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SERVICE DESIGN NETWORK

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The dilemma of the care recipient

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If we found ourselves in a situation where we needed assistance and medical care to manage our daily life, most of us would prefer to live in our own home as long as possible. We would also like to maintain our social relations and to be in charge of our own lives. In a project called TILLIT (an acronym meaning "trust"), managed by the County Council of Västerbotten and the Municipality of Umeå, Sweden, Struktur Design looked closer at senior citizens in need of both medical and practical care while still living at home.

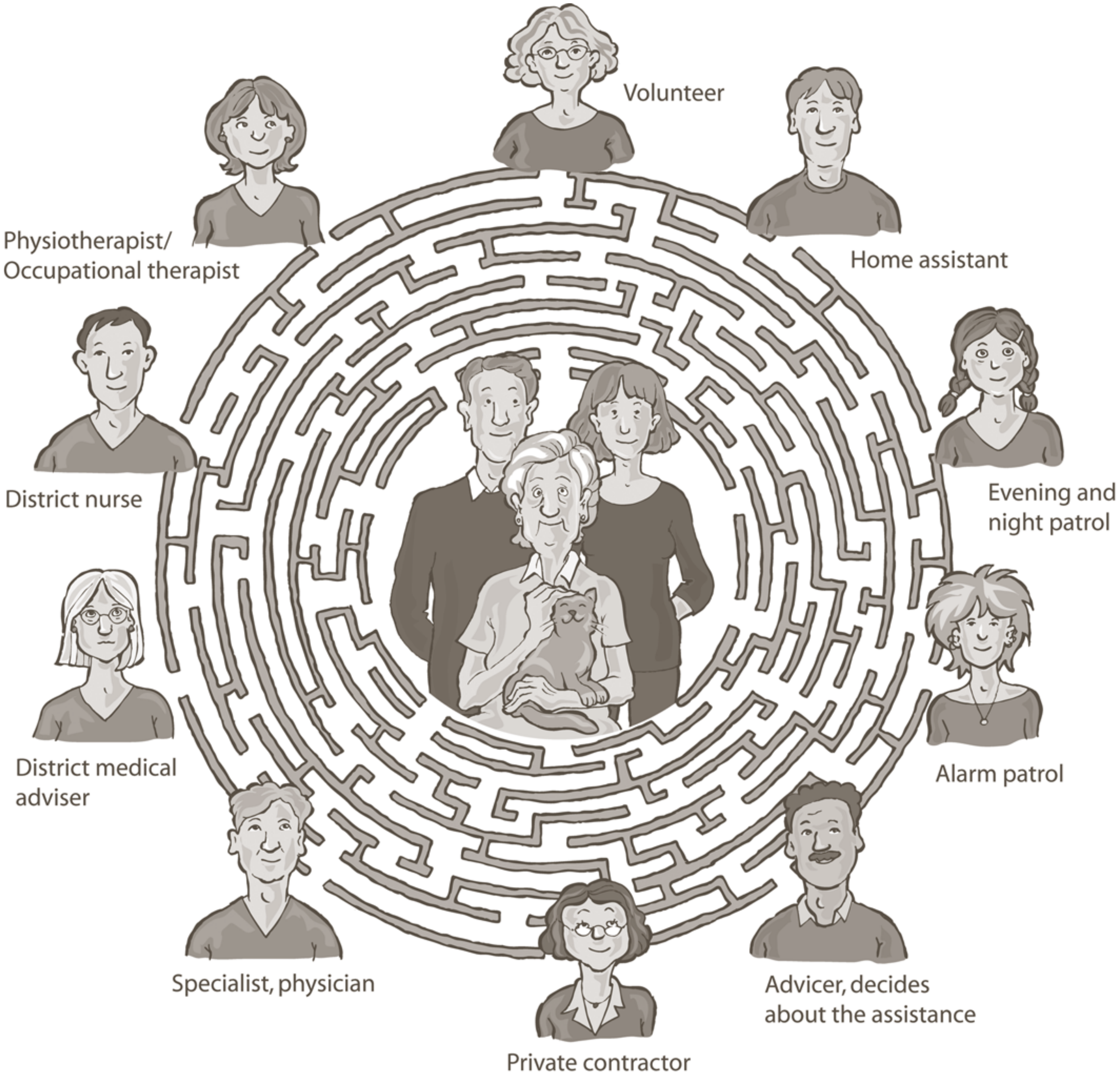
As a consequence of an interview study, we found that a lack of collaboration and communication between the different care providers results in nobody seeing the "whole picture". The right person most often does not have the right information in the right situation. How does this affect the care recipients? Do they even know who is responsible for what and whom to contact when in need of help? We worked our way through the maze to find out.

