



University
of Worcester
Association for
Dementia Studies



Helping your community group or activity club to keep going strong

Suggestions for members of groups and clubs
from the **SCI-Dem Review**



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What is SCI-Dem?

The SCI-Dem* review is a study we have done at the University of Worcester. It has been looking at the challenges that groups for people with dementia face. A group could involve a hobby, sport, exercise or leisure activity, or it could be simply for people to gather together to socialise, get help, support each other or make sure their voice is heard. If you are reading this, it is because you may attend one of these groups or clubs.

Keeping a group going year after year can be challenging, especially when money is tight. We gathered together as much information as we could find about what might help or hinder such groups to keep going long-term.

Our review has looked at all kinds of articles, reports and studies on the running of community groups. We have also spoken to people involved in such groups for their take on things. We've come up with a list of tips and advice about how best to make sure your group is sustainable – meaning that it has the best chance of keeping going long-term.

This booklet is for you, as someone who goes along to a group or activity, to understand what we have found in this study – and also how you might be able to help your group or activity to keep going strong in the future.

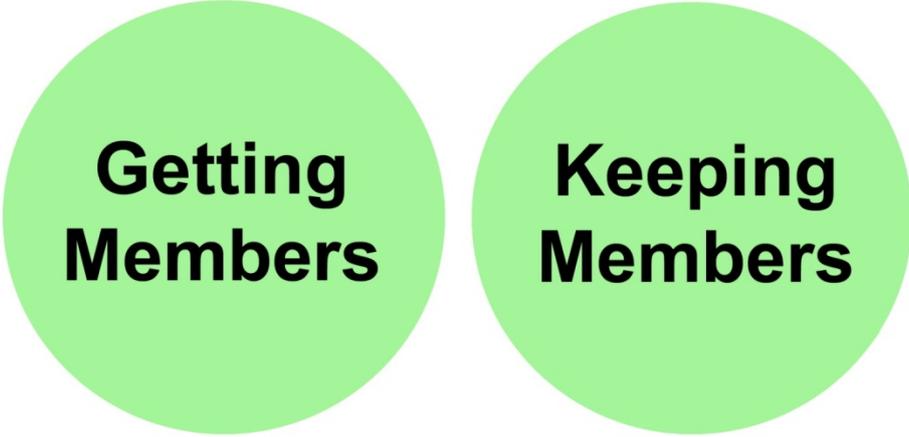
***SCI-Dem** stands for **Sustainable Community Interventions** for people affected by **Dementia**.

The key areas

Our study has found four key areas involved in keeping a community group or activity club going.

If your group can get and keep these things they will be able to keep going strong. If they can't get or keep these things, they will struggle.





Getting Members

Keeping Members

A group, club or activity needs people to come along – and to keep coming along.

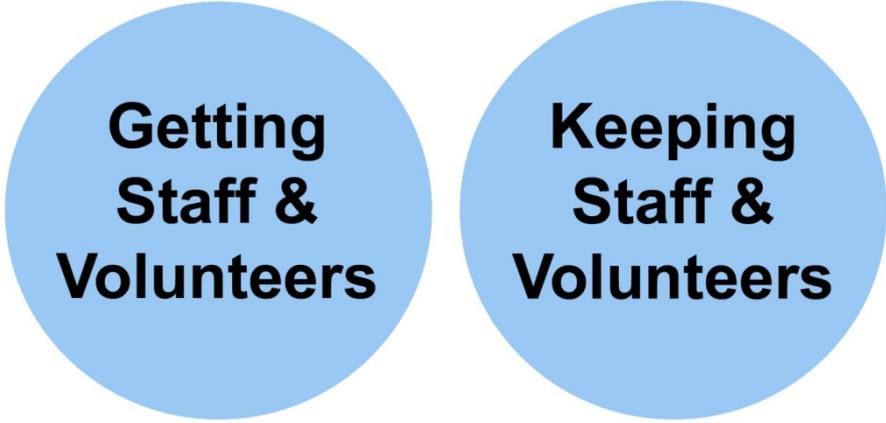
What our study tells us:

Activities that people want to do are important to get people to come. But just as important is the social side of things. People want to relax, enjoy themselves and make friends (sharing food always helps!)

A warm welcome in a comfortable, easy-to-access place, where people are respected as individuals, is key. Having information and advice on-hand also helps. Crucially, people need to be able to get there safely with cheap, reliable transport.

