DEMENCARE

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PROBLEM AND SOLUTION OVERVIEW

Our design is focused towards the people who assist the elderly people suffering from Dementia. Our target group not only assists the patients in their daily chores but also have to tackle with the safety issues of the patients. Therefore, they have to get acquainted with the house and need to keep checking that the patients do not put themselves in danger during night or while using kitchen. Moreover, while taking care of the patients, they hardly get time for themselves which also affects the relationship between them and the patients. Moreover, improper scheduling can lead to more stress and frustration for our target group. Therefore, we are trying to come up with a smartphone application that will be assisting the caretakers by managing their and the patients' schedules. With the varying schedules of the patient, the app will organize and blend in the caretaker's schedule, thus improving their relationship with the patients. The app will also provide resources to modify the house, thus improving the safety of the patient even when the caregiver is not around them.

DESIGN RESEARCH GOALS, STAKEHOLDERS, AND PARTICIPANTS

Our first interviewee, Cassey is a clinical manager of a clinic. She offered us much better insight on the common issues and current treatment of dementia. After our first interview, we learned about many problems the patients are facing during the early stage. They often have social stigma since Dementia is chronic. Some of them refuse to engage in normal social life because they do not want to embarrass themselves in front of others due to the short-term memory loss. We discovered that safety is the biggest issue that patients face. Another critical issue is that the effects of Dementia change as patient move on to the middle stage; they start to see apparition and nightmares, which confuses them with reality. There are plenty of treatments, but most of them do not include drugs as our interviewee mentioned. However, they involve providing visual cues to help patients remember how to do basic activities like brushing teeth or cooking; more complex activities like forming social support groups to help them overcome their social stigma, and taking medication to alleviate the syndrome. A good example mentioned by Cassey was, using the white color lines to lead them to the bathroom.

For the second interview, we went for someone who is a caretaker, and we also interviewed a person who is a patient himself. Interviewing Emyle the caretaker gave us a notion of her perspective. Emyle is married and is living with her husband two children and her father-in-law. She started taking care of her father-in-law when the family came to know that he was suffering from Dementia. She has been taking care of him for a year. According to our interviewee, she has to deal with the patient very carefully, and she is always trying to improve her interaction with the patient. Sometimes Emyle has to choose proper ways to interact with the patient by evading the issues or objects that may make the patient angry or disturbed. While the patient's dependence is very high on the caretaker, they find it rather difficult to cope with the time she is not around the patient. However, the biggest problem the caretaker faces is that she has no time for herself. Even though Emyle sometimes prefers to take turns to take care of the patient with other members of the family, she also wants to stay consistently with the patient for a long time so that the patient does not find it difficult to interact with someone they are not acquainted to. David, who is 84 years old, has been suffering for almost a year. From his perspective, he craves to interact with someone about his stories of past, his nightmares and he is not satisfied by the interaction with the caretaker. Moreover, we noticed that the patient was not able to remember the conversations that he is currently indulged in and repeat some of the information from time to time.

We use the interview research method direct and indirect. Although we faced many challenges in finding people's willingness to participate in the interview or create time for us, we found out that this research was an effective way to gather information for our design. We went to the Alzheimer's Association, and interviewed one of the clinic managers. The reason we chose clinic was, they deal with patients on a daily basis and they have the relevant information for our design. We also interviewed a caretaker and a patient to a glimpse of their perspective and experience on Dementia. This was an indirect interview done through phone, which helped us collect data on the experiences, behavior and the perception of the patient. By using self-reporting on us as researchers and encouraging participants for self-expression, we collected critical information for our design research.

DESIGN RESEARCH RESULTS AND THEMES

During the interview with our target group and other related stakeholders, we have discovered some common issues among these group of people. First, they have expressed concerns about the safety of the patients. Suffering from memory loss, patients could commit dangerous actions which could dramatically affect themselves and their parents. Things like, forgetting to turn off the stove after cooking or forgetting the route of the streets while driving a car can imply safety issues for the patient. Second, both the patients and the caregivers expressed concerns about their current social life. Patients do not want to socialize with other people due to their memory loss and are not satisfied by simply interacting with caretakers. Caretakers are having a hard time getting back to their previous or current social group because they need to stay with the patient for most of the times. They would like a form of solution that could help them get back to work and regular social life, while meeting the patient's needs. Finally, both the patient and caregivers are not familiar on how to modify their environment so that the patient can live sound and safe.

The issues and concerns raised by our target group and the stakeholders motivates us to design a technological solution that would prove helpful for both patients and caretakers. From the information we got, the safety concerns for patients is immense and broad. Each patient has their own issues which varies from one another depending on the stage and cause of Dementia. The first task we found interesting is, finding a way to manage the schedule for caretakers and patients. For example, the caretakers would like to spend time with themselves or other people while the patient is taking a nap. The second task that seems intriguing would be, designing a solution for the environment safety issues due to the short-term memory problems faced by the patients. We came up with the home modification design that can improve the safety for the patients without raising concerns for the caretakers. The interviewee for our design research mentioned that the patient might forget how to brush their teeth. In that case, one effective solution was visual cues. We can show the patient proper visual instructions for brushing the teeth which would help them even when they are unable to remember how to do it. Without visual cues, the caretakers need to be present with them for assistance. We are thinking of a high-level design such as providing instructions as resources that the caretakers can implement once; thenceforth the patient can use it without needing the help of caretakers.

PS: We would like to mention that this is an updated design result created based on the critiques and feedback from the staff. We were planning to implement an alert system for helping the patients and caregivers, however it was too broad and complex for the design scope. This also includes the design task for monitoring sleep problems. We also abandoned the task related to smart band since critics pointed out that the smart bands would be a subject of ethical issues since a patient may think that the caregivers are forcing them to use it.

