

# **Care in old age: an invisible crisis?**



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## ABOUT

During the summer semester 2021, we participated in the course *Housing, crisis, and catastrophes*. Crises were thereby seen as a lens on urban transformations and power arrangements in contemporary European cities. The course offered a new perspective on housing – with its materialities and everyday practices – through the lens of crisis. Investigating the complex effects of different crises, our group worked with the effects of the care crisis on housing. As housing is a fundamental infrastructure of care (Power and Mee 2019) and various care needs and practices require different forms of housing, both aspects are closely intertwined. While digging deeper into the question of whether there is a care crisis, we became aware of structural problems such as the lack of care staff and facilities, affordability problems or exclusion of elderly people from social life. Although the focus is often on the professional care sector, 56% of people in need of care in Germany are cared for only by family members or other informal caregivers (Statistisches Bundesamt 2021). In both the domestic sphere, where most care work takes place, as well as in care institutions, many aspects of this crisis remain invisible. We wanted to have a look into this black box.

Usually crises are understood as being disruptive. Whereas many dimensions of the care crisis are unfolding rather slowly, they have nevertheless critical impacts on both society and personal biographies. One consequence is that people in old age often face challenges in organising their daily activities and care. A crisis might involve realising that one's home does not suit basic care needs anymore; experiencing oneself as a burden for the family; or staying alone in a far too large house. During the course of our project, individual biographies reflected the way care is navigated personally but also exposed instances of crisis in the care system.

By interviewing seven individuals about their living situation in old age, we wanted to make visible how care is made possible through, and limited by, housing. In these portraits, care involves everyday practices of listening, remembering, and maintaining social relations alongside the work of professional

caregivers. The portraits include different forms of living and care needs, such as living in an elderly home, with assisted living, live-in care workers, and living alone or with family. The interviews show that many people we talked to draw on several kinds of care simultaneously.

Through our explorative approach, various topics came up: The interviews show that practices of housekeeping, self-care, receiving and giving care to others as well as social contact or isolation are all connected and related to the question of how elderly people *want* to live and how they *can* live. Although all interview partners had different forms of housing and care, by reflecting their personal biographies and resources, similar issues emerged in many interviews, such as adapting to (new) environments and care needs, the need for social activities, the feeling of (in)dependence and the struggle of making or maintaining a place as home. The experiences portrayed here reflect both the broadness of care as well as the universality of issues related to housing and care that almost everyone has to face.

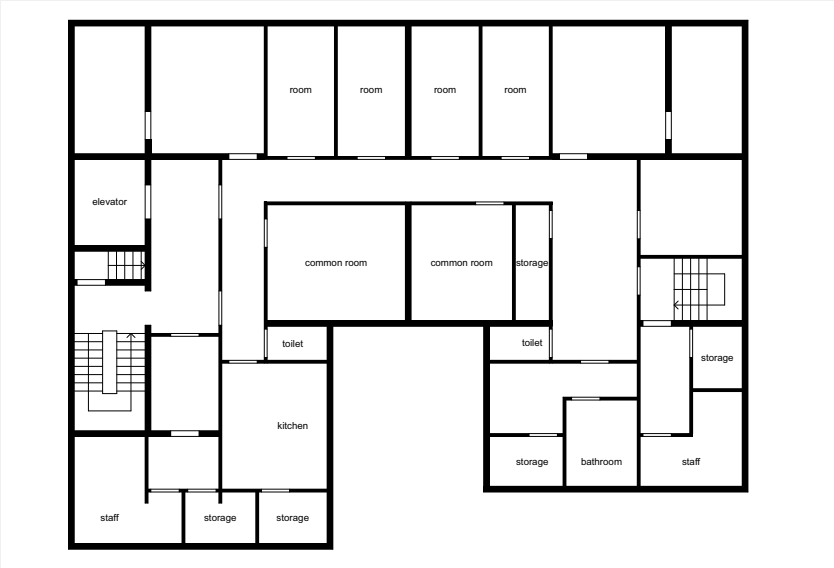
With this magazine, we would like to give a personal insight into life in old age.

