

# CareSupport

## Members and Roles

Cameron Lewis - Project Manager, Writer, Designer

Louis Phan - Storyboard Artist, Designer

Tony Quach - Storyboard Artist, Designer

## Problem and Solution Overview

When an individual develops a condition such as Alzheimer's or other forms of cognitive impairment, it becomes less and less possible for them to take care of themselves and their daily tasks without assistance. In cases where their family cannot afford professional care, one of their loved ones must devote a significant portion of their life to become a caregiver for that individual. Without the experience and training that a medical professional might have, the transition to caregiver can be extremely taxing as they adjust to a complicated new role that they are unprepared for. It can harm the social lives, professional careers, and psychological health of these people as they must devote their free time to learning how to take care of a loved one. Our design seeks to lessen these negative consequences by helping a caregiver adjust to this new role. It will assist the caregiver in their everyday life with the psychological impact of their new responsibilities and the loss of their free time as well as aiding them in learning the skills they need for their new position.

## Design Research Goals, Stakeholders, and Participants

For our participants, we wanted the perspective of regular caregivers, researchers studying the disease, and researchers who were studying effects on caregiver relationships. We wanted to get insights about our topic from as many different points of view as was possible. Each of our participants was able to inform us about a different aspect of the problems that our target group faced.

For our first design research participants, we made contact with the users of the largest online Alzheimer's caregivers' forum. This forum is a place where people can come and tell their stories and give support to each other. The method used was comparable to an internet-focused version of a graffiti wall. We decided to use a graffiti wall because anyone would be able to get a broader perspective of the caregivers without having the pressure of an interview, which gave them time to think and compose their answer. A lot of the comments noted how it was difficult to talk to people who did not understand the struggle of caregiving unless they were taking care of someone themselves, or were professionals.

For the second part of our design research, we contacted the Washington chapter of the Alzheimer's Association, a nonprofit focused on both research of the disease and the care of those who have developed it. We asked them a series of questions via email because they were more busy than the others. With the questions, we asked them to focus on what they thought were important or talk about anything they found important. They were able to give us much more information about what is currently being done to help the patient and their caregiver and give her input on what the problems could possibly be.

For our third research participant, we had an interview with one of the research coordinators of the UW Alzheimer's Disease Research Center (ADRC). With an interview, we could have a lot of back and forth discussion and ask for more information on topics we wanted to focus on or ask for clarification on things we were confused about. They gave us a lot of insight on how the caregivers feel when introduced to this situation and said that connecting the caregiver with information and with support helped ease the transition into their new situation.

## Design Research Results and Themes

The most common themes present in our research up to this point relate to the importance of the caregiver when it comes to the life of the person suffering from memory loss and the other symptoms of Alzheimer's. The first theme we identified was the difficulty that caregivers experience adapting to the role of caregiver. Caregivers are usually people close to the patient with no experience beforehand in caring for someone with such a life changing disease. They are forced to transition to a completely different relationship with that person and embrace a different role in the patient's life. Due to the difficulty of this transition, there are common psychological consequences for caregivers such as a noticeable increase in stress and even depression. There is also commonly a lack of fulfillment from this relationship. These effects can then impair the relationship further, compounding on themselves and causing the relationship to continuously deteriorate. This also causes problems in a caregiver's outside relationships. Caring for their loved one can become a full-time job, which creates more difficulties in that person's professional career and impede their ability to connect socially with other people.

A second, similar, theme was how important the caregiver's attitude was in the relationship. While it may be easy for a caregiver to feel self-pity or even resentment towards the person with memory loss for being in this situation, that does not help anyone. People with severe memory loss often seek isolation because they are embarrassed by their deficiencies, and if a caregiver has a toxic attitude towards the relationship, that will only make the isolation worse. Instead, when caregivers maintained a positive attitude and searched for the joy in each day, then the relationships were much healthier and enjoyable as a whole. The effects of the disease on the patient's life and their relationships cannot be reversed, so it becomes increasingly important to no longer compare the current situation to the past. Helping the caregiver accept the situation and improve their attitude is one of the steps needed for bringing happiness for both the patient and the caregiver. Both the patient and the caregiver must move forward and try to work with the situation at hand.

## Task Analysis

### 1) Who is going to use the design?

The design will be helpful for the caregivers caring for a person going through the early stages of memory loss. Caregivers who are new to the role and have to adjust to taking care of a family member are the primary target. This could also be helpful for the caregivers who are already in this situation and want to help relieve their stress, learn more, and help their attitude towards their new lifestyle.