ANSWER TO TASK ANALYSIS QUESTIONS

Who is going to use the design?

Our target group would be the caretakers who are having trouble taking care of the patients with dementia. Our design could help them improve the safety level of their house, patient and themselves.

What tasks are desired?

Most caretakers are not used to taking care of somebody who is partially disabled 24/7, and they have not learned how to create a safe environment for the patient by modifying their house and the environment they spend their most time in. Without proper precautions and modifications by the caretaker, the patient might hurt themselves and their family. We are also providing a schedule, manager that will manage both patient's and caregiver's schedule without hindering the patient's activities.

How are the tasks learned?

The caretaker needs to be able to use a smartphone. We are providing the caregivers with proper resources, so they can properly implement the desired tasks for the patient.

Where are the tasks performed?

The caregivers have to learn how to modify the house settings so that the patients can live safely without depending on the caretakers all the time. They also need to know how to keep the patients away from things are that dangerous to use, while suffering from Dementia. They also need to predefine the patient's schedule before adding their own schedule to the app.

What is the relationship between the person and data?

Our target group, the caretakers have to depend on the resources and data provided by our app to perform certain tasks like modifying the house safety. They also need to provide the schedule data to have the schedule manager organise their and patients' schedule.

What other tools does the person have?

Currently the caregivers use online blogs and forums along with instructions from doctors to perform the desired tasks related to patient's safety. They use basic tools like pen and paper to record the patient's schedule which can vary depending on patient's forgetfulness or emergency, thus affecting the caregiver's schedule.

How do people communicate with each other?

Right now, there are some agencies and support groups that would provide this kind of information for the caregivers. Caregivers often form support groups and meet in an online forum to share others with information they already learned or knew.

How often are the tasks performed?

The task is completed on a timely basis depending on the activities the patient is currently working on. For example, if the patient is sleeping then there are no security issues, but they need to be monitor when they are by themselves inside or outside the house. They also need to be supported when they need caretakers since the practical alarm system just tells the situation, they cannot perform the task such as turn off the stove remotely.

What are the time constraints on the tasks?

While the caretaker is a human, they need to spend some of their time to take care of themselves and also their family. So, the time when the caretakers are indulged in some activity that won't let them interact or check the patient for a while, the patient's security is unchecked.

What happens when things go wrong?

While our target group makes sure that things don't go down to the worse, if they do, they try to bring in professionals like doctors or medic who can create better solutions. Sometimes, they also try to follow proper procedures to create a temporary solution for the patients.

PROPOSED DESIGN SKETCHES

Tasks:

Task 1: Educate on how to modify house

Task 2: Scheduling time for patient

Task 3: Keep track of the safety of the patient

Task 4: Connect and share caretaking experience

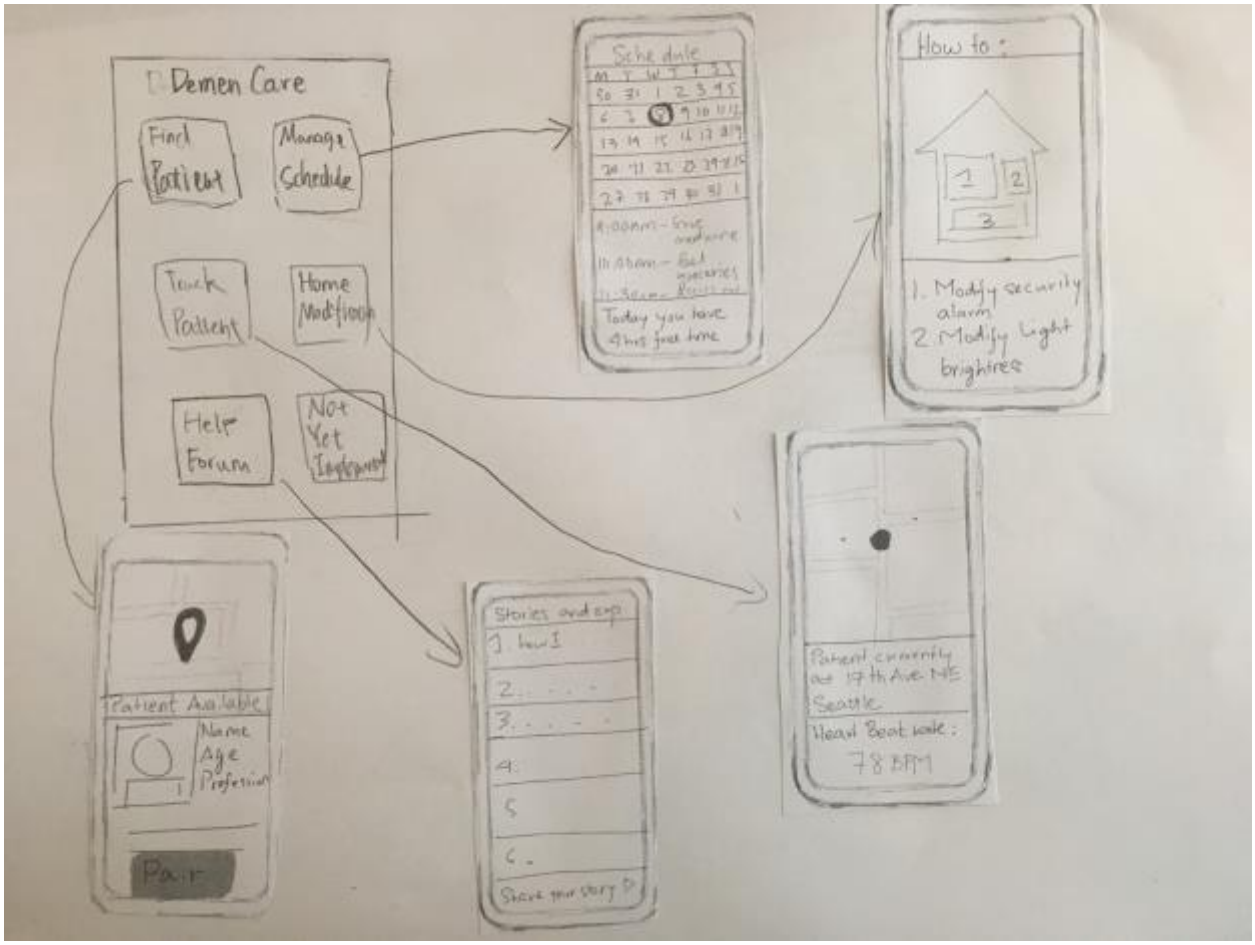
Task 5: Connect professional caretakers with the patient