// Charlotte, Franziska, Lydia and Nina

#### REMARKS

To ensure our interview partners' anonymity, we changed the names of the elderly and caregivers.

The interviews were conducted and transcribed in German. Afterwards, selected quotes were translated into English and kept as close as possible to the original statement to minimise the loss of information



## **EMMA (89) & ROSEMARIE (89), ELDERLY HOME**

Rosemarie (89) and Emma (89) are living in an elderly home since 2020. Emma came to the elderly home, because her doctor decided after a disease she has to move. When she moved to the elderly home, her apartment was dissolved by her legal guardian. Rosemarie followed her husband, who had a stroke and is sitting in a wheelchair since then. She has four children and still owns her own house with a garden. Both Rosemarie and Emma worked their whole life since they were 14 years old, leaving them with an adequate pension. They did not know the elderly home or anyone living there beforehand.

Especially for Emma, the move came all of a sudden. She became sick and had lost a lot of weight, so she would not have been able to care for herself anymore. Her doctor chose the elderly home for her. In Rosemarie's case, her daughter chose the elderly home so that she and her husband could stay together. Both did not know or decide on the specific elderly home by themselves.

**“Did you already have thoughts, fears and worries about not being able to stay at home? Did you think about it for a long time beforehand?”** Interviewer

**“Not really”** Rosemarie

**“Me neither. It came all of a sudden. The doctor came: „Mrs. Emma, pack yourself something, I'll take you to a retirement home, nursing home.” And that was here. And what would I do, I'm standing alone.”** Emma

Emma often mentions her furniture and apartment. One aspect which might have contributed to the feeling of loss is the fact that someone else cleared out her apartment and gave away all her things – for free. While asking about her birthday and if she wants to celebrate it, she replied: “I don't have a home anymore.” as a place where birthday parties usually take place.

**“No, it didn't need an adjustment, it was just that I had to give up my apartment here. With all the trimmings. With furniture... with all the things... it's all gone... I don't have a home anymore.”**

Emma

**“So I was very attached to the apartment. And I'm still attached to it today. But if it [the daily chores] doesn't work like that anymore. It's the age, isn't it.”**

Emma



**“Are you attached to your apartment?  
Do you regret that you had to leave?”**

**Emma**

**“No, why should I regret it? We're doing  
fine here. If we can't handle it anymore,  
what should we do?”** Rosemarie

**“You see, that [not being able to live  
alone anymore] is how it was with me.”**

**Emma**

**“The apartment alone won't help. It  
can be as beautiful as it is. When it's  
over, it's over.”** Rosemarie

**“I always have to think of my apart-  
ment.”** Emma

Since the recommendation of her legal advisor, Rosemarie expanded the stable and lived in the house of her parents. Later, her brother who is 13 years younger than her moved into the upper floor where he still lives. Although Rosemarie and her husband still have their house, they have not been there since they moved to the elderly home. This difference of having a

house anywhere else except of the elderly home may play into missing their old home for both women respectively.

**“At that time [when I took over the house from my parents], I took advice, I didn't want the house, and I didn't want my brother to have to pay me off, so the legal advisor recommended me: the right to reside there until the end of my life.”** Rosemarie

**“And then I moved home after years [...] and rebuilt what was a stable building as living space and that has become a beautiful five-room apartment. And it's still standing.”** Rosemarie

**„With furniture.”** Emma

**„With furniture. Fully furnished.”**

Rosemarie

**“And with you.”** Emma

**“Not with me anymore, we are here!”**

Rosemarie

For Emma, who also does not have any close relatives, her old apartment is very important. Emma's husband deceased and she has no children. Most of the relatives who are still alive are her cousins who are all old or sick. There is no one who visits her. On the contrary, Rosemarie's children and grandchildren, particularly her grandson, come and visit her and her husband

**“And I don't have any children either. Well. That's all gone to the winds. [...] What should you do then, Mrs. Rosemarie?”** Emma

quite frequently. This might also explain why Emma is grieving stronger about her old apartment.