### 2) What tasks do they now perform?

A lot of caregivers do not have people that they can talk to about their problems. Currently they have to either find support groups outside, or find support groups online to help them relieve stress or learn more about their situation. They must also take care of the needs of the person with memory loss without prior experience, as that person may not be fully capable of performing those tasks themselves as the disease progresses.

### 3) What tasks are desired?

Changing the way caregivers feel about their situation is one thing we want to achieve. We also want to be able to give them any information that they want, or be able to give them support whenever they need it when it comes to the adjustments they must make in their role as caregiver. It would also be very useful for them to be able to connect with other caregivers to get any assistance they need.

### 4) How are the tasks learned?

Professional caregivers have the training for the tasks needed, but those finding themselves taking care of family do not have the experience. They have to learn these new tasks either through trial and error or find guides somewhere else on how to perform them.

### 5) Where are the tasks performed?

As moving around in complicated environments becomes a problem, the person with memory loss is typically housebound. The caregiver must perform the tasks necessary throughout the home and the surrounding areas (e.g grocery shopping).

## **6) What is the relationship between the person and data?**

Because a lot of the information a user could reveal is very personal or could be something they don't desire to share publicly, anonymity would be required so they feel comfortable using the tool.

## **7) What other tools does the person have?**

Some caregivers use a support group to share their situations and find help. This can be either in real life, a forum, or a blog. Professionals are one of the sources of information caregivers use. The internet also has a lot of information about dementia spread out on multiple websites if they know where to look. However, some people aren't as tech savvy and will not be able to use it for this purpose.

## **8) How do people communicate with each other?**

The people communicate through talking in real life or through the web. The internet is a key resource for this communication.

## **9) How often are the tasks performed?**

The tasks take place many times throughout the day as they have to manage the new issues present in their lives as well as take care of the needs of the person they are taking care of.

## **10) What are the time constraints on the tasks?**

As unexpected emergencies could arise that both the person with memory loss and their caregiver must react to, the time constraints could potentially be very tight.

## **11) What happens when things go wrong?**

When things go wrong, both people in the relationship end up unfulfilled and unhappy. This can lead to the person with memory loss being embarrassed and isolating him/herself from others as well as the caregiver feeling resentment because they haven't adapted to their new situation. This creates a negative cycle of emotions in the relationship that only gets worse.

## Proposed Design Sketches - "3x4"

### Design 1:

Our first design is a wearable device for new caregivers designed to help them in their daily activities. It has sensors to detect the wearer's pulse and can display reminders to take a deep breath and de-stress for the purposes of handling their negative emotions (**Figure 1**). By connecting to separate sensors around the home, it would allow the caregiver to monitor the condition of the patient and their activities while the caregiver is away taking care of errands (**Figure 2**). As this device would be worn at all times, it can give advice to the caregiver and assist them in the role through voice-commands. It would help the user with day to day tasks such as nutritional and music choices to assist the patient's condition (**Figure 3**). Finally, It would have built-in informational guides that tell the user step-by-step how to deal with difficult situations they might experience with the patient (**Figure 4**).