Task 6: Monitor sleeping problems for patients to support caretakers

Design 1:

This design is based on a smartphone application which starts with a dashboard containing different features of the app. Each feature presented as buttons on the dashboard lead to different tasks which include, making schedule (Task 2), tips about modifying homes (Task 1), tracking patient (Task 3), coupling patient with pro caregivers (Task 5) and online forum with social networking (Task 4).

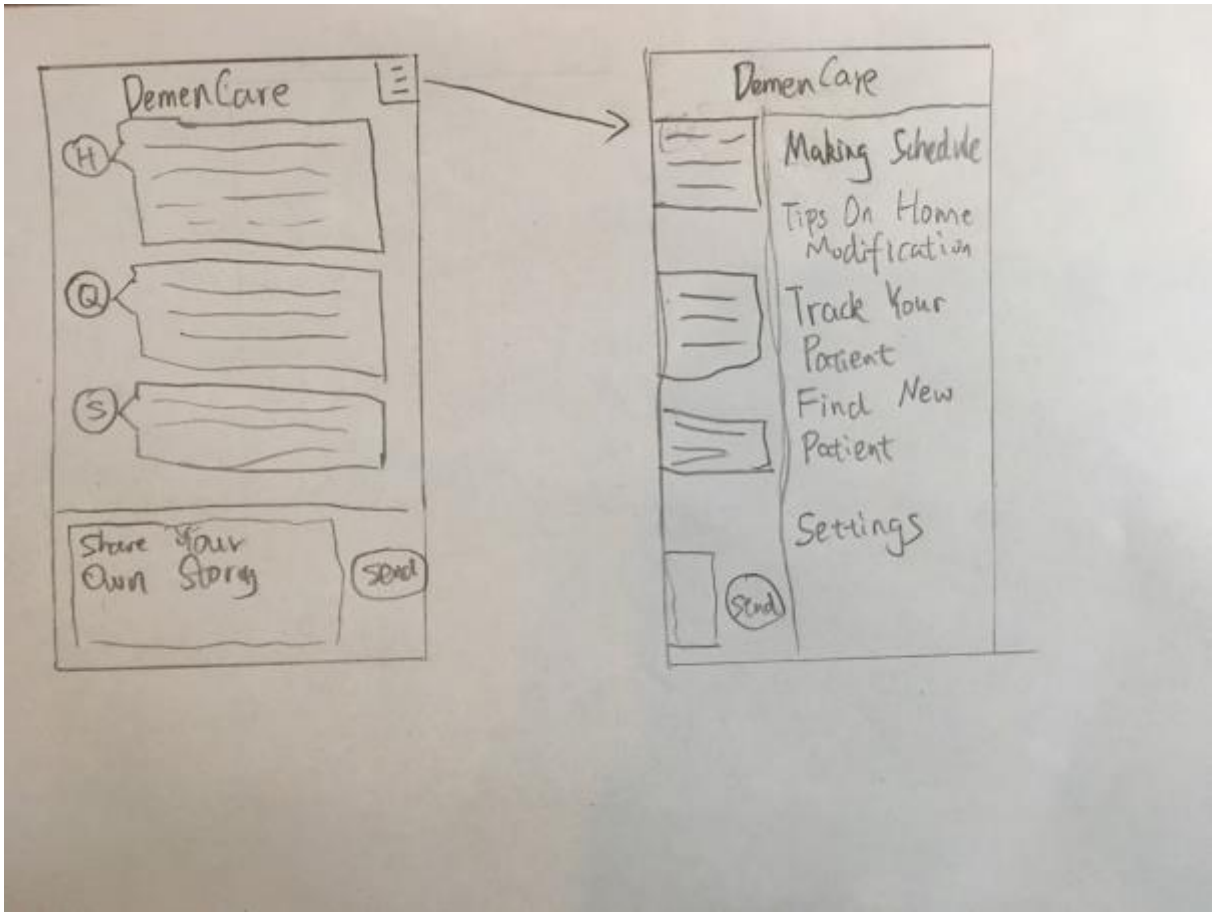
Sketch:



Design 2:

This design has a main page that shows different people sharing their own experiences. Therefore, this design focuses mainly on the experience sharing among the caregivers. In the main page, the user can look through others' stories while sharing his or her own (Task 4). On the top right corner, there is button that will display other functions including making schedule (Task 2), tips about modifying homes (Task 1), find the patient (Task 3) and find new patient (Task 5). By clicking on different buttons, it will take the user to different screens to perform various tasks mentioned above.