Initial analysis

The interview study included care recipients, their next of kin and the different care providers, with focus on the care recipient's situation. Some general questions that we wanted answered were: What information do they need to feel secure? What do they need to communicate with the care providers? Do they know what help is available? Do they trust to receive the help they need when they need it?

From the interviews we were able to identify different problems and needs. In most cases there are no routines for collaboration amongst the different care providers. The consequence is then that it becomes up to the recipient to make sure that adequate help is provided and coordinated without the necessary insight to be able to achieve this. It is not clear to the care recipient what help is actually available or even less who is responsible for which type of assistance/care.

As it is today, the care recipients often don't know who comes to visit them at



There are several different care providers working with this care situation, representing two separate responsibilities, the County Council and the Municipality.

THE DILEMMA OF THE CARE RECIPIENT

By Elin Kolterjahn, Åsa Adolfsson and Stefan Holmlid | Illustrations by Gunilla Gullbrand

Current Situation: Tilda is getting impatient. It's already noon, but still no one from the "home assistance service" has arrived. Someone should be here by now to take her for a walk. She sighs "If I had known this in advance I could have accepted that appointment at the hairdresser". Tilda knows that unforeseen things happen, which can delay the home assistants, but that they don't show up at all, is unusual.

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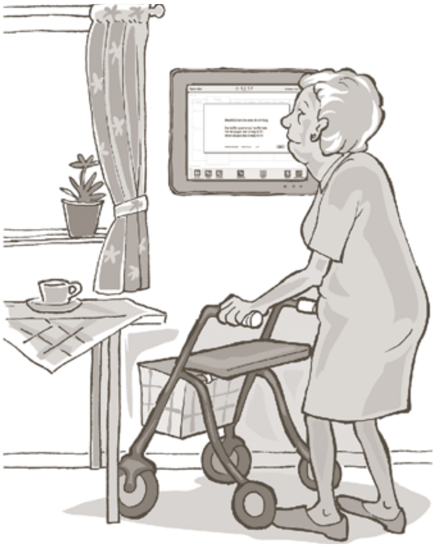
home and why. They simply don't know what decisions have been made regarding the care that they are going to receive, when they are going to receive it or even why. The care providers with the deepest insight into the recipient's situation are often not involved in the decision-making process. Inaccurate decisions are made due to this and the care recipients feel insecure and left in the dark. The involved care providers also get frustrated. Despite their best efforts they are unable to provide satisfactory and secure care.

Communicating the problem

Based on the analysis, we visualized the situation as it is today. The scenarios clearly illustrate how the shortcomings of the system cause the care recipients' and their next of kin problems. We also visualized desirable future scenarios where the care recipients, their next of kin, as well as the care providers have the information they need.

Some basic demands on the information are:

- The care recipients need to be well informed on what help they will receive, when and why. They also need to have easy access to gathered information on what help is available.



Current Situation: Tilda hears a signal from the kitchen. On the screen of her web portal she sees a message. Her walk has been postponed. The home assistant will come tomorrow at 11 to take her for a walk. "But I have an appointment at the dentist tomorrow", Tilda thinks for herself, picks up the phone to rearrange the time for the walk. As she hangs up, she hears another signal from the web portal. The new appointment for her walk is activated in the schedule. With this new equipment she feels less bound at home.