**“Well, there's nothing you can do, that's fate. One is lucky, the other is not.”**  
Rosemarie

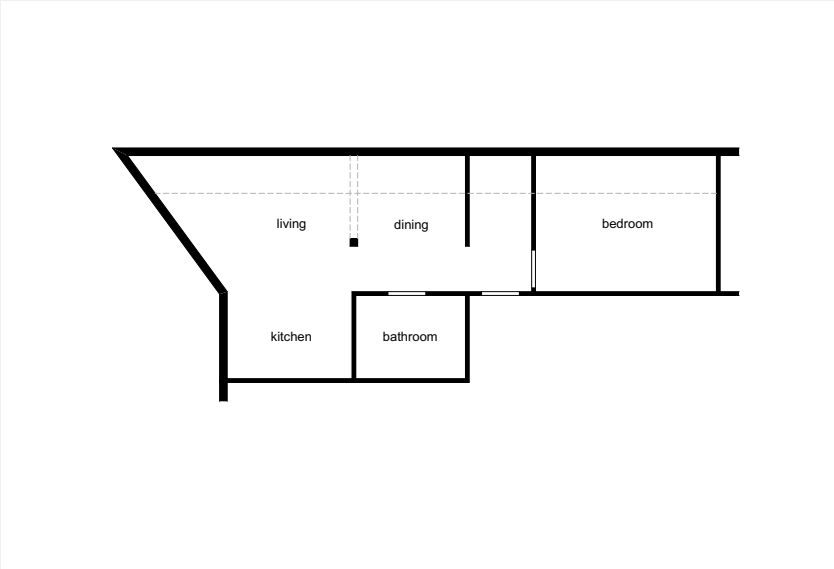
Before coming to the elderly home, Emma was living on her own. Therefore, she really enjoys the social activities and conversations with other people at the elderly home. The decoration of the elderly home with tablecloths gives both women the feeling of what they would also do at home.

**“Ach, no. You don't feel lonely here. You are always among people! And then in the morning, there is already some programme [...]”** Emma

**“Everything here is like at home. The table is set like at home. Yes, cozy. Pretty plates and cutlery.”** Emma

**“Always tablecloths. Flowers.”** Rosemarie

**“And the food always varies, even if on one day it is not so [delicious]. On the next day, it is then again all the more beautiful.”** Emma



## **WALTER (93), ASSISTED LIVING**

Although he is the oldest person in the house, Walter (93) is still the fittest of the 17 residents living in an assisted living complex. Originally from the Rhineland area, he moved to his new apartment ten years ago after his wife died, to be closer to his relatives. His granddaughter, who lives in the city nearby, organised everything because she decided he could no longer stay alone. Walter hopes to stay in his spacious flat with a view on the city for the rest of his life, where he can enjoy his independence while at the same time receiving the care he needs.

Walter prefers seeing things from the positive side, and emphasises again and again his satisfaction with his living and health situation. Still, after moving in, he fell into a heavy depression. The care worker, Mrs. Meier explains: “almost all residents who come here need about two years to adapt, and some never do.”

The depression Walter experienced after moving had to do with the fact that he felt detached from his homeplace. He decorated his apartment with family pictures, and moved the grave of his wife to Weimar. Such tangible reminders of ‘home’ play an important role in the remembering practices that are part of self-care as well.

**“Now I am happy to live here, but again, the first two years were difficult. ‘One does not transplant an old tree’, as the expression goes. I lived in the same house for 42 years.”** Walter

**“I let my wife be brought over, she is now lying in the cemetery. It was 400km, but they made it work”** Walter

**“When Walter says I am going out on the 31st of December and wake up the next day at 12:00, then he wakes up at 12:00”** Mrs. Meier

**“Here I am myself and I don’t want to be patronised”** Walter

**“It is nice though when we know where he hangs around”** Mrs. Meier

**[all laugh]**

While most care is provided for, self-determination and a feeling of independence are a main characteristic that distinguish assisted living from other types of elderly care homes. Residents receive different levels of care depending on their situation, but most people stay inside, where care services and a broad social and cultural offer are provided. Despite this sense of security, Walter values the flexibility of the home to decide his own schedule.

