Seeing the Invisible

Strengthening your care ecosystem with Atlas CareMaps

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Atlas of Caregiving is a Silicon Valley-based nonprofit conducting research on family caregiving and developing tools (like Atlas CareMaps) to help families better understand and manage their own situations. We’re making visible the invisible world and manage of family care so that all those striving to support and improve family wellbeing have a better foundation for their efforts.

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This book is for you. If you care about the wellbeing of your family — yourself, relatives, and close friends — this book is for you.

You will learn about the Atlas CareMap — a tool and process for understanding your family care ecosystem (who is involved, what they do, and how they interact) — that has already been used by many to better manage and appreciate their own lives.

Since 2016, we at Atlas of Caregiving have directly taught hundreds of people how to make use of Atlas CareMaps, and these people have in turn taught thousands more (their own relatives, friends, co-workers, neighbors, and clients).

Others are also spreading awareness. Authors Carol Levine, Donna Thomson, and Zachary White discuss Atlas CareMaps prominently in their respective books\(^1\). The Northeast Business Group on Health and AARP urge employees to draw their maps first, before deciding what other tools and services to use\(^2\).

Through this book I am sharing the key lessons we have learned in the process, in the hope that you too will benefit. It provides a primer on creating, using, and sharing Atlas CareMaps.

I invite you to spend a couple of hours reading this, drawing your own Atlas CareMap, and reflecting on what you see. Then share your map with your family, sparking a conversation about caring. I am confident that you will find this time very well spent.

To see additional and latest information about Atlas CareMaps, you can visit www.atlasofcaregiving.com/caremap/.

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\(^1\) Navigating Your Later Years For Dummies, by Carol Levine (2018, John Wiley & Sons), and The Unexpected Journey of Caring: The Transformation from Loved One to Caregiver, by Donna Thomson and Zachary White (2019, Roman and Little Field Publishers).

What is an Atlas CareMap?

The Atlas CareMap is a drawing and a process for self-reflection and action, which also provides a catalyst for conversation.

A Drawing

Most obviously, an Atlas CareMap is a drawing of your family’s care ecosystem, showing who is supporting whom, and how. The drawing has “Actors” (people, pets, professionals, and places, shown using different symbols), and “Links” (arrows that connect the Actors showing who actively provides support for whom, with different types of lines indicating how frequently the support is provided). Your placement of Actors corresponds roughly to where they live.

The drawing itself has value. It helps you more clearly see your own situation, and to describe your situation to others. Others seem to respect the drawing more than a verbal-only description of the same situation (more “data” and less “anecdote”).

You can draw Atlas CareMaps by hand or using a webapp (AtlasCareMap.org). I strongly suggest you first learn to draw by hand.

An example: Christi’s hand-drawn Atlas CareMap (top) shows the many caring relations that exist within her family, who are spread out in different parts of the US. In Princeton, NJ, Christi and Mike support his mother Maria, who has dementia and lives next door. Several other relatives and professionals also support Maria. Christi and Mike also support a son, Pablo, who has diabetes. Mike and his brother Steve (in Philadelphia) also support his father Arturo (in Baltimore), while Christi and her sister Janet support her parents Eileen and Jim (in Orlando). Two nearby friends and a local support group provide support to Christi and Mike.

A webapp-created Atlas CareMap (bottom), includes more details. For example, different colored Links indicate different types of support (e.g., the School Nurse provides medical support to Pablo, while Ruth provides emotional support to Christi). The webapp also includes additional functionality, such as for different views of the current situation and for seeing changes over time.
A Tool for Sparking Transformative Conversations

People often find great value in sharing their maps with relatives and friends. Showing and talking about your Atlas CareMap opens the door to conversations that lead to understanding, appreciation, and support. Those you speak with will often open up about their perspectives on your situation (as depicted by the map you share), as well as about their own situations. Empathy is generated and knowledge is shared. It may lead to them wanting to draw their own Atlas CareMaps, and you can show them how to do it.

In our experience, once multiple people in a group have drawn and learned from their own maps, there is a transformative change in group conversations about care. People discover they have so much to gain, emotionally and practically, from sharing their care experiences and knowledge.

A Process for Self-Reflection and Action

The process of drawing, and then reflecting on what has been drawn, has proven to be a powerful tool for deeper understanding of one’s situation. Thinking about the questions that need answering to draw the map — such as: Who provides care support to whom in your ecosystem? What are the different types of support provided? Who is deeply involved and who is not and why? — gives clarity, and often new perspectives, to the situation.

Clarity comes over time. You will likely have a new perspective immediately after drawing an Atlas CareMap for the first time (often simply because you haven’t given deep thought to your ecosystem before). The drawing and insights will stay in your mind, and as you continue to think about those questions and their answers and see the world through a new lens, your perspectives may shift again. You might find it useful to redraw your map, either literally or just in your mind, as you gain more clarity. And since life doesn’t stay still, you may want to redraw your map as the situation changes.

Once you have clarity, what do you do? That depends … people’s circumstances vary widely, so there is no definitive “next step”. However, as general statements, many have found that an Atlas CareMap helps them plan for potential difficulties, manage the many people involved, identify missing people and services, and communicate with everyone. In addition, the Atlas CareMap often helps people appreciate what is working well.
Here are a few stories of the diverse ways that people have been helped by drawing and reflecting on their Atlas CareMaps. (Some names have been changed)

**BETTY** was brought to tears when she drew her map as it made her more aware of how overwhelmed she was, of how untenable her situation was. This awareness led her to appreciate that she really needed help, and that to seek help did not mean that she was a negligent daughter/mother/wife. She shared her map with her husband and children, and they began to help much more in the care of Betty’s mother and in housework. It made a huge difference! Inspired, Betty has gone on to teach other family members, friends and even her employees to draw Atlas CareMaps and think about what it implies for their lives.

