Alzheimer's Society post, but was frustrated that he was neither given a question to ask, nor a vote.
- SURF Liverpool was also asked to comment on the plans for new build at Royal Liverpool Hospital. However, it was too late to have any impact: consultation needs to come much earlier in the design process to be meaningful.
- In EDUCATE Stockport, Mark the facilitator tends to 'gate keep' requests. The group finds that some academics can fail to think about accessible materials and language, and have poor listening skills. On one occasion Mark had to intervene in a project to provide some training about how to work with people with dementia.

Section 6: Common pitfalls and frustrations

Sometimes Boards have places for both carers and people with dementia but do not clarify what role each will take. If the carer then speaks FOR the person with dementia rather than for themselves, it can be frustrating. The lesson is to clarify in advance.

The usual suspects

There are challenges in involving a range of people so that key players are not too heavily relied on or seen as the 'usual suspects'. This can be bad for them (as the key 'spokespeople' can get very tired) and for the group (as the other members don't develop their skills or feel they have enough input). Any assumption that people lack capacity to be involved can result automatically in excluding people with more advanced dementia.

- SURF Liverpool reads out opportunities and invitations at its meetings, and explains clearly what skills or experience are needed. They then ask for volunteers for each one – if there are too many, names are put into a hat. They also use a buddy system, in which a less experienced member is linked with a more experienced one. There is no 'leader by default'.

Lack of feedback or knowledge of impact

It's important that all members get feedback on what the group is achieving. People with dementia often feel they have a 'window of opportunity' to be involved, and therefore need to see quick results from the energies they put into being involved.

- In the Kent Forget Me Nots, a 'feedback from recent events' section is a regular part of the agenda.

Section 6: Common pitfalls and frustrations

- SURF use a simple 'dashboard' on which they list their priority areas for action, and keep a track of progress through a traffic light system. The list is flexible in that it allows new opportunities to emerge, and also other things to be put on the 'backburner' until the time is right.
- EDUCATE Stockport are less formal but they also regularly review how activities have gone and agree what to focus on next. For example, a review of their recent 'Doing Dementia Differently' event led to a discussion on driving, and an action to invite a local Occupational Therapist to provide information.

Here are some other ideas for ensuring feedback about impact:

- Make sure that a simple record is kept of each significant activity – whether it is an audit, a talk, a training session, a meeting or whatever. This should include what, why and how it was done. It is best if one person (possibly the facilitator or a volunteer) takes responsibility for doing this.
- Make contact again with the 'other party' after a few months and ask them to let you know what changes they have made as a result of your work.
- Hold a celebration event (annually?) to highlight all the changes that have come about because of the group's activities

On the next page there is a simple example of an Impact Record form which could help you to do this.

Collecting this kind of information has a number of benefits:

- it enables the group to review how best to focus their efforts, especially when their time and energy may be limited
- it shows others that you mean business – particularly if you tell them about this process when they first have contact with you
- it helps maintain an ongoing relationship, rather than a one-off event

Section 6: Common pitfalls and frustrations

- it provides evidence of impact which is useful when you are trying to get funding or other types of help to keep going
- it is useful information to share with other groups
- it is good for morale!

Impact record

Activity:	Training session with local GP practice staff
Why?	Invitation from Stan's GP
Date:	3 June 2016
Members involved:	Stan, Mary and Louise
How?	30 mins informal lunchtime session, plus short film
Number of attendees:	10 staff
Feedback at end of session:	Very positive. Liked the stories and film
Changes discussed:	Offer longer appointments for people with dementia Offer quiet waiting area Refer newly diagnosed to our group

Evidence of impact (fed back September 2016)

Feedback that:

- 8 people have been given longer appointments
- no quiet area yet organized – working on this
- 6 new people have been given info about group – 4 have followed this up

Further help needed?