Vision: Martin, Tilda's son, worries a lot about his mother. She doesn't remember what happens during the days and he rarely meets the care providers, since he is at work while they visit his mother.

- The care providers need to synchronize their schedules to enable everyone concerned to see the whole picture and to avoid double-booking. They also need to communicate changes in the schedule.

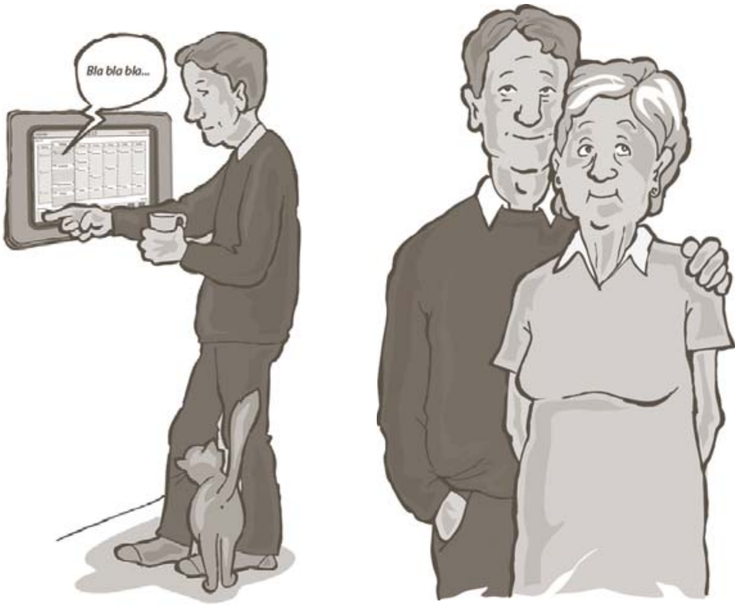
- The care providers need to share important information on the recipient's situation and what they have carried out, with each other (they may however never meet in person) as well as with the recipients and their next of kin, and vice versa.

These visualizations were used in the communication with care givers as well as politicians to illustrate the complexity of the care recipient's situation. In this project we were not able to reorganize the care system. By providing everyone involved with the same information, however, the situation for the recipient will improve a lot.

Suggested design

The final suggested concept is a home assistance web portal, where a synchronized schedule of daily activities is the main feature. Other important features are messages and contact information. The web portal not only provides the care recipient with accurate information, but also helps to enhance the collaboration between the care providers.

The most important qualities of a well functioning care system will always be collaboration and human interaction, but by providing the care recipients and their next of kin accurate information, you enable them to take control of the situation and to find their way through the maze.



Vision: With the new system, Martin can communicate with the care providers both through voice messages and text messages. The providers enter into the system what they do at Tilda's during the days and Martin can feel secure that his mother receives the care she needs.