**MYRA** too felt overwhelmed, as her map confirmed how alone she was in caring for her mother. But, the process also caused her to pay more attention to what other family members were doing, and she soon came to see that her children were in fact paying deep attention to their grandmother’s needs and helping her in many ways. While Myra’s “workload” didn’t change, it no longer felt as heavy knowing that she was not alone.

**ALICE**’s teenage son has autism. While the family had struggled in the past, their current situation was good, and her son was thriving in school. As she reflected on the map she had drawn, she took pride in the strong support system she had created, which had enabled her son to do so well. But this led to a new awareness: her son would be off to college soon. How would they create a new support system for that new environment? How would this limit his options for college? She realized she needed to draw some hypothetical future Atlas CareMaps to get prepared.

**EMILY** used her Atlas CareMap skills to help a young boy, she met at her children’s elementary school, whose parents had been deported. In addition to being devastated by that situation, the boy also felt he was all alone in the world. Emily drew his map as they talked about his life, and he saw all the people still around him that loved him: his grandmother, aunt, school teachers, and school friends. While being separated from his parents is still very hard, he no longer felt alone.

**PETRA** and her husband cared for a young daughter with cystic fibrosis. Though her daughter was now doing as well as possible, the challenges of caring for her had been a huge strain on their lives. The Atlas CareMap she had drawn made her realize that in pouring all their efforts into caring for their child, she and her husband had neglected their own needs, especially in maintaining ties to other people. She realized they needed to allow other people into their lives, to allow others to care for and support them.

**KAREN** drew a series of eight maps, one for each year 2010–2017, to see what she could learn in retrospect about her experiences caring for her parents. Over that time she and her husband went from having no significant caregiving responsibilities, to supporting a father through two bouts of cancer leading to his death, a mother through a stroke and broken hip, and an aging mother-in-law. As she describes (in https://lifeinmotionguide.com/caregiving-journey-atlas-caremap/), “I find it interesting that the drawings clearly reveal gaps I had to discover ‘the hard way’ over the past several years. The opportunities are right there in the drawings, too … The Atlas CareMap isn’t going to explain the emotional side of your caregiving equation or tell you how to resolve your caregiving challenges. What it will do, though, is give you an objective lens through which to look. What you see might surprise you!

**ROGER** had included his parents and grandparents in his map. His parents lived an hour away, while his grandparents (and many other relatives) lived in a distant state. Studying his map, he became aware that there were many heavy arrows (frequent care) connected to his grandparents, but only dashed (weekly) and dotted (less frequent) arrows to his parents. This made him wonder whether his parents should consider moving. While they were healthy at the moment, that could change as they got older, and it might be better if they were in a place where they would enjoy much more frequent interaction with family. Soon after he shared his map with his parents, and this opened a conversation about the possibility of them moving back to their home state in the near future (next few years). A few weeks later, Roger again visited his parents, and the story took a very different twist. The father said that he had realized that Roger’s map did not correctly reflect the situation. While the depiction was accurate for the mother, the father in fact had a couple of good friends that he saw all the time. There should be heavy arrows connected to him. If they move, the mother would have better connections, but he would lose some. There is no clear “right” next step, but everyone now better understands the situation.
Example: Fay

Fay has had to take a leave of absence from her PhD studies in order to care for her mother Josephine, who has dementia. As Josephine’s condition worsened over the previous few years, Fay insisted that Josephine move to live with her in the Bay Area. Josephine’s memory and decision-making skills have deteriorated to such extents that Fay now makes all decisions and provides her mother with constant caregiving support. This has impacted their mother-daughter relationship significantly. In addition, Josephine is not as mobile as she once was, has developed arthritis and suffers gastrointestinal issues. Due to the demands of caring for Josephine, Fay has had to put her studies on hold. As she faces potentially increasing expenses for Josephine’s care, having no income compounds Fay’s worry.

Fay’s map shows that Fay and Josephine, represented by simple stick figures, share a home in Oakland. A thick arrow shows that Fay supports Josephine by performing many care activities throughout the day. Four nearby doctors, represented by triangles, also support Josephine, though their involvement is infrequent, as indicated by a dotted arrow. On occasion, Aunt Joan, who lives further away in Stockton, also cares for Josephine, and provides Fay emotional support, as indicated by dotted arrows. A couple of friends support Fay: Ann (occasionally) and Betty (weekly, as indicated by a dashed arrow). Fay is also supported by a therapist, Dr Jones, and another relative, Aunt Wilma. The amoeba-shaped “circles” make it easy to see which Actors are nearby (within roughly 20 minutes — within the inner circle), in the middle-distance (within roughly 2 hours — within the outer circle), and farther away (outside the outer circle).

At a glance you can see that there are several people involved in Fay and Josephine’s care ecosystem, but that Fay is doing almost everything.
Example: Gaston

Hana and Gaston have been married for about 20 years. Before marrying, Gaston was in a serious accident that left him with a major back injury that has caused him significant pain and discomfort since. They have three grown children; one daughter lives nearby. Hanna’s brother Harvey lives with Hana and Gaston. He has intractable epilepsy, Parkinsonism, and other serious health conditions. Gaston’s mother lives nearby. Although she has very serious health issues, she insists on staying in her own home, and so Gaston often goes over to help.

Complex care relationships; not simple caregiver-patient dyads

Gaston’s map shows a web of care. Both Gaston and Hana are heavily involved in supporting Harvey, as is a daycare center. Note that there is an arrow showing that support from Harvey is important to Gaston, so the caregiving is mutual (though not “equal”). Gaston also supports his mother. Hana and Gaston’s mother also have a mutual caregiving relationship. With all this going on, Hana and Gaston are frequently supporting each other, as indicated by the heavy, bi-directional arrow.