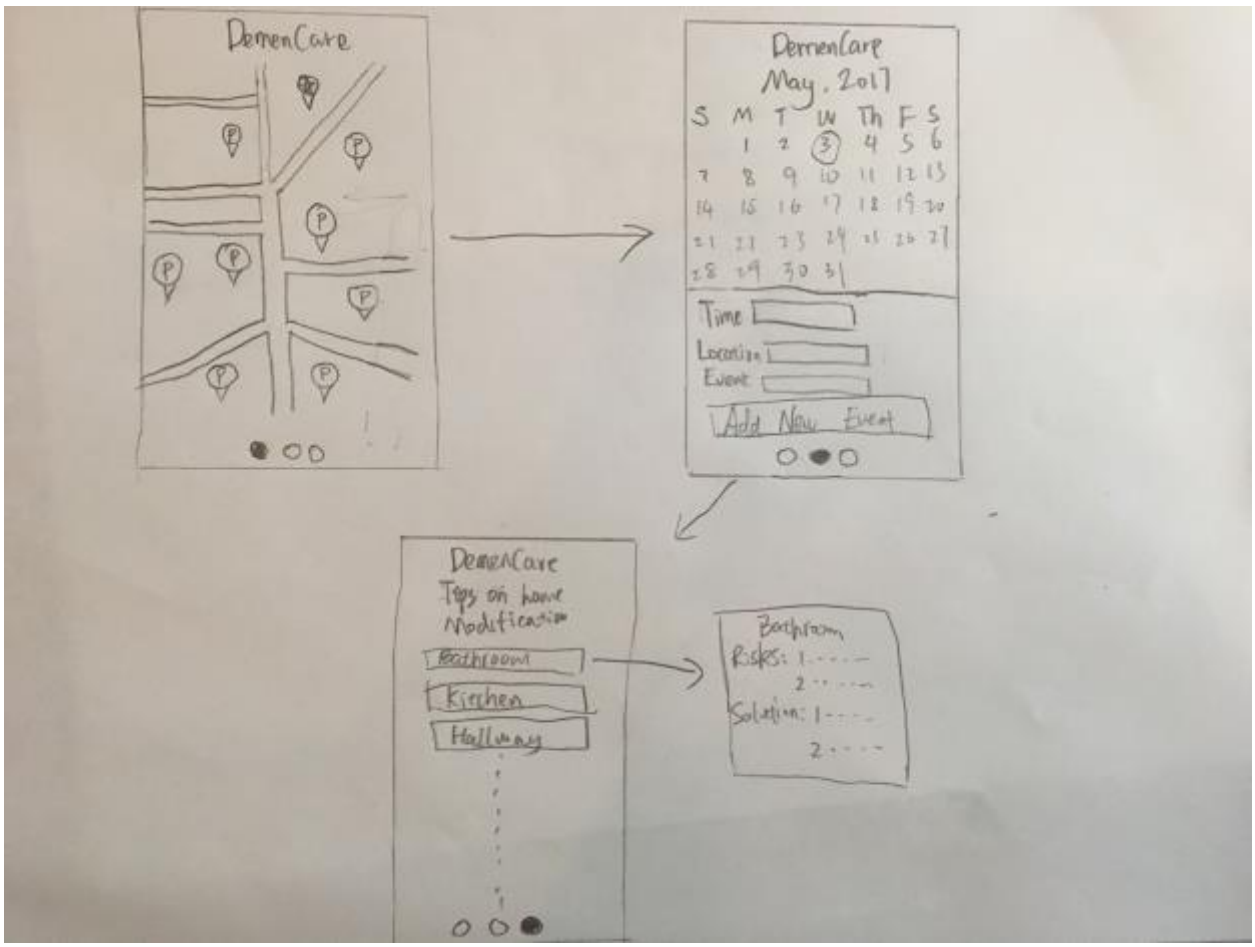
Sketch:



Design 3:

The design is a map showing the location of patients who need professional caregivers and the location of the user's patient (Task 3, 5). The user can swipe the screen to access other functions. The scheduling feature can be accessed by swiping right from the maps. The user could edit the patient's schedule in this mode (Task 2). The tips on home modification can be accessed through another swipe to the right from the calendar. This features a list of locations in a house (Task 1). When user clicks on a location, it will show the safety issues for the location and corresponding solutions.

Sketch:



OUR FINAL DESIGN AND TASK CHOICE

We are going to pursue the design interface 1. Our tasks would include helping the caregivers manage their schedule based on the patient's schedule and provide resources to educate them how to modify the house and improve safety concerns related to the patients. The reason we are going to choose the first design is that it will be relatively easy to implement the interface on a smartphone app. As for the tasks, we chose the issues that are highly common for most of the new caregivers. They are often unable to manage their schedule to create free time for themselves while taking care of the patients. They also lack proper resources that could help them modify the home setup and increase the safety level of the patient.

