

Loud and Clear!

Practical tips for newer dementia activists and their advocates and allies

Philly Hare, Innovations in Dementia
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Some practical tips for newer activists and their advocates and allies

Are you new to dementia activism – or an advocate or ally of people who are?

These tips draw on twenty years of learning by activists in Scotland.

We hope that they help you to avoid ‘bear traps’ and ‘reinventing the wheel’ – and to become a successful and well-supported activist!

To read more about the story of dementia activism in Scotland, go to the Life Changes Trust publication ‘Loud and Clear’ (<https://bit.ly/3kaKpvI>).

▶ **Try to find others who are ‘in the same boat’**

▶ **Share your stories. But then move on to find common issues**

▶ **Then work together to try to make a change**

▶ **Making connections with other groups and joining a network can be helpful**

▶ **Make the most of everyone’s skills and life experience – share jobs and activities around**

▶ **Explore if and how you can do your own research on something that is important to you**

▶ **Gradually find allies – advocates, friends, academics, local companies, policy-makers, practitioners, councillors/MPs,**

local media (between you, you will know some already)

▶ **Don't let others take over. Set your own agenda and priorities in line with what matters to you. Keep your 'license to be free'**

▶ **Leave time and space to socialise, and to discuss emotions as well as action through 'peer support'**

▶ **Meet in a nice, quiet, enabling environment**

▶ **Agree some basic rules and ways of working. But keep bureaucracy to a minimum, and language simple**

▶ **Make sure anyone who is travelling is confident, and has a clear travel plan (and support if needed)**

▶ **Keep things light and fun. Humour, games, art, music and nice food can enable everyone to relax, and then to contribute**

▶ **Respect all voices and experiences**

▶ **Maybe focus first on smaller/local issues – leave the bigger/national ones for a while**

▶ **If possible, meet separately from family carers (this can make it easier for people to talk openly)**

▶ **If you have a group facilitator, ensure they have the 'right' skills and values – and be clear about mutual expectations**

▶ **See if technology can help to connect and involve more members**

▶ **Try out creative methods to enable as many people as possible to express themselves (and to have fun!)**

▶ **Make connections beyond Scotland – in the rest of the UK, in Europe and maybe even further**

▶ **Enable more experienced members to buddy up with and support newer members**

▶ **Look after your health – don't take on too much, and keep space between meetings and events to enable you to recover**

▶ **If you are invited to take part in an event, ask for all expenses (at least) and (maybe) a fee**

▶ **Don't be afraid to ask others for help – for funding, for a room, for media coverage, for technical help... for whatever you need**

▶ **Keep a note of what you do and celebrate every achievement, however small**

▶ **Learn as much as you can from the stories of those who went before**

Getting in touch

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

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