Self-care + caregiving + care receiving

A thick arrow to himself indicates that Gaston has significant self-care activities. Every day Gaston puts in a lot of effort into caring for himself (doing self-care), supporting others (being a caregiver), and receiving support (being a care recipient). To some extent, the same is true for every person.

Care support takes many forms

Though Harvey can no longer attend his church physically, they send him a weekly DVD of services, maintaining an important connection. Hanna’s other brother is also included; he provides financial support to both Harvey and Hana. Gaston’s Atlas CareMap also shows that both Hana and Gaston receive emotional support from different online communities.
Example: Nate

Nate and Patty are a young married couple. Patty has MS (Multiple Sclerosis). She had taken comfort in knowing that Nate would care for her as her condition worsened over the years. Unfortunately, a year ago Nate was diagnosed with glioblastoma (a stage 4 brain cancer) that was expected to be terminal. While Nate was in the hospital, many friends, neighbors and colleagues jumped in to help. Unexpectedly Nate survived, and was able to go home. This doesn’t mean he is well, and his situation could worsen rapidly at any moment, but he was well enough to leave the hospital. Sadly, this has left Nate and Patty in a very difficult situation. Their care support system has disappeared, as people assume Nate is well and the crisis has passed. Nate is unable to support Patty as he used to. And Patty’s MS has flared due to the emotional and physical strain of caring for Nate, the challenges of maintaining her demanding job, and the uncertainty over their future.

Some people are isolated

Some maps include many people but other families are very isolated. Nate and Patty are very much alone, as is clear in their stark Atlas CareMap. They are almost completely reliant on each other’s support. Nate tries to continue caring for Patty, though in reality he can do very little, and feels very guilty about how little practical support he provides. Patty must do whatever she can for Nate, though the emotional stress and the overall burden have exacerbated her own conditions. She speaks to her mother occasionally, and one friend checks in on her weekly. The extensive support they once received, when Nate was in the hospital and expected to die, disappeared once he came home.

Experience of reality, not fact

There are no care professionals in this Atlas CareMap. This doesn’t mean they don’t exist. Both have doctors, and Patty spent time with a therapist the day this map was created. However, this map shows only the people whose involvement is worth noting from Nate and Patty’s perspective, the only people that matter. Atlas CareMaps are reflections of their creators’ perceptions of their lived experience.
Example: Chantal

Chantal supports her mother Debby who requires 24×7 care. Over the past six years, Chantal took on more and more care responsibilities, and eventually resigned from her job and moved into a house next door to care for Debby. Debby has a long list of medical issues. Chantal lives with her husband Bill. Two of Chantal’s brothers, who also live nearby, and a domestic care aide (Emily) help with Debby’s care. For a few hours a day, Chantal is able to get some time for herself to exercise and unwind.

Pets must not be ignored
Chantal’s dog is considered a key caregiver in the family. He seems to sense who — Debby, Chantal or Bill — most need the comfort of his presence. Pets are very much family members. They are often very important caregivers. As they age and get sick, they also are often significant care recipients.

“Other” responsibilities cannot be ignored
The evening before Chantal’s map was created, Debby was having an especially difficult time, and Chantal was feeling overwhelmed. Despite this, Bill had a very hard day at work and when he came home, Chantal felt obliged to leave Debby alone for a while to spend some time with Bill, helping him regain his calm. It’s a reminder that even while one family member is really ill, our obligations to other family members never stop.
Example: Christi

(As described earlier) Christi and Mike’s family is spread out in different parts of the US. In Princeton, NJ, they support Mike’s mother Maria, who has dementia and lives next door. Several other relatives and professionals also support Maria. Christi and Mike also support a son, Pablo, who has diabetes. Mike and his brother (in Philadelphia) also support his father Arturo (in Baltimore), while Christi and her sister support her parents Eileen and Jim (in Orlando). Two nearby friends and a local support group provide support to Christi and Mike.

Long-distance caring relationships
Christi and Mike are involved in the care of several people who live far away: Eileen, Jim, and Arturo. Supporting someone across the country, and even across the globe, is a common situation in modern times. In the Atlas CareMap such distances are indicated by placing those Actors near the edges of the map.

Multiple significant caring relationships
Even more than the earlier Gaston example, Christi’s family has many care support relationships, with many caregivers and care recipients in overlapping relationships. The Atlas CareMap makes it easier to see these simultaneous interconnections.

Moment-in-time
An Atlas CareMap shows the ecosystem at a particular point in time. For example, during summer vacations, the “School Nurse” would likely not be involved in Pablo’s care. Likewise, if Christi is visiting her parents in Orlando, her map for that time would likely look quite different than this one. For people who have regularly varying circumstances — for instance, siblings who take turns living with a parent — it may be helpful to draw two (or more) Atlas CareMaps, each reflecting a different-but-common context.
The Basics

Learn to draw and reflect upon your first Atlas CareMap. For many, mastering these basics leads to a significantly better understanding of their situation.

You can draw Atlas CareMaps by hand or using a webapp. We strongly recommend starting with hand-drawn maps. Once the basics have been mastered, you can easily learn to use the Atlas CareMap webapp, and take advantage of its expanded functionality. As described in more detail below, the basic flow is this:

- Identify key Actors — make a list of the people, pets, professionals, and places that are important in your and your family’s care.
- Then draw the Atlas CareMap — draw Actors and Links using appropriate symbols.
- Study your map — reflect on the Actors and Links you have drawn, the nature of their interactions, on what has possibly been overlooked or is missing-but-needed. Consider how things have changed from the past, and how they may again change in the future.