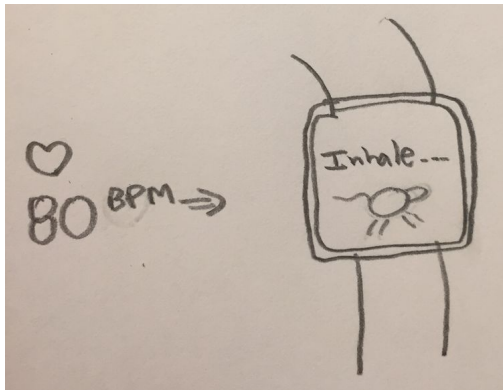


Figure 1: Emotional Support

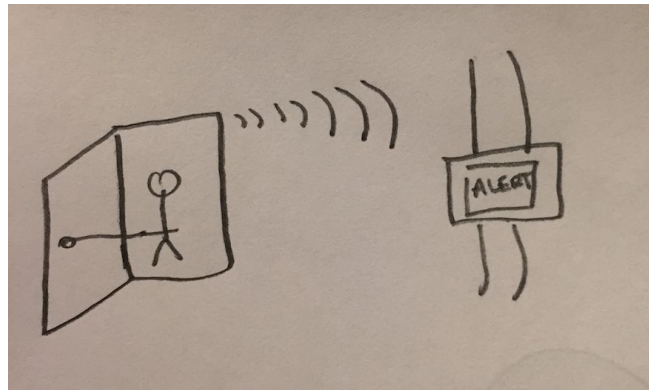


Figure 2: Monitoring Patient

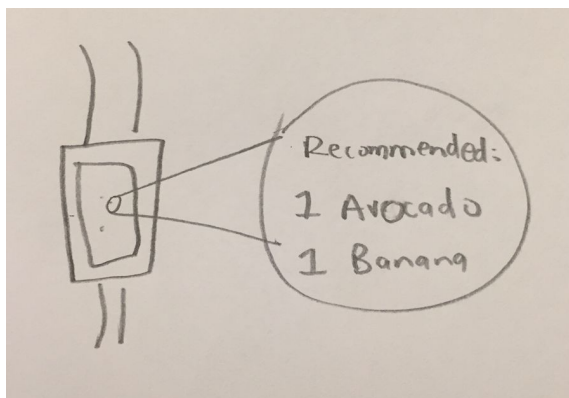


Figure 3: Nutritional Info

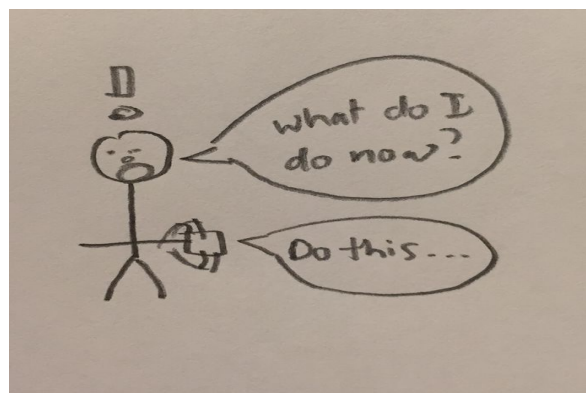


Figure 4: Situation Guide

## Design 2:

Our second design is a mobile app for caregivers focused on giving inexperienced caregivers access to important information. They would be able to quickly open up the app and find the information they need when critical or potentially troublesome situations arise. The app would be able to interface with devices around the home to provide more complex services as well as connecting the user to outside resources (**Figure 5**). Family members of patients will be able to search for caregivers to take care of their patient and request updates on the patient through the app (**Figure 6**). The mobile app will also include a forum and a chat room where the caregiver will be able to post on a forum and/or join a chat room to talk to other caregivers when they are stressed out or just want to have someone to talk to (**Figure 7**).

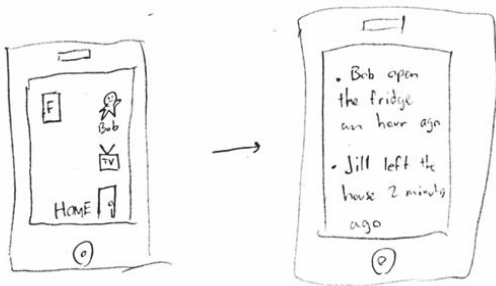


Figure 5: Monitoring Patient

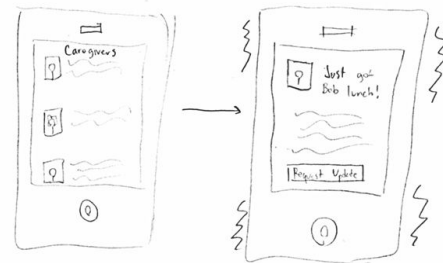


Figure 6: Finding Help

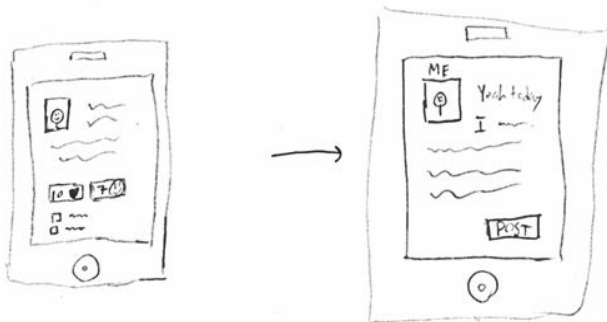


Figure 7: Social Connection & Emotional Support

### Design 3:

Our third design is a website directed at helping people who are not professionally-trained caregivers but have found themselves taking care of someone with memory loss. It would focus on helping them with general tips they might need to know as well as specific guides. There will be pages where the caregiver can learn about the proper nutrition and music that can help slow down the patient's memory loss (**Figure 11**), and guides on how to handle certain difficult situations with the patient (**Figure 9**). The caregiver can also connect to others on the social forum (**Figure 10**), and even find someone trustworthy to keep an eye on their patient while they go out to socialize for the first time in a very long time (**Figure 8**).