Yes, they would like us to do an audit of the surgery waiting room

Section 7: Making the best use of DEEP

DEEP is the national network of dementia influencing groups which is supported by Innovations in Dementia. Groups have come to the network initially through different routes: some were approached by Innovations in Dementia; others learned about DEEP at other forums such as the Dementia Action Alliance through colleagues/contacts; and others have had a chance encounter which has piqued their interest.

DEEP never tells the groups what to do, but it does help them to network with and learn from each other. Being part of something bigger makes everyone stronger. Groups say that DEEP is a place where they can be inspired and energised and can contribute to the movement. This section explains what DEEP can offer you – and what you can offer DEEP.

Keeping in touch

Here are a few suggestions of how to keep in touch with DEEP and all its member groups:

- Visit the DEEP website³⁵ regularly to keep up to date. It may be helpful, as SURF Liverpool does, to have one person who is comfortable with using the Internet ‘to keep an eye’ on what is happening with DEEP.
- Make sure the whole group has access to the monthly DEEP newsletter - some groups read it out at their meeting. Kent Forget Me Nots say that DEEP has given them access to many projects of which they would not otherwise been aware.
- Be willing to share your successes and challenges via the newsletter or the website - think about sending in short articles.
- Keep in touch with your DEEP Coordinator, Paul³⁶ (Scotland, N Ireland and N England) or Rachel³⁷ (S England and Wales), who will have an overview of and contact with all the groups. Their contact details are on the website and the newsletter.
- If you use Twitter, use the #DEEP hashtag and mention DEEP (@DementiaVoices) so that other groups can find your Tweets.

Section 7: Making the best use of DEEP

Joining forces with others

There have been some great examples of joint work within DEEP. One was the Dementia Words campaign:

- Linking with the national Dementia Action Alliance, this campaign produced a film, an infographic, a guide and a set of posters, and resulted in over 350 signatories³⁸ - all based on workshops involving groups that are members of DEEP. Many groups have been able to build on this in their own work: when Jo and Mark from EDUCATE Stockport were interviewed on Radio 5 Live, Jo challenged the interviewer on her use of the word 'sufferer'³⁹.

Another joint venture came out of Joseph Rowntree Foundation's project⁴⁰ 'Dementia through the Eyes of Women'.

- Agnes from the Scottish Dementia Working Group came together with many other women at a national conference at York University in 2014. Since then a Women's Group has been set up in York which involves a number of members of York Minds & Voices.

A third example of joint work is the DEEP guide on involving people with dementia in dementia friendly communities⁴¹.

- This guidance note is based on discussions by 15 people with dementia and 8 carers at a DEEP networking event in 2015. The event was hosted by Face it Together (FIT) group which is supported by Alzheimer's Society in Bradford. They were joined by members of Shindig from Sheffield and Minds & Voices from York.



Section 7: Making the best use of DEEP

Some DEEP members have joined up to form a new DEEP group which is called the Dementia Policy Think Tank. Members of this group have already met with the Department of Health to ensure that DEEP is included in plans for monitoring the 2020 Challenge.

Mentoring or being mentored

Groups have so much to learn from each other. Older groups can inspire newer ones – but even the most well-established can be refreshed with new ideas.

- A visit by members of the EDUCATE Stockport group to the new Bradford group gave an early impetus to involving people with dementia in raising awareness about dementia friendly communities. The group has also mentored a new group in Cardiff. Through DEEP, EDUCATE is also planning a project with other groups in York, Oldham and Rochdale to increase the involvement of people with dementia in post diagnostic support.
- SURF Liverpool plans to support a group wanting to set up in East Cheshire, and often receives visits from others wanting to set up new groups.
- Members of the Scottish Dementia Working Group (SDWG) travelled to Belfast to talk with a group of 10 people with dementia about setting up a country-wide influencing group, the Northern Ireland Dementia Action Group. The SDWG shared its 12 years of experience of developing and running a large membership group and has kept in touch with the new Northern Ireland group as a sounding board.
- Kent Forget Me Nots was the first involvement group for people living with a diagnosis of dementia in the area, but members have been active in helping to set up new involvement groups. Members from the Forget Me Nots have visited two new local groups to share experiences, answer questions and provide guidance. These three Kent based groups are now planning a trip to Dover Transport Museum in 2017 and hope to work together on other projects.