As a ‘Rhineland’er, Walter takes up the role of animator in the house, bringing in the fun and atmosphere. This dependence on social contact can be seen as a form of (self-)care, through which Walter battles loneliness. He can hardly stay a day in his room, because he needs people to talk to.

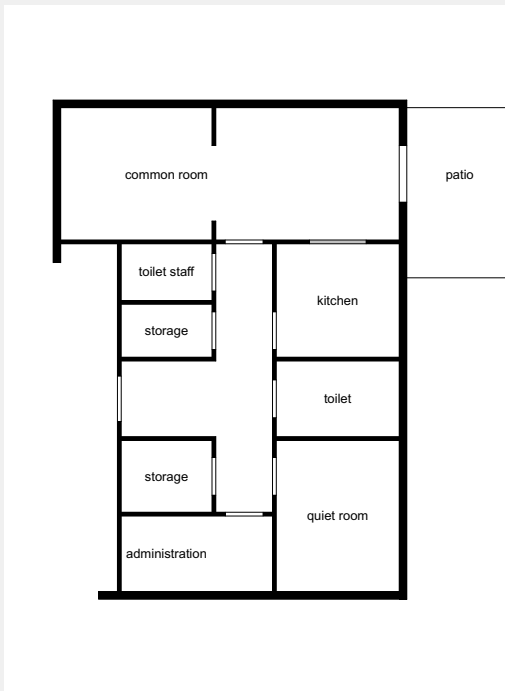
**“So all 17 of us are sitting outside. We have a table, and are sitting on chairs. That’s always much fun. But that doesn’t come by itself, the fun. For example, I was sitting there this morning, and no one said a word. When I don’t say anything, no one says a word”** Walter

Emotional care in the form of listening is an important aspect of the daily care provided by Mrs. Meier and her colleagues. “There are also really bad days, when the war experiences and so on are processed, which he has to tell again and again in order to somehow sleep well.” This makes professional care a very social type of work, although there is often not enough time available for such tasks.

**“That was the good thing in Corona times. Simply to have a bit more time for the individual conversation.”** Mrs. Meier

Walter was lucky that his granddaughter quickly found a place for him in an assisted living home, as the average waiting time is around two years. To Walter, the conditions in an elderly home seem to be worse, as it often includes a shared apartment. In his home, he has his own apartment and more independence.

**“There is a long waiting time. They have to build more! It also produces a lot of money. That is the future, then we don’t need elderly homes, and just steer towards assisted living”** Walter





## **LEONORE (91), DAY CARE CENTRE**

When Leonore (91) was found unconscious in her flat several times, her children decided that she could not live alone anymore. After spending one year in an elderly home, which she abhorred, she now lives with one of her sons and his family in a heritage protected former school-building in the countryside. During the week, an outpatient care service helps her every morning with showering, dressing and specifically her compression stockings. Three days a week she spends at a day-care centre in the city. She and the other elderly people are picked up by drivers of the centre in the morning and are brought home in the afternoon.

Leonore has lived in the same city her entire life. When her son took her in to live with his family and to take care of her, Leonore had to move to the countryside. Although the people there are nice, the village does not have a lot to offer. Besides missing the city life, Leonore also has some problems with her legs, making it hard to go for walks. Most of the time she spends in her room, doing handiwork or reading historical novels. Going to the daycare center, being in contact with peers and participating in the activities organised by the care workers bring back a feeling of having something to do and being active. Leonore joyfully talks about short trips to the city centre for ice cream just as much as about the bigger annual trips.

**“So that's how it was. When I got the care level 2, we were there with someone from the office of the Diakonie. And they discussed everything, that I get the level 2, and then she said [to my son]: “You know, your mom sits here alone all day long. I'll see if I can get a place for her!”** Leonore

Leonore shares her struggles with the transition from living alone and independently to moving to her son and needing support with daily tasks. Especially in the beginning, it was hard for her to accept help. For her, “the hardest thing” is that her son has to shower her on the weekends, when the outpatient care service does not come. An uncomfortable situation for both her son and her: while she grits her teeth, her son sings songs to ease the situation. Most care is provided by family members. At best, loving and intimate, family care is also challenging in terms of reconciling care duties and other responsibilities or coming to terms with changed relationships - e.g. between old parents and their adult children.