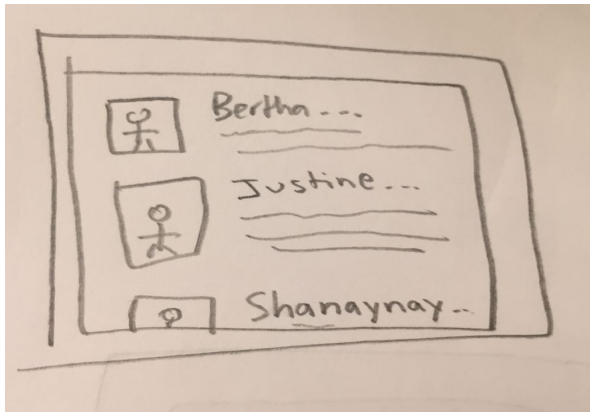


Figure 8: Finding Help

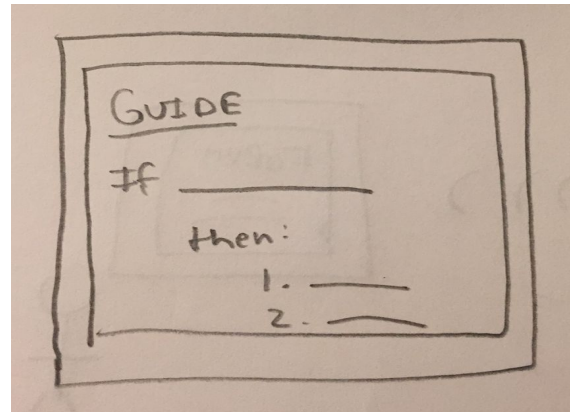


Figure 9: Situation Guide

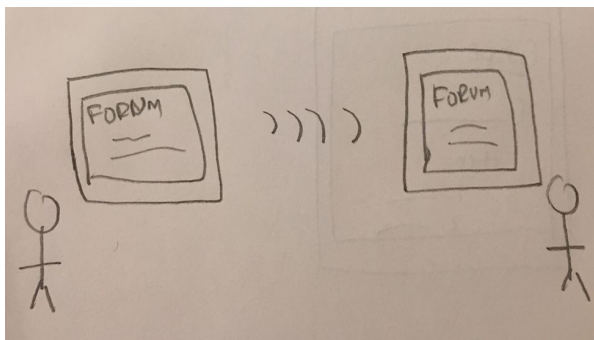


Figure 10: Social Connection

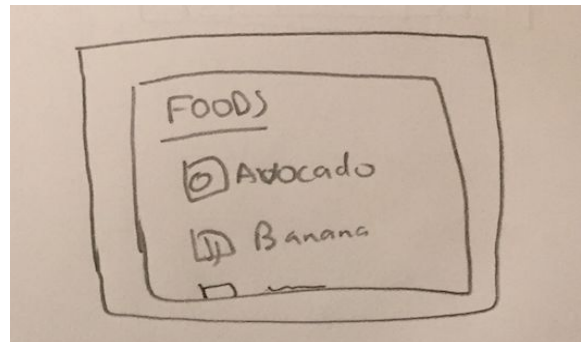


Figure 11: Nutritional Info



## Chosen Design

After considering the target audience of our design and the types of tasks we thought most important to assist them with, we decided that a cell phone app would be the best fit for what our group wanted to accomplish. With caregivers of those with memory loss being the general target user of the design, we determined that helping inexperienced and untrained caregivers new to this role would be the most important group to reach within this audience. We wanted to make sure that this particular sub-group would have no problem gaining access to our design and could access it whenever they needed throughout the day. Therefore an application for these caregivers that they could simply install on their phone seemed the most fitting. When deciding on our tasks, we chose tasks that a caregiver might want to do on a frequent basis but that they don't have all of the knowledge or experience necessary to know how to do on their own.