WRITTEN SCENARIOS

Modify house to improve patient's safety

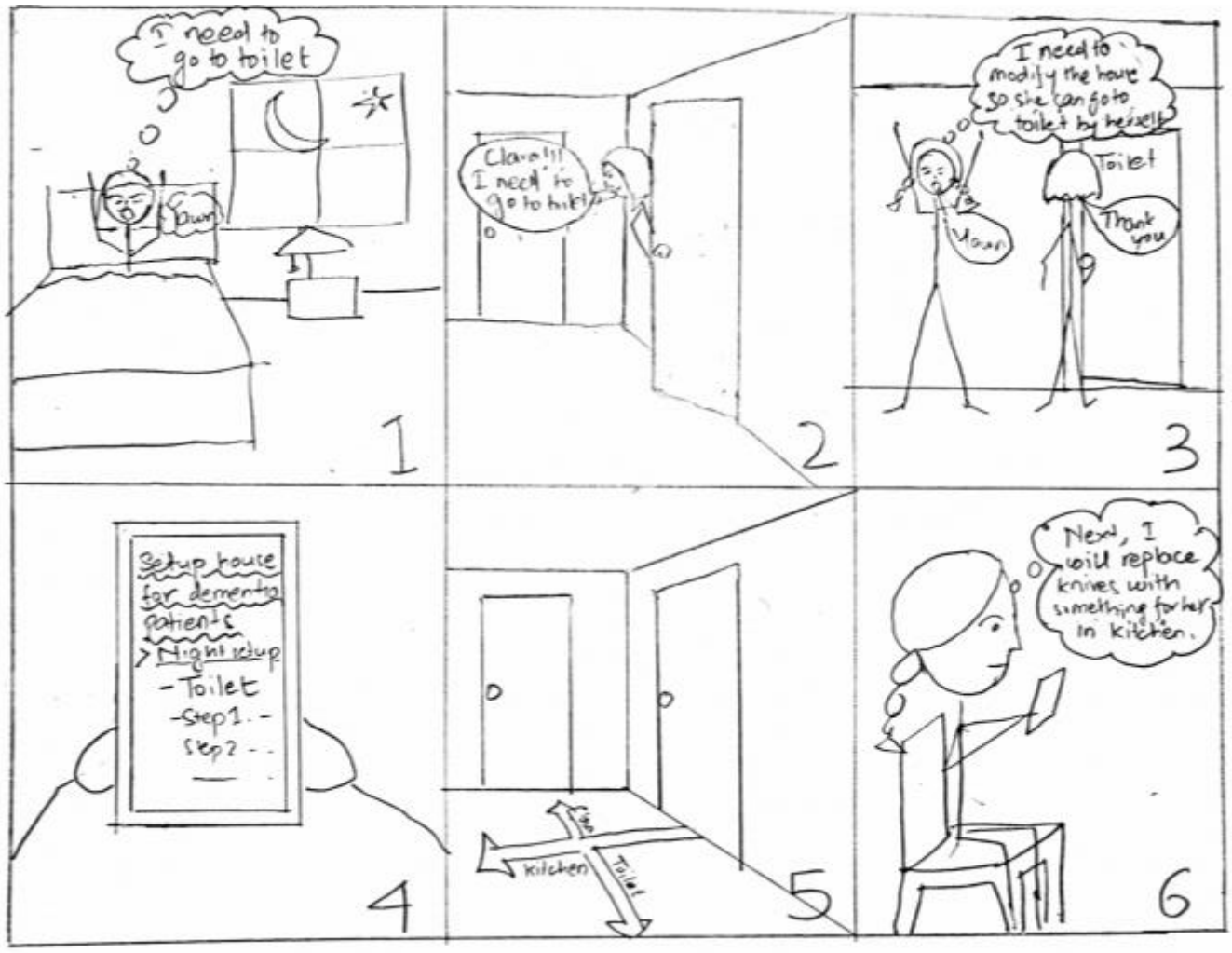
Nancy is a retired accountant who is suffering from Dementia and is at middle stage. She could get lost on her way back to home easily, if she is alone. One night, she woke up and wanted to go to the bathroom. Unfortunately, no matter how she tried, she just could not remember the route to the bathroom even if it is only 20 feet away from her. Unable to go to the bathroom, she called her daughter Clara. Clara woke up and showed her mom the way to the bathroom. Worried that her mom could go to some other places with like kitchen with unsafe objects, instead of the toilet, Clara decided to modify the house so that her mom could find her way to the destination by her own. She opened the app and tried to find instruction on how to do this. She later bought necessary materials and finished the modification. Since then, her mother is able to locate the way to anyplace in the house by her own. Recently, she is planning to modify the kitchen so that her mom would not get hurt by accident and she is using the app to find detailed instructions which would allow her to make modifications.