**“Well, and then I said to myself: Leonore you can't, you need help! So you have to grit your teeth. You have to!”** Leonore

Leonore's children take care of everything in her life. While her daughter manages her finances and expenditures, her youngest son and his wife, with whom she lives, clean her room, prepare food and help with daily chores. Several times throughout the interview, Leonore expressed her worries of being a burden for

**"I sometimes worry that I'm a burden to my children. Because there are two grandchildren as well, [...] they also want their parents when they come home from work. That's why I sometimes think I'm a burden."** Leonore

them. She seems to feel guilty for occupying their time especially as they both work full-time jobs and have children to care for as well.

**"I'm mostly in my room. I leave the family to the family. I only go to dinner."**

Leonore

For Leonore it was easy to get a place at the day-care centre. However, although she would like to go everyday, her financial situation only allows her to visit the day-care center three times a week. She is also aware of the critical working conditions in the care sector. She relates a report about the care crisis which she watched on the TV to her son's situation, who works in the care sector as well. Despite a full-time job as a professional

**"I heard on TV that there are so few caregivers because they are so poorly paid. Yes, I can see that with my children [who work as caregivers], that they are badly paid. My son delivers newspapers in our village, early at 5 a.m. to earn a little money on the side because they are so poorly paid. And who wants to do that?"** Leonore

care worker, Leonore's son delivers newspapers in the village to stock up their monthly income.



## **EDITH (90), LIVE-IN CARE WORKER**

Since her wedding almost 70 years ago, Edith (90) has lived in a big house on a farm in the countryside. After her husband died and her dementia worsened, she did not want to leave her house but needed care. One of her sons lives next door and another son stays overnight on some weekends. But because she could not stay alone at all anymore, they decided to organise a 24h live-in care worker. For five years, Anja and another woman from Poland take turns to stay for around six weeks each time.

Edith says that she loves to live in the countryside and that she has always lived in a big house. Although living there has become challenging for her in old age, she does not necessarily perceive it that way. Due to emotional attachment, financial issues

**“An advantage is...it is a habit not to live in a two or three room flat, but how I am used to: a bit bigger, so visitors and children can come. [...] A disadvantage of course: You live here alone. It is not a village, not a city. Usually that’s fine for me: all okay. But when you are old and sick and have to go somewhere. You cannot take the car anymore or the bus.”** Edith

or because they feel they cannot adapt to a new environment, many elderly people stay in their big homes, which are often very high-maintenance, not suitable for their care needs or even dangerous. If persons with high care needs want to stay at home, live-in care work is one of the few options besides family care. On the other hand, live-in care arrangements also require having enough space at home for at least one spare room.

It is very important for Edith to have a family graveyard behind her house, where her husband and daughter are buried and where she can go anytime. This illustrates how connected she feels to her house as the place where she is close to her family, and that it is no option for her to leave. In the interview she emphasises again and again how important it is for her to have a big family and a house big enough for them to visit.

**“I have even gone to the graveyard in my nightgown.”** Edith

Edith and Anja spend the whole day with each other and do some of their chores together. Anja stresses that although her care work involves much household work, she is not there to clean but to look after Edith’s well being and most of all, talk with her and be her companion. As live-in care workers stay with a single person or a couple around the clock, they provide social and physical care work at an intensity that is usually impossible for care workers in other settings. Most live-in care workers are women from other countries, usually Eastern Europe, who often work under precarious or even informal employment conditions, with constant duty, few breaks and wages far below the minimum (Tagesschau 2021).