## Written Scenarios - "1x2"

### Social Support

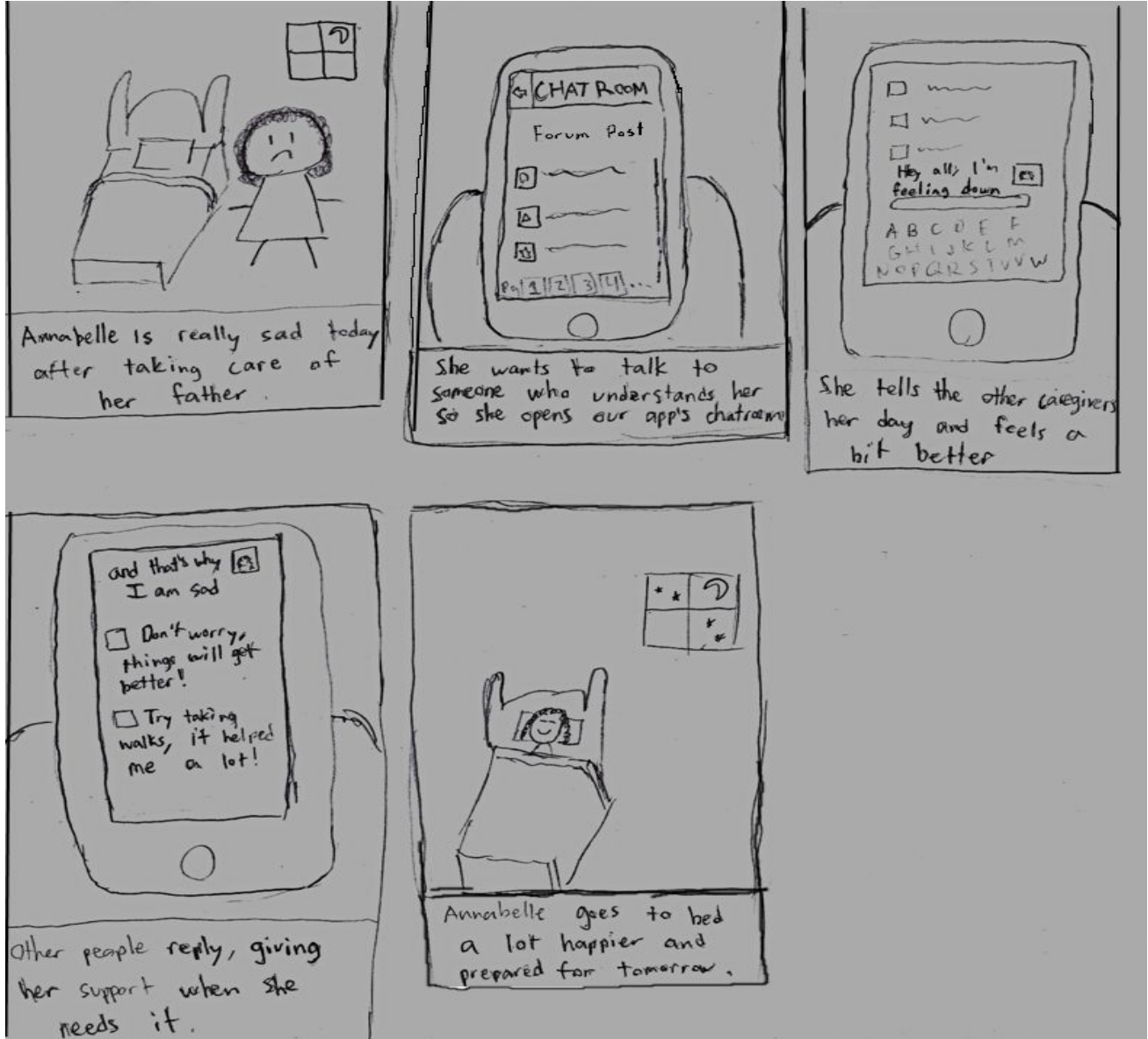
After a long day at work and taking care of her father, Annabelle finally returns to her room, tired and stressed out. She lays on her bed and opens the CareSupport app and begins reading other posts on the forum from other caregivers as she settles into bed. She reads about someone else's day and decides that she wants to vent a bit too. She opens up the chat and joins a chat room with a group of caregivers she frequently talks to. She posts a message about her day in the chat room and switches to another app. 5 minutes later, she switches back and reads the many messages giving her support. She thanks them and talks with them for another 10 minutes before closing her phone to sleep, feeling happier about her day.

### Situational Support

Stacy has recently transitioned to becoming a full-time caregiver for her father with memory loss. Being a new caregiver, she does not know how to react when her father forgets where he is and starts to have a panic attack. Stacy opens the CareSupport app on her phone and using voice-commands, describes the situation she is in by saying keywords like "panic attack". The app searches through its expansive guide and finds the recommended action for this situation, and walks Stacy through the entire ordeal. Stacy follows these spoken (and written) instructions and is able to calm down her father. Stacy is happy that she has this app to help her out in any difficult situation, which relieves a lot of stress for her in this tough transition to becoming a caregiver.

# Storyboards of the Selected Design

## Task 1



## Task 2

