



Setting up a relatives group

A guide for care homes

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1. Introduction

Home managers frequently tell us 'their door is always open' for relatives. It is, on the face of it, a commendable policy but, for many relatives, the fact that a door is open does not make it any easier to walk through it and ask questions, raise concerns, make a complaint or even offer to help out with the Christmas Fair. The main priority of a care home must be the care and wellbeing of each and every one of their residents but addressing the concerns and worries of relatives, carers and friends can lead to improvements in the way the care home runs, to productive and constructive relationships between residents, visitors and staff and can enhance the quality of the care given to residents.

The R&RA believes that Relatives Groups are an important way for homes to establish and maintain good relations with relatives, express concerns, address difficulties and help relatives make a positive contribution to the life of the care home.

Why we wrote the guide

We have many requests from homes, and from relatives and friends as well, for information about setting up Relatives Groups. We have drawn on the successes and failures reported by homes and relatives to let other people know what seems to work.

The guide is addressed to home managers but we hope it will also be read by relatives and friends who visit care homes and staff that work in them.

There are three important points to remember:

1. Each home is different and so are the relatives. There is no blue-print for how a Relatives Group should operate and the way groups function may vary from home to home, and may change over time.
2. Setting up a Relatives Group needs careful planning. Initially managers and relatives may have different ideas about the purposes of the group and how it should be run. Honest discussion about this at the outset between managers and relatives is essential.
3. The type of interaction described in this guide is relevant for all communication between relatives and their loved one's care home whether or not there is a Relatives Group in operation.

Are Relatives Groups a good idea for relatives?

There are many good reasons for relatives coming together to exchange their views with each other and with the management and staff. For many relatives having a husband, wife, parent or friend go into a home leads to a sense of unease and uncertainty, and often to feelings of grief and guilt. Relatives value the opportunity to share these feelings especially those new to the role of relative of someone in a care home and who may feel out of the depth and uncertain. At this crucial time they may be uncertain how they fit into the home, about what is expected of them and of their relationships with the staff. After perhaps years of caring for their loved one, relatives can suddenly feel they are just visitors on the outside at a time when many wish to stay close or draw closer to the resident and have more involvement in their care. It is much easier for them if they have the opportunity to share these feelings, and have their concerns, suggestions and questions considered collectively. If they feel involved, understand more about the home's policies, and can see what they might do themselves to add to the quality of life of the residents, this is to everyone's advantage.

Are Relatives Groups a good idea for homes?

Managers can worry that encouraging relatives to meet and exchange views risks creating difficulties for them and it is true that open communication can sometimes expose problems or changes that are needed in the way the home is run or residents are cared for. But relatives, especially those that visit regularly will be aware of any problems within the home already. If there is good communication and understanding relatives can be allies that can contribute to positive change and improvement. Homes which welcome and encourage a collective communication will earn the respect and confidence of families through this evidence of an open approach. After all, few relatives want the care home to fail. The vast majority want 'their home' to be good.

2. Ways in which a relatives' group can help

Support for each other

Being a relative of someone going into a home can be painful and difficult. It can also be extremely lonely. Giving support in that difficult initial time of transition to the relative of a resident can be immensely valuable to the relative, the new resident and to the home itself.

- Relatives Groups can help 'new' relatives overcome their sense of grief and anxiety, and familiarise themselves with the home.
- Meeting other relatives and sharing experiences can help new relatives realise they are not alone.
- Relatives can take an interest in residents who have no visitors, or whose family or friends can only visit occasionally. Keeping in touch with other relatives over the phone can be a great help too.
- Relatives can help each other in visiting the home. Some visitors do not have a car and may have long or complicated journeys. Relatives could share cars or represent each other at meetings, raise issues on their behalf and feedback the results of discussions.

Feedback about the way the home is running

Relatives mostly want to question, make suggestions, understand and discuss; It helps them and the home if concerns can be talked about openly.

- Relatives need to know about the environment in which their family member or friend is now living, and they need to feel at ease in asking questions and making suggestions. It may be difficult for a home to appreciate how confused many relatives are, how unfamiliar a home is at the beginning, and how anxious they are to do the right thing.

Information about developments or changes

Relatives are often distressed or angry when changes suddenly happen. It helps relationships within the home if you can explain or even get their views beforehand.

Opportunities for care staff and relatives to exchange views

Often both relatives and staff are uncertain about their relationships and the group can provide an occasional means for exchanging and understanding each others points of view.

- Many Homes encourage relatives to 'make themselves at home', but offer little further guidance on what is expected and what is or is not acceptable. Relatives then feel rather lost, and talking together with staff about this can be of great mutual benefit.