**“A normal day... having breakfast [...] baking a bit of cake and cleaning the windows.”** Edith

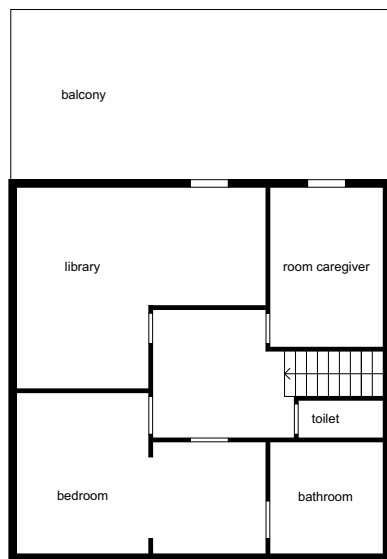
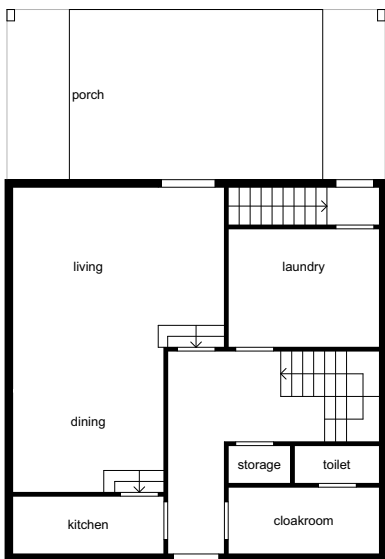
**“Well, actually I don’t clean much, also not the windows, [the cleaning lady] is doing that. But, I look after the flowers.”** Anja

**“Or grocery shopping!”** Edith

**“Yes, or grocery shopping or going to the pharmacy, or giving you your medicine or checking blood pressure. [...]”** Anja

**“Or baking cake.”** Edith

**“Yes, of course also baking a cake sometimes. But I also have to make lunch...or just talking a lot together. [I am] not just walking, walking, walking. It is also about talking with each other... I am caregiver, not just cleaner [...] And then we make lunch and have a nap. Then we have coffee and talk more and go for a walk. [...] Yes, you have to get a lot of fresh air. Not just sitting at home. You have to function normally, you know? And then go back home, have dinner and watch some TV. I also have to sort the medicine and check it every day. That's the job of a caregiver.”** Anja





## **MARTHA (85), OUTPATIENT CARE SERVICE**

For many years, Martha (85) cared for her husband, who had several amputations. After he died, she moved away from her city to her new partner. For eight years, she has lived with him in the countryside, next door with his son's family. Her own daughters both live far away, but visit her often. Because her partner developed severe dementia, they had both an outpatient care service coming once a day and later also a live-in care worker from Poland, so he could stay in his known environment. Since her partner died this winter, Martha lives alone in the house.

**“We had a ground level house, where everything was plain, right? Totally flat!**

**No steps, nothing. [...] And that was very well planned. That was done by a woman. [...] A woman who also makes food and plans and is in the kitchen [...]**

**So maybe that plays a role. The men weren't so familiar with the kitchen... back then.”** *Martha*

Martha’s previous house was completely flat, which she always found remarkable. It was very practical for housekeeping and turned out to be of even greater help when she later cared for her husband who needed a wheelchair and a nursing bed. The fundamental design aspects of homes can facilitate or inhibit everyday care and intensive medical care practices. Therefore, it is important to envision the different (care) needs that can emerge throughout a lifetime already when planning a building.

**“She [the care worker] prepares breakfast while I am getting ready upstairs [...] And it is also important to have someone to talk to, no? She is a very interesting woman. [...] And that is good, because otherwise I hardly have that [being around another person] the whole day.”** *Martha*

After her partner passed away, Martha decided to keep the outpatient care service, which she has known for a long time. Although she does most of her household chores by herself, she is reassured by having someone present when she showers, in case she falls. Most of all, however, she appreciates the care worker as someone to talk to. As she left her previous hometown and was not out much since her partner got ill, she does not have many close contacts nearby besides her partner’s family.

Having a care worker live with them for 24h a day was not always easy for Martha, although she stressed that she knew it was necessary. When her partner could hardly leave their bedroom and bathroom on the first floor, they moved a table up to have meals there together. This overlap of the room usage as both a space for intense care work (changing diapers) but also a shared living space (having meals) also caused a conflict between her and her care worker. This shows how (care) practices have to be navigated in domestic space, which can become more conflicting if space is reduced to a minimum.