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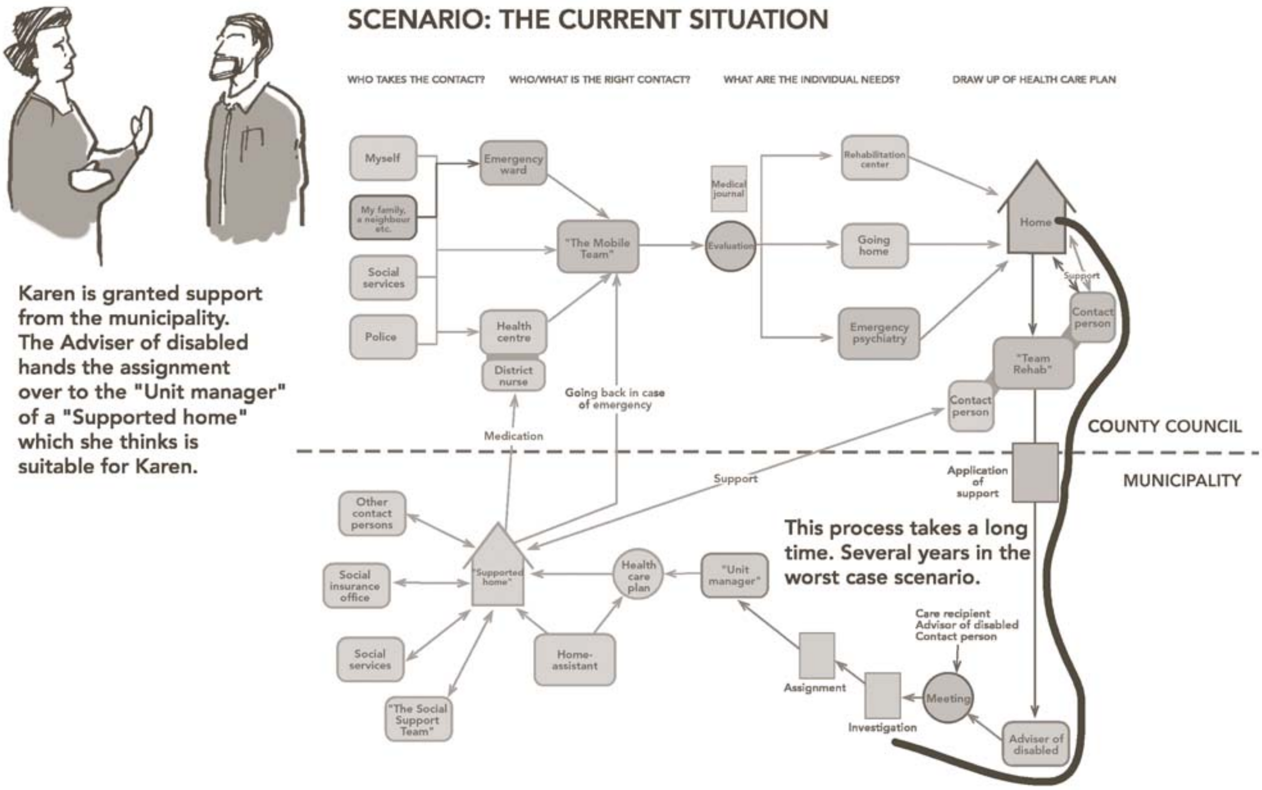
The journey through the care system as mentally disabled

A vision of a care chain, built on the needs of the care recipients

There are large demands put on the systems of healthcare. The system should provide large amounts of help initially, and be adaptive and flexible with respect to individual needs over extended periods of time. The care recipient should be allowed and invited to participate and cooperate. The system should be capable of configuring, sustaining, and developing multi-professional teams to meet the needs of care recipients.

In Sweden these demands are challenged by a set of problems; there are several different operators involved in the care chain, with two different funders; the dependence on individuals in the system is large; there is no shared overview of planned and executed actions across the operators.

These demands and challenges where found by Struktur Design, in a project managed by the County Council of


Karen is granted support from the municipality. The Adviser of disabled hands the assignment over to the "Unit manager" of a "Supported home" which she thinks is suitable for Karen.

This process takes a long time. Several years in the worst case scenario.

Figure 1: When out of emergency care, getting the right treatment can take several years of administrative handling