Opportunities for relatives to learn more about how the home works

Many relatives welcome being able to discuss and learn more about aspects of running the home, such as:

- ownership, management and policies of the home itself
- care planning, key worker systems, training schemes
- food and menus and arrangements about meal-times
- activities and maintaining individuality
- risks and residents' rights
- health care in its many aspects, including GP care and access to consultant and other specialist nursing or medical advice
- regulation and inspection of care homes.

Practical support to the home

An important part of many Relatives Groups is arranging and running social activities such as a summer fair or Christmas party. Relatives can get an enormous amount of satisfaction from successfully raising money for a special treat or simply seeing residents enjoying themselves as a result of their labours. Relatives can

- help to arrange and support outings and social events
- use their abilities, skills or hobbies to add interest to the life of the residents and home
- help out with activities or help residents take an active part in the life of the home
- persuade other family and friends to be involved or visit regularly such as grandchildren and great grandchildren.

Overall Relatives Groups help to build trust and co-operation and can help to create an atmosphere in which relatives feel they are actively participating with the home in securing the best possible care for all residents.

3. Getting started

Ground work

An element of planning is a good idea. First, ask relatives' views about having a group. They may have different ideas about what they want from the group, how often it should meet, who should be included and what its purpose should be. An event at the home might be a good occasion to introduce the topic to relatives as a group or you might feel more comfortable talking to relatives individually. You may be able to identify an enthusiastic regular visitor who could encourage other relatives to express their views and join the group. A more formal approach would involve writing a letter asking for views. Whichever way you do it, it's a good idea to include some discussion about practical arrangements such as where, when and how often to hold the meetings.

Whose group is it?

Be clear about whose group it is. Who makes the rules? What if problems arise? This has to be discussed at the outset. Relatives may sometimes want it to be their group, ie a group which they organise and run which feeds views back to the home. Some may feel that managers are determined to control the group. Managers on the other hand are responsible for the home as a whole, and may feel they must determine the scope of the group and what it is allowed to consider. A balance has to be achieved which meets the needs of the group and of the home manager. Is the meeting for relatives with staff invited as necessary or is the group intended to be a joint forum for both?

Questions to think about

There are many advantages in relatives meeting collectively within a home, but this does create a subtle difference in their relationship with the care home. No longer simply visitors, relatives are talked to and their views sought on a range of issues, not simply the care and welfare of the resident that they visit. It is advisable to consider possible reactions to this in advance.

Reactions from residents

Having relatives more involved and more easily able to raise matters on behalf of residents should have advantages for the residents - but some of the residents might worry that relatives are interfering, talking about them, undermining their independence, or misinterpreting their wishes? Tensions may also arise if the Relatives Group's meetings take place in resident's space.

Should residents be able to join the Relatives Group if they want to? It may help if residents feel resentful of the Relatives Group. Could relatives meetings be arranged without depriving residents of their normal living space?

Reactions from other relatives

Some people are natural 'joiners' and organisers. Others may feel uncomfortable joining a group and there will be some who will not want to get involved. It is important that a minority of relatives, and their views, do not dominate. A Relatives Group is a useful forum, and in trying to build a successful Relatives Group effort should be made to ensure it is accessible and welcoming to all, but it should not replace good communication and consultation with all relatives.

- Consider the barriers to joining. Some may have little spare time or energy on top of visiting, they may have awkward journeys or commitments at home. Think about the timing and frequency of meetings to accommodate as many relatives as possible?
- Relatives Groups with a wide remit can result in long meetings that get bogged down in the detail of organising a social event for example. Would forming sub groups to deal with specific topics that report back to the main meeting help keep Relatives Group meetings more manageable and relevant to all?
- A relative, or indeed a member of staff, that is seen to 'own the meeting' can be very off-putting to new members. Although it is often difficult to persuade people to take on responsibility within the group, it is worth avoiding the Relatives Group being overly identified with an individual or a small group of people. Would regular changes of 'chair' spread responsibility and influence around and help all members to feel ownership of the group?
- Many of those moving into a home may not live for long. The group may be affected by a rapid turnover in membership. What if relatives want to stay involved after their loved one has died? 'Ex-relatives' can make very committed volunteers.
- Will confidentiality be an issue? Some relatives may take the opportunity of a Relatives Group to raise specific complaints about their loved ones care. A Relatives Group is unlikely to be the right forum for such discussion and what is or is not appropriate to raise at the Relatives Group must be made clear at the outset and regularly re-affirmed.

