

SharedLivesPlus

THE UK NETWORK FOR SMALL COMMUNITY SERVICES

Setting up an Independent Shared Lives carer group



www.sharedlivesplus.org.uk

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What is an Independent Shared Lives carer support group?

Shared Lives carer support groups are groups of Shared Lives carers who come together – either in person, on the phone or through the internet – to offer each other support, share ideas and information or sometimes just have fun and socialise.

Shared Lives carer support groups give people the opportunity to talk about their feelings with others who are in similar situations and understand how they're feeling.

Shared Lives carer support groups can be anything the group want it to be. They can be formal, informal or a mixture of both. Some groups may meet at a community building, in someone's home, while other groups may meet in a café. A group is what you make it.

Why create an independent Shared Lives carer support group?

Shared Lives Plus believes that independent carer support groups in each scheme can be invaluable in resolving issues and improving services.

Talking to a scheme worker or manager on some issues such as respite or payment can be intimidating for some people, because those relationships tend to place more power with the scheme worker.

In a support group people can speak collectively through elected representatives

or spokespeople. In this way individuals can draw attention to particular issues without feeling vulnerable or exposed.

Being part of a support group can help Shared Lives carers feel less alone and more understood. Support can come in the form of conversation and sharing experiences and resources or by simply listening to others.

Support groups enable people to work together to solve their own problems.

Getting started

Ask other Shared Lives carers for help

The first and most important rule in starting a support group is not to do everything by yourself. Getting a group started takes a bit of time. Find two or three other people who are interested in starting a local group with you. This will help share the organising; bring together skills and ideas; and ensure that you get a mix of views.

Ask your local scheme for help

Schemes can help in a variety of ways from assisting with location of venues to distributing letters inviting carers to come to the support group and publicising dates of meetings.

Ask Shared Lives Plus for help

We can offer practical support and advice to help you to get a group started:

Facilitation - we can facilitate your first sessions to help you identify your aims, objectives and elect reps (if your group chooses to have an elected representative)

Communications - we can help by advertising your gathering to other Shared Lives Plus members.

Ideas and Enthusiasm - sometimes you just need to be told you're doing a good job or be given an extra idea for how to carry on.

Networking - co-ordinating phone-conferencing facilities and conversations with other nearby carers and existing groups.

What type of group is it?

The first step in planning for your group is to decide on its purpose.

Will it be a discussion group whose focus is to provide information to members, a campaigning group, or simply an informal group providing friendship and emotional support?

These are not of course all totally mutually exclusive and the group's focus may change from time to time depending on current circumstances.

Some people are put off by very formal structures. Others by attending meetings that seem to have no purpose.

We can put you in touch with successful groups in other areas to help you get some ideas and talk through how they are organised.

Where will the group meet?

It should be easy to get to the meeting place, especially if the group has Shared Lives carers who are older or who have a disability. Things to think about when finding a place to meet:

- Central location
- Wheelchair access
- Nearness to public transport
- Can you park? (for free?)
- Tea/coffee making facilities
- Degree of privacy if meeting in a public place

You may choose to hold meetings in group members' homes at first. This has advantages in that it's free, informal and relaxed but on the other hand there probably won't be room for a large group to meet.

If your group is very small and mostly about providing informal support you could just meet in a local café. (Garden centres usually have cafés and lots of free parking)

Your local library or community centre may also have space you can use at low or no cost.

We can provide a grant to help you to establish your group.

How often will the group meet?

Bearing in mind that you all have caring responsibilities this can be quite tricky to get right.

Some groups choose to meet on the same day, such as, the first Monday of the month, rather than specific dates, as this is easier to remember.

Others vary the day and time of their meetings so that the same people are not always excluded.

You won't get it right for all of the people all of the time just go for what will be most convenient for the majority of members.

Suitability of time and venue is something that it is good to check at each meeting.

What format will the group & meetings take?

There is no right or wrong way to run a group – the format of your group will depend on the wishes of the people involved and what you want to achieve. Many groups change as they develop, so there's no need to get bogged down before you've even started.

You may decide that a 'drop in' will work best for you, for example: Carers know that the group meets from 9 – 11am every Tuesday and people come and go at any time.

Some groups prefer a meeting that is more structured with an agenda that starts and finishes at a specific time with people staying, as far as possible, for the whole session.

Does size matter?

Your first meetings do not have to be large to make them successful. Most groups start small and grow over time.

A note on confidentiality

Sometimes Shared Lives carers will seek advice and support from the group so how you will handle confidentiality is something that needs careful thought. It should be possible to talk about your caring role without disclosing or sharing detailed information about specific individuals.

Just as it is important to respect the right to privacy of the people you support, it is important not to discuss another Shared Lives carer's issues outside the group without permission, or people may be reluctant to speak up.