Scheduling time for patient

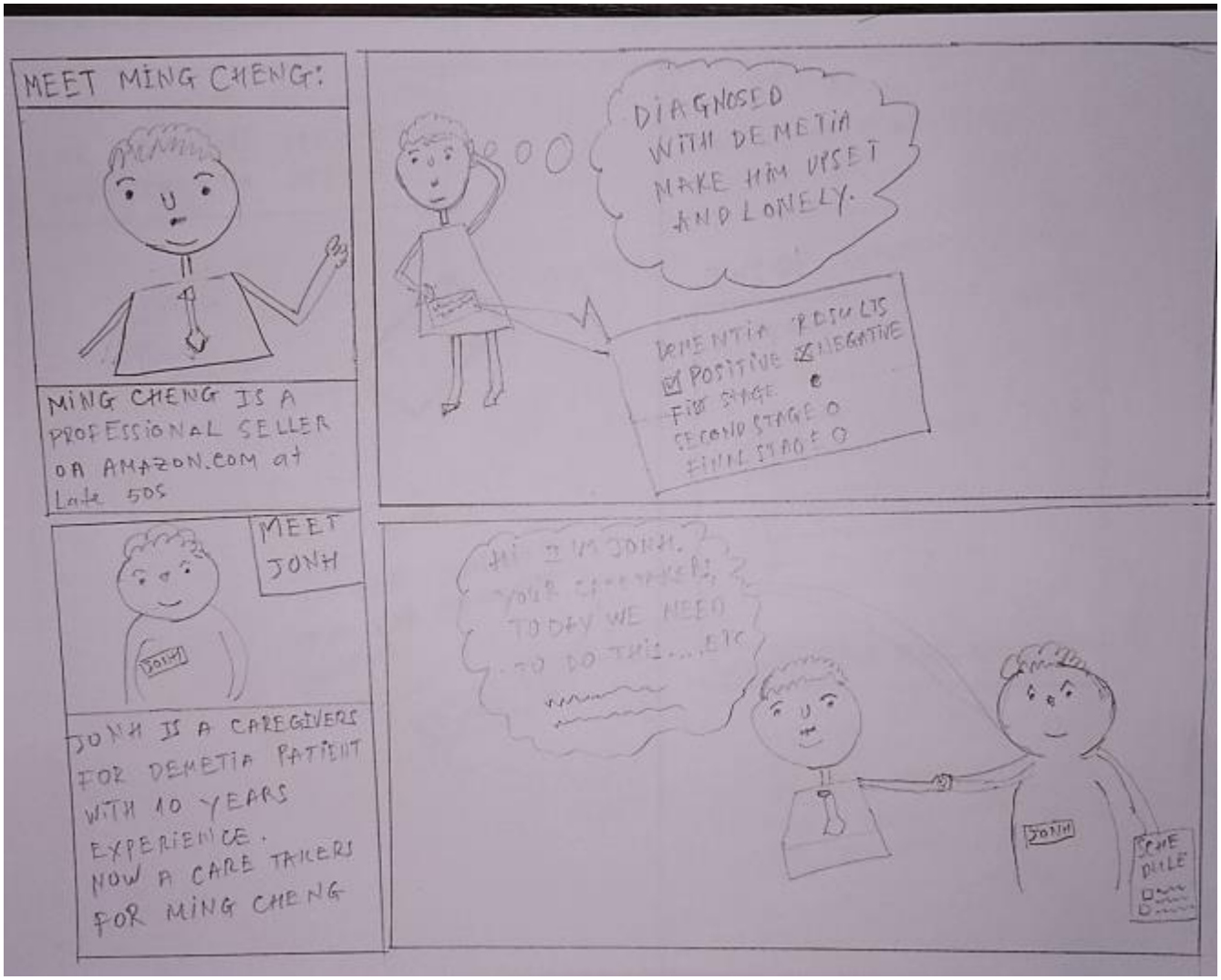
Ming Cheng is a professional seller who suffers from first stage dementia. While working in a stressed environment, he sometimes forgets important schedules and details about the product he is selling. Because Ming is too busy to take care of himself, he hired a professional caregiver John who takes the charge of the schedule of Ming and helps him live the way he used to, before dementia. However, with a very tight schedule of Ming, John is having trouble modifying and organizing the schedule for Ming. The scheduling becomes more complicated when Ming tells him to add very important schedules that he forgot to mention before. In that case, John has to reschedule everything which is very time consuming. Trying to find a better way to organize Ming's schedule, John started searching on the Internet and found this app called DemenCare. To make a schedule for the patient, John has to enter all of the patient's schedules prioritized based on their importance. The app will automatically generate the proper schedule. Sometimes, when he has a tight schedule for himself, he just needs to enter the patient's schedule followed by his own, the app will take care of it. Used to spend 2-3 hours managing schedules for Ming, John can finish scheduling in minutes.