Reactions from care staff

There can be great advantages for care staff if they and relatives can communicate more easily and better understand their respective points of view. Better relationships can be built if relatives help with activities and support residents to have a better quality of life. Staff need to feel appreciated and know their work is understood and valued - but

- Will staff worry that relatives are discussing their faults? How far staff can be involved in the group will depend on the way that it is run but it may be that staff can attend regularly or be invited by the relatives to talk about specific issues. The manager's job will involve reassuring any staff who feel threatened by the establishment of a Relatives Group and making sure staff get regular feedback from the group.
- Will they feel the relatives are having more say than they are? Similarly, managers will need to reassure staff if they feel that relatives are influencing decision in the home unduly. It is easy for people to feel resentful if they feel excluded from discussion and decision making.

Manager's reactions

Relatives who are working together, helping each other and the home, feeding back their comments and improving their knowledge of the way the care home works can be very beneficial to the home and its staff. On occasion the relationship between the group and the staff may be challenging and that should not be feared. Being challenged about how we do our job and why it is done the way it is done, is good for us all. Occasionally, however, a group may become disruptive or cause tension within the home. It is worth thinking about what to do if this happens.

- Is the problem limited to one relative or a small group that is not representative of the majority of relatives? Dissolving the group for a period or even in extreme cases, excluding a member – with the agreement of other members – may be the answer.
- If the tension and difficulties are more widespread, clearly the home management need to address the problems. While you may not have envisioned the Relatives Group as being the forum for complaints, if complaints are made they must be addressed.

Is a Friends of the Home Group an alternative to a Relatives Group?

Many homes already have Friends organisations but usually Friends Groups have different aims and a different remit to Relatives Groups although sometimes homes assume that inviting the relatives to join the Friends Group is a sufficient alternative. Friends of the Home Groups are usually concerned with fund-raising, organising social events, functions and outings. While there may be some overlap:

- * Relatives Groups will want to focus on the care being given within the Home and on their relationships with the Home.
- * Friends groups can become close knit local social groups making it more difficult for relatives who may not be local or part of the social group to join.

However there is no reason why Relatives Groups and Friends Groups, if they co-exist, should not do things together and support each other's initiatives.

4. Organisation

The first meeting

The best approach is one which recognises the joint interests of management and relatives in having a successful group. This would recognise both the relatives' need for time on their own to look at things independently and the manager's overall responsibility for the home, and the desire to foster good communication and a good atmosphere in the home. How this sharing could be achieved should be considered at initial meetings.

- Encourage relatives to talk together on their own

Relatives need a chance to get to know each other, and to consider among themselves how they would like to see the group developing. Many find it hard to adapt to their role as a relative, or to assess whether any worries they have are shared by others. Initially they find it a great relief to be able to talk together on their own about their experiences.

- Allow time for feedback and for the manager to show they are taking account of relative's views

For the first time relatives will have been discussing their feelings together and there may be a lot of questions and comment which it is best they should put to you at the end of this initial meeting. You can arrange to provide answers at the next meeting if there are things to look into.

Occasionally relatives have seemed so upset that homes have worried about the effect of carrying on with the group. Don't worry and don't be over-defensive; this phase will pass if you take their worries seriously and act over legitimate concerns.

Ongoing organisation

Who should be members of the group? At the outset the relatives and friends (including advocates or voluntary visitors) of existing residents, but there are others who could be included later on or on occasion such as:-

- relatives of residents who have recently died, if they are still keeping in contact with the home
- residents who would like to belong
- people visiting the home to provide help with activities
- members of the staff
- members of the Friends of the Home group.

The Relatives Group will need to consider if the presence of others would prevent the group from operating in the way it was designed or would input from others help broaden the way the group works by introducing new ideas or encouraging discussion.

Who should chair the meetings?

Who takes the chair is an important decision. If the manager takes the chair the group may lose its sense of independence; however it can be difficult to find relatives willing to take responsibility especially at first when relatives don't know each other well. If the

manager organised the initial meetings, it may be preferable for the first few to be informal with the appointment of chair an item for the third or fourth meeting.

Appointment of meeting co-ordinators or facilitators

Both the home and the relatives could appoint a co-ordinator or facilitator for the meetings. The home's co-ordinator could be a member of the management team, and would be the home's channel of communication with the relatives' co-ordinator. They would jointly see that the group worked, i.e. that meetings were arranged, topics for discussion and speakers etc. organised, ideas put forward and problems investigated.

Keeping notes

Whoever organises the meetings should also make sure that notes are taken and circulated. Note taking could be a job allocated to a relative but if there is a problem in finding someone willing to take it on, for a time this may have to fall back on the home's meeting co-ordinator. Relatives should recognise however that this is an additional task which it is preferable for the relatives to undertake.