Hand-draw an Atlas CareMap

- Identify key Actors •

First, think about who will be in your Atlas CareMap. If you’re doing this for the first time, we encourage you to limit yourself to a few people, those that are most top-of-mind, rather than being thorough. You can always add more later.

Who else is in your household? Those who live with you, including pets.

In the example, using the Atlas CareMap Worksheet (blank available in the Reference), Joan is creating a map. Joan lives with her husband Fred, son Tim, dog Rex, and mother Laura.

Who do you care for, and who lives with them? Who are the people you actively support? If you’re wondering what “care support” might include, read the next section first. When doing this for the first time, I encourage you to limit yourself to one or two people. Later on, once you’re adept at the basics, you’ll find it much easier to add more Actors and details. Then list the names of those who live with them (leave blank if they live with you, or live alone).

Joan supports her mother Laura, who has various health issues. She also supports her friend Mary, who is recovering from a broken leg. Mary lives with her husband Joe, and cat Gizmo.

Who else supports them? List the names of whoever else cares for them. Again, if you’re doing this for the first time, limit yourself to a few people.

Laura’s other caregivers include: a home health aide Rosa; a daycare center The Oaks; her other children Janet, Cindy, and Steve; and three doctors, Dr Welby, Dr Smith and Dr Shah. Mary’s other caregivers include her husband Joe.

Who supports you? These could be people who directly support you (including emotional support), or those who help in ways that allow you the time for your caregiving responsibilities.

Joan is supported by her husband Fred, a Facebook group, her brother Steve, and her friends Ruth and Angela.
What counts as “care support”?*

Our working definition of “care support” or “caregiving” is: everything you do to assist a relative or friend due to that person’s illness, disability, injury, or frailty. For “self-care” it includes everything that you consciously do to manage your own health.

We leave it to you to decide whether some action is just normal interaction, or something extra “due to that person’s illness …”. Also, for inclusion in your Atlas CareMap, we leave it to your judgement as to whether some involvement is significant enough to be worth showing. We suggest you start with a relatively sparse map, with whatever is top-of-mind, and then add more over time.

To spark your thinking of what may be worth including, here are some categories of types of care support:

**Care Coordination**, such as: Keeping family and friends informed; Managing family caregivers and paid home care aides; and Managing community services (paratransit, meals on wheels, etc.).

**Financial**, such as: Providing direct financial support; and Providing reassurance of financial support when needed.

**Healthcare Management**, such as: Arranging appointments; Communicating with health professionals; Visits with health professionals; Buying prescriptions and supplies; Managing insurance and payments; Researching conditions

**Household Chores**, such as: Cleaning; Cooking; Getting / Moving / Using things; Laundry; Managing bills and savings; Shopping; and Transportation to/from home. (Note: Professionals sometimes refer to these as “IADLs, Instrumental Activities of Daily Living”)

**Medical Activities**, such as: Assisting with consumption of medications and supplements (including injections, IVs, oxygen, etc.); Helping with exercises and therapies; Managing medications and supplements (including organizing, reminding, and tracking); Preparing and maintaining medical equipment; Preparing special meals; Tracking symptoms and body measurements (weight, blood pressure, etc.); and Wound management. (Note: Professionals sometimes refer to these as “nursing tasks”)

**Personal Help**, such as: Bathing and toileting (including assistance with incontinence); Dressing and grooming; Feeding; Getting in/out of bed, chair, etc.; and Moving around the home. (Note: Professionals sometimes refer to these as “ADLs, Activities of Daily Living”)

**Social / Emotional**, such as: Providing companionship and emotional support; and Planning and supporting participation in social activities.

**Other**, such as: Everything else!
For the question “Who supports you?” we expand the definition of support to include actions that allow you the time, space or money to support someone else. For example, a sibling gives money so that you can leave work to support a parent, or a neighbor mows the lawn so that you have more time to care for a child.
• Draw an Atlas CareMap •

Here are some helpful hints before you start drawing:

• For drawing Actors, we suggest these simple symbols: stick figures for relatives and friends; circles for pets; triangles for professionals; and squares for services and facilities. For groups of people, such as a support group, you can enclose a few stick figures in a rectangle. These symbols are shown on the bottom of the Atlas CareMap Drawing Sheet (blank available in the Reference). Feel free to create your own symbols (e.g. a little house with a cross for a church, or wavy lines for your favorite beach).

• Draw a house around groups of people that live together.

• Write the names and locations of Actors under their symbols.

• Draw yourself in the middle of the page, and then use space on the page to represent geographical distance: if someone is nearby draw them near you; if they are far away draw them near the edges of the paper.

• Link arrows go from caregivers to care recipients. Use different types of lines to represent frequency of support provided: a heavy line for many times a day; a regular line for daily support; a dashed line for weekly support; and a dotted line for less frequent or occasional support. Example arrows are shown on the bottom of the Atlas CareMap Drawing Sheet.

• If caregiving is mutual (Actor A supports Actor B, and vice versa), draw two separate Links. If both Links are the same type of arrow, representing the same frequency of support, then you may draw a line with arrow heads on both ends. Even then, if space permits, draw two separate Links to make it obvious.

• Your Atlas CareMap will likely be messy the first time you draw it. Don’t worry about it. It will be understandable to you, and you can always redraw it to make it neater.

You can draw your map on any blank sheet of paper. However, you may find it helpful to use the Atlas CareMap Drawing Sheet as it includes the symbols.

Follow these steps to draw your Atlas CareMap, referring to your CareMap Worksheet for the names of various Actors you will be drawing:

1. **Draw yourself and others in your home.** First, write your name and date at the top of the drawing sheet. (If you are drawing a situation in the past, or a possible future, you will want to note that as well.) Begin by drawing yourself and the other Actors who live with you in the middle of the page. Be sure to write their names. Then, draw a house around this group. Finally, note the location.