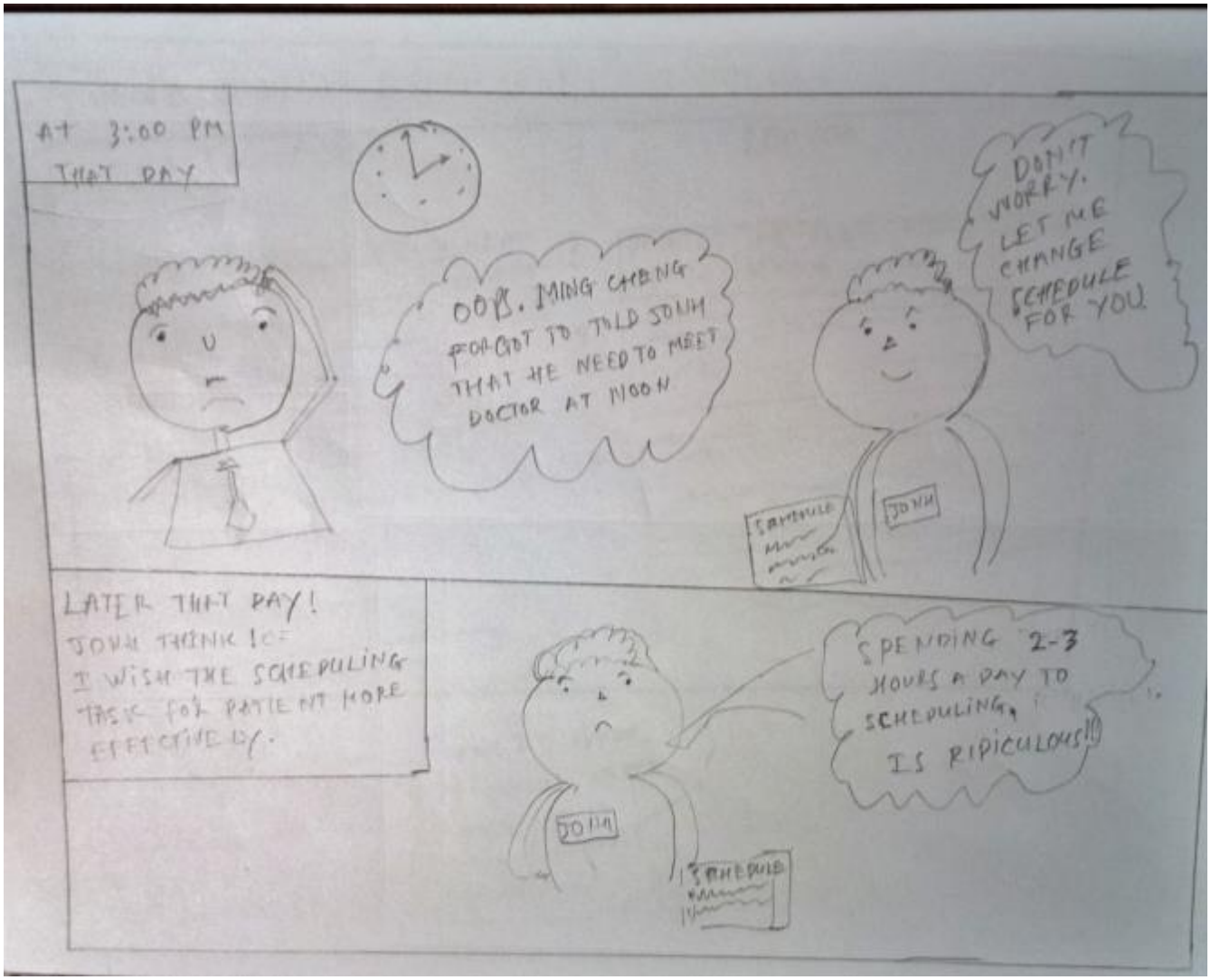
STORYBOARDS OF THE SELECTED DESIGN

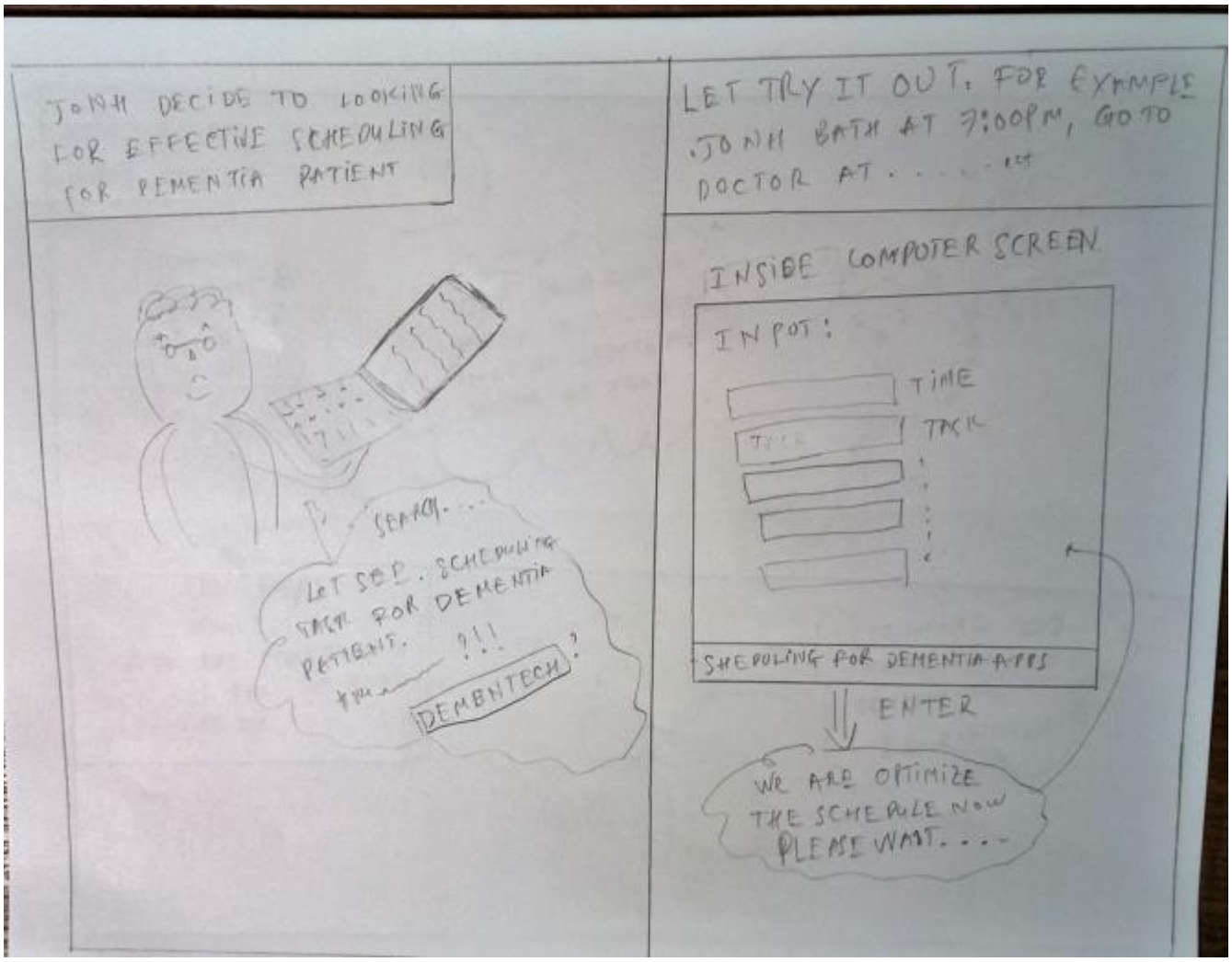
Task 1: Modify House to improve patient's safety