On occasion, a difficult situation might arise that you feel you would like some help to address.

Remember you can ring Judith on The Shared Lives Plus carer help line for advice and support.

Should at any time you feel that a vulnerable adult or child might be at risk this must be referred on immediately to your Shared Lives scheme.

Top Tips

How your group develops will depend on the interests and agreements made by group members. Whether your group is formal or informal the following could be useful.

Gather names and contact details - ask everyone who attends if you can have their contact details. This can be done by simply passing a sheet round group members. Remember to ask people how they want to be contacted ie email, phone, daytime, evening.

It is worth asking your local scheme if they will contact other Shared Lives carers asking if it's ok to share their contact details with your group so you can reach as many carers as possible.

You can also publicise your group in both your scheme carers Newsletter (if they have one) in the Shared Lives Plus carers magazine and on the Shared Lives Plus website.

Get to know each other - when you first meet up you will probably want to spend some time getting to know each other and talking about your experiences.

Don't be put off if some people have a lot to say. This is normal, especially if people have not had much chance to talk about their experiences as a Shared Lives carer.

You may want to build in time at each meeting for people to off load. This can be tricky to facilitate and it is important to get it right. Some groups give members the opportunity to share at the start of each meeting 'something they've felt good about and something that's getting them down'.

Doing this can help people feel listened to and ready to move on.

Some practicalities

Checklist of things to consider:

- How long will the meetings last?
- Will there be a break?
- Will there be refreshments? If so who will provide them, who will pay for them and who will clean up?
- How often will the group meet and at what time?
- How will the group keep a list of members' contact details?
- How will the group be chaired, facilitated or coordinated?
- What do people do if they are not happy with something that's happened in the group?

Future meetings

You may want to think about how you can grow your group. Some groups will choose hot topics as discussion points and regularly invite visiting speakers.

How you publicise your group depends on the sort of group it is. Some groups have agendas that are circulated in advance, some use word of mouth. Most carers tell us personal contact is one of the most effective ways of encouraging new people to join.

Some successful groups make a point of asking everyone who comes along to spread the word amongst other carers they know. Some do it informally, others ask members to commit to doing a practical job ie ringing a certain number of people to remind them of when the group is next meeting.

This can also be a great way of making new members feel useful and involved.

Chair/facilitator/coordinator? How groups organise themselves vary. Usually someone will need to take on the job of chairing or coordinating. If no-one in your group is confident in these roles think about inviting someone independent of the group to facilitate the first few meetings.

This will give you time as a group to think about and discuss how the meetings are going to be organised in the future. Some groups prefer to have the same person chairing each meeting or taking on a lead role, others take it in turns and share jobs.

We have found that groups that share roles and responsibilities tend to be successful.

Take notes of the meeting - these don't have to be very detailed, but it is helpful to make a note of any decisions made, and most importantly who has agreed to take on any jobs. Share the job of taking notes between group members so one person doesn't always get landed with it.

More formal groups

Some groups choose to continue to meet on an informal basis others in time choose to formalise their group. If your group wants to become more formal, some things to think about are:

Aims of the group – You will probably have spent time talking about the purpose of the group already. More formal groups may want to turn these conversations into a written statement. If you choose to do this it is worth checking that members are in agreement with the written aims on an ongoing basis. You may want to turn this into a terms of reference.

Terms of reference – a “Terms of Reference” (TOR) is just the written description of the aims and structure of a group. The TOR will depend on what the people in the group want to get out of it. You don't have to have one at all but if you do it could include

- What the group is for (aim of the group)
- Who will take part in the group (ie Shared Lives carers from xxxx scheme)
- Who will do what (ie is there a chair/co-ordinator/elected reps)
- How it will be financed

If you have a Terms of Reference it should be agreed by members and each member of the group be given a copy.

Setting the ground rules - Ground rules can

be a helpful way of making sure meetings run smoothly. If you choose to have them. It is important that they are agreed by all members and they can be added to or amended as the group progresses.

Don't forget to let new members know about the ground rules and ask if they have anything to add.

Some simple ground rules may include –

- All views are equal
- Respect each other
- Respect confidentiality
- Be constructive

Who will do what - often those who start the group will take on tasks informally others in time elect members to specific roles. It doesn't matter how it works, as long as it works for your group and everyone is clear about who does what.

Finances - a carer group shouldn't cost much money to run. As soon as your group has some money, it's important to give one person responsibility for keeping track of it.

We can provide support and information on

- *Preparing agendas for meetings*
- *Writing Terms of Reference*
- *Chairing/facilitating co-ordinating meetings*
- *Taking Notes/Minutes*
- *Confidentiality agreements*

Developing a group

Some groups grow and develop naturally, according to the number of people attending and what they want out of the group.