   Continuing with the earlier example, Joan writes her name and date. In the center of the page, she draws stick figures for herself, Tim, Fred, and Laura. She draws a circle for Rex. She draws a house around the five of them, and notes that their home is in Palo Alto.
2. **Draw the Actors you support.**
If those you support live with you, then they’re already on the map, but if they live elsewhere you have to add them. Draw these Actors near you, near the middle of the page, if they live nearby; draw these Actors near the edges of the page if they live far away. Also add those who live with them. Draw a house around this group, and note their location.

Joan’s mother Laura is already on the map, but she adds her friend Mary. Mary lives with Joe and Gizmo, also in Palo Alto. As they live nearby, Joan draws Mary’s house near her own in the middle of the paper.

3. **Draw Links to show who you support.**
Remember the arrow goes from you to them, and draw the type of arrow that reflects how frequently you care for them.

Joan draws a heavy arrow from her to Laura, indicating that she provides support many times a day. She usually checks in on Mary once a day, so draws a regular arrow to her.
4. Draw other Actors who also support those you support, and their Links. Place them near or far, as appropriate, and note their locations. Use the appropriate symbols for different types of Actors. Remember that Link arrows are drawn from the caregiver to the care recipient.

Joan adds others who support Laura. She draws home care aide Rosa, daycare center The Oaks, and Drs Welby, Smith, and Shah nearby. She draws her sister Janet a little further away. She draws her siblings Steve and Cindy near the edges of the paper as they live far away. Rosa’s Link is a heavy arrow as she spends 3-4 days a week supporting Laura. Laura goes to The Oaks once a week, indicated by a dashed arrow. Mary’s husband Joe provides a lot of support her, indicated by a heavy arrow.

5. Draw the Actors who support you, and their Links. For the placement of online groups with no physical location (such as an online community like a Facebook group), you can place them near or far depending on how important they are to the person they are providing care for.

Joan draws appropriate Links from Fred and Steve, who are already on the map. Then she adds her friends Ruth and Angela, and a Facebook group.
6. Draw circles to indicate distance.
Draw a line to encircle those who are “Near” you. These are people close enough that they can visit if needed without much hassle — we suggest those that are within twenty minutes of you. Everyone inside this circle is Near. Draw another line to indicate those who are “Far” from you — we suggest more than two hours from you. Everyone outside this circle is Far.

Joan’s Near circle encloses her home, Mary’s home, Rosa, The Oaks, the doctors, and her friend Angela. Janet and Ruth are between the two circles, in the Middle distance. Steve, Cindy and the Facebook group are outside the Far circle.
Learning From Your Atlas CareMap

Just the process of drawing your Atlas CareMap may have given you a new perspective on your situation. Here are ten questions to further your reflections, some having to do with what you have drawn, and some with what may be missing.

1. Who is indispensable, and what happens when they're not available?

Who are the people that are most involved in day-to-day care, those whose absence would be most disruptive? What happens when they are absent, perhaps because they get sick, or have to go out of town? How does your family manage? Some families have great “back-up systems”; many don’t. In either case, it’s good to be aware of what the situation is.

2. Are the different people aware of each other’s involvement?

As the saying goes, “out of sight, out of mind”. We human beings seem to easily forget what is no longer visible. In family care, people are often all too aware of the difficulties and nuances of whatever it is that they themselves do. But they may be practically oblivious to the contributions and challenges of others, especially those they don’t see. Sometimes people in a family’s care ecosystem are not even aware of other people’s involvement.

Such non-awareness can contribute to family-strife (“How come he never does anything to help?!”). It can also make helping, especially providing respite to primary caregivers, very difficult, as the person stepping in has no clear idea about who else is involved and what they do, and who to call for what.

Once you have drawn your Atlas CareMap, you might consider showing it to the others drawn on your map, to make them aware of the others who are involved.

3. What are the different kinds of support and skills people provide?

Think broadly, including practical (medical assistance, transportation, research, etc.) as well as social (companionship, laughter, comfort, etc.) — see the section What counts as “care support”? You might notice that due to personalities, circumstances, relationships, and skills, different people contribute in different ways. Someone nearby and with a flexible schedule may be providing hands-on and logistical support. A geographically distant relative with great management skills may be helping with healthcare research and managing lots of paperwork. Another geographically distant but sociable friend may contribute by phone providing conversation and a sympathetic ear. It is often helpful to recognize and appreciate these varied contributions. It is often helpful to recognize and appreciate these varied contributions.

4. How are responsibilities divided amongst the different people?

In a similar light, consider how responsibilities are currently divided amongst family members, and whether it is desirable and possible for things to be different. Could a different distribution share the joys and burdens of care more equitably? Could responsibilities be shifted to better fit people’s personalities, circumstances, relationships, and skills?

5. How do you communicate, coordinate, and negotiate issues with everyone?

If there are many people involved in care, it’s easy and natural to say “Isn’t it nice that so many people are helping out?” However, more people also means more overhead — more communication to keep everyone informed, more coordination with more calendars to juggle, and more negotiation with more opinions to consider. Reflect on the current situation, on what is good about how the issues are managed within your family, and what could possibly be improved.

6. Have you forgotten anyone important?

We have noticed that, surprisingly often, people forget to draw really close family members, including spouses and/or siblings. This is reflective of the fact that sometimes people are so much a part of our lives, so ever-present, that they and their contributions become invisible. Sometimes people forget to include those they support because they think of that person as “my husband”, “my sister”, etc. and not “a care recipient”. So, look at your Atlas CareMap and ask yourself if you’ve overlooked someone important.

