

Share the Care - How to Organise a Group to Care for Someone Who is Seriously Ill

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Share the Care, as the name implies, is a system of organising all your willing helpers into a more efficient and reliable caring team. When someone is seriously ill they usually get plenty of offers of help from family and friends. However, if the help offered isn't well organised, it can become ineffective through lack of planning which results in overlapping as well as gaps in meeting the needs of the sick person. The idea of organising help was conceived by an American psychotherapist by the name of Sukie Miller. She set up the first Share the Care group for a patient of hers named Susan. Susan had cancer, was single and her family lived far from where she was. She had numerous friends but they only met her for lunch or accompanied her to the doctor or rang her late at night to give words of comfort. They did not realise that what would help her the most was if they were available to help with those increasingly difficult practical daily chores such as shopping, cleaning, tidying up, cooking and so on.

Cappy Capossela and Sheila Warnock wrote a book entitled *Share the Care, How to Organise a Group to Care for Someone Who is Seriously Ill* which explains clearly how to go about setting up such a group. It tells you how to get started—who should be setting up the group, who to invite to the first meeting, how to ask people to the meeting and how to run the meeting. They provide all the forms you'll need for people to complete. You just have to photo-copy them. At the meeting people are asked to think about what they'd gain from being part of the group, are reassured that they only need to do as much as they can and what they are comfortable doing. The leaders (there should be two) should have a combination of people skills as well as organisational skills. At that meeting people fill in forms which show how often they're available and when, and what they're good at and what they aren't. With this information the leaders draw up a roster whereby 2 people are in charge each week. Not everyone has to take turns at being in charge. Some helpers may prefer to just be called on for what they are able to do.

So when the roster is drawn up, one of the week's 2 organisers contacts the sick person to find out all their needs for the week. For example this week I need someone to take me swimming on Tuesday and Friday, do my grocery shopping for me, take me to the hairdresser, walk me around the block, help around the house on Wednesday and Saturday, pick up a Medicare claim form and fill it in for me and post all my mail. The week's organisers will then ring the others in the group to see who can do what. She will refer to the information sheets re everyone's availabilities and list of can and can't do's. When asked, each person is not obliged to say yes. The organisers' job is to find someone who is willing and available for each task that week.

The more people who are willing to be rostered on as organisers, the less frequently each person has to do their turn. I have 14 organisers so each person is only on every 7 weeks. Altogether there are more than 20 people in my Share the Care team. This means that there's always someone who'll take up the tasks. It sounds complicated at first but soon as everyone is familiar with the system, the group runs pretty smoothly. For example you soon learn who's available when and who'll say yes for certain tasks so the ringing around becomes quite simple in the end.

As a person who is cared for in this way I feel comfortable with the system because I know that people are only helping when and with what they're really willing to do. This takes a lot of the worry of wondering whether you should be asking in the first place. Also the system allows for people to say no because they're not saying it to you directly. You won't even know who said no to what each week. Having a middle person like this takes the burden off both the person in need of help and the helper. Above all, you know that no one is burning out because no one is helping you that intensively. Hopefully they might even feel good about what they are doing because they're giving while not feeling exploited. After more than a year of using this system I feel confident that it is a healthy way of asking for help. You don't need to pressure anyone or hold back from asking in the knowledge that whoever is doing what you've asked for is doing so quite willingly. Furthermore, because no one person is really in charge of your welfare, no one has a lot of power over you as I imagine a sole carer would have. In the case of someone who does have a main carer I feel that this system could provide much welcome relief both for the carer and the person cared for.

As to the carers themselves, here's what some of them have to say about being part of my Share the Care team.

Dennis: It makes it easy to play my part to care for Zana, because I am not afraid of committing myself to more than I can deliver. To take on caring for Zana unaided would be a greater task than I could manage, but it is a pleasure to be able to play a useful part and know that others are sharing the work.

Suellen: Dennis & I were the two leaders who set up the group and we are part of the group as well. The initial organising was fun at the same time as seeming to be a fair amount of work. Since then, it has been easy. What is wonderfully inspiring about the group to me is that we are doing it, actually cooperating together reasonably smoothly and getting the job of caring for Zana done. Whenever I think about this I think we have done, and are doing a great thing. Each helper ends up doing hardly any organising—just making maybe six phone calls, if that. And your turn to help doesn't come around very much, so when the time comes, you are looking forward to it. It is very reassuring to know that the system is ticking over and that the responsibility is being capably shared by others who love Zana too. Having regular contact with Zana means that I get emotional support from her, too, because she always knows my ups and downs, and has such a good listening ear. As well as this, the others in the group have become closer to me as friends, some of whom I did not know at all beforehand.

Wendy: I think the arrangement works very well especially because there are a lot of people to share the work so it doesn't get too much and everyone is used to the system now. Also it's good that the system allows for Zana to communicate her needs without having to wait to be offered because some of her needs we wouldn't even think of such as undoing lids, putting things away, etc—things we'd take for granted for ourselves. It's nice to know that the little I do makes a big difference to Zana. Sometimes there's a tendency as the week's organiser to do all the work rather than farm it out to the others which can make for an exhausting week after work. I think that's where meetings and getting to know the other helpers is helpful because you then feel less reticent to contact them.

Rae: It's an excellent system especially for someone like Zana who doesn't have family here. I really don't mind giving my commitment because it isn't much. The work is shared so no one has to do a lot.

The resource book again, is *Share the Care: How to Organise a Group to Care for Someone Who is Seriously Ill* by Cappy Capossela and Sheila Warnock published by Simon and Schuster, New York, 1995.

When I rang around for a copy, none of the bookshops knew of it and neither did Simon and Schuster in Sydney. Bookshops will order it from the US but will use sea delivery. I ordered mine direct from a bookshop in Atlanta and used air mail, costing approximately \$35 a copy. It is more expensive this way and should the parcel go astray, the loss is yours. But it's quicker.

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