Section 7: Making the best use of DEEP

Using the DEEP guides to inform and influence yourselves and others

Some of the DEEP guides were co-produced with people with dementia, others were created independently by groups of people with dementia. There are over a dozen to date⁴²:

For people who have dementia:

- Travelling with Dementia—A guide developed by the Scottish Dementia Working Group
- Enhancing communication—A ‘By us, For us’ guide for people like us with early stage memory loss
- Using sound recording—A DEEP guide to getting your message heard
- Telling Our Stories—A guide to using film to hear the voices of people with dementia.

For organisations and communities:

- Setting up an influencing group
- Involving people with dementia in Dementia Friendly Communities
- Language
- Writing dementia-friendly information
- Creating websites for people with dementia
- Tips for consulting people with dementia about written documents
- Choosing a dementia-friendly meeting space
- Collecting the view of people with dementia
- Involving people with dementia at conferences and events
- Guide for conference presenters
- For film makers
- Involving people with dementia in recruitment
- Tips for employers who want to be more dementia friendly

Section 7: Making the best use of DEEP

Representing or promoting DEEP

There are regular opportunities to represent DEEP. These are usually publicised in the newsletter, or your group may be approached directly through the DEEP Coordinator (there are two of these, Rachel and Paul).

You may also wish to attend Dementia Action Alliance (DAA) events and meetings to represent DEEP. The Dementia Action Alliance can reimburse travel and other expenses for a (limited) number of people. If you can't attend, you could ask the service users who are on the Board (currently Keith and Tommy) to put forward any issues.

People from DEEP member groups often speak at conferences and events which are brokered by DEEP.

- Kent Forget Me Nots provide training in user involvement to every new member of staff at the Alzheimer's Society. This is a good opportunity to show a film about DEEP and explain what the network does.

Applying for project funding

Grants of between £300 and £5,000 have been distributed throughout the DEEP network, resulting in over 30 projects, including setting up of new groups or supporting existing groups; work to develop a lesbian, gay, bisexual, transgender network; making films; buying iPads to connect group members; building a website; writing a play; planning a conference; and leaflets. The grants have empowered groups to design their own projects and to share their outcomes with the rest of the network.

- Kent Forget Me Nots have used small DEEP grants to top up grants they have had from the Alzheimer's Society for specific projects.

Section 8: Summary of key messages

Below are some of the key messages coming from the groups which have been involved in putting this guide together:

- 1) Take time to think and talk about your aims.
- 2) Explore together who will 'host' the group; how structured you want to be; how you can attract new members; if and how carers will be involved; what help might you need – and how you will get it.
- 3) Plan how to gain a local (or even a national) profile.
- 4) Be clear with others about your expectations of them.
- 5) Pay attention to communicating well with each other, to keeping everyone involved, and to group dynamics.
- 6) Keep in touch with DEEP and work when, appropriate, with other DEEP member groups.
- 7) Try out different ways of raising public awareness and understanding such as the arts and the media.

Enjoy it and be proud of what you achieve together!

Section 9: Sources

This booklet draws on evidence from:

- Meetings with three DEEP groups and a 24-hour event held in Spring 2016
- The DEEP newsletter
- Research evidence including:
 - Hare,P. & Dean,J. (2015) How can we make our cities dementia friendly? Sharing the learning from Bradford and York. JRF: York⁴³
 - Litherland,R. (2015) Developing a national user movement of people with dementia. JRF: York⁴⁴
 - BrightPurpose (2016 forthcoming) DEEP 2 Final evaluation report