7. Are there relatives or friends who could be more involved?

You may find it valuable to think about relatives and friends who aren’t depicted on your map, and reflect on their non-involvement. If they have the capacity to help, what might be preventing their involvement and what could make a change? Sometimes people are not involved because they haven’t been asked, they don’t know how to offer their assistance, or simply don’t know how they could be helpful.
8. Are there professionals or services that are missing and needed?

Similarly, are there professional services that would make a difference? Many caregivers have difficulty answering this question, as they simply don’t know what exists, what would be useful, and/or how to access them. This is where experts on family caregiving, such as social workers, care consultants, and case managers, can be very helpful. Once they understand your family situation (helped by viewing your Atlas CareMap), they can offer suggestions.

9. How has your Atlas CareMap changed over time? How might it look in the future?

It can be helpful to reflect on the past (how things have changed over time) and contemplate the future (how the situation may be different). For example, one person realized he had not found a new therapist after a long-distance move, and that this gap in his map was likely contributing to his current emotional state. Another person realized that her autistic teenager currently enjoyed a strong ecosystem, but that they would have to take steps to ensure a similarly strong ecosystem when he went off to college in the near future.

10. What is good in your current situation; what would you not want to change?

When drawing and reflecting on an Atlas CareMap, some people have a tendency to focus on the negatives, on the currently poorly-met needs, and on how these problems can be addressed. This is an understandable, and possibly valuable, area of focus. However, it should not be the only one. It’s often very valuable to look at the opposite as well — what is good about the current situation? It is worth acknowledging and celebrating these positives, and working to ensure that these factors continue. In fact, to improve the current situation, it is often easier and better to build upon your existing assets (the people, and their skills and relationships) than to bring in new people and/or services to address existing deficits.

Taking Action (with deliberation)

After reflecting on those questions, you will likely have actions you want to take. If these actions include asking for assistance from others, or asking others to change what they do, sharing your map and reflections with them will likely be very helpful. See the section Conversations with Relatives and Friends for some suggestions on how to have such conversations.

Beyond that, it’s difficult to give you specific advice on the actions to take as people’s circumstances vary widely, and I can’t know what yours is. But one piece of advice seems to be universally valuable, and that is: don’t rush to act. Give yourself some time — for your mind to ponder these questions in the background, for your eyes and ears to things they’d overlooked before, for your family to add their thoughts — and perhaps your views on your current situation and the “right” actions will change. So, take action, but with deliberation and not rashness.
Beyond the Basics

You can use the Atlas CareMap webapp to draw your map and take advantage of its rich functionality. There are also many ways to include more information in hand-drawn Atlas CareMaps.

Extend and Personalize Your Atlas CareMap

What you draw is your Atlas CareMap. Add to it or modify it as you think best. Here are some ideas, but I also encourage you to use your own imagination:

Add more Actors.

• Add the people that your care recipients support. It can be very helpful to appreciate that your care recipients are also caregivers themselves. Many older people, stereotypically regarded only as care recipients, are in fact actively contributing to the wellbeing of their relatives, friends and neighbors.

• Likewise you may want to include other care recipients of the caregivers on your Atlas CareMap. For example, suppose you are supporting your mother as well as a child. Your map also includes your mother’s friend as a caregiver for your mother. If your map also shows that that friend is also supporting two relatives (a husband as well as a sister), you’ll have a better sense of how much that friend is able to help.

• You could include activities and/or places that are especially important to your or other Actors’ wellbeing. People have included: religious places; a bridge club; a beach and a favorite trail (a daily moment of serenity); and their job (“my work family”). Similarly people have included activities, such as swimming and yoga, that they felt crucial to their emotional wellbeing.

• You may want to include Actors who you “care about” but are not actively involved (not currently providing or receiving support). Though there won’t be any Links connected to these Actors, you are acknowledging their overall importance in the ecosystem, and they may be actively involved in the future.

Add details to the Links

• You can indicate the types of support different people provide by adding some characteristics to the Links. You could do this by using different colors for the arrows. For example: yellow for emotional support; green for financial support; red medical support, etc. Such coloring may be difficult if people are providing multiple types of support. An alternative is to place letter or symbols next to the arrows: “E” or a smiley face (😊) for emotional support; “F” or a dollar sign ($) for financial support; “M” or a plus sign (+) for medical support, etc. See the section What counts as “care support”? for helpful categories of support.

• Similarly, you can use symbols or colors to emphasize characteristics other than geographic distance and frequency, such as “emotional intensity” or “value” of support. For example if a distant Actor who has infrequent contact is still very important to another Actor’s wellbeing, you can draw a star or just write “Very important!” next to the Link.

• Also, note that you can draw a Link from a person to himself, to indicate self-care. There are two situations where it can be important to show this: when a person has a lot of self-care, requiring a lot of time and/or mental energy; and when a person is receiving a lot of support, and you want to ensure that anyone looking at the map does not forget that the person is actively involved in his own care as well (not just a passive recipient).

Use your artistic skills

• You need not limit yourself to simple symbols (stick figures, triangles, etc.). If you have the artistic skills to draw more meaningful people, pets, etc., do so.
Draw With the Atlas CareMap Webapp

Atlas CareMaps can be drawn using the webapp available at atlascaremap.org. The webapp-generated example on the right shows Kate’s CareMap.

As noted earlier, I strongly suggest you first learn to draw Atlas CareMaps by hand. Once you are comfortable with the concept, then you can use the webapp to take advantage of its extra functionality. You will use many of the same skills you have learned in drawing by hand — such as drawing and placing Actors and Links — in using the webapp.

The webapp has several built-in features to teach you how to use it. A wizard walks you through placing the first few Actors. After the wizard creates the starting map, you are free to add many more Actors and Links. Also after the wizard, a set of instructional cards show how to use other features. Tool-tips provide a reminder of what different tools do.