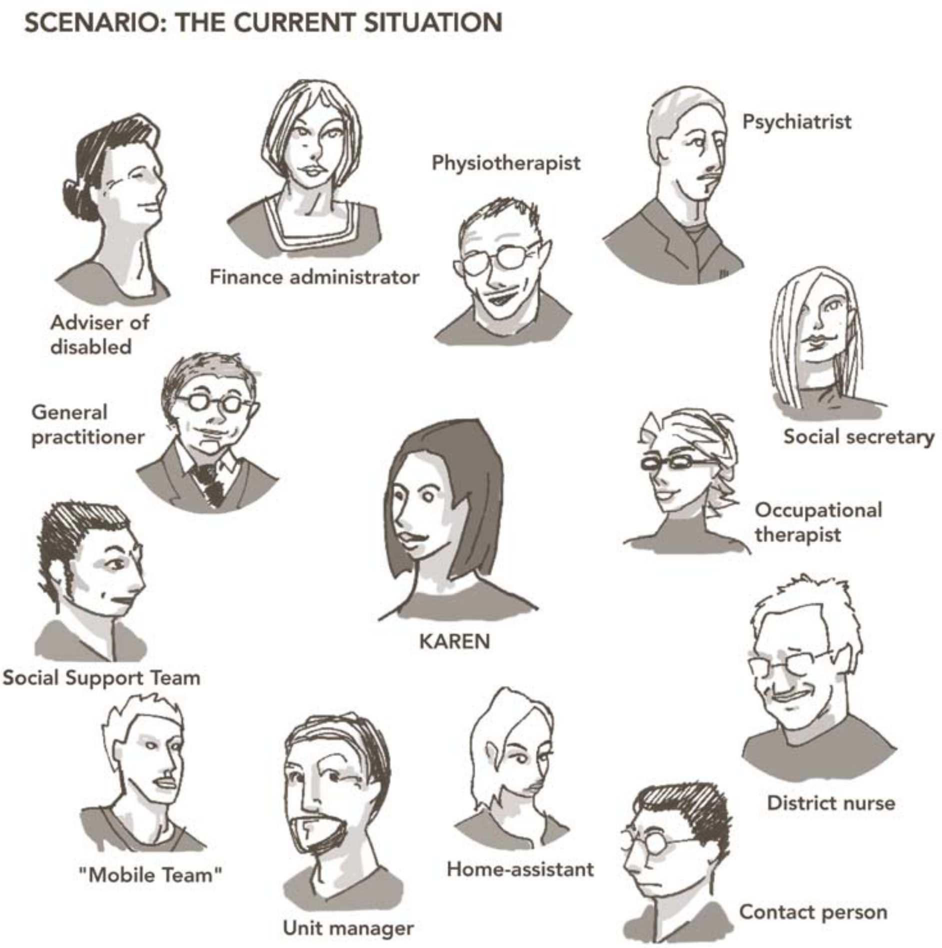


Figure 2: The many contacts managed by the care recipient in the care network

Västerbotten and the Municipality of Umeå, when we looked closer at the case of a journey through the system for a mentally ill person. We conducted an interview study to understand how the care system works and to gather information on the needs of the mentally disabled. The purpose of the project, called TILLIT *(an acronym but it also means Trust)*, was to create a coherent care chain across the county council, the municipality and private contractors.

The current situation

Some major problems within the system were identified as well as important demands, which if they were fulfilled would improve the situation for the mentally disabled considerably. One of these problems is the long time spans *(Figure 1)*. Another is the sheer amount of contacts that the ill person has to handle herself in order to get the correct treatment *(Figure 2)*. A third is the lack of communication between organisations,