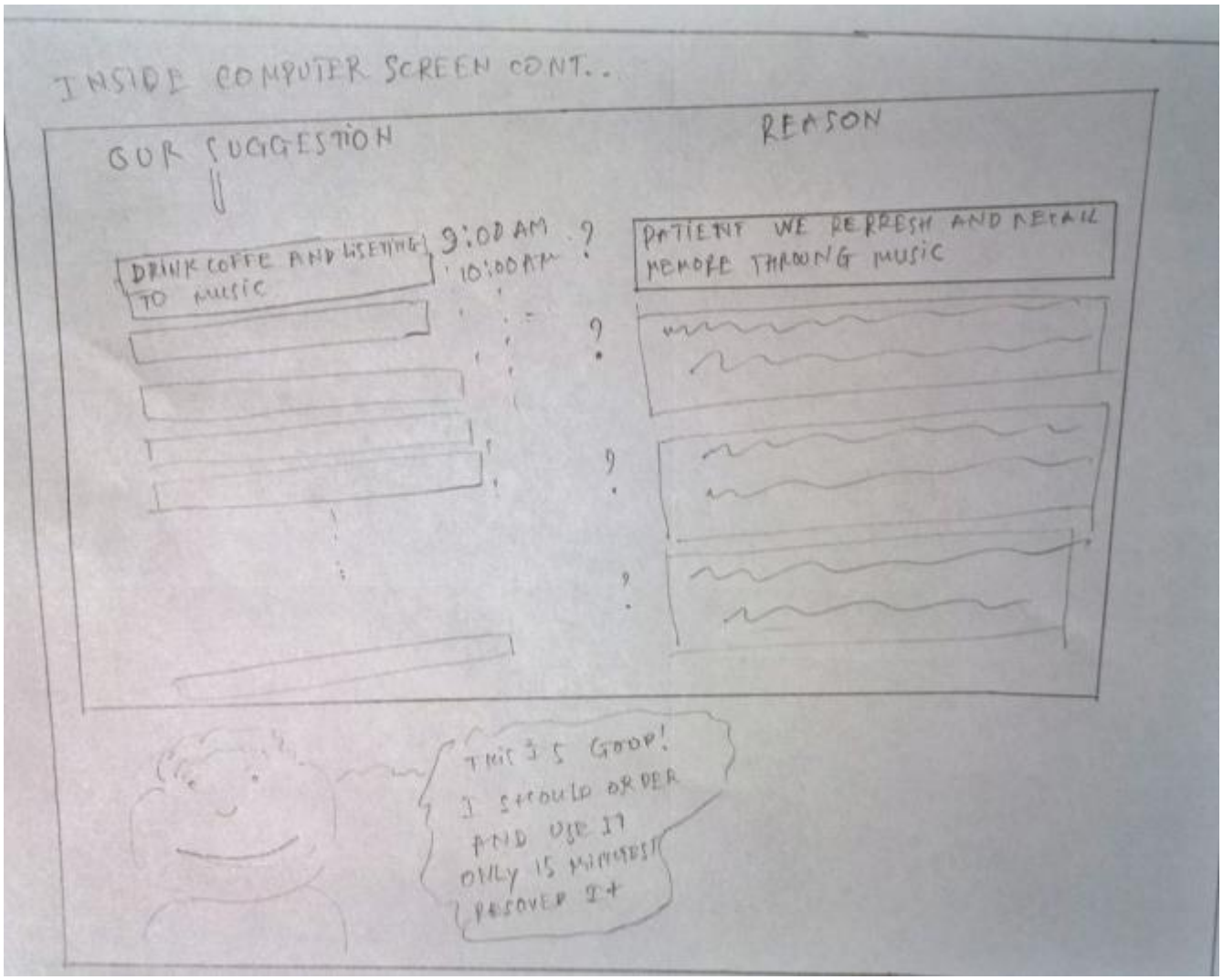


Task 2: - Scheduling time for patient




AT 3:00 PM THAT DAY
OOPS. MING CHENG FORGOT TO TOLD JOHN THAT HE NEED TO MEET DOCTOR AT NOON
DON'T WORRY. LET ME CHANGE SCHEDULE FOR YOU
SCHEDULE
JOHN
LATER THAT DAY!
JOHN THINK IT:
I WISH THE SCHEDULING TASK FOR PATIENT MORE EFFECTIVELY.
SPENDING 2-3 HOURS A DAY TO SCHEDULING, IS RIPICULOUS!!!
JOHN
SCHEDULE


JONH DECIDE TO LOOKING FOR EFFECTIVE SCHEDULING FOR DEMENTIA PATIENT
SEARCH...
LET SEE. SCHEDULING TASK FOR DEMENTIA PATIENT.
DEMENTECH
LET TRY IT OUT. FOR EXAMPLE JONH BATH AT 7:00PM, GO TO DOCTOR AT.....
INSIDE COMPUTER SCREEN
INPUT:
TIME
TASK
SHEDULING FOR DEMENTIA APPS
ENTER
WE ARE OPTIMIZE THE SCHEDULE NOW PLEASE WAIT....


INSIDE COMPUTER SCREEN CONT..
OUR SUGGESTION
REASON
DRINK COFFE AND LISTING TO MUSIC
9:00 AM
10:00 AM
PATIENT WE REFRESH AND RETAIL MEMORE THROUNG MUSIC
THIS IS GOOD!
I SHOULD ORDER AND USE IT
ONLY 15 MINUTES!
RECOVER IT