How you might help your group:

- Let people at the group know what you want – if you want more time to socialise, say so; if you want different activities, say so.
- If you like the group, spread the word to family and friends about it – the best advertising is word of mouth!
- Let the professionals know if you value your group too – e.g. your GP, care workers, dementia advisor or social services. They may pass your recommendations on to others.



**Getting
Staff &
Volunteers**

**Keeping
Staff &
Volunteers**

A group, club or activity needs the right staff and volunteers – and enough of them.

What our study tells us:

Staff and volunteers need to be reliable and have good people skills. There are various types of people in the local community who may come to help as volunteers, such as friends and family, charity workers and healthcare students.

Staff need to feel valued and secure in their jobs, and need time off now and again or they will be exhausted and burn out. Volunteers need to feel valued too, and not overworked.

How you might help your group:

- Ask friends and family if they know anyone who might want to volunteer to help out with the group.
- If you appreciate what the staff and volunteers at your group do, let them know this.



**Getting
Support of
Other
Organisations**

**Keeping
Support of
Other
Organisations**

A group, club or activity needs other organisations to work with it—whether that’s other community groups, local authorities or health services.

What our study tells us:

Raising awareness in your community and getting to know others in the neighbourhood helps. Other groups might see you as competition, so talking to them and offering to help each other is a good idea. If like-minded groups band together they can share things and plan together.

Large organisations – such as the council, big charities, faith groups, local businesses, schools and colleges – may be able to help in some way. For example they may be able to supply equipment, a building to use, or an extra pair of hands.

How you might help your group:

- If you have any contact with other groups and people in your community, then speak to them about your group – tell them how valuable it is, and how it could use their support.
- Again, let the professionals know if you value your group – e.g. your GP, care workers, dementia advisor or social services.



Getting Funding & Income

Keeping Funding & Income

A group, club or activity costs money to run – so it needs to find a way to keep meeting those costs.

What our study tells us:

Planning ahead is essential – groups need a realistic plan to get funds and manage them long term. Having more than one source of income is good because it means you don't have all your eggs in one basket. Working with other organisations helps keep costs down and is also something outside funders like to see.

Getting funding can be a real challenge for smaller groups. It's a good idea to keep in touch with organisations that might fund you, keep them informed and make sure they know the value of what your group does. Longer term funding would help groups feel more secure and plan ahead better.

How you might help your group:

- If you feel able, make your voice heard about your needs and how your group meets them – whether that's to your local NHS, national charities, the council or the government. Make it clear you think your group should have long-term support.
- While some find it easy to speak up, others might benefit from joining a group that advocates on their behalf. There is a list of contacts for such groups on the next page.

Groups that advocate for people affected by dementia

The following groups aim to help people with dementia, and those caring for them, to be heard and get better support:

Alzheimer's Society

Website: www.alzheimers.org.uk

General enquiries: 0330 333 0804 Dementia Connect support line: 0333 150 3456

DEEP (The UK Network of Dementia Voices)

Website: www.dementivoices.org.uk

Rachel Niblock (UK co-ordinator): 07720 538851 Email: niblock@myid.org.uk

TiDE (Together in Dementia Everyday, for carers of people with dementia)

Website: www.tide.uk.net

England office: 0151 237 2669 Scotland office: 0141 353 5607 Email: carers@tide.uk.net

YoungDementia UK

Website: www.youngdementiauk.org

General enquiries: 01993 776295

Age UK

Website: www.ageuk.org.uk

Advice line: 0800 055 6112

If you want more detailed information on how to help a group keep going long term, please see our other booklet:

**Keeping Community Groups and Activities Going -
Recommendations for Practice from the SCI-Dem Project**

FOR MORE INFORMATION:

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www.alzheimers.org.uk

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University of Oxford (Nuffield Dept of Primary Care Health Sciences): Realist Synthesis Expert: **Dr Geoff Wong**



**University
of Worcester**

**Association for
Dementia Studies**

The Association for Dementia Studies – Changing Hearts and Minds in Dementia Care

Led by Professor Dawn Brooker, the Association for Dementia Studies is a multi-professional University research and education centre. We make a cutting-edge contribution to developing evidence-based practical ways of working with people living with dementia, their families, friends and carers that enable them to live well.

If you think that we can help please feel free to contact us.

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