

Put Your Family Caregiving on the Map

A care map is a helpful way to visually represent all the people and services involved in a family caregiving situation. Drawing your own will show you and others at a glance who cares for whom, how frequently they provide their care, and roughly how far away they live.

This mapping concept comes from the Atlas of Caregiving project. The maps help them understand how caregiving works in the families they study.

Once you've drawn your care map you'll almost certainly find it helps everyone – family members, friends, and health professionals – better appreciate who's involved and what they're doing.

Care maps don't just help you see who's involved, they can also show who or what might be missing. Perhaps there are people who could be helping, but currently aren't. Maybe there are services that could be supporting you, but you're not making use of them right now.

Drawing your own care map is easy. Making use of it is straightforward too. So we'll show you how to do it, how to learn from it, and how to act on what you learn.

The Basics

How do you draw a care map?

Before you draw your map, if you have access to the Internet, you may want to view this video that demonstrates the drawing of a care map for a fictional man, Mike Stephens: <http://atlasofcaregiving.com/put-your-family-caregiving-on-the-map/>. It gives a quick overview of the main techniques involved in care mapping. A copy of this map is attached to this information.

Getting Started

The Materials

You will need some blank paper, pencils and an eraser. You will make mistakes – everyone does – so extra paper allows you to start fresh so that you don't need to feel that you must get everything perfect from the start.

Use Symbols

Use simple symbols to represent the different people. **This is not intended to demonstrate how well you can draw.** Here are some suggestions:

- Stick men and stick women — for male and female family and friends.

- Triangles — for professional caregivers.
- Circles — for pets (or draw little animals if you prefer)
- House — for facilities, such as a daycare center
- Box with small stick figures — for groups, such as online communities or support groups

Begin by drawing yourself right in the middle of the paper, then steadily add other people. As you do this, try to use distance on the paper to represent geographical distance. So if someone's nearby, draw them close to you on your map. If they're far away, draw them near the edge of the paper.

Identify the People

As you draw people and their connecting lines, ask yourself these four questions:

- Who lives in your home?
- Who do you care for? And who else cares for them?
 - In answering the questions "Who do you care for?" and "Who else cares for them?" think of all those you help due to their illness, disability or aging. Be sure to include pets, those in your home, and especially those you care for. Recognize that such support can take all forms, from helping with medical activities and healthcare management, to lending a hand with personal activities and housework, and even just keeping people company, or perhaps keeping alert in case they're needed.
- Who cares for you?
 - When it comes to "Who cares for you?" you may want to think more broadly, including anyone whose support allows you to care for others. Perhaps a friend makes meals for you, knowing you're too busy caring for your mother to take proper care of yourself. Maybe there's somebody you meet up with now and then who gives you emotional support and lets you safely vent about your frustrations. Maybe your employer provides you with flex time or the ability to work from home to accommodate your caregiving responsibilities.

Know Your Connections

Connect people with differently styled lines to show how frequently care is provided, using arrowheads to indicate who cares for whom. These are the types of line styles used in the Mike Stephens example, when caregiving is:

- Often (many times a day) — Thick
- Daily — Simple
- Weekly — Dashed
- Occasionally (less than weekly) — Dotted

You could also use different colors for family, friends, and professionals. Or use bolder colors for those heavily involved, and paler shades for those lightly involved.

Note that sometimes both ends of a connecting line need an arrowhead, when two people care for each other.

It's helpful to write names under the symbols for the people, places and services on your map. As you add information, don't worry about trying to make it perfect or complete. There'll be plenty of time to add missing people and make other corrections once you've established the overall structure, and don't forget that you have an eraser.

To make the care map useful in an emergency why not include phone numbers under people's names? You can always add these when you get home.

If you have enough room on your paper, you could add a few words about how each person helps. For example: "keeps company", "helps with health decision-making", "financial assistance", "provides respite when needed", or "does everything!".

Location, Location, Location

When you have finished adding people to your map, draw enclosing areas to group together those who are:

- In your Home
- Nearby (less than 20 minutes away)
- In the Middle Distance (between 20 minutes and two hours away)
- Far Away (more than two hours away).

Finally add your name and the date. Caregiving situations often change over time, so you may decide to redraw your map once in a while.

You can also use the computer and the features the internet provides to draw your care map. It is up to you and what you are most comfortable with.

You've drawn your care map — now what?

- After you've drawn your care map, capturing your thoughts on paper, one useful tip is to start by taking a "helicopter view" of your creation.
- Literally step back from it so you're not distracted by its detail, and examine its overall shape.
- Does it seem complex to you? Or is it surprisingly simple?
- How about its balance? Are some parts of it "busier" than others?
- Have you drawn something that feels as though it has caregiving connections all around the center, or is it somewhat one-sided?
- If it's the latter, what might that suggest?

- Having taken a helicopter view, it's time to get back down to ground-level again, and look at your care map in detail.

Look carefully at what you've drawn. You almost certainly carried all this information in your head, but it could be the first time you've seen your caregiving situation laid out as a diagram. Your care map could therefore help you get a clearer understanding of your own situation.

Here are some questions you could ask yourself:

- Who are the people on the map who are indispensable (perhaps including you)?
- What would happen if they/you were temporarily unavailable?
- Who could step in? Are they prepared to do so? Where is there an opportunity for respite for you?
- Are there key people missing from your map altogether?
- Perhaps there's someone you take so much for granted (for example, a spouse, child or best friend) that you've simply forgotten to put them on the map?
- Are there key family members who really should be involved, but aren't?
- Are there key professionals missing?
- Is everyone on your map aware of who else is involved? Does everyone know who does what?
- Does everyone know how their actions impact on other people?
- Who makes the major decision about this caregiving situation? Does that seem right or fair?
- Are people aware of all the time, physical, emotional, and financial costs involved?

You've learned from your care map. How can you take action?

Reflecting on your care map could help you become more aware of your own workload and responsibilities, and how you feel about this. Being conscious of it is an important first step in getting help, and if you use your care map to talk to others, it increases the possibility that you'll find people to lend a hand.

Share your care map with others to spark conversations about the overall situation, your needs, and their involvement. A good place to start is with the friends and family members who are also on the map. Perhaps even give people their own copy.

You might be surprised to learn how unaware they are of the wider caregiving structure, so talk it all through with them so they get a better appreciation of who else is involved and what everyone does. Talk together about what's easy, what's hard, and what might make things better.

It might even help the other person to compile a care map of their own, so why not suggest this and help them draw it?

Be sure to share your care map with all the key care professionals. It will help them form a picture of all the people involved, who needs to be a part of decision-making, who needs to be consulted and informed, and who might benefit from training or education.

Also use your care map to help these professionals appreciate the fullness of your situation – all the people you care for, as well as your non-caregiving responsibilities. Having a deeper understanding of your life could help ensure they don't overburden you.

Redraw your care map from time to time as things change. You might learn something by thinking about those changes. Has a new person's involvement made things easier? Has the absence of someone changed what those remaining are doing?

Credits: These materials are products of the Atlas of Caregiving Pilot. **Rajiv Mehta** is the Project Director and a lead investigator. The project can be found at atlasofcaregiving.com

<http://atlasofcaregiving.com/put-your-family-caregiving-on-the-map/>