**“We carried up a table to put it in front of the window. That maybe wasn’t the best place. [...] Right there at the toilet door. I had a big fight [with the live-in care worker] [...]. Well, they have to change his diapers! And when they had a lot of waste and always left the bathroom door wide open... Sometimes, I even shouted. I said: Damn it, the door has to be closed! Then I will suffocate, [she said]! [...] This was the only time we really had a fight.”** Martha

**“But it is also a bit like another perspective on what is a good living, or housing situation. I mean for example [the care worker]: Maybe for her it was pragmatic to leave the door open to move quickly between the rooms?”** Interviewer

**“Yes! ... but not at mealtime. That was the problem.”** Martha



## **KURT (84), LIVING ALONE**

Three years ago Kurt (84) moved to a building that was adapted to the needs of elderly people. After his wife passed away, he did not want to stay in his former flat. Like seventy other people above 65 years, he now rents a small apartment with a balcony. He does not receive any professional care, but gets occasional help from his daughter or a friend living close by. Because he is the tenant representative in his building, Kurt is in contact with the housing company and actively involved in the organisation of tenant activities.

Kurt values his independence. He also considered moving to an elderly home, but besides the higher costs, he is afraid of not having anything to do or being told what to do. He is capable of taking care of himself and his daily chores and appreciates that living alone challenges him to stay fit as long as possible. A great advantage of his flat is that all important facilities are so close by “that you can go there with house slippers”. Having a person who cleans at his place and ordering some deep frozen meals with home delivery makes his housekeeping more doable.

Among other reasons, Kurt moved into this building because he could live together with people in his age group and because there were some shared tenant activities. The weekly coffee parties in the club room helped him to feel comfortable at his new home soon after he moved there. However, since the outbreak of Covid19, the clubroom is closed. He and some tenants still gather in the garden most days to have some social contact. But Kurt is worried that people suffer from isolation. In better times, this form of housing has the advantage of facilitating social (peer group) contact for elderly people who live alone. Kurt’s observations also show the real threat of social isolation for many elderly people.

**“They do everything for you there [in the old age home]. I don’t want this at the moment, because then you become totally dependent! Here [at my place] it is like this: If I leave this dirty cup here today, it will still be here tomorrow. No one will do that for me. But at least, here I have to stay independent - as long as it is possible. And that is guaranteed here. For many others that is probably quite arduous, but...”** Kurt

**“Social contact is very important for me. I don’t want to end up alone and bitter. If I would not see anyone at all for four weeks and just be in my apartment.... you become depressed. [...] I can’t just sit here the whole day and look at the walls or the photos [of my wife].”** Kurt

The housing company advertises the house where Kurt lives as being adapted to the needs of elderly people. Although there are several accessibility features like a ramp, a broad elevator, handles in the flats and corridors and a concierge with extra keys, important spaces, like the bathrooms, are not really accessible. Kurt's attempt to adapt the shower shows the difficulties to create barrier free environments in houses that were built before accessibility was considered. Kurt also observed that there might be a misunderstanding among some tenants about the care level offered in this form of housing. He stresses that this building is merely operated by a housing company and not by a care provider, which is also reflected in the moderate rents.

**“You cannot really call it barrier free, rather barrier reduced. For example: You saw the shower. The shower has a high plinth. That is very problematic. Also: The cubicle used to be 20 cm smaller, like a square. It was so narrow that I touched the wall when I had to bend down. So I enlarged the shower. Costs: 1900 Euros. I paid 1500 Euros and the [housing company] paid the rest. Well, I cannot take anything with me anyways. Yes, that's problematic, to be barrier free the shower would have to be at ground level. [...] [But] to install it at ground level, you would need to break through the floor and put the drain pipes at the neighbour's ceiling. He will be very amused and it would probably interfere with the whole building's statics.” Kurt**

**“The professional care is not well organised in Germany, that is for sure. I might be wrong but I see it like this: There is nothing to change about that. There are several thousand, probably a few hundred thousand private care companies. If you dispossess them, there will be a palace revolution.” Kurt**

According to Kurt, there is not a lack of care services in Germany, but a problem with the organisation of care. For example, because everyone is free to choose their own care service, many people who move to his house keep their old care service. So, the caregivers have to drive all across the city, wasting time needed for care.





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## IMPRINT

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