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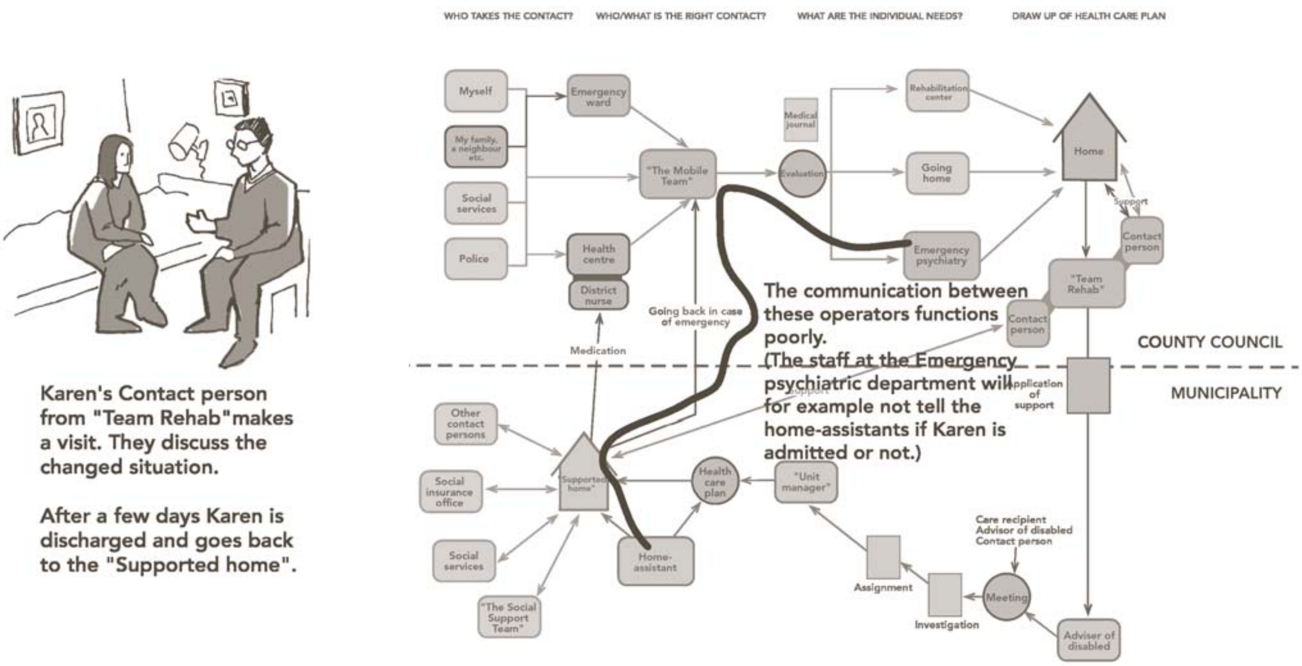


SCENARIO: THE CURRENT SITUATION

Karen's Contact person from "Team Rehab" makes a visit. They discuss the changed situation.

After a few days Karen is discharged and goes back to the "Supported home".

The communication between these operators functions poorly.
(The staff at the Emergency psychiatric department will for example not tell the home-assistants if Karen is admitted or not.)

Figure 3: Lack of communication between organisations

which can cause devastating problems for the care recipient (*Figure 3*).
The care chain is incomprehensible to the uninitiated, even the care providers does not see the whole picture, and yet we expect the mentally disabled, who often have difficulties dealing with human relations, to control the situation.

The suggestion

To deal with the identified challenges we created a new model for the care chain, starting with the needs of the care recipients. It meant that we reduced the number of people that the care recipient herself had to keep in contact with. We also suggested that a support-person is introduced into the care chain already at the emergency stage. By doing that the care recipient is relieved of the pressure to manage contacts and care givers. The lack of communication will be less obvious because the contact person interacts with the different organisations.

Final thoughts

Using visualizations such as scenarios and simple actor maps for the current care chain and the future model was powerful. They helped express problems, solutions, and possibilities. We used these visualizations to communicate within the project, with care providers and with politicians. It enhanced the insight among the care providers and was a useful tool to create understanding for the consequences of a malfunctioning system.