The most important extra functions of the webapp are:

**Easy editing**
A basic advantage of using the webapp, over pen and paper, is that it can be edited — Actors and Links can be added, deleted, moved, and modified easily.

**More information at-a-glance**
You can add extra details about Actors and Links. For example, there are a variety of icon choices for Actors, and you can note pertinent details (phone, conditions, etc.). A few of the Actor icons are shown at right.

For Links you can specify the types of care support provided, and the frequencies of each type of support, as shown. In the example, it’s easy to see that Jessica is providing frequent social/emotional support to Kate, and that Dr Smith provides occasional medical support to Mary and James.
View the map in different ways

Your map can be viewed in different ways, by using a filter to determine which Links will be shown.

In this simplified example, the image below shows an Atlas CareMap with seven Actors and a variety of Links. These include: Caregiver is providing multiple types of support to Care Recipient; Friend is providing daily social/emotional support to Care Recipient; and Spouse is providing weekly medical support to Dog.

In the top right image, the view has been filtered to highlight social/emotional support provided on a frequent, daily or weekly basis. In the bottom right image, the view has been filtered to highlight medical support provided on a daily or weekly basis.
See changes over time

You can capture a snapshot of the current map at any time. These snapshots can be named, and are saved in a timeline, to make it easy to see how things have changed over time.

In the simplified example, four such snapshots are shown. In 2014 (below), Care Recipient was healthy and provided social/emotional support to Caregiver, who in turn assisted with household activities.

By 2015 (top right), Care Recipient was supported by Caregiver, Friend, and a Health Professional. Spouse and Dog had entered Caregiver’s life.

By 2016 (bottom right), Care Recipient required much more support from Caregiver, Friend, and multiple Health Professionals. Friend and Spouse also supported Caregiver.

By 2018 (previous page, bottom left), Care Recipient is supporting both Care Recipient and Spouse, and Care Facility has been added to Care Recipient’s support team.
Share and Print your Atlas CareMap

You can download a pdf of your Atlas CareMap that you can print or email. The pdf includes the map, as well as all details you have entered about the Actors and Links. A few pages from the pdf of Kate’s CareMap are shown, including the map itself, a portion of the Actors Table (with details about all the Actors), and a portion of the Links Table (with details about care support each Actor gives and receives).
You may find it interesting to know how we think about the Atlas CareMap, about our key design principles. The concept has been developed over many years. Along the way we have made many decisions about what to include on the map or not, and how to lead people through the drawing of it, especially the first time.

**Design Philosophy**

You may find it interesting to know how we think about the Atlas CareMap, about our key design principles. The concept has been developed over many years. Along the way we have made many decisions about what to include on the map or not, and how to lead people through the drawing of it, especially the first time.

**Everything is designed for the primary benefit of the person doing the drawing** Other concepts, such as ecograms and genograms, have been designed for care professionals (social workers, therapists, etc.) or researchers to learn what they need to learn to provide good service. Whether the client (or patient or subject) learns something is of secondary consideration at most. By contrast, the Atlas CareMap is designed for you, whoever you are, as a person with your own personal care ecosystem.

**Simplicity & approachability** The basics of drawing and reflecting upon Atlas CareMaps have been consciously designed such that almost everyone feels right away that “I can do this”, and can in fact easily learn to do it. But it also allows those who desire to include much more information in their maps or more in-depth analysis to do so, as described in the *Beyond the Basics* section.

**Web of care** The Atlas CareMap explicitly acknowledges that people can simultaneously be caring for themselves, caring for others, and being cared for. People are not restricted to being only “a caregiver” or only “a care recipient”. Circumstances can also change over time. As a result, there is often no central focus, not just a single person receiving care, but rather an active web of care.

**Activities** Links are about active support: one person is doing and/or providing something for the other person. The emphasis is on the Actors actively involved in the family’s ecosystem. Of course, people do sometimes include non-involved Actors in their maps, but they don’t draw Links to such people. (For example, they may want to show all their siblings, to make clear who is involved, with Links, and who is not, without Links.)

**Presence** Even in today’s ever more electronic world, we believe physical presence matters a great deal for human-to-human care. Therefore the Atlas CareMap emphasizes presence, both in terms of physical/geographic location (those who are near or far), and in terms of time (frequency of interaction).

**Top-of-mind** We believe a lot can be learned from an “incomplete”, top-of-mind Atlas CareMap. We believe that perceptions-of-reality matter. We believe, in fact, that vital insights can be missed if there is too much information, too much detail. A map, any map, is useful because it is a simplification that makes it easy to see what is important.

**In-the-moment** Caregiving, like life, is fluid. Tomorrow can be different than today, sometimes dramatically so. An Atlas CareMap represents a moment in time. To show changing situations, make multiple maps. The Atlas CareMap webapp provides a timeline feature for this purpose.

**Awareness & reflection** The Atlas CareMap is not designed to lead to clear and immediate action(s). It is not meant to be primarily a “gap-analysis” tool. You may take actions, you may discover gaps to be filled, but the primary purpose is a tool for helping you realize a clearer understanding of your current situation, of what is valuable and should be continued, and of what could benefit from change.
Helping others create their own Atlas CareMaps

You may think of others in your family who would benefit from a deeper understanding of their own situation. Rather than drawing an Atlas CareMap for them, we urge you to teach them how to draw their own. Much of the learning comes from the slow process of reflection and drawing, rather than simply looking at the resulting map. Also, give them the time and space to reflect. Don’t expect them to get everything “right” the first time; allow them to slowly discover their own perceptions, only gently informed by your own. To aid their reflection, share with them the questions in the section Learning From Your Atlas CareMap.