New members - as a group develops and word gets around, more carers may come along. It's worth thinking about how the group responds to newer member. It can be intimidating being the 'newbie' in any situation where you think that everyone else already knows each other, so it is important to make sure the group is welcoming and supportive. Remember to do group introductions at the start of each meeting.

Get to know each member of the group - find out what everyone values about coming to the group. Ask if there is anything that could make the group an even better experience and follow up on suggestions and comments.

All members are equal - all members should have chance to help plan and facilitate meetings on topics of personal importance. Group members need to feel the group is worth coming to. Once they buy in, this will help the group to thrive as members will have opportunities to use their talents for the good of the whole group.

- be realistic about what the group can accomplish
- share jobs and responsibilities among group members
- take time out (such as over holiday periods)

- keep it interesting - arrange different activities, topic, speakers etc.

Shared Lives Plus are happy to arrange regular contact with group members or just to be on the end of a phone if you need us. We can also attend a few of your meetings to discuss or raise certain issues or topics of particular interest or concern to group members.

Review, with the group, what has been done and what parts they like and dislike. Remember, the group is there for all Shared lives carers, so even if you feel the group is not progressing as it should, you may need to accept that other Shared lives carers may think otherwise.

Connect with other Shared Lives carer groups - Communicating with Shared Lives carers from different schemes can be a useful way of sharing ideas, finding solutions to common problems and identifying issues that are shared.

We can put you in contact with other Shared Lives carer groups.

Representation

It is important to think about how and who will communicate ideas or raise areas of concern with the Shared Lives scheme. Some groups choose to elect Reps others have a spokesperson, others still choose to speak collectively.

We can help you to communicate with your scheme as appropriate.

Working positively with your scheme

Remember a Shared Lives scheme is a 3-way partnership between people who use the service, carers and staff.

It's all about making shared lives as good as it can possibly be.

While Shared lives carer groups should be independent it can be helpful to agree early-on what the relationship is between the Shared lives carer group/ reps and scheme.

In order to make this work **everybody** involved must be willing to be constructive and schemes should be willing to help but not control.

It is important that your group makes its own decisions but schemes are more likely to listen to groups if those decisions are made democratically and views are expressed in a positive, constructive way.

What can Shared Lives carer reps do to help?

- Raise issues with scheme manager from SL carer group
- Act as a contact for all SL carers, not just those who turn up
- Represent SL carers in decision-making structures
- Report back to and respond to SL carers about progress within the decision-making structures.

- Collective representation - not individuals

What can Shared Lives carers do to help?

- Work constructively and positively with the group
- No pointless opposition
- Agree with scheme early-on what the relationship is between SL carer reps/ scheme/group
- Let everyone have a voice
- Engage with the group - you get out what you put in

What can the Shared Lives scheme do to help?

- Seek permission for SL carer reps to have contact details of all SL carers
- Assist with venues
- Forward communications to SL carers
- Respect independence and confidentiality of the group/SL carer reps
- Keep groups informed of changes to structures
- Be available to answer questions
- Champion the desirability of SL carer reps in decision-making structures both within the Scheme and within wider structures when they are making decisions about issues that affect Shared Lives carers

What can Shared Lives Plus do to help?

- Communicate/advertise meetings to our members
- Coordinate phone-conferencing facilities
- Facilitate conversations with other groups (incl reps speaking to reps)
- Provide early-stage support, such as independent Chairs/facilitators and sessions to help a group identify their aims, objectives and elect reps
- Help the SL carer group and scheme work together through facilitating joint meetings, workshops etc.

Support and mediation

Sometimes, for whatever reason Shared Lives carers and their schemes do not see eye to eye. As supporters we will help groups to speak and have a voice. We will provide information and work with groups to help them identify the issues they have, and support them to put in writing or voice their concerns in a constructive way. We will also work with them on the steps they may need to take to make progress towards a resolution.

Sometimes it's about misunderstanding as much as conflict.

The mediation we offer is about helping Shared Lives carer groups and scheme staff/management who are struggling to work together positively to arrive at mutually acceptable agreements.

As mediators we will take a neutral position but will be available to contribute information and/or advice based on the good practice which Shared Lives Plus promotes and the expectations of regulators.

For further information please see Shared Lives guidance 77 [Disputes - Protocols for Shared Lives role](#)

And finally

Groups should be open to all carers but it is important to remember that not all carers want to be part of a group.

If attending a group is not for you, the on-line forum on the Shared Lives Plus website may be of interest.

Further details can be obtained from <http://www.sharedlivesplus.org.uk/>

<http://sharedlivesplus.invisionzone.com/>

If you'd like support with an existing Shared Lives carer group, help to set up a new one or just want to know more about Shared Lives plus then please get in touch.

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