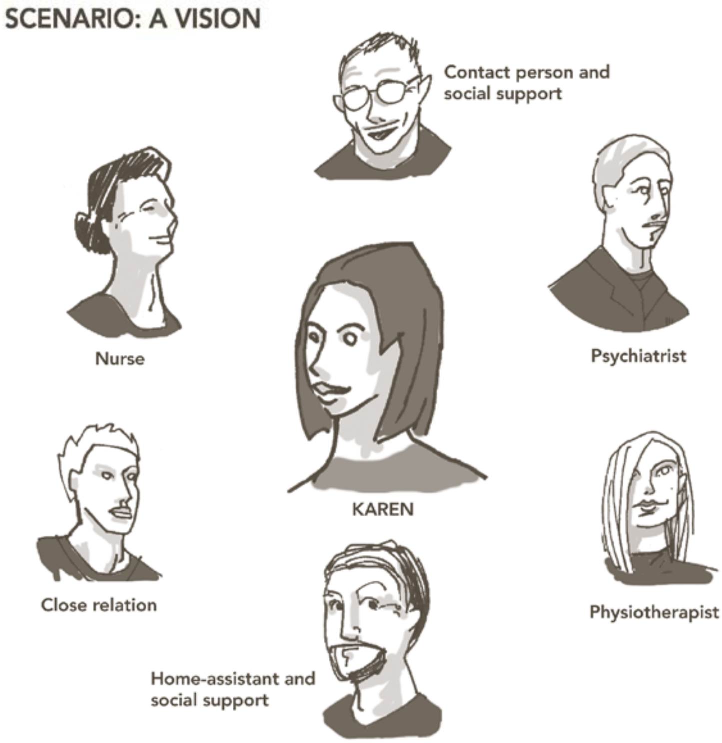
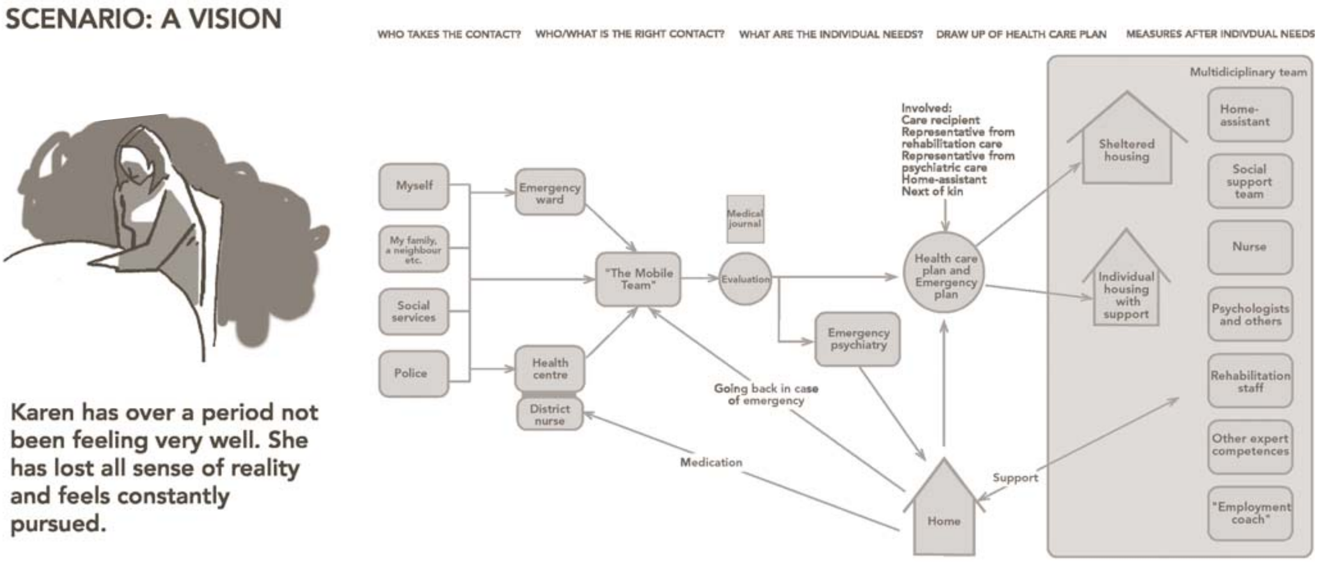


Figure 4: The contacts managed by the care recipient in the new care network



Karen has over a period not been feeling very well. She has lost all sense of reality and feels constantly pursued.

Figure 5: The care chain where a support person is introduced at an early stage