As important, I strongly urge you to refrain from jumping into problem solving. If your mother, or brother, or friend has just learned to draw, and just begun to reflect on what they can learn from it, they may not at all be ready to have a conversation about what they need to do to improve their situation, or to make commitments to certain actions. That’s just too much! This is a conversation to be had over time.

Social conversations about care

Talk about caring for our families is not commonplace in modern society; not a taboo topic, but rather a non-topic. We have seen that familiarity with Atlas CareMaps changes this. When a group of friends has drawn their maps, and shared their drawings and observations with each other, this has led to social conversations about care becoming commonplace. Asking about changes in each other’s care situation, and trading tips and ideas, becomes normal and unremarkable. People have discovered that this normalcy has enormous value, as they benefit from the emotional and practical support provided by their friends.
If you have drawn and reflected on your Atlas CareMap, and especially if you have had the opportunity to converse with family members and friends about your respective maps, you will likely have become aware of some realities of family caregiving, obvious now but previously invisible:

• Everyone you know is caring for others; everyone is actively contributing to the health and wellbeing of relatives and friends.

• Almost all care support is likely to be provided by your family, not by professionals. People’s maps usually feature very few professional Actors, and their Links show that their involvement is infrequent.

• Care support takes many forms. The Actors you have drawn contribute in many different ways.

• Life is fluid, and a family’s care situation can change in an instant. Your map depicts a moment in time. You’ll want to draw more maps as the situation changes, to plan for the future, and perhaps to better understand your past.

If you haven’t yet drawn your Atlas CareMap, note that there is often a huge difference in understanding between reading about the concept and actually studying your own situation. So, I encourage you to spend a couple of hours drawing your map, and reflecting on what you see. Then, share your experience with your family, and learn from each other’s perspectives. You already are caring for one another; you will definitely benefit from seeing this more clearly.

Finally, thank you, dear reader, for your commitment to care for those around you.

For ideas on using Atlas CareMaps to help others, see the companion booklet *Sparking Transformative Conversations: Using Atlas CareMaps to strengthen families and communities*, available through the Atlas of Caregiving website.
Reference for Hand-drawn Atlas CareMaps

If you are just learning to draw an Atlas CareMap, please start at the start of this book. On the other hand, if you have done this before, this section provides a helpful reminder of the key steps.

Step 1: Identify Key Actors

Use the Atlas CareMap Worksheet to note all the names.

Who lives with you? Enter their names in the appropriate section. Don’t forget your pets!

Whom do you care for, and who else cares for them? Enter the names of the people you care for. Then enter the names of those who live with them (leave blank if they live with you, or live alone). In the section below, enter the names of whoever else cares for them.

Who cares for or supports you? These could be people who directly care for you (including emotional support), or those who help in ways that allow you the time for your caregiving responsibilities. Enter their names.

Step 2: Draw an Atlas CareMap

Here are some helpful hints before you start drawing:

For Actor symbols, use those shown on the bottom of the Atlas CareMap Drawing Sheet: stick figures for relatives and friends; circles for pets; triangles for professionals; and squares for services and facilities. For groups of people, such as a support group, you can enclose a few stick figures in a rectangle.

Draw a house around groups of people that live together.

Write the names and locations of Actors under their symbols.

Draw yourself in the middle of the page, and then use space on the page to represent distance: if someone is nearby draw them near you; if they are far away draw them near the edges of the paper.

Link arrows go from caregivers to care recipients. As shown on the bottom of the Drawing Sheet, use different types of lines to represent frequency of care provided. A heavy line for many times a day; a regular line for daily care; a dashed line for weekly care; and a dotted line for less frequent, or occasional care.

If caregiving is mutual (person A cares for person B, and vice versa), draw two separate Links if space permits to make it obvious.

Follow these steps:

1. Enter your name and date at the top of the Drawing Sheet.

2. Draw yourself and the other Actors who live with you in the middle of the page. Be sure to write their names. Then draw a house around this group, and write the location.

3. Draw the Actors you care for, if they are not already on the Atlas CareMap, and those who live with them. Remember to draw them near you or near the edges of the paper depending on how far away they are.
4. Draw Links to show who you care for. Remember the arrow goes from you to them, and draw the type of arrow that reflects how frequently you care for them.

5. Next draw other Actors who care for those you care for, and their Links.

6. Draw the Actors who care for or support you, and their Links.

7. Draw a line to encircle those who are “Near” you. These are people close enough that they can visit if needed without much hassle — we suggest those that are within twenty minutes of you. Everyone inside this circle is Near.

8. Finally draw another line to indicate those who are “Far” from you — we suggest more than two hours from you. Everyone outside this circle is Far.

Step 3: Reflect on Your Atlas CareMap

Just the process of drawing your Atlas CareMap may have given you a new perspective on your situation. Here are a few questions to further your reflections:

• Who is indispensable, and what happens when they’re not available?

• Are the different people aware of each other’s involvement?

• What are the different kinds of care and skills people provide? Think broadly, including practical (medical assistance, transportation, research, etc.) as well as social (companionship, laughter, comfort, etc.).

• How are responsibilities divided amongst the different people?

• How do you communicate, coordinate, and negotiate issues with everyone?

• Have you forgotten anyone important? (spouses and siblings are often overlooked)

• Are there relatives or friends who could be more involved?

• Are there professionals or services that are missing and needed?

• How has your map changed over time? How might it look in the future?

• What is good in your current situation, what would you not want to change?
<table>
<thead>
<tr>
<th>Who cares for you or supports you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whom do you care for?</td>
</tr>
<tr>
<td>Your name: ______________________________</td>
</tr>
<tr>
<td>Who else is in your household?</td>
</tr>
<tr>
<td>If 'a' does not live with you, who else is in their household?</td>
</tr>
<tr>
<td>Who else cares for 'a'?</td>
</tr>
</tbody>
</table>