The immediate circulation of brief notes is a good idea so that those who have not been at the meeting know what was discussed, what decisions were made and about future plans. Make sure all relatives get a copy and if necessary post them. Homes will have to take responsibility for this as relatives' names and addresses should not be passed on without their permission. Don't rely on putting copies of notes on the notice board. Relatives may neither visit frequently nor look at the notices.

When and how often should meetings take place?

This will depend on the group and when the majority can come. If the aim is monthly meetings, the times could vary, i.e. alternating morning, afternoon and evening meetings. The group may decide that to meet once every two or three months is sufficient. The aim should be to meet often enough to maintain good contact but not too often that the meetings struggle to fill an agenda. The group must feel that something is being achieved through meeting.

Where should the group meet?

The natural place for meeting is within the home but only if there is no detrimental effect on the residents. If the home doesn't have space away from the residents for the group to meet it may need to meet elsewhere such as in the home of a relative or some other local meeting place?

The pattern of the meetings

This will be determined by the members themselves. The main point to consider is whether they should be purely informal. Informal meetings may suit smaller homes and an informal manner may be helpful while the group is getting established. But members can become bored with meetings if they turn into discussion without getting anywhere. Even if it is not thought necessary to have terms of reference or a constitution, meetings usually work better if there are agendas or standing items including an information exchange.

Meeting the groups' running costs

The costs of running the group should be low if meeting space and refreshments are provided by the home, and typing notes of meetings is done on a voluntary basis. Costs will mainly be for postage and stationery, apart from any costs for bringing speakers in or for outside meeting places. Some homes regard the costs as part of their service; some groups have a collection box at meetings or ask for a small contribution from relatives; some contribute stamps or stamped addressed envelopes.

Letting all relatives know about the group

The group is a way in which relatives can express their views and work with the home. Not all relatives will want to come to meetings or be interested but the work of the group will be relevant to all of them and they should know about the group, what is discussed and what decisions have been made.

Once the group is established they might discuss how relatives could be contacted. The manager might give all relatives the contact detail's for the Relatives Group (i.e. chair or co-ordinator) and/or ask whether relatives would mind their own names and addresses being passed on so that a member of the group could contact them.

Relatives should be told about the group as part of the information given to residents and their families on admission. They should be told practical information about where and how often the group meets but also its purposes and how it might be able to help them. If possible give the new relative the contact details of a member of the group so they can make contact with a member before the first meeting they attend. Or they could be asked if they mind having their contact information passed on so that someone from the group could get in touch with them.

5. When things don't work

Relatives Groups can start in an atmosphere of enthusiasm and commitment. However problems do arise and if they are not addressed groups can create difficulties for the home, members of the group or even residents.

Relatives raise matters the home prefers not to discuss

Some home managers become concerned when the Relatives Groups ask questions or start discussions in areas that make the managers feel uncomfortable. The reaction of managers can be to want to try to limit the role of groups; however if there are matters which relatives feel are in serious need of discussion and sorting out, they are likely to persist.

It is the responsibility of the manager to decide what areas are appropriate for discussion at the Relatives Group but don't underestimate the advantages in explaining to relatives some of the difficulties care homes can face and the attempts you are making to address the problems.

Limited interest

If only two or three people turn up is it worth persisting? One of the values of a Relatives Group is that it is available even if, at that time, the relatives of current residents do not use it. They may in the future be new relatives who may value the meetings. Also don't under-estimate the importance of the Relatives Group to the small number of people who do attend, and the importance to the home manager and staff of getting feedback from those relatives. Of course Relatives Groups benefit from lots of attendees so asking relatives why they don't attend and trying to address those issues may encourage others to come.

Relatives keep changing

The average length of stay of residents, and therefore of relatives involvement, is decreasing. Relatives Groups need to reflect this reality. A large part of the work of the group may be about helping new relatives orientate themselves and offering practical help to people settling in. It is important that relatives are made aware of the group when they first become involved in the home so they can access this support.

The home is too small for a group

A small home, particularly if relatives live locally, may already in effect be running a group in that residents, relatives, staff and management are regularly able to exchange their views and all feel involved with the Home. There are benefits though; not least in terms of fulfilling quality assurance requirements, in recording exchanges of views and discussions in a more formal way.

The relatives leave it all to the management

Some relatives will turn up to meetings but do not want to play any active part. They may just be too old or frail or busy themselves or they may not think of themselves as the sort of people who go to meetings and be too nervous. If this is so, the management may have to carry the organisation; but make sure it is not your efficiency and personality which is inhibiting them.

The Relatives and Residents Association is a charity that supports and advises older people living in long term care, their friends and relatives. It runs a telephone advice line offering information and help on finding and paying for a care home, quality of care issues and tackling problems. It campaigns for improved standards of care by working with national and local government and care providers on projects and reports.

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